# The 17th International Meeting on Psychosocial Aspects of Hereditary Cancer (IMPAHC)

## Welcome

Dear Colleagues,

On behalf of the IMPAHC Planning Committee, we welcome you to the 17th International Meeting on Psychosocial Aspects of Hereditary Cancer (IMPAHC) in Washington, DC!

The meeting will showcase scientific presentations across a wide breadth of contemporary topics in hereditary cancer research and clinical care. We are delighted to showcase keynote lectures on health communication and health information technology as well as the experiences of adolescents and young adults in the context of inherited cancer syndromes. Podium talks and parallel paper sessions will feature topics including promoting cascade testing, navigating complex family communication, achieving health equity, and managing psychological challenges of risk management, decision making, and cancer care. Across two poster sessions, emerging findings regarding intrapersonal and interpersonal aspects of how patients, families, and providers navigate hereditary cancer syndromes across the cancer control continuum will be presented.

IMPAHC has more than 120 attendees registered in-person for the 2023 meeting, and more than 300 attendees joining virtually! Attendees are joining from 5 continents and 23 countries including: Argentina, Australia, Brazil, Canada, Chile, Columbia, Dominican Republic, Ecuador, France, India, Italy, Malaysia, Mexico, Myanmar, The Netherlands, New Zealand, Pakistan, Peru, Portugal, Spain, Taiwan, the United Kingdom, and the United States. We are thrilled to have this opportunity to come together and learn from one another.

Kind Regards,

Allison Werner-Lin, PhD, LCSW
University of Pennsylvania
Conference Co-Chair

Jada Hamilton, PhD, MPH
Memorial Sloan Kettering Cancer Center
Conference Co-Chair

On behalf of the IMPAHC Planning Committee: Rowan Forbes Shepherd, PhD; Chloe Huelsnitz, PhD, MPH; William Klein, PhD; Camella Rising, PhD, MS, RDN; and Sharon Savage, MD.

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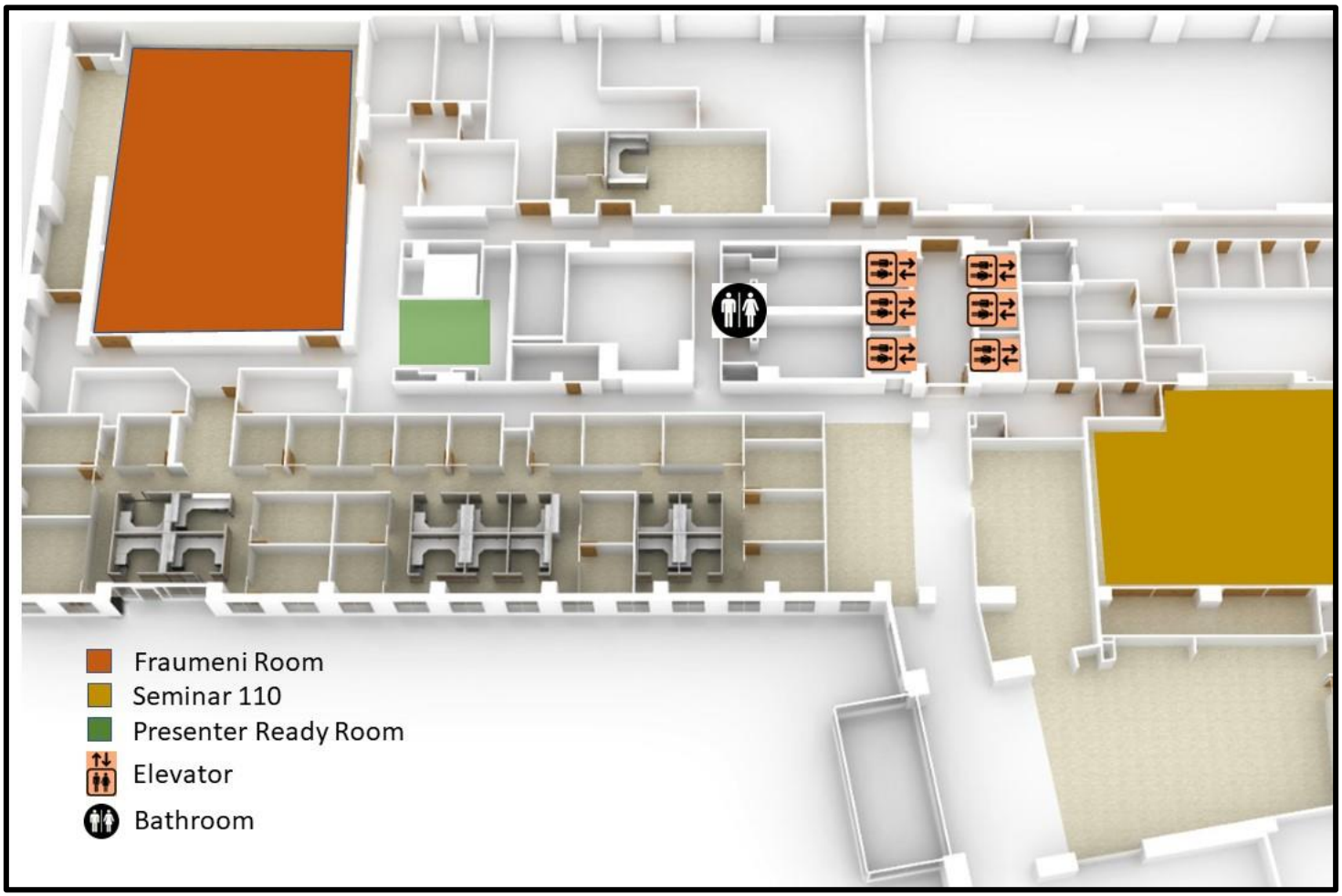
## Meeting Room Floor Plan

**Terrace Level**



**2nd Floor**

## Online Connectivity

For participants attending virtually, please access the conference via the link below. Sessions will begin at 8:30 a.m. U.S. Eastern Time.

### Join by web

https://cbiit.webex.com/cbiit/j.php?MTID=mb98a5225009a77e854324d6a2a794db5
Meeting number: 2316 372 0652
Password: dpSTHTW@642

### Join by video system

Dial 23163720652@cbiit.webex.com
You can also dial 173.243.2.68 and enter your meeting number.

### Join by phone

1-650-479-3207 Call-in toll number (US/Canada)
Access code: 231 637 20652

**Important Notes**

- During the conference you will be muted and unable to turn your web camera on.
- During question-and-answer sessions, please provide any questions you may have into the Q&A box and a conference moderator will ask your question as time permits.
- If you require accessibility options, please click the “CC” button in the bottom left corner to launch the real-time closed captioning. Note you will be muted and unable to turn your camera on.
- For breakout sections, you will be able to select which room you would like to attend from the same link. Breakout section names correspond with the presentation number (i.e., PA1).

## Meeting Schedule

| **Tuesday, May 23, 2023** | |
|---|---|
| 8:00 – 8:30 a.m.<br>Lobby | **Registration** |
| 8:30 – 8:45 a.m.<br>Fraumeni Room | **Welcome**<br>*Conference Co-Chairs: Allison Werner-Lin, PhD, LCSW, University of Pennsylvania, United States, and Jada G. Hamilton, PhD, MPH, Memorial Sloan Kettering Cancer Center, United States*<br><br>*Special Remarks: Sharon A. Savage, MD, National Cancer Institute, United States* |
| 8:45 – 9:30 a.m.<br>Fraumeni Room | **Keynote: Impact of health communication and health information technology approaches on delivery of cancer genetic services (KEY1)**<br>*Kimberly Kaphingst, ScD, University of Utah, United States*<br>*(Introduction: Jada G. Hamilton, PhD, MPH, Memorial Sloan Kettering Cancer Center, United States)* |
| 9:30 – 9:50 a.m.<br>Fraumeni Room | **Invited Talk: Recognizing barriers to hereditary cancer genetic testing: Insights from a population-based, publicly funded hereditary cancer program (INV1)**<br>*Kasmintan Schrader, MBBS, FRCPC, PhD, DABMGG, The University of British Columbia, Canada* |
| 9:50 – 10:45 a.m.<br>Fraumeni Room. | **Podium Talks: Diversity, equity, and inclusion in hereditary cancer care (POD1)**<br>*(Moderators: Kasmintan Schrader, MBBS, FRCPC, PhD, DABMGG, The University of British Columbia, Canada and Allison Werner-Lin, PhD, LCSW, University of Pennsylvania, United States)*<br>• ÁRBOLES Familiares action projects: Implementation of trainee knowledge about hereditary breast and ovarian cancer into the Latinx community – *Sabrina Oliveros, MS, Icahn School of Medicine at Mount Sinai, United States (POD1-1)*<br>• Adaptation and evaluation of a decision aid for *BRCA1/2* genetic testing in high-risk Malaysian families – *Sook-Yee Yoon, MA, Cancer Research Malaysia, Malaysia (POD1-2)*<br>• Hereditary cancer risk assessment in transgender adolescents and young adults: A scoping review of the qualitative, quantitative, and committee opinion literature – *Shelly McQuaid, MS, Ann & Robert H. Lurie Children's Hospital of Chicago, United States (POD1-3)* |
| 10:45 – 11:15 a.m.<br>Cafeteria | **Break** |

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| 11:15 – 11:45 a.m.<br>Fraumeni Room | **Invited Talk: Body image, health behaviors, and health-related quality of life in young people with inherited multi-organ cancer risk: A call for mindful self-compassion-focused interventions (INV2)**<br>*Camella Rising, PhD, MS, RDN, National Cancer Institute, United States and Amelia Coffaro, C-IAYT, University of Wisconsin-Milwaukee, United States* |
| 11:45 a.m. – 12:30 p.m.<br>Fraumeni Room | **Podium Talks: Expanding cancer care beyond risk management (POD2)**<br>*(Moderator: Allison Werner-Lin, PhD, LCSW, University of Pennsylvania, United States)*<br>• Personalising genetic counselling (POETIC) trial: A hybrid type II effectiveness-implementation randomised clinical trial of a patient screening tool to improve patient empowerment after cancer genetic counselling – *Laura Forrest, PhD, Peter MacCallum Cancer Centre, Australia (POD2-1)*<br>• How do young people with a hereditary cancer predisposition syndrome understand and experience cancer survivorship? "With Li-Fraumeni syndrome, it's just an intermission" – *Allison Werner-Lin, PhD, LCSW, University of Pennsylvania, United States (POD2-2)*<br>• Courageous conversations: Voicing My CHOiCES and other communication tools for children, adolescents and young adults living with a serious illness – *Lori Wiener, PhD, National Cancer Institute, United States (POD2-3)* |
| 12:30 – 2:00 p.m.<br>Front Circle<br><br>1:15 – 2:00 p.m.<br>Room 2W910/912 | **Lunch**<br><br>**Early Career Investigator Interest Group – Networking Opportunity**<br>*(Moderators: Chloe Huelsnitz, PhD, MPH, National Cancer Institute, United States and Rowan Forbes Shepherd, PhD, National Cancer Institute, United States)* |
| 2:00 – 3:00 p.m.<br>Fraumeni Room | **Parallel Paper Session: Traceback genetic testing: A novel approach for retrospective identification and cascade testing for hereditary cancer risk (PA1)**<br>*(Moderators: Nora Henrikson, PhD, MPH, Kaiser Permanente Washington, United States and Alanna Kulchak Rahm, PhD, CGC, Geisinger, United States; Discussant: Charlisse Caga-anan, JD, National Cancer Institute, United States)*<br>• Implementing traceback programs for hereditary cancer in three health systems – *Cabell Jonas, PhD, Mid-Atlantic Permanente Research Institute, United States (PA1-1)*<br>• Your Family Connects: A theory-based intervention to encourage communication about inherited cancer risk among ovarian cancer survivors and close relatives – *Yue Guan, MB, PhD, ScM, Emory University, United States (PA1-2)*<br>• Feasibility of a traceback approach to provide genetic risk information to families in the Genetic Risk Analysis in Ovarian Cancer (GRACE) study – *Jessica Hunter, PhD, RTI International, United States (PA1-3)* |

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| 2:00 – 3:00 p.m.<br>Seminar 110 | **Parallel Paper Session: Cancer risk management for individuals with pathogenic *CDH1* variants (PA2)**<br>*(Moderator: Eveline M. A. Bleiker, PhD, The Netherlands Cancer Institute, The Netherlands)*<br>• The lived experience of emerging adults with a *CDH1* disease causing variant: An interpretative phenomenological approach – *Yi Liu, MS, National Cancer Institute, United States (PA2-1)*<br>• Grieving the loss of life with a stomach: Examining identity changes after prophylactic total gastrectomy for individuals with a *CDH1* pathogenic/likely pathogenic variant – *Rachael Lopez, MPH, RD CSO, National Institutes of Health Clinical Center, United States (PA2-2)*<br>• Development of an online decision support tool for those at high risk to develop gastric cancer – *Eveline M. A. Bleiker, PhD, The Netherlands Cancer Institute, The Netherlands (PA2-3)* |
| 3:00 – 4:00 p.m.<br>Cafeteria<br><br>Seminar 110 | **Break**<br><br>**Poster Session #1** |
| 4:00 – 5:15 p.m.<br>Seminar 110 | **Parallel Paper Session: Experiences of uncertainty in living with hereditary cancer risk (PA3)**<br>*(Moderator: Paul Han, MD, MA, MPH, National Cancer Institute, United States)*<br>• The use of social media to express and manage medical uncertainty in Dyskeratosis Congenita – *Emily Pearce, MPH, University of North Carolina at Chapel Hill, United States (PA3-1)*<br>• Uncertainty management for hereditary cancer: Personalised, shared decision-making with providers complemented by an interactive patient decision aid website – *Kelly Kohut, MSc, University of Southampton/ St George's University Hospitals NHS Foundation Trust, United Kingdom (PA3-2)*<br>• Developing psychosocial and educational materials for families living with RUNX1-FPD – *Vainavi Gambhir, University of Maryland, College Park, United States (PA3-3)*<br>• What is the impact of *BRCA1/2* status on young women's reproduction and relationships after predictive testing? An Australian case-control study – *Laura Forrest, PhD, Peter MacCallum Cancer Centre, Australia (PA3-4)* |
| 4:00 – 5:15 p.m.<br>Fraumeni Room | **Parallel Paper Session: Experiences and communication among parents/caregivers and children at risk for hereditary cancers (PA4)**<br>*(Moderator: Rowan Forbes Shepherd, PhD, National Cancer Institute, United States)*<br>• What do high-risk parents perceive to be the benefits/harms of pediatric DTC genetic testing for adult-onset inherited cancer syndromes? Implications for children's healthcare – *Marcelo Sleiman Jr, BA,* |

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| | *Georgetown University Lombardi Comprehensive Cancer Center, United States (PA4-1)*<br>• Parents' sequencing-related distress following disclosure of pediatric oncology germline sequencing results – *Katianne Howard Sharp, PhD, St. Jude's Children's Research Hospital, United States (PA4-2)*<br>• PLAY-THE-ODDS: Co-designing a communication tool to help parents talk about genetic cancer risk with their children – *Hernâni Oliveira, PhD, University of Évora, Portugal (PA4-3)*<br>• Adjustment of AYA and caregivers of pediatric probands tested for a genetic cancer predisposition – *Lisa Schwartz, PhD, The Children's Hospital of Philadelphia (CHOP), United States (PA4-4)* |
| 6:30 – 9:00 p.m. | **Optional Social Event:** An evening of bowling and snacks held at Bowlero Rockville (15720 Shady Grove Road, Gaithersburg, MD 20877) – *Pre-registration required* |

| **Wednesday, May 24, 2023** | |
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| 8:00 – 8:30 a.m.<br>Lobby | **Registration** |
| 8:30 – 9:45 a.m.<br>Fraumeni Room | **Keynote Panel: Identifying and meeting the needs of adolescents and young adults (AYAs) with inherited cancer syndromes (KEY2)**<br>*(Moderator: Allison Werner-Lin, PhD, LCSW, University of Pennsylvania, United States; Panel Moderator: Amelia Coffaro, C-IAYT, University of Wisconsin-Milwaukee, United States)*<br>• The AYA-RISE intervention: Risk information and screening education for adolescents and young adults with genetic cancer risk syndromes – *Jennifer Mack, MD, MPH, Dana-Farber Cancer Institute, United States (KEY2-1)*<br>• A focus on the mental health of young people with inherited cancer syndromes: A mixed-method study of Li-Fraumeni syndrome – *Rowan Forbes Shepherd, PhD, National Cancer Institute, United States (KEY2-2)*<br>• "Sometimes I don't want to hear it, sometimes I'll hear it": A qualitative analysis characterizing parent-AYA communication about their cancer predisposition in AYA with Cancer – *Katianne Howard Sharp, PhD, St. Jude Children's Research Hospital, United States (KEY2-3)* |
| 9:45 – 10:30 a.m.<br>Fraumeni Room | **Podium Talks: Novel technologies in action (POD3)**<br>*(Moderator: Chloe Huelsnitz, PhD, MPH, National Cancer Institute, United States)*<br>• Preliminary findings for the implications of polygenic risk scores on prophylactic mastectomy decision making experiences in women with *BRCA1/2* pathogenic variants – *Jada G. Hamilton, PhD, MPH, Memorial Sloan Kettering Cancer Center, United States (POD3-1)* |

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| | • Parents' experiences of germline genomic sequencing carried out as part of their child's participation in a precision medicine trial for poor prognosis paediatric cancer – *Kate Hetherington, PhD, University of New South Wales, Australia (POD3-2)* |
| 10:30 – 11:00 a.m.<br>Cafeteria | **Break** |
| 11:00 a.m. – 12:15 p.m.<br>Fraumeni Room | **Podium Symposium: Intervention strategies to facilitate access to cancer genetic services: Re-thinking approaches to mitigating disparities (POD4)**<br>*(Moderators: Kimberly Kaphingst, ScD, University of Utah, United States and Catharine Wang, PhD, Boston University School of Public Health, United States; Discussant: Yvonne Bombard, PhD, University of Toronto, Canada)*<br>• Evaluating disparities in uptake and outcomes with digital alternatives for pre-test education in return of cancer genetic research results – *Angela Bradbury, MD, University of Pennsylvania, United States (POD4-1)*<br>• Impact of automated tools on disparities in reach and utilization of cancer genetic services – *Kimberly Kaphingst, ScD, University of Utah, United States (POD4-2)*<br>• Incorporating patient and relative preferences in the design of traceback cascade testing initiatives – *Alanna Kulchak Rahm, PhD, CGC, Geisinger, United States (POD4-3)*<br>• Understanding drivers of disparities in accessing cancer genetic services – *Catharine Wang, PhD, Boston University School of Public Health, United States (POD4-4)* |
| 12:15 – 1:45 p.m.<br>Farmers' Market<br><br>12:15 – 1:00 p.m.<br>Room 2E908<br><br>1:00 – 1:45 p.m.<br>Fraumeni Room | **Lunch**<br><br>**Meeting of Scientific Committee**<br><br>**Meet NCI/NIH Program Directors**<br>• ***Erica Breslau, PhD, MPH,*** *Health Systems and Interventions Research Branch, Healthcare Delivery Research Program, National Cancer Institute, United States (virtual attendees only)*<br>• ***Charlisse Caga-anan, JD,*** *Genomic Epidemiology Branch, Epidemiology and Genomics Research Program, National Cancer Institute, United States*<br>• ***Sylvia Chou, PhD, MPH,*** *Health Communication and Informatics Research Branch, Behavioral Research Program, National Cancer Institute, United States*<br>• ***Lucia Hinderoff, PhD, MPH,*** *Lead Extramural Training Program Director, National Human Genome Research Institute, United States*<br>• ***Nicole C. Lockhart, PhD,*** *Division of Genomics and Society, National Human Genome Research Institute, United States* |

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| | • ***Wendy Nelson, PhD, MPH,*** *Basic Biobehavioral and Psychological Sciences Branch, Behavioral Research Program, National Cancer Institute, United States (virtual attendees only)*<br>• ***Nonniekaye Shelburne, CRNP, MS, AOCN,*** *Clinical and Translational Epidemiology Branch, Epidemiology and Genomics Research Program, National Cancer Institute, United States* |
| 1:45 – 3:00 p.m.<br>Fraumeni Room | **Parallel Paper Session: Approaches to promoting hereditary cancer cascade testing (PA5)**<br>*(Moderator: Laura Forrest, PhD, Peter MacCallum Cancer Centre, Australia)*<br>• Motivational drives and psychological determinants of men's adherence to cascade screening for *BRCA1/2 – Giulia Ongaro, MSc, European Institute of Oncology, Milan, Italy (PA5-1)*<br>• Early outcomes of the ECHO Study: Evaluating cascade communication methods amongst individuals and families with a confirmed hereditary cancer predisposition syndrome – *Danielle McKenna, MS, University of Pennsylvania, United States (PA5-2)*<br>• Decision satisfaction and regret among genetic testing patients offered health system-led direct contact of at-risk relatives – *Nora Henrikson, PhD, MPH, Kaiser Permanente Washington, United States (PA5-3)*<br>• "I didn't have to worry about it": Patient and family experiences with a new U.S. health system-mediated direct contact program – *Paula Blasi, MPH, Kaiser Permanente Washington, United States (PA5-4)* |
| 1:45 – 3:00 p.m.<br>Seminar 110 | **Parallel Paper Session: Decision making and adjustment to hereditary cancer risk management (PA6)**<br>*(Moderator: Camella Rising, PhD, MS, RDN, National Cancer Institute, United States)*<br>• Factors that differentiate cancer risk management decisions among females with pathogenic/likely pathogenic variants in *PALB2*, *CHEK2*, and *ATM – Marleah Dean, PhD, MA, University of South Florida, United States (PA6-1)*<br>• Identification of men with a genetic predisposition to prostate cancer: Targeted screening of *BRCA1/2* mutation carriers and controls (The IMPACT study Quality of Life Study) – *Elizabeth Bancroft, RN, PhD, The Royal Marsden NHS Foundation Trust, United Kingdom (PA6-2)*<br>• The benefits and burden of annual whole-body MRI screening of individuals with Li-Fraumeni syndrome – *Eveline M. A. Bleiker, PhD, The Netherlands Cancer Institute, The Netherlands (PA6-3)*<br>• Understanding scanxiety among individuals with Li-Fraumeni syndrome undergoing periodic cancer screening: A qualitative study – *Rowan Forbes Shepherd, PhD, National Cancer Institute, United States (PA6-4)* |
| 3:00 – 4:00 p.m.<br>Cafeteria<br><br>Seminar 110 | **Break**<br><br>**Poster Session #2** |

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| 4:00 – 5:15 p.m.<br>Fraumeni Room | **Podium Talks: Uncovering psychological influences on family communication about hereditary cancer risk (POD5)**<br>*(Moderator: Sook-Yee Yoon, MA, Cancer Research Malaysia, Malaysia)*<br>• "I told them that they had to get tested, and they did": Sibling social influences on LFS testing, screening, and decision-making – *Chloe Huelsnitz, PhD, MPH, National Cancer Institute, United States (POD5-1)*<br>• Identifying effective resources for family communication about Lynch Syndrome cascade testing – *Yanete Rodriguez, BS, University of Utah, United States (POD5-2)*<br>• Communication preferences regarding genetic testing in individuals from hereditary breast/ovarian cancer families with identified pathogenic variants in a diverse Asian setting: A qualitative study – *Tiara Hassan, MGenCouns, Cancer Research Malaysia, Malaysia (POD5-3)*<br>• Unmet psychosocial needs among individuals with a telomere biology disorder: A mixed-methods study – *Catherine Wilsnack, MSW, University of Texas at Austin, United States (POD5-4)* |
| 5:15 – 5:30 p.m.<br>Fraumeni Room | **Closing Ceremony and Presentation of Awards**<br>**2025 Conference Announcement**<br>*Allison Werner-Lin, PhD, LCSW, University of Pennsylvania, United States*<br>*Jada G. Hamilton, PhD, MPH, Memorial Sloan Kettering Cancer Center, United States* |

## Poster Session #1: (POS1)

- Perceived value of genetic testing for hereditary cancer among previvors: A qualitative study among previvors – *Emerson Dusic, MPH, University of Washington, United States (POS1-1)*
- Cancer screening and surveillance behaviors in recipients of cancer-related secondary genomic findings – *Charlotte Early, BS, National Human Genome Research Institute, United States (POS1-2)*
- Requests for provider-mediated counseling and genetic testing choices among patients with metastatic cancer referred for genetic testing in the eReach Study – *Dominique Fetzer, BA, University of Pennsylvania, United States (POS1-3)*
- Collecting complete family history greatly increases identification of patients who meet clinical criteria for cancer genetic testing in a community setting – *Erika N. Hanson, BA, University of Michigan, Michigan Medicine, United States (POS1-4)*
- Parental attitudes and experiences with germline genetic testing in the pediatric oncology setting: Implications for the practice of genetic counseling – *Wendy Kohlmann, MS, University of Utah Huntsman Cancer Institute, United States (POS1-5)*
- Practices and views of U.S. oncologists and genetic counselors regarding patient recontact following variant reclassification: Results of a nationwide survey – *Sukh Makhnoon, PhD, MPH, University of Texas Southwestern, United States (POS1-6)*
- Association of genetic counseling and testing experience with emotional outcomes in individuals with variant of uncertain significance results from cancer multiplex genetic testing – *Hannah Ovadia, MA, Memorial Sloan Kettering Cancer Center, United States (POS1-7)*
- Impact of COVID-19 pandemic point-of-care genetic testing of advanced cancer patients – *Kelsey Spielman, MS, University of Pennsylvania, United States (POS1-8)*
- "I'm grateful it's just me having to fight for myself:" The supportive care needs of individuals with de novo TP53 variants-- *Ashley S. Thompson, BS, National Cancer Institute, United States (POS1-9)*
- Mothers' and children's psychological distress and family communication behavior about genetic breast cancer risk: Considerations for research, counseling, and cancer prevention – *Mary Rose Yockel, BA, Georgetown University Lombardi Comprehensive Cancer Center, United States (POS1-10)*

## Poster Session #2: (POS2)

- A mixed methods study examining primary care provider needs for conducting clinical cancer consultations – *Sarah Conner, MPH, University of Washington, United States (POS2-1)*
- *CDH1* cascade genetic testing in at-risk relatives: An assessment of the impact of proband characteristics on uptake – *Grace-Ann Fasaye, ScM, National Cancer Institute, United States (POS2-2)*
- Evaluation of the breast cancer mainstream genetic testing program at the Parkville Familial Cancer Centre, Victoria, Australia: Patients and clinicians' experiences and health service outcomes – *Laura Forrest, PhD, Peter MacCallum Cancer Centre, Australia (POS2-3)*
- "Miracle of technology" or "playing God"? A qualitative exploration into the role of Judaism in observant Jewish women's patient decision-making about PGD for BRCA – *Samantha Klein, MA, The New School, United States (POS2-4)*
- Communication about hereditary cancer risk to offspring: A systematic review of children's perspective – *Esperança Lima, University of Porto, Portugal (POS2-5)*

- Caregiver experiences navigating telomere biology disorder-related social support with family and friends – *Camella Rising, PhD, MS, RDN, National Cancer Institute, United States (POS2-6)*
- Impact of ambiguity aversion on genetic testing concerns following "mainstreaming" hereditary cancer multigene panel testing – *Caroline Salafia, MA, University of Connecticut, United States (POS2-7)*
- Pediatric oncology, tumor molecular profiling, and paired genetic testing: Parents' experiences and implications for healthcare delivery – *Marcelo Sleiman Jr, BA, Georgetown University Lombardi Comprehensive Cancer Center, United States (POS2-8)*
- Care priorities among BRCA mutation carriers: A pilot survey – *Emily Webster, MD, Weill Cornell Medicine, United States (POS2-9)*
- Facilitating return of genetic research results from a biobank repository: Participant uptake and utilization of digital interventions – *Elizabeth Wood, MS, University of Pennsylvania, United States (POS2-10)*

# Abstracts

## Keynote Presentations

KEY1

### IMPACT OF HEALTH COMMUNICATION AND HEALTH INFORMATION TECHNOLOGY APPROACHES ON DELIVERY OF CANCER GENETIC SERVICES

**Kimberly A. Kaphingst, ScD.** Department of Communication and Huntsman Cancer Institute, University of Utah, United States

Communication about genetic and genomic information in clinical settings increasingly faces challenges related to information complexity, uncertainty, and volume. Successful translation of this information into improved patient-centered care and health outcomes depends upon patients' and providers' genetics-related knowledge and skills. This presentation will frame communication challenges in genetics and genomics around the concept of genetic literacy (i.e., genetics-related knowledge and skills). The presentation will first discuss the state of the cancer genetic communication literature, identifying critical gaps related to the dearth of studies examining genetic literacy as well as gaps in populations included in studies and use of social and behavioral theory. Findings from a recent review of studies assessing genetic literacy will also be discussed, highlighting issues in conceptualizing and measuring this construct. The presentation will then focus on two recent studies illustrating how genetic literacy and health literacy frameworks can inform health communication and health information technology approaches to the communication of genetic information. The first study examined whether health literacy was related to cognitive and emotional responses to genetic test results for the *MC1R* gene in a diverse primary care patient population. In this study, patients were offered genetic testing via a website developed based on plain language and clear communication principles. While reported confusion about genetic test results was generally low, patients with limited health literacy were more likely to report confusion, and health literacy impacted the degree to which patients elaborated upon their findings. The second study is utilizing an AI-enabled conversational agent (i.e., a chatbot) to deliver cancer genetic services. The presentation will describe how genetic literacy considerations informed the creation of the chatbot and will present data describing how patients utilize the pre-test genetics education chat. The implications for how health technology approaches may address disparities in the utilization of cancer genetic services by patients across subgroups defined by race, ethnicity, language preference, health literacy, and gender will be discussed. The presentation will then conclude with recommendations for future research directions.

KEY2

## PANEL: IDENTIFYING AND MEETING THE NEEDS OF ADOLESCENTS AND YOUNG ADULTS (AYAS) WITH INHERITED CANCER SYNDROMES

**Moderators: Allison Werner-Lin, PhD, LCSW.** University of Pennsylvania, United States
**Amelia Coffaro, C-IAYT.** University of Wisconsin-Milwaukee, United States

KEY2-1

## THE AYA-RISE INTERVENTION: RISK INFORMATION AND SCREENING EDUCATION FOR ADOLESCENTS AND YOUNG ADULTS WITH GENETIC CANCER RISK SYNDROMES

**Jennifer Mack, MD, MPH.** Dana-Farber Cancer Institute, United States

**Coauthors:** Jaclyn Schienda, ScM, CGC;[1,2,5] Kayla Hamilton, MS, CGC;[1,2] Huma Q. Rana, MD MPH;[1] Emilie Simmons, MSc;[3] Moran Snir, MSc MBA;[3] Guy Snir, BSc, MBA;[3] Lauren Fisher, MPH;[1] Andrew Khalaj, BA;[1] James L. Klosky, PhD, ABPP;[4] Christopher Porter, MD;[4] Bojana Pencheva, MMSc, CGC;[4] Joshua Schiffman, MD;[5] Luke Maese, DO;[5] Wendy Kohlmann, MS;[5] Tara Henderson, MD, MPH;[6] Ami Desai, MD, MSCE;[6] Sarah Savage, MS, CGC;[7] Judy Garber, MD, MPH;[1] Lisa Diller, MD;[1] Junne Kamihara, MD, PhD[1,2]

Affiliations: [1]Dana-Farber Cancer Institute, and [2]Boston Children's Hospital, USA; [3]Nest Genomics, USA; [4]Emory University, USA; [5]Huntsmann Cancer Institute, USA; [6]University of Chicago, USA; [7]Invitae Corporation, USA

**Objective:** Genetic counseling and testing is increasingly recommended for adolescents and young adults (AYAs) with cancer; however, no AYA-specific models for cancer risk communication have been developed. We developed a patient- and family-centered cancer risk communication tool using a chatbot to meet the needs of AYAs. In this study, we evaluated feasibility, acceptability, and preliminary outcomes of the AYA Risk Information and Screening Education (AYA-RISE) intervention. **Method:** In collaboration with AYAs with cancer risk syndromes, family members, and clinicians, we developed a chat using Invitae's Gia® chatbot to communicate cancer risk information and recommended screening for AYAs aged 12-24 years with 9 different syndromes: Li-Fraumeni syndrome*; DICER1*; Hereditary Paraganglioma-Pheochromocytoma; Hereditary Retinoblastoma; Familial Adenomatous Polyposis; *BRCA1* and *BRCA2*-Associated Hereditary Breast and Ovarian Cancer; Lynch syndrome; Von Hippel Lindau syndrome; and Neurofibromatosis Type 1. AYAs with one of the included syndromes were enrolled at the time of a scheduled follow-up visit to the Pediatric Cancer Genetic Risk Program at Dana-Farber Cancer Institute. Cognitive screening was conducted with the NeuroQOL to confirm eligibility. Patients were asked to complete a pre-visit survey to report their knowledge of cancer risk, recommended screening, and distress. They then had their clinic visit and were given time to interact with the syndrome-appropriate chat, followed by completion of the post-visit survey. **Results:** 10 AYAs were enrolled; diagnoses were Li-Fraumeni syndrome (n=3), Hereditary Paraganglioma-Pheochromocytoma (n=3); Hereditary Retinoblastoma (n=1); Familial Adenomatous Polyposis (n=2); and *BRCA1* (n=1). Enrollment and chat use were feasible. Eighty

percent of AYAs scored acceptability as ≥4 on a 5-point scale, exceeding our threshold for acceptability. In the pre-visit survey, 40% of AYAs correctly reported 10-year cancer risk, and 20% correctly reported lifetime cancer risk. Following the visit and use of the chat, 60% correctly reported 10-year risk and 90% correctly reported lifetime risk. Distress had minimal change, with pre-visit distress thermometer mean score 3.6 and post-visit mean 3.6. **Conclusions:** The AYA-RISE chat intervention was feasible and acceptable for use in AYAs. Preliminary outcomes included improved knowledge without increasing distress when used in conjunction with a cancer risk clinic visit. A randomized trial is underway.

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KEY2-2

## A FOCUS ON THE MENTAL HEALTH OF YOUNG PEOPLE WITH INHERITED CANCER SYNDROMES: A MIXED-METHOD STUDY OF LI-FRAUMENI SYNDROME

**Rowan Forbes Shepherd, PhD.** National Cancer Institute, United States

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**Objective:** Inherited cancer syndromes give rise to unique psychosocial stressors. Li-Fraumeni syndrome (LFS), for example, is characterized by whole-body cancer risks from birth, limited preventive options, and risk of early mortality. Adolescents and young adults (AYAs) occupy a critical period of development and may be vulnerable to poor mental health outcomes due to experiencing the significant physical and psychosocial burdens of LFS. To inform the design of targeted psychosocial support, this mixed-method study examined AYAs' reported mental health and their intersection with LFS- and lifespan-related factors. **Method:** AYAs (aged 15-39 years) recruited from the National Cancer Institute's LFS study (NCT01443468) completed qualitative interviews and/or an online survey with validated measures, including the Genetic Psychosocial Risk Instrument (GPRI). Statistics were calculated using SPSS. An inter-professional team thematically analyzed interview data using Dedoose™. **Results:** Thirty-seven AYAs completed surveys (78% female, 51% cancer history) and 38 AYAs completed interviews (71% female, 66% cancer history), 11 completed both. Mean GPRI scores were high (62.6/100) with 84% of survey respondents scoring above the 50-point threshold for psychosocial distress. Survey respondents self-reported past emotional problems (n=26, 70%), depression or anxiety diagnoses (n=25, 68%), and suicidal ideation (n=16, 43%). Past suicidal ideation was significantly correlated with younger age at awareness of LFS ($r=-.391$, $p<0.05$) but not with personal cancer history. Interviewees described personal and familial cancer diagnoses and cancer worry, grief, and loss that challenged their mental health. Integrating high cancer risk into daily life induced a range of adaptive responses and most AYAs engaged in extensive meaning making as a form of coping.

The chronicity and uncertainty of living with LFS was a commonly reported source of distress. Although most survey respondents (n=29, 78%) had previously received mental health counseling, fewer (n=11, 30%) reported receiving counseling currently. **Conclusions:** AYAs with LFS are at risk of poor mental health outcomes due to uncertainty and loss in multiple domains of personal and familial life. Acute periods of co-occurring developmental and LFS-related change are unique stressors that require specialist mental health support. This study provides critical mental health data for the design of psychosocial interventions for LFS.

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KEY2-3

## "SOMETIMES I DON'T WANT TO HEAR IT, SOMETIMES I'LL HEAR IT": A QUALITATIVE ANALYSIS CHARACTERIZING PARENT-AYA COMMUNICATION ABOUT THEIR CANCER PREDISPOSITION IN AYA WITH CANCER

**Katianne Howard Sharp, PhD**. St. Jude Children's Research Hospital, United States

**Coauthors:** Alise Blake, MS, CGC;[1] Jessica Flynn, MS;[1] Sydney Brown;[1] Jihan Rashed, BS[1]

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**Objective:** Parents of children with cancer predisposition report uncertainty in how to communicate with their child about their cancer risk and a desire for assistance with these conversations; however, little is known about how families currently communicate about cancer predisposition in the context of a prior cancer. This study sought to characterize parent-child communication about cancer predisposition in adolescents and young adults (AYA) with cancer history and an underlying predisposition. **Method:** AYA (n=21; 13-21 years old) with a germline pathogenic variant in a gene linked with cancer and their parents (n=20) completed semi-structured qualitative interviews regarding the impact of germline results identifying cancer predisposition and parent-child communication about results. All AYA completed germline testing at a cancer predisposition clinic at a pediatric oncology hospital following a diagnosis of cancer, with results disclosed 1-4 years before interviews. Two coders used the constant comparative method for inductive content analysis. **Results:** Sixteen (76%) AYA reported communicating with their parents about their genetic test results; however, 19 (95%) parents described communicating with their child. Communication consisted of disclosing/explaining genetic test results, discussing the future cancer risk to self or offspring, educating about surveillance to manage future risk, and providing reassurance. Of those who communicated, half of AYA (n=8) described a one-time conversation following disclosure. Communication was described by many parents as "surface-level" or pared down in scope, with many saying they do not know how much their child understands; however, most AYA (n=15, 71%) did not anticipate future communication. Families communicated through humor; metaphor; a focus on proactive planning; answering AYAs' questions; AYAs' medical appointments; and, in one family, a PowerPoint presentation. **Conclusions:** Although nearly all parents described communicating with their child regarding their cancer predisposition, not all AYA remembered, and some appeared to differ from their parents in expectations for future communication. Although literature has recommended ongoing, developmentally tailored education about the

implications of hereditary cancer risk to ensure that young adults are prepared to become active advocates in their own healthcare, findings do not support ongoing communication for many in this population.

## Invited Talks

INV1

### RECOGNIZING BARRIERS TO HEREDITARY CANCER GENETIC TESTING: INSIGHTS FROM A POPULATION-BASED, PUBLICLY FUNDED HEREDITARY CANCER PROGRAM

**Kasmintan Schrader**, **MBBS, FRCPC, PhD, DABMGG.** Co-Medical Director, Hereditary Cancer Program, BC Cancer, British Columbia, Canada

**Objective:** The Hereditary Cancer Program is a population-based service delivering care to British Columbia and Yukon since 1996. Delivery of care is centralized to the province, mainly via virtual health. As cost is not a barrier in Canada for hereditary cancer index and cascade carrier testing, we undertook several studies to understand rates of testing and patient reported outcomes in our population-based clinic cohort. **Method:** Over 3 separate studies we: 1) Reviewed standardized multigene panel testing from October 2014 to August 2017 in patients aged ≥18 years undergoing index genetic testing, 2) analyzed the Multidimensional Impact of Cancer Risk Assessment (MICRA) patient reported outcomes in 917 patients, and 3) analyzed mutation-positive index cases from 2015-2018, and the corresponding carrier tests for their relatives from 2015-2019. Self-reported ancestry was reviewed in all. **Results:** Review of index genetic testing for hereditary cancer susceptibility suggests uneven testing of minorities. Individuals of Asian, Pacific Islander, Black Canadian, Indigenous and Latin American ancestry were significantly underrepresented as compared to the 2016 BC population census. Analysis of the MICRA revealed patients of Asian ethnicity scored higher than those of European ethnicity on the distress and uncertainty subscale, and patients with pathogenic variants either on index or carrier testing experienced greater distress, uncertainty, and feelings of negative experiences as compared to those who did not have any mutations identified. Review of cascade testing revealed more than half of families of European origin had at least 1 member tested for the familial variant as compared to less than half of families of Asian and Indigenous origin ($p<0.05$). **Conclusions:** Despite testing costs not being a barrier, patients of ethnic minority populations appear to access index and cascade genetic testing less than expected when compared to population census data and non-ethnic minority population testing rates. When testing is achieved, there may be a need for increased psychological support in pathogenic variant carriers and some minority subset populations. Systematic interventions, new technologies, and new partnerships to improve culturally competent care, are several ways that may help address disparities in testing and psychological outcomes.

INV2

**BODY IMAGE, HEALTH BEHAVIORS, AND HEALTH-RELATED QUALITY OF LIFE IN YOUNG PEOPLE WITH INHERITED MULTI-ORGAN CANCER RISK: A CALL FOR MINDFUL SELF-COMPASSION-FOCUSED INTERVENTIONS**

**Camella Rising, PhD, MS, RDN.** National Cancer Institute, United States
**Amelia Coffaro, C-IAYT, Certified Yoga Therapist.** University of Wisconsin-Milwaukee, United States

**Coauthors:** Chloe O. Huelsnitz, PhD, MPH; Rowan Forbes Shepherd, PhD; Catherine Wilsnack, MSW, LMSW; Alix G. Sleight, PhD, OTD, MPH, OTR/L; Patrick Boyd, PhD; Payal P. Khincha, MD; Allison Werner-Lin, PhD, LCSW

**Objective:** Cancer-related shifts in bodily appearance and function may negatively affect body image, health behaviors, and health-related quality of life (HRQOL) in adolescent and young adult (AYA) cancer survivors. We aimed to extend the literature by exploring how AYAs with inherited multi-organ cancer risk associated with Li-Fraumeni syndrome (LFS) adjust to bodily changes, modify health behaviors, and describe their HRQOL. **Method:** Participants (N=57) were AYAs with LFS aged 15-39 years enrolled in the National Cancer Institute LFS study. AYAs completed wave 1 (n=38) and/or wave 2 interviews (n=30) and/or an online survey (n=37). We asked AYAs about their health and wellbeing, health behaviors, and adaptation to LFS and bodily changes in interviews. Survey items measured reported body acceptance and HRQOL. Quantitative and qualitative data were analyzed concurrently. We partnered with AYA patient advocate and yoga therapist, A.C., to verify findings and discuss translation into future intervention research focused on meaningful outcomes. **Results:** AYAs were mostly female (n=44/57, 77%), with mean age 30 years and ≥1 primary cancer (n=33/57, 58%). Controlling for prior cancer history, lower reported body acceptance was associated with lower physical (β=.50, 95% CI [.20, .80]), psychological (β=.60, 95% CI [.33, .88]), and social health (β=.61, 95% CI [.35, .88]). Interviewees described complex, sometimes distrusting or disconnected, relationships with their bodies due to frequent self-monitoring, whole-body scans, risk-reducing surgeries, and cancer treatment. Most reported heightened body attunement, which facilitated self-protective behaviors but, at times, triggered worry and preoccupation. AYAs described “healthy” eating and physical activity as important aspects of cancer (p)rehabilitation and strategies to mentally cope with LFS. However, they also mentioned difficulty balancing these behaviors with life enjoyment and feeling burdened by overthinking or overcontrolling behaviors. **Conclusions:** Findings suggest AYAs with LFS may experience challenges adjusting to bodily changes and adapting health behaviors for dynamic shifts in health. Past research suggests mindful self-compassion (MSC) interventions may ameliorate these challenges by building adaptive coping skills and improving self-acceptance. We will explicate the potential benefits of MSC approaches in the AYA-LFS context and share strategies for incorporating them in research and clinical practice.

## Podium Talks

POD1

**DIVERSITY, EQUITY, AND INCLUSION IN HEREDITARY CANCER CARE**

**Moderators: Kasmintan Schrader, MBBS, FRCPC, PhD, DABMGG.** The University of British Columbia, Canada
**Allison Werner-Lin, PhD, LCSW.** University of Pennsylvania, United States

POD1-1

### ÁRBOLES FAMILIARES ACTION PROJECTS: IMPLEMENTATION OF TRAINEE KNOWLEDGE ABOUT HEREDITARY BREAST AND OVARIAN CANCER INTO THE LATINX COMMUNITY

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**Objective:** Significant gaps remain in uptake of genetic risk assessment for hereditary breast and ovarian cancer (HBOC) in the Latinx community. These gaps are due to numerous barriers, including lack of access to care, lower rates of referrals, language barriers, and low awareness of HBOC. Prior research in cancer education demonstrates that community outreach and health education professionals can effectively increase knowledge and awareness about cancer screenings and care. The ÁRBOLES Familiares Training Program has trained 256 community outreach and education professionals (CORE-Ps) to improve the knowledge, skills, and confidence of CORE-Ps about cancer genetics HBOC. After a 2.5-day in-person workshop and 6 online sessions, CORE-Ps submit a final ÁRBOLES Action Project. Action Projects consist of a tool or educational materials that CORE-Ps can use in the Latinx community to educate and/or navigate individuals who may be at-risk for HBOC. The objective of this study was to describe and explore the goals and proposed uses of CORE-Ps Action Projects. **Method:** We purposefully selected 34 action projects from 3 recent ARBOLES Familiares training cohorts (completed from March 2021 to June 2022) representing different languages, CORE-P characteristics and occupations, and project topics. We developed and iteratively refined a coding system used by 2 independent raters to delineate Action Project characteristics, themes, and goals. Raters compared codes and discussed with a third rater to reach a consensus. **Results:** The 34 action projects included varying formats: 8 flyers, 10 presentations, 7 posters, 7 guides, 1 FAQ, and 1 video. 38.2% were in Spanish, 41.2% in both Spanish and English and 20.6% in English. CORE-Ps appeared able to successfully apply accurate knowledge about HBOC into the Action Projects.

Four themes emerged as the primary goals of the Action Projects: explanation of hereditary cancer, strategies to support navigation to genetic risk assessment, risk assessment tools, education about the scientific components of HBOC (e.g., foundations of genetics and processes). **Conclusions:** Results suggest that CORE-Ps were able to develop information about HBOC in a way that is approachable, accurate, and culturally and linguistically appealing to the Latinx community. CORE-Ps may serve as a vital bridge between genetics professionals, researchers, and the Latinx community at risk for HBOC.

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POD1-2

## ADAPTATION AND EVALUATION OF A DECISION AID FOR BRCA1/2 GENETIC TESTING IN HIGH-RISK MALAYSIAN FAMILIES

**Sook-Yee Yoon, MA.** Cancer Research Malaysia, Malaysia

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**Objective:** Despite more than 20 years since the discovery of *BRCA1* and *BRCA2*, challenges remain in the uptake of genetic testing and counselling by probands and their family members in Malaysia. To date, no decision aid (DA) is available for the Asian population considering genetic testing for *BRCA1/2* to support informed decision-making. While adapting existing DAs could be advantageous, translation by itself does not warrant equivalent or linguistically appropriate translation, end-user comprehensibility, and the cultural appropriateness of the tool. We report on the alpha testing for a DA that was adapted from an existing DA used in Australia. **Method:** An existing DA developed for the Australian context was translated into 4 languages spoken in Malaysia. In the alpha testing phase of the evaluation, a qualitative methodology was used. Individual and focus group interviews were conducted in different languages with 11 probands from high-risk breast/ovarian cancer families who had already gone through the decision-making experience. In addition, 8 healthcare professionals were interviewed. **Results:** Reflective thematic analysis showed that the DA was too detailed, that the information and language needed to be simplified for people with lower educational levels, and that it needed to include more visual information. **Conclusions:** A DA must be designed based on culturally specific nuances. In this case, we have shown that adapting a DA from a different patient population may not be fit for purpose. Based on these findings, the DA will have to be revised and re-designed to incorporate the changes for a culturally compatible DA targeted for individuals with varying degrees of health literacy.

POD1-3

## HEREDITARY CANCER RISK ASSESSMENT IN TRANSGENDER ADOLESCENTS AND YOUNG ADULTS: A SCOPING REVIEW OF THE QUALITATIVE, QUANTITATIVE, AND COMMITTEE OPINION LITERATURE

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**Objective:** Cancer genetic counselors are serving an increasing number of transgender and nonbinary adolescents and young adults to assist in risk assessment as it pertains to medical and surgical transition. As our evidence-base and availability of gender-affirming care expands, more patients are able to consider and access interventions in adolescence, such as pubertal blockers, hormone therapy, or gender-affirming surgeries. To ensure appropriate patient consent, current practice is not to offer hereditary cancer testing for adult-onset conditions prior to the age of 18 years except in specific circumstances. However, in the setting of gender-affirming care, the implications of age-based guidelines for hereditary cancer risk assessment and genetic testing have not been thoroughly explored. Healthcare providers in pediatric cancer predisposition have a unique opportunity to utilize cancer family history and genetic testing to support patients' individualized embodiment goals. Our objective is to review the evolving paradigm of hereditary cancer risk assessment and genetic testing for transgender youth. **Method:** A scoping literature review is underway following the Joanna Briggs Institute methodology (Peters et al., 2015). Data is being extracted through a data-charting form created by the study team for this review. **Results [preliminary]:** Cancer risks for transgender people are largely understudied and undefined. Risk assessment, genetic testing, and management guidance for transgender individuals are extrapolated from studies of presumed cisgender patients. Hereditary cancer genetic counseling and testing prior to transition is supported by committee opinion (ACOG, March 2021) and is suggested to be medically necessary before 18 in individuals meeting established criteria (Sutherland et al., 2020). For example, identification of a *BRCA1* variant in a transgender male desiring gender-affirming chest surgery may change surgical technique as compared to a patient at general population cancer risk. **Conclusions:** Long-term prospective research on cancer risk is needed in the transgender population. Initiating data collection in the pediatric period has the potential for greater impact over time. As the importance of genetic testing for transgender and nonbinary adolescents at risk of hereditary cancer syndromes gains recognition, we theorize that genetic counseling can be a valuable facet of gender-affirming care.

POD2

**EXPANDING CANCER CARE BEYOND RISK MANAGEMENT**

**Moderator: Allison Werner-Lin, PhD, LCSW.** University of Pennsylvania, United States

POD2-1

## PERSONALIZING GENETIC COUNSELLING (POETIC) TRIAL: A HYBRID TYPE II EFFECTIVENESS-IMPLEMENTATION RANDOMIZED CLINICAL TRIAL OF A PATIENT SCREENING TOOL TO IMPROVE PATIENT EMPOWERMENT AFTER CANCER GENETIC COUNSELLING

**Laura Forrest, PhD.** Peter MacCallum Cancer Centre, Australia

**Objective:** Genetic counselling aims to identify and address patient needs while facilitating informed decision-making about genetic testing and promoting empowerment and adaptation to genetic information. Increasing demand for cancer genetic testing and genetic counsellor workforce capacity limitations may impact the quality of genetic counselling provided. The use of a validated genetic-specific screening tool, the Genetic Psychosocial Risk Instrument (GPRI), may facilitate patient-centered genetic counseling. The aim of this study is to assess the effectiveness and implementation of using the GPRI in improving patient outcomes after genetic counselling and testing for an inherited cancer predisposition. **Method:** The Personalizing genetic Counselling (POETIC) trial is a hybrid type 2 effectiveness-implementation trial using a randomised control trial to assess the effectiveness of the GPRI in improving patient empowerment (primary outcome), while also assessing implementation from the perspective of clinicians and the healthcare service. Patients referred for a cancer risk assessment to the conjoint clinical genetics service of 2 metropolitan hospitals in Victoria, Australia, who meet the eligibility criteria and consent to POETIC will be randomised to the usual care or intervention group. Those in the intervention group will complete the GPRI prior to their appointment with the screening results available for the clinicians' use during the appointment. Appointment audio recordings, clinician-reported information about the appointment, patient-reported outcome measures, and clinical data will be used to examine the effectiveness of using the GPRI. Appointment audio recordings, health economic information, and structured interviews will be used to examine the implementation of the GPRI. **Conclusions:** The POETIC trial takes a pragmatic approach by deploying the GPRI as an intervention in the routine clinical practice of a cancer-specific clinical genetics service that is staffed by a multidisciplinary team of genetics and oncology clinicians. Therefore, the effectiveness and implementation evidence generated from this real-world health service setting aims to optimise the relevance of the outcomes of this trial to the practice of genetic counselling while enhancing the operationalisation of the screening tool in routine practice.

POD2-2

## HOW DO YOUNG PEOPLE WITH A HEREDITARY CANCER PREDISPOSITION SYNDROME UNDERSTAND AND EXPERIENCE CANCER SURVIVORSHIP? "WITH LI-FRAUMENI SYNDROME, IT'S JUST AN INTERMISSION"

**Allison Werner-Lin, PhD, LCSW.** University of Pennsylvania, United States

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**Objectives:** Despite many formulations, no clear consensus exists regarding what constitutes a cancer survivor, save one immutable feature: one who has lived through a diagnosis and its treatment. The meaning of cancer survivorship may be uniquely complicated for adolescents and young adults (AYAs) with hereditary cancer syndromes, as they live with significantly increased lifetime cancer risk. Survivorship may integrate concerns for cancer recurrence, new tumor development, and the health and wellbeing of family members. Focusing on Li-Fraumeni syndrome (LFS), a hereditary cancer syndrome with high risk of multiple primary cancers from birth, limited options for prevention, and risk of early mortality, we explored how AYAs experience cancer survivorship. **Method**: An interprofessional team conducted 30 semi-structured interviews with AYAs (aged 18-41, mean 31 years) enrolled in the National Cancer Institute's LFS Study (NCT01443468). Twenty had experienced at least 1 cancer diagnosis. Interview data were thematically analyzed by an inter-professional team using interpretive description and thematic analysis. **Results:** Participants viewed "survivorship" as a period marked by no evidence of formerly diagnosed disease. By contrast, participants felt the label "survivor" was tenuous since LFS is characterized by multiple primary malignancies and uncertainty about intervals between one diagnosis and the next. Many AYAs viewed survivorship as requiring a high degree of suffering, which participants witnessed in familial and LFS-related social groups. Though many personally rejected "survivor" identities, almost all articulated its various functions including positive, negative, and more complicated connotations. Instead, they chose language forged in relationship to family and community members to represent a range of beliefs about survival, longevity, prognosis, and activism. **Conclusions**: Survivorship care for AYAs with heritable cancer risk syndromes requires interprofessional interventions that address unique biomedical, developmental, and psychosocial needs. Such care may be localized in survivorship clinics that holistically address the range of sequalae of a cancer diagnosis in the context of ongoing genetic risk.

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POD2-3

## COURAGEOUS CONVERSATIONS: VOICING MY CHOICES AND OTHER COMMUNICATION TOOLS FOR CHILDREN, ADOLESCENTS AND YOUNG ADULTS LIVING WITH A SERIOUS ILLNESS

**Lori Wiener, PhD.** National Cancer Institute, United States

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**Objective:** Adolescents and young adults (AYAs) who are living with a serious illness or medical conditions with uncertain outcomes are faced with unique developmental and psychosocial needs that can go unrecognized or unmet over the trajectory of their care. They are expected to navigate illness while experiencing an emergence of independence and identity development and are often unprepared or left out of treatment discussions. This is especially true when it comes to discussing preferences for care if they become seriously ill and at end-of-life. **Method:** Starting with focus groups with AYAs living with cancer and other chronic conditions, an advance care planning guide was drafted, tested, and adapted. Further testing led to the development of Voicing My CHOiCES (VMC). VMC has since undergone further evaluation for content adaptation in 7 hospital sites across the United States using a 1-month pre-posttest design. 129 AYAs (cancer, NF1, Li-Fraumeni, Dock8, HIV) completed baseline measures about advance care planning communication, anxiety, and social support prior to critically reviewing each page of the document and then completing several pages. One month later, the measures were readministered. AYAs shared the document with a family member, friend, or health care provider who were then interviewed. **Results:** VMC has been found to be helpful, appropriate for AYAs and associated with reduced anxiety immediately after completing several pages of the document and at 1-month follow-up. Family members who communicated with the AYA about what was written in VMC described the conversation as a positive but also difficult experience and appreciated having VMC to facilitate the discussion. Family (76%), friends (67%), and health care providers (50%) did not think the AYA would have discussed end-of-life preferences without completing VMC. **Conclusions:** Communication tools specifically created for AYAs can decrease anxiety and increase communication with family members in and beyond the hereditary cancer risk context. Future research should examine ways advanced care planning can be introduced more consistently to this young population to allow their preferences for care to be heard, respected, and honored, particularly by their healthcare providers.

POD 3

## NOVEL TECHNOLOGIES IN ACTION

**Moderator: Chloe Huelsnitz, PhD, MPH.** National Cancer Institute, United States

POD 3-1

## PRELIMINARY FINDINGS FOR THE IMPLICATIONS OF POLYGENIC RISK SCORES ON PROPHYLACTIC MASTECTOMY DECISION MAKING EXPERIENCES IN WOMEN WITH *BRCA1/2* PATHOGENIC VARIANTS

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**Objective:** The generation of polygenic risk scores (PRS), based on multiple common genetic markers associated with cancer risks, holds promise for improving risk estimation and risk stratification. For women with *BRCA1* or *BRCA2* pathogenic variants associated with hereditary breast and ovarian cancer, specific PRS may help to inform their decisions about risk management strategies. To explore this possibility, we are conducting research to investigate interest in novel PRS-based testing among women with *BRCA1/2* pathogenic variants, as well as their psychological and decision-making responses to PRS-based test results. **Method:** We conducted formative qualitative research among women with *BRCA1/2* pathogenic variants (n=30) to develop risk communication materials for PRS-based test results and to explore patients' perceived utility of such testing. We are now conducting a prospective trial among breast cancer-unaffected women with *BRCA1/2* pathogenic variants (target n=295) to examine effects of PRS-based testing to provide updated breast cancer risk estimates on outcomes including participants' decisional conflict about prophylactic mastectomy, prophylactic mastectomy choice predisposition, and emotional distress. **Results:** Qualitative data demonstrated fairly high interest in PRS-based testing and identified anticipated benefits to guide challenging decisions about how to manage future disease risk. Preliminary trial data from participants who have completed a baseline pre-PRS-based test survey (n=226; ages 25–71, median=36; 3.1% Hispanic/Latina ethnicity; 92.5% White) demonstrate that 38.2% had levels of decisional conflict about prophylactic mastectomy consistent with uncertainty and decision delay, 46.7% reported clinically significant generalized anxiety, and 35.0% reported moderate or severe levels of cancer-specific distress. Analyses suggest significant reductions in decisional conflict (p=0.002) and anxiety (p=0.011) from before testing to 1-week and 6-months following receipt of PRS-based test results. The magnitude of PRS-based breast cancer risk estimates is associated with participants' risk management preferences. **Conclusions**: PRS may influence how patients make complex choices about hereditary cancer risk management. Additional research is needed to explore how PRS-based risk information shapes actual uptake of surgical and screening behaviors, as well as longer term reactions of patients and healthcare providers to such information.

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POD 3-2

## PARENTS' EXPERIENCES OF GERMLINE GENOMIC SEQUENCING CARRIED OUT AS PART OF THEIR CHILD'S PARTICIPATION IN A PRECISION MEDICINE TRIAL FOR POOR PROGNOSIS PAEDIATRIC CANCER

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**Objective:** Paediatric cancer patients are increasingly being offered germline genomic sequencing through precision medicine trials. Such germline sequencing may reveal pathogenic/likely pathogenic variants in cancer predisposition genes in >10% of children, with implications for diagnosis and treatment as well as the child and family's future cancer risk. Testing in this context requires patients/their parents to comprehend the distinction between somatic and germline sequencing and occurs when the family are already coping with significant emotional upheaval (e.g., childhood cancer diagnosis/relapse). Understanding parents' perspectives of germline sequencing is critical for the successful clinical implementation of genomics and precision medicine in childhood cancer care. The current study examined parents' expectations of germline sequencing, their preferences for the scope of information returned to them, and their recall of the results received. **Method:** 182 parents of children (<18 years) with poor prognosis cancers (<30% expected likelihood of survival) enrolled in an Australian precision medicine trial (PRISM) completed questionnaires at enrolment and after the return of their child's results, including clinically relevant germline findings (received by 13% of parents). We also interviewed 45 parents in-depth about their experience receiving germline results. **Results:** At trial enrolment, most parents (63%) believed it was at least "somewhat likely" that their child would receive a clinically relevant germline finding. Almost all expressed a preference to receive a broad range of germline genomic findings, including variants of uncertain significance (88%). Some parents whose child received a germline finding (38%) were unsure whether they received a germline finding, and some parents whose child had not received a germline finding (29%) recalled they had. Qualitatively, some parents expressed confusion and uncertainty about their child's genome sequencing results. **Conclusions:** Many parents of poor prognosis childhood cancer patients enrolled in a precision medicine trial expect their child may have an underlying cancer predisposition syndrome. Parents wish to receive a wide scope of information from germline genome sequencing but may feel confused by the reporting of trial results. Findings highlight the need to design informed consent and return of results processes to manage parents' expectations of germline sequencing and facilitate their understanding of results received.

POD4

**PODIUM SYMPOSIUM: INTERVENTION STRATEGIES TO FACILITATE ACCESS TO CANCER GENETIC SERVICES: RE-THINKING APPROACHES TO MITIGATING DISPARITIES**

**Moderators: Kimberly Kaphingst, ScD.** University of Utah, United States
**Catharine Wang, PhD.** Boston University School of Public Health, United States
**Discussant: Yvonne Bombard, PhD.** University of Toronto, Canada

Prior research has shown important disparities in access to and utilization of cancer-related genetic services. Various intervention strategies are being actively investigated to address disparities in medically underserved communities, including changes to system-level processes, interpersonal strategies, and digital tools. This symposium will describe ongoing intervention efforts to increase access to and utilization of cancer genetic services, focusing on differences in outcomes across patient subgroups defined by race, ethnicity, language preference, health literacy, and/or rurality. Research will examine the impact of intervention strategies in different healthcare system contexts and describe issues of patient engagement across various communities. The first presenter will describe the impact of race, education and genetic knowledge on uptake of genetic research results and completion of digital alternatives to pre-disclosure education. The second presenter will discuss findings on differences across subgroups by race, ethnicity, and language preference of unaffected primary care patients in identification by an automated algorithm and utilization of automated tools (patient portal, conversational agent) designed to improve access to cancer genetic services in 2 large healthcare systems. The third presenter will describe the use of human-centered design to ensure patient-centeredness of a traceback genetic testing program for individuals with ovarian cancer and their family members across three diverse healthcare systems and the impact of that engagement and system-level factors on program design and testing uptake. The fourth presenter will describe racial disparities in genetic testing uptake, which varied across 15 clinical sites that utilized different workflows for implementing a digital system to systematically screen for hereditary cancer risk. Finally, the discussant will summarize the implications of the work presented and propose additional considerations for intervention efforts to mitigate disparities in access and utilization of cancer genetic services that continue to persist.

POD4-1

**EVALUATING DISPARITIES IN UPTAKE AND OUTCOMES WITH DIGITAL ALTERNATIVES FOR PRE-TEST EDUCATION IN RETURN OF CANCER GENETIC RESEARCH RESULTS**

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**Objective:** Evaluation of novel delivery models for return of individual research results to research participants is needed to reduce barriers to receipt of results. **Method:** A stakeholder informed digital pre-disclosure intervention was developed as a self-directed alternative to pre-disclosure education with a genetic counselor (GC). Women at 3 sites who participated in gene discovery research studies were contacted to consider receiving research results for 25 cancer susceptibility genes. Participants could choose to complete pre-disclosure education through the digital intervention or with a GC. All results were disclosed with a GC. Outcomes included uptake of education and research results and participant cognitive and affective outcomes. **Results:** Of 819 participants contacted in the RESPECT2 Study, 21.7% actively and 20.4% passively declined return of results; 474 (57.8%) enrolled. Research participants who actively or passively declined results were more likely to be Black (OR 2.04, p=0.002), to have lower education (OR 1.85 high school vs. college, p=0.026) and not be permitted phone follow-up after the invitation letter (OR 2.83, p<0.001). 88.5% of participants chose the digital intervention for pre-disclosure education and 82.5% completed. Selecting digital education was associated with higher education, higher baseline knowledge, and having lower depression. Completing pre-disclosure education was associated with selecting a GC (OR 11.39, p=<0.01), higher education (OR 3.20 college vs. high school, p=0.002), higher knowledge (OR 1.05/point, p=0.031), and having more relatives with cancer (OR 1.14/relative, p=0.031). Among those who completed pre-disclosure education, most received their research results, which did not differ by method (web vs. GC). In regressions, knowledge increased significantly from baseline to other time points with no significant differences between web and GC education. There were no significant increases in distress between web and GC education. **Conclusions:** Uptake of web-based pre-disclosure education for return of genetic research results was high and there were no significant declines in knowledge or increases in distress with digital pre-disclosure education as compared to education with a GC. However, disparities in uptake of testing and completion of digital alternatives highlight the need to develop and evaluate tools that will increase access to genetic results and not exacerbate health care disparities.

POD4-2

## IMPACT OF AUTOMATED TOOLS ON DISPARITIES IN REACH AND UTILIZATION OF CANCER GENETIC SERVICES

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**Objective:** Advances in genetic technologies are enabling the identification of more individuals who could benefit from cancer genetic testing. Novel approaches are needed to deliver genetic services to meet this demand and different automated tools are being developed. It is critical to examine whether automated tools affect disparities in reach and utilization of cancer genetic services. We are examining this issue in the Broadening the Reach, Impact, and Delivery of Genetic Services (BRIDGE) randomized clinical trial. **Method:** A clinical decision support algorithm utilized cancer family history data available in the electronic health record to identify unaffected primary care patients aged 25-60 in 2 U.S. healthcare systems (University of Utah Health [Utah] and NYU Langone Health [NYU]) who meet guidelines for cancer genetic testing. We outreached through the patient portal to a randomly selected 2,780 eligible patients, with 1:1 randomization to intervention (i.e., delivery of pre-test education and return of negative results via chatbot) or control (clinical standard of care) arms. We are examining disparities by race, ethnicity, and language preference on identification by the algorithm, engagement with the patient portal, and uptake of cancer genetic services. **Results:** Of 169,405 Utah patients, 7,340 (4.3%) met algorithm criteria for cancer genetic evaluation; at NYU, 21,913 (5.6%) of patients met criteria. At both sites, patients who were White, non-Latino, and English-preferring were more likely to be identified compared with patients from other racial groups, Latino, and Spanish-preferring. We found that having information about cancer family history present in the electronic health record differed significantly by race, ethnicity, and language preference at both sites (all $p<0.001$). We are currently examining differences in utilization of the patient portal and pre-test genetic counseling services by race, ethnicity, and language preference. **Conclusions:** We have found systematic differences in identification by an automated algorithm of patients eligible for cancer genetic evaluation in 2 healthcare systems with different clinical structures and patient populations. System-, provider-, and patient-level efforts are needed to improve the collection of family history information to address under-identification of patients from historically underserved groups. We are examining how the use of automated tools (e.g., chatbot) impacts patient engagement.

POD4-3

**INCORPORATING PATIENT AND RELATIVE PREFERENCES IN THE DESIGN OF TRACEBACK CASCADE TESTING INITIATIVES**

**Alanna Kulchak Rahm, PhD, CGC.** Geisinger, United States

**Coauthors:** Katrina Romagnoli; Cabell Jonas; Tracey Klinger; Ilene Ladd; Zachary Salvati; Anna Dinucci; Paula Blasi; Leigh Sheridan; Aaron Scrol; Nora Henrikson

**Objective:** People with ovarian cancer and their biologic relatives can benefit from genetic testing for hereditary cancer risk, yet fewer than one-quarter of women with ovarian cancer are tested. A “Traceback” cascade testing approach seeks to retrospectively identify and offer testing to ovarian cancer patients and their relatives. The FACTS project focuses on the feasibility of a traceback approach, with emphasis on communication strategies, the legal landscape, and an implementation science approach to determine the feasibility of a Traceback cascade screening program and provide information on culturally appropriate language and communication strategies to guide broader implementation. **Method:** We engaged ovarian, fallopian, or peritoneal cancer (probands) and people with a family history of ovarian cancer (relatives) at 3 integrated health systems in the Unites States selected for geographic and population diversity. Using a qualitative, human-centered design approach, we asked about preferred messages and modes for communicating about ovarian cancer genetic testing and to design their ideal experience for receiving information about a Traceback genetic testing program. **Results:** Thirty-one probands and 39 relatives (total n=70 interviews) participated in the design process across the 3 health systems. Overall, a Traceback genetic testing program was acceptable across sites/participants. Participants strongly prefer discussing genetic testing with their doctor but are comfortable discussing with other clinicians. Five preferred experiences for program design were identified and varied by health system and the population served. The most highly preferred experience for both probands and relatives was to have a conversation with a knowledgeable clinician who can answer questions, followed by directed (sent directly to specific people) or passive (shared in a public area). **Conclusions:** Human centered design methods can help illuminate preferred messages and modes of communication for genetic education. While many findings were similar across all participants, small differences in communication preferences by site were identified. These findings informed the Traceback genetic testing program design at all 3 sites.

POD4-4

**UNDERSTANDING DRIVERS OF DISPARITIES IN ACCESSING CANCER GENETIC SERVICES**

**Catharine Wang, PhD.** Boston University School of Public Health, United States

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**Objective:** Public health calls to ensure equity in genomics and precision medicine (Khoury et al., 2022) necessitate a closer examination of how these efforts might differentially affect access to genetic services across demographic subgroups. This study set out to identify and describe racial/ethnic disparities along the cancer genetic service delivery continuum. **Method:** Data are drawn from 15 clinical sites across 6 states in the United States, which screened for individuals at-risk for hereditary cancer and either 1) referred individuals to be scheduled for an appointment with a genetic counselor (referral workflow) or 2) offered genetic testing at the point of care (POC workflow). Logistic regression analyses were conducted to evaluate the associations between race and ethnicity and several outcomes, including appointment scheduling, genetic counseling and genetic testing, controlling for demographics, clinical factors, and county-level covariates. **Results:** A total of 43,079 patients were screened and 14,665 were identified as at-risk based on National Comprehensive Cancer Network (NCCN) criteria. Overall, race and ethnicity were significantly associated with genetic testing uptake, with Black non-Hispanic patients having significantly lower odds of testing compared to White non-Hispanic patients (aOR = 0.839, 95% CI 0.705, 0.999). Moreover, this disparity was observed for sites deploying a referral workflow (aOR=0.605, 95% CI 0.416, 0.879) but not observed for sites deploying a POC workflow (aOR=1.075, 95% CI 0.863, 1.340). Among referral workflow sites, race and ethnicity was not associated with appointment scheduling. However, among patients scheduled, Black non-Hispanic patients had decreased odds of genetic counseling (aOR=0.277, 95% CI 0.166, 0.463), suggesting that factors influencing show rates for genetic counseling visits may be explaining the disparities seen in genetic testing uptake. **Conclusions:** Understanding drivers of disparities along the care continuum is critical to addressing ongoing inequities observed in genomics and precision medicine.

POD 5

## UNCOVERING PSYCHOLOGICAL INFLUENCES ON FAMILY COMMUNICATION ABOUT HEREDITARY CANCER RISK

**Moderator: Sook-Yee Yoon, MA.** Cancer Research Malaysia, Malaysia

POD 5-1

### "I TOLD THEM THAT THEY HAD TO GET TESTED, AND THEY DID": SIBLING SOCIAL INFLUENCES ON LFS TESTING, SCREENING, AND DECISION-MAKING

**Chloe Huelsnitz, PhD, MPH.** National Cancer Institute, United States

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**Objective:** Social influence refers to efforts by others to change a person's emotions, beliefs, and/or behavior. Evidence suggests social influence in families with inherited cancer syndromes likely occurs in families with Li-Fraumeni syndrome (LFS), as families work to address cancer and cancer risk(s) while also maintaining their relationships. Influence tactics may be direct and explicit or indirect and implicit. We sought to understand perspectives on social influence among siblings in LFS families and to identify tactics used to exert influence. **Method:** An interprofessional team conducted 13 semi-structured interviews with sibling groups (n=40, 2-3 siblings per group) enrolled in the National Cancer Institute's LFS Study. A semi-structured, IRB approved interview guide included questions about family closeness, information sharing, and perspectives on screening and cancer care. The research team collaboratively conducted thematic analysis on verbatim transcripts. **Results:** Participants reported attempts to influence their siblings' thoughts or behavior regarding LFS-related genetic testing, cancer screening, and health behaviors using both explicit and implicit tactics. Some participants reported being recipients of influence. Participants articulated diverse opinions on the degree to which influence was relationally and personally acceptable. This depended, in part, on the sibling's role in the relationship (e.g., parentified/functional oldest). Some participants expressed respect for sibling autonomy regarding risk management decisions. Others reported, given concern for their siblings' health, that they used direct or indirect tactics aimed at changing their siblings' perspective or behavior. For example, some participants reported directly challenging their siblings' decision to decline testing, or they used soft (i.e., implicit) influence tactics, such as giving their sibling a testing kit or asking about testing. **Conclusions:** Siblings reported diverse aims, strategies, and circumstances under which they employ influence to support desired LFS decision making and behavior. Findings suggest siblings believe that influence may meaningfully impact LFS risk management, suggesting a pathway for increasing cascade testing, screening participation, and other risk management behaviors. Future research might examine how siblings influence one another's likelihood of participation in testing, screening, and care that could be encouraged amongst families with LFS.

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POD 5-2

## IDENTIFYING EFFECTIVE RESOURCES FOR FAMILY COMMUNICATION ABOUT LYNCH SYNDROME CASCADE TESTING

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**Objective:** Cascade testing is integral for the prevention, early diagnosis, and management of cancers for high-risk individuals affected by hereditary cancer syndromes such as Lynch syndrome (LS). In the United States, communication with at-risk relatives about cascade testing largely relies on family members, yielding a low uptake of genetic testing for at-risk relatives. We

aim to identify gaps between resources provided by genetic counselors (GC) and resources that LS patients find effective when discussing cascade testing with at-risk relatives. **Method:** We conducted semi-structured interviews with 20 GCs practicing in oncology who regularly see LS patients. We also recruited 52 patients diagnosed with LS within the past 24 months to complete an online survey about perceptions of family communication resources. **Results:** The most common resources currently provided by GCs to LS patients include family letters, supportive groups and organizations, GC contact information, informational tools, and institutional support. Of the 52 LS patients, 46% have sought information to assist them in family communication about LS cascade testing; they primarily sought information from family letters (n=17) and websites (n=14). Sixty-six percent of patients reported receiving their resources from a GC. The most helpful features of the resources were information about cancer risks and characteristics, the identified pathogenic variants, and medical management. In contrast, 54% of patients had yet to seek information to assist them in family communication and plan to refer to websites (n=26) and their family letter (n=22). Nonetheless, 33% (n=17) of patients reported needing additional resources for family communication about cascade testing, such as prevention trials data and pamphlets with facts about LS. **Conclusions:** The family letter was the primary resource provided by GCs and one of the most sought tools (in addition to websites) for patients to facilitate family communication of LS cascade testing. GCs should continue to offer and emphasize the importance of family letter distribution and discuss different service delivery models for cascade testing during post-test counseling. Although most patients had available resources, many still needed additional information to communicate with their families. Further efforts are needed to optimize the content of family letters and patient-facing websites to facilitate family communication about LS cascade testing.

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POD5-3

## COMMUNICATION PREFERENCES REGARDING GENETIC TESTING IN INDIVIDUALS FROM HEREDITARY BREAST/OVARIAN CANCER FAMILIES WITH IDENTIFIED PATHOGENIC VARIANTS IN A DIVERSE ASIAN SETTING: A QUALITATIVE STUDY

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**Objective:** Studies assessing communication preferences regarding genetic testing in individuals from hereditary breast/ovarian cancer (HBOC) families with identified pathogenic variants have been undertaken exclusively in Western societies. The aim of the study is to explore family members' experience in receiving and/or communicating *BRCA*-related information within

families, as well as their decisional needs regarding whether to undertake *BRCA* predictive testing in an ethnically diverse sample of Malaysian people from HBOC families. **Method:** Probands and at-risk relatives from HBOC were invited to semi-structured qualitative in-person or telephone interviews. Interviews were transcribed, translated where applicable and data were analyzed using thematic analysis. Of 20 participants interviewed, 10 were probands and 10 at-risk relatives. **Results:** Findings revealed three themes: 1) "Accept everything that is fated by God with an open heart" – learning about hereditary breast/ovarian cancer in the family; 2) "Let it be a secret in our life" – family communication about hereditary breast/ovarian cancer; 3) "I prefer to tell them first" – family communication support needs. When asked about how they wish to be informed about the availability of genetic testing, being sent a letter by the clinic was the least preferred format. Many were interested in information being provided by experts and rated information seminars as their preferred format, while others preferred a leaflet or a communication prompt sheet to legitimize the information that they shared and provide strategies for them to talk to their family. **Conclusions:** Findings provide the basis for the development of culturally compatible interventions for family members considering predictive BRCA genetic testing.

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POD 5-4

## UNMET PSYCHOSOCIAL NEEDS AMONG INDIVIDUALS WITH A TELOMERE BIOLOGY DISORDER: A MIXED-METHODS STUDY

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**Objective:** Telomere biology disorders (TBDs) are caused by pathogenic germline variants resulting in very short telomeres for age. Individuals with TBDs are at very high risk of bone marrow failure, cancer, lung and liver disease, and many other life-threatening complications. There are multiple modes of inheritance, and all ages can be affected by these progressive disorders. The aim of this study was to identify unmet psychosocial needs among individuals with TBDs. **Method:** At the National Cancer Institute, we recruited individuals through patient advocacy and health provider groups specializing in TBDs (NCT04959188). In this mixed-methods study, participants completed an anonymous online survey (Needs Assessment of Family Caregivers-Cancer [NAFC-C]) and/or an in-depth interview. Survey respondents rated their reported needs according to perceived level of importance and level of satisfaction with fulfilling the need (1=not at all to 5=extremely). We calculated NAFC-C scores (range=0–16), which are indices that represent unfulfillment of a specific need. We used descriptive statistics to analyze data. An interprofessional team used qualitative content analysis to analyze transcribed data. **Results:** Twenty-one participants with a TBD completed the survey and 13 completed interviews. Survey respondents were mostly White (n=19), female (n=19), and college educated (n=17), with mean age 44 years (range=26-69). Reported unmet needs

included emotional distress (n=18, median=7, range=0–16), getting the best possible care (n=15, median=6, range=0-16), balancing work or school (n=9, median=8, range=0-12), accessing disease and health-related information (n=8, median=7.5, range=0-16), and having enough insurance coverage (n=5, median=12, range=2-16). Interview data revealed extensive diagnostic journeys, uncertainty about their mortality at a young age, multidimensional grief and loss, and complicated healthcare regimens. **Conclusions:** This is the first mixed-methods study to examine psychosocial needs among individuals diagnosed with TBDs. Results demonstrated multifaceted, disease-specific unmet emotional, social, and financial needs. The qualitative findings helped to characterize emotional distress for study participants. Interprofessional collaboration is needed to develop accessible, supportive interventions for individuals with TBDs and their families. Future research could examine how needs may differ by lifespan phase.

## Paper Sessions

PA1

**TRACEBACK GENETIC TESTING: A NOVEL APPROACH FOR RETROSPECTIVE IDENTIFICATION AND CASCADE TESTING FOR HEREDITARY CANCER RISK**

**Moderators: Nora Henrikson, PhD, MPH.** Kaiser Permanente Washington, United States
**Alanna Kulchak Rahm, PhD, CGC.** Geisinger, United States
**Discussant: Goli Samimi, PhD, MPH.** National Cancer Institute, United States

**Objective:** Genetic testing of everyone with ovarian cancer improves detection of *BRCA* and other high-risk genetic variants and is the current standard of care for people with newly diagnosed ovarian cancer, but testing uptake is limited and the standard of care has evolved over time. A "Traceback" cascade testing program, where people with ovarian cancer and their relatives are retrospectively contacted and offered testing, is a possible solution. However, the feasibility and implementation strategies involved in this type of outreach are not well understood. **Method:** Three National Cancer Institute-funded projects are developing, implementing, and evaluating Traceback programs for ovarian, fallopian tube, and peritoneal cancers. In each, individuals with a history of ovarian cancer who did not receive genetic testing at diagnosis are identified using cancer registries or electronic health records. Once identified, they or their personal representative are contacted and invited to receive genetic testing, with the goal of cascade testing at-risk relatives. In addition to evaluating program uptake, the 3 projects also have unique additional foci, including assessment of patient and family preferences; ethical issues around use of previously stored tissue samples of living and deceased individuals; use of citizen science methods; and legal assessment of the of ethical issues relating to Traceback programs. **Results:** Investigators from each of the 3 projects will provide an overview of their program, present preliminary progress to date, including uptake of testing, patient and family preferences, and lessons learned, and describe future research directions. Goli Samimi, PhD, MPH, Project Scientist for the Traceback NCI Cooperative Agreement, will facilitate discussion of implications and future research needs. **Conclusions:**

Traceback programs are new for U.S. settings and understanding of both patient and family preferences and facilitators to implementation is critical for successful program implementation.

PA1-1

**IMPLEMENTING TRACEBACK PROGRAMS FOR HEREDITARY CANCER IN THREE HEALTH SYSTEMS**

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**Objective:** Identify the practical and psychosocial barriers and facilitators to genetic testing for cancer patients and at-risk family members through Traceback testing programs. **Method:** Geisinger Health, Kaiser Permanente Mid-Atlantic States (KPMAS) and Kaiser Permanente Washington (KPW) developed and piloted three Traceback testing programs based on each organization's population and clinical care infrastructure. Program design was informed by preferences identified using human centered design methods with patients and at-risk family members. We identified eligible patients through electronic health record data and chart review. We conducted interviews with patient participants to assess experiences with the program. Interviewees included patients who accepted or declined testing and patients with pathogenic, variant of uncertain significance (VUS), or negative genetic testing results. **Results:** Across the 3 sites, 2,155 patients with a history of ovarian, fallopian tube, or peritoneal cancer were identified. After time intensive chart review, 516 patients met eligibility criteria for genetic testing; 444 patients were invited to the Traceback programs and 80 completed genetic testing (6% Geisinger, 37% KPMAS, 20% KPW). Four percent of patients who completed testing had a pathogenic result, 30% VUS, and 66% negative results; VUS results were highest at KPMAS, at 36%. To date, 21 interviews have been conducted; 12 with patients who accepted genetic testing and 9 with patients who refused testing. No at-risk family members were interviewed. Patient-reported facilitators of testing included the acceptability of outreach timing and content, and the ease of the testing process. Patient-reported psychosocial barriers to testing included a desire for outreach customized to a patient's clinical history, concerns about the cost of testing, and competing priorities. **Conclusions:** Results to date suggest Traceback programs can effectively identify eligible patients and are an acceptable approach to encouraging patients to consider genetic testing. Time-intensive chart review was a major barrier to identifying eligible patients, and the very low number of pathogenic results provided few opportunities to test at-risk relatives. To address patients' psychosocial barriers to testing, Traceback programs

could consider ways to tailor outreach to patients' clinical histories, clarify cost, and encourage responsiveness by further emphasizing personal/family benefits and ease of testing.

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PA1-2

**YOUR FAMILY CONNECTS: A THEORY-BASED INTERVENTION TO ENCOURAGE COMMUNICATION ABOUT INHERITED CANCER RISK AMONG OVARIAN CANCER SURVIVORS AND CLOSE RELATIVES**

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**Objective:** Encouraging family communication about inherited risk has become among the most important avenues for achieving the full potential of genomic discovery for primary and secondary prevention. Yet, interventions to promote appropriate family-wide risk communication (i.e., conveying genetic risk status and its meaning for other family members) are few. Relational-level theories (e.g., interdependence theory) suggest that interventions that consider specific relationships among families and their motives to preserve these relationships will be most effective for encouraging shared risk communication. **Method:** We engaged citizen scientists affected by ovarian cancer to develop a scalable, message-based communication outreach intervention—Your Family Connects (YFC). We engaged 14 survivors of ovarian cancer and their close blood relatives in this mixed methods study to collect quantitative surveys and qualitative interviews. We report the iterative process of distilling and mapping the citizen science findings, consideration of relational-level theories, and the resulting communication intervention. **Results:** Citizen scientists collected 261 surveys and 39 structured interviews over 12 weeks (October through December 2020). Survivors strongly preferred personal contact with close relatives, whereas relatives were more receptive to being approached by alternative contact options (e.g., health professional). Both groups agreed that outreach should vary according to the specific nature of each relationship. Results informed a procedure for enumerating at-risk relatives that included a menu of contact options (i.e., personal, health professional team, delayed contacts) for each specified close relative and guiding rationales were provided to help survivors decide which relatives might be amenable to alternative methods for personal contact. **Conclusions:** Our intervention represents a novel application of relational-level theories and partnership with citizen scientists to expand genetic services reach to increase the likelihood for fair distribution of cancer genomic advances.

PA1-3

## FEASIBILITY OF A TRACEBACK APPROACH TO PROVIDE GENETIC RISK INFORMATION TO FAMILIES IN THE GENETIC RISK ANALYSIS IN OVARIAN CANCER (GRACE) STUDY

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**Objective:** The Genetic Risk Assessment in Ovarian Cancer (GRACE) study aims to identify families with an increased genetic risk for cancer by offering genetic testing to individuals with a prior diagnosis of ovarian cancer (OC). One goal of the study is to characterize feasibility of providing genetic information to relatives of deceased individuals through germline testing of archived pathology specimens. **Method:** Search of tumor registry data at 2 health care systems (Kaiser Permanente NW and Colorado) identified cases of OC diagnosed 1998-2020 who either did not have genetic testing or had genetic testing limited to *BRCA1/2* and could benefit from testing with a comprehensive panel of cancer risk genes. OC survivors or relatives were contacted and offered testing. Genetic testing of the familial variant was offered to first- and second-degree relatives if a pathogenic or likely pathogenic variant was detected. **Results:** Several challenges have arisen in recruitment of relatives of individuals who are deceased including legal and regulatory guidance on family contact and health information disclosure, availability of family contact information in medical records, and genetic testing of archived pathology specimens. Recruitment has mainly focused on OC survivors but has recently shifted to relatives of deceased individuals. To date, relatives of 17 deceased individuals have been recruited, with 3 (18%) consenting to testing of the pathology specimen. Genetic test results are pending. For OC survivors, all 317 eligible cases have been recruited; 79 (25%) consented for testing. Sixteen (21%) were found to carry a pathogenic or likely pathogenic variant in a cancer risk gene. Of 79 relatives eligible for cascade testing, 20 consented (25% uptake) and 9 were found to carry the familial variant. We expected higher enrollment among survivors with more recent diagnoses; however, uptake of genetic testing was not significantly associated with time since diagnosis. **Conclusions:** Uptake of testing by OC survivors and their relatives reflects a strong interest in genetic risk information. However, practical barriers must be addressed to provide genetic risk information to relatives of individuals who are deceased. Overall, the GRACE study can inform broad implementation of future Traceback programs across health care.

PA2

## CANCER RISK MANAGEMENT FOR INDIVIDUALS WITH PATHOGENIC *CDH1* VARIANTS

**Moderator: Eveline M. A. Bleiker, PhD.** The Netherlands Cancer Institute, The Netherlands

PA2-1

### THE LIVED EXPERIENCE OF EMERGING ADULTS WITH A *CDH1* DISEASE CAUSING VARIANT – AN INTERPRETATIVE PHENOMENOLOGICAL APPROACH

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**Objective:** To understand the lived experience of the medical management decision-making process toward gastric cancer risk for emerging adults (EA) who carry a *CDH1* pathogenic or likely pathogenetic variant (P/LPV). Identify the unique psychosocial experience of emerging adults carrying a *CDH1* P/LPV on their medical decision-making process. List the psychosocial supports emerging adults may need and direct them to proper resources. **Method:** Qualitative interpretative phenomenological analysis was used on seven participants who were *CDH1* P/LPV carriers, ages 18-29, unaffected with *CDH1* related condition, had not undergone prophylactic total gastrectomy, and had deliberated *CDH1* medical management. Semi-structured telephone interviews were transcribed verbatim and major themes were evaluated from the interview data. **Results:** This study explored EAs carrying a *CDH1* P/LPV medical management decision-making for gastric cancer risk and how they are making sense of this experience. Results showed they wanted to avoid developing diffuse gastric cancer (DGC) but felt they were not ready for prophylactic total gastrectomy. They expressed concern that prophylactic total gastrectomy could affect their identity exploration, financial stability, and careers. Most do not want to pass the P/LPV to future children; however, costs of pre-implantation genetic testing with in vitro fertilization were concerning. Family medical history, understanding of endoscopy results, and implications of prophylactic total gastrectomy highly influenced decision-making. Endoscopy's DGC detection rate understanding was inconsistent, and some overestimated the efficacy. Body image was not concerning for most, but they worried about dietary restrictions after prophylactic total gastrectomy. Lastly, connection to peers having the same experience was important. EAs may take an extended time (i.e., years) to decide on their management options. **Conclusions:** EAs are in a unique life stage characterized by creating identities, seeking relationships, career establishment, and navigating financial instability. These issues complicate the already difficult decision about whether to have prophylactic total gastrectomy or continue with surveillance with a risk of missing gastric cancer and treatment delay. Therefore, it is vital for this population to work and get support from a multidisciplinary team with expertise in *CDH1* and hereditary diffuse gastric cancer, including dietitians, psychologists, and genetic counselors.

PA2-2

## GRIEVING THE LOSS OF LIFE WITH A STOMACH – EXAMINING IDENTITY CHANGES AFTER PROPHYLACTIC TOTAL GASTRECTOMY FOR INDIVIDUALS WITH A *CDH1* PATHOGENIC/LIKELY PATHOGENIC VARIANT

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**Objective:** To understand the long-term psychosocial implications, including social experiences, health identity, and career options, resulting from prophylactic total gastrectomy for individuals with a *CDH1* P/LPV. **Method:** Individuals with a *CDH1* P/LPV were enrolled between January 2017 and November 2022 and seen by the same registered dietitian for nutrition consultation prior to surgery, during admission for prophylactic total gastrectomy, and at frequent intervals post-operation. Nutrition consultation included assessment of weight trends, micronutrient levels, adherence to vitamin supplementation, diet tolerance, post-gastrectomy symptoms and barriers to or challenges with the post-gastrectomy diet and lifestyle. **Results:** Of >140 consecutive patients undergoing prophylactic total gastrectomy, 100% had to modify their diet and lifestyle to mitigate the unintentional weight loss, ensure adequate hydration, prevent adverse sequela from micronutrient deficiencies and to manage gastrointestinal symptoms after prophylactic total gastrectomy. As a result, individuals expressed grief surrounding the loss of normal stomach functions. Without hunger cues, eating was no longer pleasurable and became work. The need for a regimented meal schedule with specific diet restrictions led food and eating to change from a social, pleasurable experience to a calculated, monotonous, and often isolating process to meet their nutritional needs. The risk of post-gastrectomy symptoms often caused stress and anxiety around eating, especially in social situations. The diet and lifestyle modifications also impacted professional identity and career trajectory. In a subset analysis of 75 patients, 10 of the 63 (16%) who were working before surgery had to change jobs or even careers to accommodate their diet needs after prophylactic total gastrectomy. The altered nutrition needs also led to changes in health identity surrounding changes in body habitus and risk of new diagnoses related to prophylactic total gastrectomy, including osteopenia/osteoporosis, regardless of age. In a subset analysis of 94 patients, 92of 94 lost substantial weight, with an average weight loss of 26.5% and average bone mineral density decreased in all 94 patients at 1-year follow-up. This change in body composition impacted physical performance, limiting fitness regimens and specific leisure activities for many individuals. **Conclusions:** Individuals with a *CDH1* P/LPV who underwent prophylactic total gastrectomy experience lifelong diet and lifestyle modifications that impact multiple psychosocial facets, including social relationships and career trajectories.

PA2-3

## DEVELOPMENT OF AN ONLINE DECISION SUPPORT TOOL FOR THOSE AT HIGH RISK TO DEVELOP GASTRIC CANCER

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**Objective:** Carriers of a pathogenic variant in the *CDH1*- or *CTNNA1*-gene are at increased risk of developing gastric cancer (and lobular breast cancer for *CDH1*). They face life-changing decisions, such as whether to opt for DNA-testing or for surveillance or prophylactic surgery. Unfortunately, information and support tools for carriers of this rare condition are lacking. The aim of this study was 1) to assess the information needs of these carriers, and 2) to develop an online decision aid and support tool for these carriers. **Method:** We followed the international IPDAS criteria, consisting of 4 phases: 1) set up of a national, multidisciplinary, working group, 2) a needs assessment with semi-structured interviews with patients (n=16) and health care professionals (n= 17), 3) creation of the tool, and 4) a usability test of the tool. **Results:** The following themes were identified as relevant by patients and health care professionals: genetics of gastric cancer, gastric surveillance, living without a stomach, breast surveillance and surgery, services and patients' federation. An online information support tool was developed that included specific information on these themes and subthemes. Furthermore, 3 decision aids were developed on whether to undergo 1) DNA-testing, 2) preventive breast surgery, and 3) preventive gastrectomy. Importantly, patients' stories were used to illustrate some of the pros and cons of each decision, and illustrations were created. Professionals valued the information as helpful, but there was too much detail for patients. In contrast, the professionals would have preferred even more detail. **Conclusions:** A website was developed, including information about the most important themes as identified by carriers of a pathogenic variant in the *CDH1*- or *CTNNA1*-gene and their health care professionals. Besides the textual information about the 6 most important themes, the online tool includes decision aids, patient stories, and illustrations. We learned that there is no "one size fits all" format for such a tool, but layered information (e.g., when clicking is needed to get more detailed information) is a solution to keep the balance between too few and too many details.

PA3

## EXPERIENCES OF UNCERTAINTY IN LIVING WITH HEREDITARY CANCER RISK

**Moderator: Paul Han, MD, MA, MPH.** National Cancer Institute, United States

PA3-1

### THE USE OF SOCIAL MEDIA TO EXPRESS AND MANAGE MEDICAL UNCERTAINTY IN DYSKERATOSIS CONGENITA

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Affiliations: [1]Team Telomere, USA; [2]Clinical Genetics Branch, National Cancer Institute, USA; [3]University of North Carolina at Chapel Hill, USA; [4]Behavioral Research Program, National Cancer Institute, USA

**Objective:** Social media has the potential to provide social support for rare disease communities, but little is known about the use of social media for the expression and management of medical uncertainty, a common feature of rare diseases. We evaluated the expression of medical uncertainty on social media in the context of dyskeratosis congenita (DC), a rare, cancer-prone, inherited bone marrow failure and telomere biology disorder (TBD). **Method:** We content analyzed uncertainty-related posts among patients with DC/TBDs and caregivers on Facebook (FB) and Twitter managed by Team Telomere, a patient advocacy group for this rare disease. We assessed the frequency of uncertainty-related posts, uncertainty sources, issues, and management strategies using the Han Taxonomy and associations between uncertainty and social support. **Results:** Across all DC/TBD social media platforms, 46% of posts were uncertainty related. Most uncertainty-related posts were authored by Team Telomere on Twitter or appeared in conversations within the FB Community Group. While uncertainty-related posts reflected multiple sources, issues, and management strategies, they primarily focused on information exchange related to diagnostic and prognostic uncertainty. All platforms had high frequency of emotional support, but only in the FB Community Group was emotional support significantly more frequent in uncertainty vs. non-uncertainty related posts ($X^2$=7.76, DF=1, p=0.005). In all platforms, offers or requests for informational support were significantly more frequent in uncertainty-related compared to non-uncertainty-related posts ($X^2$=468.0, DF=1, p<0.0001). Analysis of post creator characteristics suggested most users of DC/TBD social media have low engagement rates and represent only a subset of the DC/TBD community (White, female, parents of patients with DC). **Conclusions:** While uncertainty is a pervasive and multifactorial issue in DC/TBDs, our findings suggest the discussion of medical uncertainty on DC/TBD social media is largely limited to brief exchanges about scientific or practical issues, rather than ongoing supportive conversation about the impact of uncertainty on personal life. More research is needed to understand the dynamics of social media engagement to manage medical uncertainty in the DC/TBD community.

PA3-2

## UNCERTAINTY MANAGEMENT FOR HEREDITARY CANCER: PERSONALISED, SHARED DECISION-MAKING WITH PROVIDERS COMPLEMENTED BY AN INTERACTIVE PATIENT DECISION AID WEBSITE

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**Objective:** Uncertainty is pervasive in medicine and is particularly relevant for patients living with hereditary cancer risk and providers helping to treat these patients because of the changing meaning of genetic information over time. The issue of uncertainty is often unacknowledged and unexplored in clinical encounters. The objective of this presentation is to share findings from a co-design approach to developing a patient decision aid website/booklet (PtDA) with patients to complement shared decision-making about hereditary cancer risk management. **Method:** We conducted semi-structured interviews (n=20), a full-day workshop (n=10), and focus groups (n=28) with patients with a lived experience of cancer and/or genetic testing in order to ask patients to lead discussions about important factors during decision-making and how experiencing uncertainty may have affected decision-making and well-being. Thematic analysis was applied to qualitative data and findings were used to revise the logic model for theoretical underpinning of the PtDA. **Results**: Analysis of interview transcripts and workshop notes identified the theme "uncertainty": being unsure about what would happen or what to do. Patients found the "maybe phase" hard, which could introduce decision avoidance/paralysis, or conversely prompt a quick, non-deliberative decision (e.g., to pursue risk-reducing mastectomy). PtDA logic model revisions included adding the purported mediators "reducing uncertainty", "empowerment," and "self-efficacy" as "active ingredients" in a recipe for quality decisions. Patients wanted providers to take the time and compassion needed to "understand what matters to me" and "treat me as an individual" because "a good decision is one that feels right for me." Revisions to the PtDA aimed to improve relevance, meaning and uptake for better outcomes including reduced anxiety/decisional conflict, increased decision-making confidence and improved management of hereditary cancer. **Conclusions:** Decision-making for hereditary cancer testing and risk management is highly personal and can be influenced by patient experience of uncertainty. Collaborative work is required to achieve shared humility, flexibility, and courage and forge an adaptive, hopeful 'worldview of uncertainty tolerance'. Patient-centered collaboration and co-design of resources is recommended to promote shared decision-making and foster personalised, holistic, and supportive care for hereditary cancer.

PA3-3

## DEVELOPING PSYCHOSOCIAL AND EDUCATIONAL MATERIALS FOR FAMILIES LIVING WITH RUNX1-FPD

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**Objective:** Familial Platelet Disorder (FPD) is a dominant condition caused by germline deleterious variants in the *RUNX1* gene. *RUNX1*-FPD is characterized by qualitative and quantitative platelet defect and predisposition to myeloid malignancy. Quality of life for persons living with *RUNX1*-FPD is currently unknown. Through structured psychosocial assessment with families participating in a NIH *RUNX1* Natural History study, we identified a need for educational materials to help parents better communicate with their child(ren) about the diagnosis and for age-appropriate guidance for teens. Parents also asked for child coping strategies. In response, we developed educational materials to facilitate difficult conversations and assist in navigating medical and psychosocial care. **Method:** An interdisciplinary working group identified areas of need. The Child and Teen Wellness Toolkit was developed, utilizing evidence-based wellness interventions and coping strategies frequently used by child-life specialists. Next, Paving the Road: A *RUNX1* Communication Guide for Parents was developed to help parents build conversations and enhance their child's understanding. The third guide, *RUNX*-101: An Adolescent's Guide to Understanding and Communicating about *RUNX1*-Familial Platelet Disorder (FPD) was created to support adolescents with independently learning about their condition. **Results:** Paving the Road utilizes a WALKS mnemonic of "tools" to help parents set up the conversation. It then provides foundational "bricks," including sample topics the child might raise (with responses), conversation starters, and other resources to further comprehension–organized according to the child's grade level. A glossary at the end supplements each definition with a child-friendly explanation from which that parents can directly pull. The Adolescent's Guide addresses the fundamentals of *RUNX1* and its psychosocial implications. This guide delves deeper into concepts not mentioned in the parent communication guide–such as genetic testing, family planning, social media, communication with friends/teachers/parents, and potential sports precautions. Each guide is now publicly available. **Conclusions:** Based on needs families shared during participation in the Natural History Study, educational materials were created for families impacted by *RUNX1*-FPD, tailored according to the needs of the reader. Future research should examine the usefulness of these guides and assess needed adaptations.

PA3-4

**WHAT IS THE IMPACT OF *BRCA1/2* STATUS ON YOUNG WOMEN'S REPRODUCTION AND RELATIONSHIPS AFTER PREDICTIVE TESTING? AN AUSTRALIAN CASE-CONTROL STUDY**

**Laura Forrest, PhD.** Peter MacCallum Cancer Centre, Australia

**Objective:** The psychosocial implications for young women of living with a *BRCA1/2* pathogenic variant (PV) are thematically well evidenced but not well quantified. The aim of this study is to investigate the impact of *BRCA1/2* status on women's reproduction and partnering. **Method:** Data were collected using an online survey with a case-control design from June 2019 to August 2021. Eligible participants were invited from eight Australian clinical genetics services, recruiting women aged 18-40 years who had predictive *BRCA1/2* testing, received either a positive or negative result, and were unaffected by cancer. Outcomes included childbearing, relationship status, intimacy, and adaptation. Descriptive and inferential statistics were used; p values <0.05 were considered statistically significant. **Results:** 579 women participated (62.0% *BRCA1/2* positive; 38.0% *BRCA1/2* negative). More women who were *BRCA1/2* positive had children compared to those who tested negative (49.0% c.f., 40.5%; p=0.045). No other demographic differences were observed. Multivariate regression analyses determined that women's *BRCA1/2* status did not predict whether they were partnered (p=0.38) or their experience of intimacy (p=0.88). Women who were *BRCA1/2* positive were more likely to have children after genetic testing (p=0.03) and were likely to have more children after genetic testing (p=0.01) compared to women who were *BRCA1/2* negative. Subgroup analyses examining outcomes for women who were *BRCA1/2* positive indicated that increasing age was negatively associated with adaptation (p<0.001), whereas uptake of risk-reducing mastectomy was positively associated (p<0.001). **Conclusions:** Receiving a positive predictive *BRCA1/2* result changes women's reproductive outcomes compared to those who test negative. These findings contribute to the evidence-base to inform long-term follow-up for women after predictive *BRCA1/2* testing.

PA4

**EXPERIENCES AND COMMUNICATION AMONG PARENTS/CAREGIVERS AND CHILDREN AT RISK FOR HEREDITARY CANCERS**

**Moderator: Rowan Forbes Shepherd, PhD.** National Cancer Institute, United States

PA4-1

**WHAT DO HIGH-RISK PARENTS PERCEIVE TO BE THE BENEFITS/HARMS OF PEDIATRIC DTC GENETIC TESTING FOR ADULT-ONSET INHERITED CANCER SYNDROMES? IMPLICATIONS FOR CHILDREN'S HEALTHCARE**

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**Objective:** High-risk parents carrying pathogenic variants (PVs) in genes associated with adult-onset inherited cancer syndromes (AOICS) may seek information about their children's cancer risks from direct-to-consumer (DTC) genetic tests. However, such testing is not recommended by physicians or policymakers for children as its potential benefits (e.g., health guidance) may not outweigh its harms (e.g., psychological upset). This study describes parents' perceptions of the benefits/harms of pediatric DTC testing to inform healthcare. **Method:** A mixed-methods analysis of 167 high-risk parents (Mean age=47) carrying AOICS PVs who rated their perceptions of pediatric DTC testing's potential benefits/harms for their children across 10 Visual Analog Scale items initially set to neutral/50 (0–100 scale). Cluster analysis of the items determined their benefit (>66), harm (<33), or benefit-harm hybrid (34-65) ratings and labeled similar groups: in-depth interviews with a subset of parents (n=30) further contextualized the clusters. **Results:** Three clusters were revealed (Ward's F=35.05): Cluster 1 "Benefits" (n=27 parents, 24%, n=5 items); Cluster 2 "Harms" (n=57 parents, 53%, n=3 items); and Cluster 3 "Hybrid" (n=27 parents, 24%, n=2 items). More parents endorsed "Harms" vs. "Benefits" (or "Hybrid) to pediatric DTC testing (Fisher's Exact X2=0.0002, p<0.05). "Benefits" included DTC testing's convenience (72%), usefulness (70%), and validity (53%). "Harms" were the lack of physician (68%) or genetic counselor (64%) engagement and children's psychological risks (45%). Hybrid perceptions were testing's financial costs (e.g., affordable for some, expensive for others) and privacy of genetic information (e.g., protection against genetic discrimination, lack of medical guidance). In coded interviews (K>0.70), approximately 10% of parents reported their children had been tested. Major themes included parents' endorsement of DTC testing companies' trustworthiness for delivering fast and accurate results, counterbalanced with a need for professional support surrounding results disclosure and monitoring of children's psychological impacts. **Conclusions:** High-risk parents perceive more potential harms than benefits to testing their children for PVs in AOICS genes using DTC methods, consistent with guidelines. Additional family counseling to engage parents in reflecting upon their motivations and to encourage discussions about their testing interest with healthcare providers is warranted.

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PA4-2

## PARENTS' SEQUENCING-RELATED DISTRESS FOLLOWING DISCLOSURE OF PEDIATRIC ONCOLOGY GERMLINE SEQUENCING RESULTS

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**Objective:** To characterize the emotional impact of germline sequencing among parents of children with cancer and to identify demographic, clinical, and psychosocial factors that may be associated with sequencing-related distress. **Method:** Participants were 104 parents of children with cancer recruited from a pediatric oncology hospital for a prospective study of clinical tumor and germline genomic sequencing. Parents completed psychosocial questionnaires at consent (i.e., genetic knowledge), prior to disclosure of results (i.e., sequencing-related worry), and ≥5 weeks following disclosure of results (i.e., sequencing-related distress). Bivariate associations with distress were tested using t-tests or ANOVAs for categorical variables and correlations for continuous variables. Variables with significant bivariate relations were included in a multiple regression model predicting distress related to sequencing results. **Results:** Parents' sequencing-related distress significantly differed across parent relationship status (Mean single=11.55, Mean partnered=7.12; t[39.34]=2.12, p=0.04) and result-type (pathogenic, uncertain, vs. negative results; t[2,101]=3.37, p=0.038), and was significantly correlated with higher pre-disclosure genetics knowledge (r=0.27, p=0.006) and worry about potential sequencing results (r=0.41, p<0.001). Parents of children with pathogenic results endorsed significantly more distress than those with negative results (p=0.029); however, those with uncertain results did not differ in distress from those with negative results (p=0.548). Pathogenic results continued to be significantly associated with distress (F[4,92]=9.95, p<0.001; β=0.19, p=0.031) even after controlling for relationship status (β=-0.19, p=0.029), genetic knowledge (β=0.20, p=0.022), and pre-disclosure worry (β=0.38, p<0.001). **Conclusions:** Parents of children found to have a genetic variant linked with cancer predisposition may benefit from psychosocial screening or referral to a psychosocial provider for evaluation of distress. Specifically, screening parents' relationship status and worry about sequencing prior to learning results may be informative in identifying parents most likely to benefit from further support. Reporting uncertain results does not appear to yield elevated distress for parents. Further research about the duration of distress following a pathogenic result and the ideal way to disclose these results and support families experiencing distress is warranted.

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PA4-3

## PLAY-THE-ODDS: CO-DESIGNING A COMMUNICATION TOOL TO HELP PARENTS TALK ABOUT GENETIC CANCER RISK WITH THEIR CHILDREN

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**Objective:** Disclosing hereditary cancer risk (HCR) information to children and maintaining an open communication over time is crucial for family psychosocial adaptation. In the absence of available resources to facilitate education or parental empowerment toward open and developmentally appropriate communication with children, both health providers and parents call for robust supplemental tools to assist them in this process. Werner-Linn proposes a model describing the phases for age-specific communication between parents and children. Theoretically framed in this model, our project aims to develop a game-based tool to help parents and children communicate about HCR. The aim of this paper is to showcase the interdisciplinary codesign process of solutions for this tool. **Method:** Using a participatory and interdisciplinary approach, we brought together people with HCR syndromes and their families, genetic counselors (GC), psychologists, communication designers and gamification specialists, for a total of 20 participants. We followed a human-centered design process, with the combination of agile methods, focusing on Lean and Biodesign methodologies. Over 4 codesign workshops, participants identified priority needs for each dimension (Wks 1), ideated (Wks 2) and validated solutions (Wks 3), and ended by reassessing results and conceptualizing the aggregation of all solutions in a unified resource (Wks 4). **Results:** The codesign approach in a dynamic and agile environment allowed the participants to feel empowered with strategies to complete the process of finding viable solutions for the needs they identified. Participants expressed gratitude and enthusiasm for being invited and allowed to be part of the solution. At the end of the 4 workshops, we prepared a simplified model for prototyping and aggregating all the co-designed solutions. **Conclusions:** The insights shared by end users and the expertise brought by health and design specialists in a codesign process allowed a deeper understanding of the problem of psychosocial adaptation to HCR, while the adoption of agile methodologies allowed the fast-paced creation of solutions to this problem. This experience highlighted the value of interdisciplinary collaboration for the creative development of evidence-based solutions for psychosocial adaptation to HCR.

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PA4-4

## ADJUSTMENT OF AYA AND CAREGIVERS OF PEDIATRIC PROBANDS TESTED FOR A GENETIC CANCER PREDISPOSITION

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**Objective:** It is unclear how adolescents and young adults (AYA), and caregivers of pediatric probands, adjust to genetic testing for cancer predisposition or how it differentially impacts

underserved groups. Via mixed methods, we analyzed adjustment outcomes for AYA and caregivers by race and ethnicity, caregiver (primary or second), and status of testing (positive or not) **Method:** Of 103 families with a child referred for testing, 100 primary caregivers (92 mothers, 6 fathers, 2 other; M age=40; 74.5% Non-Hispanic White [NHW]), 57 second caregivers (47 fathers, 6 mothers, 4 others; M age=41; 78.0% NHW), and 31 AYA (M age=16; 45% female, 84% NHW) participated. Subjects completed surveys at testing and 1-month post-results. Using t-tests, we examined T2 scores and changed scores by caregiver, minoritized, and positive status (31 children of caregivers had a positive result), and descriptives were provided on AYA scores. Seventeen primary caregivers and 11 secondary caregivers, as well as 9 AYA, were interviewed. **Results:** Differences with p-values <0.05 are reported. Having a child with a positive result related to an increase in distress and uncertainty and less regret. Minoritized caregivers had greater decisional regret. Those with minoritized children had greater increase in distress and uncertainty. Secondary caregivers had greater increase in perceived benefit and perception of child cancer risk. Qualitative content analysis identified themes of distress, including guilt and uncertainty. Minoritized caregivers were less likely to express understanding of the testing process and implications. Secondary caregivers, especially minoritized caregivers, were more likely to feel less engaged than the primary caregivers. NHW caregivers with a family history of pre-disposition were more likely to discuss decisional satisfaction and perceived benefits of testing. AYA reported high decisional satisfaction, genetic knowledge, and minimal distress, regardless of demographics. Interviews supported positive quantitate outcomes. **Conclusions:** While distress is common for caregivers of children undergoing genetic testing for cancer predisposition, especially with positive results, the impact over time can be different on some outcomes for primary versus second caregiver and those who are minoritized. Caregivers would benefit from individualized support and psychoeducation, both at time of testing and after.

PA5

## APPROACHES TO PROMOTING HEREDITARY CANCER CASCADE TESTING

**Moderator: Laura Forrest, PhD.** Peter MacCallum Cancer Centre, Australia

PA5-1

## MOTIVATIONAL DRIVES AND PSYCHOLOGICAL DETERMINANTS OF MEN'S ADHERENCE TO CASCADE SCREENING FOR *BRCA1/2*

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**Objective:** Pathogenic variants in the *BRCA1* and *BRCA2* genes increase the relative and absolute risks of breast, ovarian, prostate, and pancreatic cancer. First-degree relatives (FDRs) of carriers have a 50% chance of inheriting the mutation. However, despite the benefits of cascade screening in terms of allowing at-risk relatives to pursue appropriate cancer screening and risk reduction strategies, testing uptake is relatively low, particularly in at-risk men. Men's decision regarding cascade screening seems to be related to familial—rather than individual—disease risk, linking the decision to a family duty. Little is known about psychological determinants of adherence to cascade screening in at risk-men and research on their motivational drives to be tested is particularly missing. **Method:** Applying some principles of the Health Action Process Approach model, the present RCT tested 1) a model of relationships on the adherence to *BRCA1/2* cascade testing, 2) the effectiveness of 2 gain-framed messages, one narrating a self-referred story (SM) and the other a family-referred story (FM), in promoting intention to adhere to cascade screening. A total of 110 male FDRs of carriers participated in the study and were randomized in 2 groups (N=55). **Results:** Analysis revealed no differences between SM and FM groups on the intention to adhere to cascade screening. Significant associations emerged between the intention to uptake *BRCA1/2* genetic testing and age, parental status, breast cancer risk perception, self-referred outcome expectancies, perceived benefit, coping self-efficacy, and planning. Higher perceived benefit predicted increases in intention, and higher intention and coping self-efficacy predicted increases in planning. Intention resulted as a positive total mediator of the relationship between benefit and planning. **Conclusions:** Results supported the importance of integrated genetic counselling sessions with a strict collaboration between geneticists and psychologists together with interventions planned to increase men's self-monitoring ability to support their self-efficacy. Further studies are needed to test other forms of health campaigns and communications based on other motivational drives. A comprehensive understanding of barriers and facilitators in a pre-intentional phase in which men have not yet benefited from any genetic counselling session is necessary to support decision-making processes and promote adherence to cascade screening.

PA5-2

## EARLY OUTCOMES OF THE ECHO STUDY: EVALUATING CASCADE COMMUNICATION METHODS AMONGST INDIVIDUALS AND FAMILIES WITH A CONFIRMED HEREDITARY CANCER PREDISPOSITION SYNDROME

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**Objective:** The identification of a hereditary cancer syndrome (HCS) in an individual has direct implications for at-risk relatives (ARRs). Though crucial for stratifying and managing risks, uptake of cascade testing remains low and not well studied beyond first-degree relation. This study evaluated whether a 3-part disclosure toolkit (TK), provided to probands with an autosomal dominant-HCS at a single academic institution, enhanced familial communication and uptake of ARR genetic testing. **Method:** Three cohorts were comprised of proband participants (PP), disclosed relative participants (DRP), and non-disclosed relatives (NDRs). PPs were administered questionnaires at baseline and 3-month intervals through 1 year. At baseline, the PP was provided a study-specific email with TK contents (family letter, URL to customized web-based materials, customized GIA chatbot) and instructed to disseminate all or desired pieces to ARRs. With PP consent, disclosed relatives were contacted and offered study participation, comprised of a one-time survey to evaluate TK preference, utilization, genetic testing status, and decisions/barriers against testing. Decliner data was captured. At end of study, PPs could share non-disclosed ARR contact information for purposes of clinical contact off study. Survey data was tracked via Redcap. Initial analysis included evaluation of PP genetic testing sharing practices, TK distribution, and percent of tested ARRs. **Results:** Thirty PPs and 6 DRPs have consented. All PPs shared genetic testing results with at least 1 ARR. From highest frequency, genetic testing sharing included phone, in-person, self-drafted email, and TK study email. Thus far, 30 ARRs have had cascade testing as a result of their relative reaching out. Of note, 71% of completed PPs reported they would have preferred their genetic provider reached out to ARRs on their behalf. **Conclusions:** Early data suggests traditional familial communication (phone, in-person) is high and preferred versus TK. ARR genetic testing rates are equitable or higher than the reported literature. There is an early suggestion that study introduction (as opposed to the TK itself) has contributed to increases in disclosure and subsequent ARR genetic testing. Future works include continued recruitment, exploration of contact with NDRs and formal in-depth descriptive statistics at study closure, to include study reach of ARR beyond first-degree relation.

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PA5-3

## DECISION SATISFACTION AND REGRET AMONG GENETIC TESTING PATIENTS OFFERED HEALTH SYSTEM-LED DIRECT CONTACT OF AT-RISK RELATIVES

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**Objective:** Cascade testing can improve outcomes for at-risk relatives of people with pathogenic variants associated with cancer risk, yet many relatives never learn of their risk. We are evaluating a new direct contact program where the care team contacts relatives to offer cascade testing. We assessed decisional satisfaction, regret, and family sharing in probands and relatives. **Method:** We conducted a single-arm, prospective mixed-methods intervention study

(R01HG010144) at an integrated health system. We recruited adults awaiting pre-test genetic counseling for hereditary cancer risk and offered the direct contact program. We surveyed all study participants at 6-8 weeks follow-up. **Results:** Enrolled probands (n=55) were mean age 58; 75% female (n=41), 88% White race (n=45); and 7% Hispanic. The majority (69%, n=37) were married; 58% (n=31) reported college education or more. Half of probands (n=28, 51%) requested direct contact of relatives and provided consent to contact 101 relatives; 44% (n=45) of relatives consented to be contacted. Endorsement of the idea of direct contact was similar for probands who had and had not used the program (100% of program users vs 82% of non-users). Direct contact users were more likely than non-users to report they would make the same decision again (100% vs 64%; $p<0.05$). 83% of direct contact users and 36% of non-users reported the study had helped their family. 56% of direct contact users reported that their relatives only learned of their risk because of the program. Results sharing with family members, proband-reported genetic testing in at-risk relatives, and family communication about cancer risk was similar in both groups. Enrolled relatives (n=45) were similar to probands in demographic characteristics, family history, and history of genetic testing. To date, 93% of relatives (n=27) have endorsed the direct contact concept, and 89% report decision satisfaction. 71% reported that the study helped their family, and 50% reported that relatives only learned of their risk through the program. Thirty-four percent of relatives reported speaking with another relative about genetic testing after being contacted. **Conclusions:** Participants who used a direct contact program reported high decisional satisfaction, low decisional regret, and benefits to family. Additional planned analyses include cascade testing in relatives, genetic testing outcomes, and impacts on family communication.

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PA5-4

## "I DIDN'T HAVE TO WORRY ABOUT IT": PATIENT AND FAMILY EXPERIENCES WITH A NEW U.S. HEALTH SYSTEM-MEDIATED DIRECT CONTACT PROGRAM

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**Objective:** The ongoing Lynx study (R01HG010144) aims to develop, implement, and evaluate a novel, health system-mediated familial risk notification program in which a genetic counselor meets with patients seeking testing for Lynch syndrome or hereditary breast and ovarian cancer syndrome and offers to contact at-risk relatives directly. We examined experiences and impacts of the program for probands and relatives. **Method:** We invited all study participants (n=100 from 55 families) to participate in 1-on-1 semi-structured telephone interviews at 6–8 weeks after return of genetic test results. Discussion topics included reasons for participating,

experiences, and impacts of the program on patients and families. We thematically analyzed interview transcripts. **Results:** We interviewed 32 participants from 22 families. Probands (n=17) were median age 67 (range 29-82), 77% female, 100% non-Hispanic White, and 53% had a 4-year college degree or more. Relatives (n=15) were median age 54 (range 19-82), 67% female, 93% non-Hispanic White and 33% had a 4-year college degree or more. Reasons for participating were similar for probands and relatives and included concerns related to family and personal medical history, learning information that could inform medical decisions, and contributing to research. Probands and relatives reported generally positive experiences with the direct contact program, noting they felt in control of decisions and comfortable sharing their relatives' contact information. For probands, the main impact of the program was reduced burden of notifying relatives ("I was very glad that the genetic counselor was taking care of contacting them, so I didn't have to worry about it."). For relatives, impacts included the opportunity to learn more about familial cancer risk, motivation to pursue preventive health actions or genetic testing, and more family discussions. No relatives reported adverse experiences associated with being contacted. Participants from 3 families reported that without the direct contact program, relatives might not have been notified ("I would have had no idea."). **Conclusions:** Health system-mediated contact of at-risk relatives supported probands in reaching at-risk relatives who otherwise might not have been notified and was acceptable to participants. Additional planned analyses include reasons for non-participation, cascade testing uptake in relatives, genetic testing outcomes, and impacts on family communication.

PA6

## DECISION MAKING AND ADJUSTMENT TO HEREDITARY CANCER RISK MANAGEMENT

**Moderator: Camella Rising, PhD, MS, RDN.** National Cancer Institute, United States

PA6-1

### FACTORS THAT DIFFERENTIATE CANCER RISK MANAGEMENT DECISIONS AMONG FEMALES WITH PATHOGENIC/LIKELY PATHOGENIC VARIANTS IN PALB2, CHEK2, AND ATM

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**Objective:** Given limited information on cancer risk management (CRM) decision-making for those with inherited breast cancer predisposition in more recently discovered genes, our goal was to identify factors distinguishing females who do or do not follow national CRM guidelines. **Method:** As part of a larger, mixed-methods project, 33 females with P/LP variants in *PALB2*, *CHEK2*, and *ATM* completed surveys and in-depth phone interviews. Factors identified during

qualitative data analysis of transcribed interviews were analyzed using coincidence analysis (CNA). CNA is a new configurational comparative method of causal inference and data analysis to answer research questions about combinations of conditions that are sufficient for an outcome and identify the possible presence of multiple causal paths to an outcome. **Results:** Two patterns of factors explained 18 of 20 females who are following National Comprehensive Cancer Network (NCCN) guidelines for breast and/or ovarian CRM: 1) patient anxiety along with trust in care or 2) absence of anxiety and no prophylactic surgery prior to testing. Three unique patterns of factors explained 11 of the 13 females who underwent prophylactic surgery, which was inconsistent with NCCN guidelines: 1) patient anxiety in the absence of trust in care; 2) provider recommending surgery inconsistent with NCCN guidelines; or 3) surgery occurring before genetic testing. **Conclusions:** Results demonstrate the influence of several factors in females' CRM decisions, primarily related to trust in care, cancer-related anxiety, and healthcare providers' recommendations. Findings suggest that providers may better prepare females by emphasizing that not all genes have equal risk and underscoring that with moderate penetrance genes (such as *ATM* and *CHEK2*) there is insufficient evidence to recommend risk-reducing surgeries for cancer prevention. Additionally, our data suggests the importance for providers to assess whether their patients' anxiety is proportionate to their cancer risks and provide tools/resources/referrals to help address the psychosocial impact of fear and uncertainty before the pursuit of preventive surgery.

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PA6-2

## IDENTIFICATION OF MEN WITH A GENETIC PREDISPOSITION TO PROSTATE CANCER: TARGETED SCREENING OF BRCA1/2 MUTATION CARRIERS AND CONTROLS (THE IMPACT STUDY QUALITY OF LIFE STUDY)

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**Objective:** To report the long-term outcome data from a longitudinal psychosocial study that forms part of the IMPACT study, a multinational investigation of targeted prostate cancer (PCa) screening among men with a known pathogenic germline mutation in the *BRCA1* or *BRCA2* genes. **Method:** Men enrolled in the IMPACT study were invited to complete a questionnaire at collaborating sites prior to each annual screening visit. The questionnaire included

sociodemographic information and the following measures: Hospital Anxiety and Depression Scale (HADS), Impact of Event Scale (IES), Short Form 36 (SF36), Memorial Anxiety Scale for PCa (MAXPC), Cancer Worry Scale (CWS), risk perception and knowledge. **Results/Conclusions:** 776 men completed questionnaires: 209 men with pathogenic variants in *BRCA1*, 272 men with pathogenic variants in *BRCA2* genes, and 295 controls (familial mutation negative). The baseline results have been published and found that no clinically concerning levels of general or cancer-specific distress or poor quality of life were detected in the cohort at study entry. A small subset of participants reported higher levels of distress, suggesting the need for additional support for men with certain risk factors. The longitudinal data are being analysed and will be presented to compare with the baseline values and to see whether there is any change in psychosocial impact of screening in this cohort over time.

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PA6-3

## THE BENEFITS AND BURDEN OF ANNUAL WHOLE-BODY MRI SCREENING OF INDIVIDUALS WITH LI-FRAUMENI SYNDROME

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PA6-4

## UNDERSTANDING SCANXIETY AMONG INDIVIDUALS WITH LI-FRAUMENI SYNDROME UNDERGOING PERIODIC CANCER SCREENING: A QUALITATIVE STUDY

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**Objective:** Emotional distress leading up to, during, and after an imaging scan, colloquially termed “scanxiety,” is a common experience for cancer survivors who undergo repeated scans to assess disease response, progression, or recurrence. The prevalence and severity of scanxiety varies widely among cancer survivors based on sociodemographic and clinical characteristics, although its measurement has been inconsistent and limited to certain patient populations. Currently, little is known about scanxiety among individuals with inherited cancer syndromes who undergo regular, intensive imaging scans to screen for incident cancers, potentially for life. This study explores experiences of scanxiety among individuals with Li-Fraumeni syndrome (LFS), an early onset inherited cancer syndrome with limited prevention options. **Method:** Adults (≥18 years) with LFS who were receiving periodic cancer screening (e.g., whole-body MRIs and organ-specific imaging) through the National Cancer Institute’s LFS study (NCT01443468) completed in-depth qualitative interviews exploring the nature, extent, and

causes of scanxiety, and coping strategies. An inter-professional team is thematically analyzing transcripts using Dedoose™. Data collection and analysis are ongoing. **Results:** Fourteen individuals completed interviews to date (86% female, 86% personal cancer history, mean age 45.8 years). Participants were highly engaged and experienced with screening, having attended an average of 10.5 clinical visits (range 6-19), either for annual screening or clinically indicated follow-up. Preliminary findings suggest screening-related distress varies in severity but is uniquely influenced by the cyclical and ongoing nature of screening for LFS. Several factors warrant further attention: the shared experiences of scanxiety when more than one family member is diagnosed with LFS (especially children); the relationship between uncertainty and scanxiety; variation in coping strategies in families over time (before, during, and after screening); and participants' longitudinal adaptation to life-long screening. **Conclusions:** Our work to date suggests individuals with LFS may have unique experiences of scanxiety due to their lifelong and multi-organ cancer risks. This work can broaden our understanding of the nature of scanxiety and its implications for individuals with different conditions.

## Poster Sessions

Poster Session 1- POS1

POS1-1

### PERCEIVED VALUE OF GENETIC TESTING FOR HEREDITARY CANCER AMONG PREVIVORS: A QUALITATIVE STUDY AMONG PREVIVORS

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**Objective:** Individuals are willing to pay for genetic testing for hereditary cancer, despite high costs, so long as it is affordable and worthwhile. If patients do not perceive value that outweighs potential harms, we risk missing eligible patients who could be identified through testing. To understand how individuals determine the value of genetic testing, we spoke with previvors—those who have received positive genetic test results—about their willingness to pay for and perceived benefits of having gone through genetic testing. **Method:** Previvors were interviewed from the Early Detection of Genetic Risk (EDGE) Study, which provided free genetic testing to individuals with a family history of hereditary cancer (n = 1677) in the primary care setting. Interviews took place 6-9 months after receiving results. **Results:** To date, 15 previvors have been interviewed. The average age of participants was 62, 33% identified as male, and 47% reported a personal cancer history. Interviewees had pathogenic variants in *MUTYH, PMS2*, *MSH6*, *ATM*, *BRCA1*, *BRCA2*, *APC*, and *CHEK2*. Many participants said they would pay for testing had it not been offered for free (n=7) so long as it was "reasonable and affordable." Some stated

they would be willing to pay for testing because they are interested in learning more about their genetics. Previvors with a history of cancer saw the benefit of genetic testing for their relatives. Four participants would probably pursue testing depending on their financial situation. Most of the participants who would not have pursued testing (n=4) were previvors without a previous cancer history, one of which mentioned that they "wouldn't have seen any reason to do it." Affected previvors who said they would have declined testing or were unsure either had some form of genetic testing already or felt confident in their current screening methods. Among all participants, the amount they would be willing to spend on testing ranged from $10 to $8,000, with highest values endorsed by those with a personal cancer history. **Conclusions:** Variability in willingness to pay is driven in part by perceived significance of the information previvors gained from genetic testing. If individuals without a prior cancer history will not pay for testing, we miss a key population that would benefit from early identification. Future work should explore ways to leverage perceived value to encourage those without a personal cancer history to undergo genetic testing.

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POS1-2

## CANCER SCREENING AND SURVEILLANCE BEHAVIORS IN RECIPIENTS OF CANCER-RELATED SECONDARY GENOMIC FINDINGS

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**Objective:** Medically actionable secondary genomic findings are associated with 19 distinct cancer-predisposition syndromes. Few data exist examining the complexity of returning medically actionable secondary genomic findings and the extent to which recipients engage in protective health behaviors. Our study investigates adherence to cancer screening and surveillance recommendations in recipients of these findings. **Method:** We administered a condition-specific survey listing several specific cancer screening and surveillance behaviors recommended by experts; participants specify how often they have engaged in these behaviors since result receipt. Some behaviors (such as mammography) are recommended in multiple conditions. We summed adherence and frequency data for 23 health behaviors across conditions**. Results:** We analyzed 54 completed surveys from participants with variants associated with 6 distinct conditions: hereditary breast and ovarian cancer, Lynch syndrome, multiple endocrine neoplasia-type 2, *PTEN*-hamartoma tumor syndrome, juvenile polyposis, and hereditary paraganglioma-pheochromocytoma syndrome. The average time between report date and date of survey completion was 17 months (4-60 months). The most frequently reported health behaviors were a dermatology exam (59%), serum CA-125 assessment (64%), transvaginal ultrasound (80%), and colonoscopy (75%); participants reported engaging in these behaviors at least once. In contrast, 67% of participants reported never engaging in urinalysis to

measure metanephrines and catecholamines, and 57% never had a prostate exam. More women (64%) reported having had at least 1 mammogram compared to only 19% of men. Among women who had not undergone mastectomy, 60% reported having never had a mammogram and another 20% reported having had only 1 mammogram. Every participant was asked whether they had seen either a doctor or a genetic counselor specializing in the condition associated with their result, and 80% of women and 48% of men reported doing this at least once. **Conclusions**: Our data demonstrate wide variability in adherence to recommendations among recipients of cancer-related secondary genomic findings. This suggests that implementing precision medicine-informed healthcare may be challenging for many individuals in this population.

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POS1-3

## REQUESTS FOR PROVIDER MEDIATED COUNSELING AND GENETIC TESTING CHOICES AMONG PATIENTS WITH METASTATIC CANCER REFERRED FOR GENETIC TESTING IN THE EREACH STUDY

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**Objective:** With U.S. Food and Drug Administration approval for PARP inhibitor treatment for advanced breast and ovarian cancer, and studies supporting benefit in pancreatic and prostate cancer, there is therapeutic rationale for testing all patients with advanced/metastatic breast, ovarian, pancreatic, and prostate (AM-BOPP) cancer for germline *BRCA1/2* (gBRCA) mutations. The traditional model of pre- (V1) and post-test (V2) counseling with a genetic counselor (GC) will be unable to support these rising indications for gBRCA testing. There is an urgent need for alternative delivery models (ADM) to facilitate gBRCA testing while maintaining adequate patient outcomes. **Method:** A randomized non-inferiority study using a 2x2 design where traditional genetic counseling is replaced with a self-directed, web-based eHealth intervention (WBI) to study delivery of gBRCA testing in patients with AM-BOPP cancer, while maintaining quality of care and favorable cognitive, affective, and behavioral outcomes. Analyses assessed factors associated with requesting a GC when assigned to a WBI visit and panel testing choice (smaller disease-specific [O1] vs. large [O2] vs. custom [O3]). Participant characteristics included demographics, health literacy and baseline knowledge, anxiety, depression, cancer-specific distress, and depression. Descriptive statistics with Rank Sum and Fisher's Exact tests were used for analyses. **Results:** Among 205 participants, 9% to 16% assigned to WBI V1 or V2 have requested a GC visit. Requesting a GC visit is associated with lower knowledge scores (p=0.03).

Among 158 participants who have made a testing choice, 70.3% selected O2, while 14.6% selected O1, and 15.2% selected O3 with a GC consult. Having higher anxiety (p=0.056), cancer specific distress (p=0.005), and being at a non-academic community site (p=0.003) were associated with selecting O1, while completing V1 with a GC was associated with selecting O2 (p<0.001). Selecting O3 with a GC instead of O2 was more common among women (p=0.031) and patients with breast and pancreatic cancer (p=0.008). **Conclusions:** While WBI alternatives may increase access and reduce burdens associated with genetic services, some patients prefer provider-mediated counseling. Additionally, when given options for testing, some AM-BOPP patients choose more limited testing focused on results that could directly impact treatment. These data suggest that maintaining patient-centric choices with ADM may remain critical for patients with advanced cancer.

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POS1-4

## COLLECTING COMPLETE FAMILY HISTORY GREATLY INCREASES IDENTIFICATION OF PATIENTS WHO MEET CLINICAL CRITERIA FOR CANCER GENETIC TESTING IN A COMMUNITY SETTING

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**Objective:** Identification of hereditary cancer syndromes can have implications for cancer treatment and prevention. However, only a fraction of cancer patients undergo germline genetic testing (GT), in part due to not meeting criteria based on their own clinical history. Obtaining a complete family history has been shown to increase yield of patients meeting genetic testing criteria [1-3]. We employed a family health history tool (FHHT) to assist in identifying cancer patients eligible for GT in the outpatient oncology setting. **Method:** Patients with cancer with a visit scheduled at a community-based oncology practice received email invitations to complete a web-based FHHT that elicits cancer type and age at diagnosis for 1st and 2nd degree relatives. National Comprehensive Cancer Network guidelines were applied to identify individuals meeting clinical criteria for GT. **Results:** 2,313 patients completed the FHHT from August 1, 2021, to January 1, 2023, 484 (20.9%) of whom qualified for GT. Of these, 119 (24.6%) patients confirmed that they had not previously undergone GT; 55 (46.2%) qualified for GT based on their personal history alone and 64 (53.8%) qualified with the addition of family history, an increase of 116.4%. The most common criteria for qualification from personal history alone was breast cancer diagnosed under age 50 (n=26, 47.3%). The most common qualification criteria with personal and family history combined was personal history of prostate with a family history of pancreatic cancer (n=16, 25%). Overall, those with prostate cancer met criteria the most often with the addition of family history (n=28, 43.8%). **Conclusions:** Collecting a complete family history more than doubled the number of patients who qualified for GT compared to

personal history alone. Appropriate family history collection is key to identification of patients at risk for hereditary cancer syndromes.

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POS1-5

## PARENTAL ATTITUDES AND EXPERIENCES WITH GERMLINE GENETIC TESTING IN THE PEDIATRIC ONCOLOGY SETTING: IMPLICATIONS FOR THE PRACTICE OF GENETIC COUNSELING

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**Objective:** Germline genetic testing (GGT) is increasingly being conducted along with tumor analysis for oncology treatment planning in children. We conducted a behavioral assessment among parents about GGT, including how to optimally integrate into oncology care. **Method:** Living, English-speaking patients aged <18 years who were diagnosed with cancer and who had GGT were identified from the Huntsman Cancer Institute over a 24-month interval. A multidimensional self-report survey was administered to parents/guardians via email, and a subset completed telephone interviews. **Results:** Forty-one families were contacted and 13 (32%) surveys were received: 11 patients received GGT <4 months of diagnosis. Two were tested more than 6 years after their initial diagnoses due a new cancer in the family or recurrence, and 4 reported that testing identified a pathogenic variant in a cancer predisposition gene. All parents reported being aware that GGT was being performed, receiving sufficient information about GGT, and discussing results with a genetic counselor. Regarding tumor sequencing, 6 reported it had been performed, 6 were unsure, and 1 reported no tumor sequencing. All parents stated GGT was important for children with cancer and recommended it for other children diagnosed with cancer. Participants generally felt that their child's GGT was performed at an appropriate time (n=11); however, 1 was unsure, and 1 reported "no" because testing was delayed due to sample issues. In qualitative interviews (n=6), both parents of children who did and did not have a pathogenic variant expressed relief in having information from GGT. They all reported being highly satisfied with their decision to have their child tested; 1 felt there may be families who would not want this information because it could add to anxiety. When asked about resources for understanding GGT results, respondents noted that printed materials and access to a genetic counselor were helpful. Being able to connect with peers was also cited as being helpful for those with a genetic condition. **Conclusions:** Parents of children with cancer are highly interested in GGT, and felt this information was valuable to their children's health and decision making. While the primary purpose of paired tumor/germline testing is for physicians making treatment choices, efforts should be made to explain germline components of these tests and to incorporate genetic counseling into these new genetic testing workflows to ensure optimal outcomes.

POS1-6

## PRACTICES AND VIEWS OF U.S. ONCOLOGISTS AND GENETIC COUNSELORS REGARDING PATIENT RECONTACT FOLLOWING VARIANT RECLASSIFICATION: RESULTS OF A NATIONWIDE SURVEY

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**Objective:** Over a 5-year or 10-year period, between 6% and 15% of germline cancer genetic variants undergo reclassification. Up-to-date interpretation can clarify a variant's clinical significance and is facilitated by the availability of updated information about normal human genomic diversity, especially among underrepresented populations. As the frequency of reclassifications increases, the issue of whether, how, when, and which providers should recontact patients with information about reclassification becomes important. However, the field lacks research evidence and definitive guidance from professional organizations about how providers should recontact patients. To address this gap, we compared the perspectives of U.S. oncologists in subspecialties that frequently use germline genetic testing and manage patient care following variant reclassification and cancer genetic counselors (GCs) to describe their practices and views regarding recontact. **Method**: A survey was developed using themes identified from semi-structured interviews with oncologists and GCs and disseminated in a national sample of genomic providers between July and September 2022. **Results**: In total, 634 respondents completed the survey including 349 oncologists and 285 GCs. Both groups primarily practiced at academic medical centers and were frequently involved in ordering genetic tests, returning genetic test results, and interpreting them. On frequency of recontacting patients with reclassified results, 40% of GCs reported recontacting often compared to 12.5% of oncologists. Neither group reported recording patient preference for recontact on EMR. Both groups agreed that all reclassified variants, even when they do not impact clinical management, including VUS downgrades should be returned to patients. They also reported that notification via EMR messages, mailed letters, and phone calls from GC assistants were more suitable for downgrades. For upgrades, face-to-face meetings and phone calls were preferred. Remarkably, oncologists were more likely to endorse face-to-face return of results and were more likely to endorse return through a non-genetics provider compared to GCs. **Conclusions:** These data on current recontact practices and opinions provide a foundation for developing guidelines with explicit recommendations on patient recontact that can help maximize clinical effect and consider patient preference for recontact within resource-constrained genomic practice settings.

POS1-7

## ASSOCIATION OF GENETIC COUNSELING AND TESTING EXPERIENCE WITH EMOTIONAL OUTCOMES IN INDIVIDUALS WITH VARIANT OF UNCERTAIN SIGNIFICANCE RESULTS FROM CANCER MULTIPLEX GENETIC TESTING

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**Objective:** Multiplex genetic testing can reveal genetic variants of uncertain significance (VUS) with unclear associations with cancer risk. Little is known about how people emotionally respond to receiving VUS, yet some studies have reported worry, uncertainty, and a greater lack of understanding of VUS compared to definitive results. There is some evidence that genetic counseling (GC) may be important for promoting adaptive responses to VUS, which warrants additional exploration given a rise in alternative testing options outside traditional clinical settings. **Method:** Participants (n=695) from the online Prospective Registry of Multiplex Testing (PROMPT) with a cancer susceptibility gene VUS completed a survey including the emotional outcomes of uncertainty (range 0-45), decisional regret (0-100) and distress (0-30). An "informed and confident" score (0-3) was calculated from items pertaining to the testing experience: feeling sufficiently informed when undergoing testing, being informed of the possibility of VUS before testing, and confidence in the meaning of the result. Participants also reported whether they had ever received cancer GC (yes/no). We hypothesized that receipt of GC would be associated with lower levels of each emotional outcome, and these effects would be mediated by feeling informed and confident. We tested this with Hayes' (2013) PROCESS macro in SPSS in models using 5,000 bootstrap samples adjusted for relevant covariates. **Results:** Most (81%) participants had received GC and reported modest levels of uncertainty (9.0±8.1), decisional regret (6.1±13.4) and distress (3.1±5.0). As predicted, there was a significant total effect of GC on uncertainty (B=1.6, p=0.05), which was fully mediated by feeling informed and confident (B= -2.9, p<0.001; indirect effect=1.9, 95% CI=1.3-2.6; direct effect of GC=ns). There was also a significant total effect of GC on regret (B=4.3, p<0.001) fully mediated by feeling informed and confident (B= -3.0, p<0.001; indirect effect=2.0, 95% CI=1.1-3.0; direct effect of GC=ns). GC was not associated with distress. **Conclusions:** GC is important for individuals with a VUS result from cancer multiplex genetic testing regarding uncertainty and decisional regret, and these results shed light on specific factors that may drive the benefits of GC. In cases where GC is not convenient or feasible, particular attention should be given to making patients feel sufficiently informed during testing and confident in the result.

POS1-8

## IMPACT OF COVID-19 PANDEMIC POINT-OF-CARE GENETIC TESTING OF ADVANCED CANCER PATIENTS

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**Objective:** Timely genetic testing for advanced cancer patients is critical, as results can impact treatment decisions and clinical trial eligibility. Disruptions and delays in oncology care during the COVID-19 pandemic have been a subject of much study. However, these studies primarily focused on the impact on general health services, diagnosis, and cancer treatment. We examined the impact of COVID-19 on genetic testing in our advanced prostate (PR) and pancreatic cancer (PC) cohorts by comparing the completeness and timing of genetic testing through a "mainstreaming" model pre-pandemic (YPP) to that during the pandemic (FYP). **Method:** Data are reported from a single-site cohort of PR and PC patients who are part of a larger multicenter prospective study. Participants received standardized education and consented to multigene panel testing (MGPT) at the point of oncology care. Post-test phone counseling was performed by a genetic counselor. Participants included those consented March 1, 2019, through February 29, 2020, denoted as YPP and those consented March 1, 2020, through February 28, 2021, denoted as FYP. **Results:** Participants in YPP (n=360) and FYP (n=232) were mostly white (76% both cohorts) and male (72% YPP, 78% FYP) and PC (58% YPP, 61% FYP). Frequency of pathogenic variants (PV) was similar across time cohorts (9% YPP, 10% FYP). In YPP, 99% of participants received genetic test results. The following year, 41 (18%) participants did not receive results. The most common reasons for not receiving a result were death (n=19; 46%) or not providing a sample for testing (n=14; 34%). The average time between date of consent and date results received was 20 days in YPP (median=12; SD=33) and 52 days in FYP (median=25, SD=83). The difference was statistically significant. **Conclusions:** The COVID-19 pandemic introduced disruptions in point-of-care MGPT. Nearly a fifth of individuals did not receive results in FYP because they did not return a sample for testing. It also took significantly more time for participants to receive their results during the pandemic. There were no notable differences in distribution of gender or race between YPP and FYP cohorts; however, completion of testing differed by race. Future research should examine the interruptions of COVID-19 pandemic on genetic testing given the implications for patients and their family members and should focus on interventions to increase testing completion and reduction in racial disparities.

POS1-9

## "I'M GRATEFUL IT'S JUST ME HAVING TO FIGHT FOR MYSELF": THE SUPPORTIVE CARE NEEDS OF INDIVIDUALS WITH *DE NOVO TP53* VARIANTS

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**Objective:** Li-Fraumeni syndrome (LFS) is a hereditary cancer predisposition syndrome primarily caused by inherited *TP53* variants, yet approximately 20% of individuals with LFS have variants which are not inherited (i.e., *de novo*) and no suggestive family cancer history. Literature and clinical guidelines focus on LFS kindreds, obscuring the challenges of those with *de novo TP53* variants. This study sought to identify the unique medical challenges and supportive care needs of individuals with *de novo TP53* variants as they navigate risk management and cancer treatment. **Method:** Individuals enrolled in the National Cancer Institute's LFS study (NCT01443468) with confirmed (n=14) or possible (n=12) *de novo* variants in *TP53* were invited to complete a qualitative interview. An interprofessional research team developed a semi-structured, IRB-approved interview guide that elicited genetic testing experiences, informational and psychosocial challenges, and unmet needs. Interviews were transcribed verbatim and analyzed using thematic analysis. **Results:** *De novo* participants discussed steep learning curves regarding LFS to understand their cancer diagnoses, make treatment decisions, interpret genetic test results, adjust to lifelong risk, and develop a long-term screening plan. For many, *TP53* positive genetic testing results provided an opportunity for sense-making with regards to their early and rare cancer diagnoses. Though participants reported gratitude that family members did not have LFS, they also experienced psychosocial burden as the only affected individual in the family. Communication and support received from family members was challenged by the absence of shared cancer risk. Many sought emotional support from knowledgeable healthcare providers, spouses, and online rare disease communities. Further, many reported a sense of responsibility to engage with the hereditary cancer community to reduce the isolation of others and to engage in research due to the rarity of LFS. **Conclusions:** Individuals with *de novo* variants may lack familial guides and providers to address disease management and uncertainty. Ongoing follow-up for such patients will support decision-making, continued understanding of lifetime cancer risks, and cancer risk mitigation. Specialty health and mental health providers may support *de novo* patients by validating their uncertainties and connecting them with disease-specific patient advocacy groups that support adjustment to chronic cancer risk.

POS1-10

## MOTHERS' AND CHILDREN'S PSYCHOLOGICAL DISTRESS AND FAMILY COMMUNICATION BEHAVIOR ABOUT GENETIC BREAST CANCER RISK: CONSIDERATIONS FOR RESEARCH, COUNSELING, AND CANCER PREVENTION

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**Objective:** Some mothers who participate in genetic counseling/testing (GCT) for inherited cancer mutations openly share this information with their children. Family discussions about cancer risk are important to promote awareness and early cancer preventive behaviors, such as healthy lifestyle choices. We examined how psychological distress in mothers surrounding testing for BRCA variants, and the perceived stresses of their children, impact the parent-child relationship and communication about cancer. **Method:** Grounded in the Family Systems Genetic Illness model and Baum's theory of stress and coping, we conducted a secondary analysis of data among a cohort of 256 mothers (M age = 45.02 years, 71.3% White) with children ages 8-18 years. Participants completed telephone interviews prior to pre-test GCT for *BRCA* mutations assessing cancer communication with their children, maternal and child psychological distress, and openness in the parent-child communication relationship. Bivariate analyses between and among these dimensions were analyzed, and in a multivariable regression model. **Results:** Maternal psychological distress ($r=-0.125$, $p<0.05$), children's distress ($r=-0.358$, $p<0.05$), and cancer communication history ($r=0.205$, $p<0.05$) were significantly associated with the quality of openness in the parent-child relationship: mothers and children with more distress, and who engaged in fewer discussions about hereditary cancer, had less open parent-child communication styles. In a regression analysis adjusted for maternal psychological distress, children's distress ($B=-0.34$, SE B $=-0.33$, $t=-5.34$, $p<0.001$) and cancer communication ($B= 0.29$, SE B$=0.11$, $t=2.51$, $p=0.01$) remained significantly associated with dyadic communication openness. Mothers whose children were more distressed, and those who spoke with their children less often about hereditary cancer, had poorer communication outcomes with their children. Additionally, open communication styles were positively associated with sharing information with children about maternal participation in GCT ($t=3.18$, $df=254$, $p<0.001$). **Conclusions**: In the context of pre-test GCT for hereditary cancer risk, mothers and children with greater psychological well-being engage in more conversations about cancer, and this is associated with a healthier parent-child relationship, including sharing information about GCT. Further research into ways that counseling can strengthen family-based mental health may be beneficial for cancer prevention.

Poster Session 2 – POS2

POS2-1

## A MIXED METHODS STUDY EXAMINING PRIMARY CARE PROVIDER NEEDS FOR CONDUCTING CLINICAL CANCER CONSULTATIONS

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**Objective:** As population-based screening efforts for hereditary cancer syndromes are expanded, it is crucial to ensure that primary care providers (PCPs) have the knowledge and skills to communicate about genetic risk with their patients. However, prior efforts to train clinicians have not yielded significant improvements in practice (Wilkes et al., 2017; Paneque et al., 2016). This mixed methods study sought to better understand physicians' needs in conducting cancer risk consultations. **Method:** Data are from the Early Detection of Genetic Risk Study, a population-based screening initiative in the primary care setting. A cross-sectional, baseline survey was completed by 60 PCPs from 12 clinics, and 16 of these providers participated in follow-up interviews. Self-efficacy/confidence was assessed in seven communication elements; responses were scored on a 4-point Likert scale ranging from 0 (Not confident at all) to 3 (Very confident). **Results:** Although PCPs reported being confident in their abilities overall (64% somewhat/very confident), variability existed across skills necessary in a genetic risk consultation. PCPs are somewhat or very confident initiating conversations about cancer with their patients (98%), recording relevant information on a patient's family history (98%), responding to patients' questions about cancer risk based on family history (72%), and discussing age-related cancer risk (71%). In contrast, confidence was much lower for responding to patients' questions about genetic testing for cancer risk (32%), explaining lifetime cancer risk to their patients (33%), and providing support to patients going through genetic cancer risk assessment (47%). Interview data supported survey results and revealed most PCPs are not ordering cancer risk genetic testing even when it might be appropriate. The most commonly cited reasons for not ordering genetic testing were concerns about their own lack of knowledge about which test to order, how to order the tests, how to interpret the results, how to relay that information to their patients, and how to get the testing covered by insurance. **Conclusions:** Study findings reveal lower provider confidence in certain skill areas that may need to be addressed in training programs to achieve meaningful practice changes. For population-based screening efforts to be successful, PCPs will need to acquire additional skills to effectively deliver clinical care related to identification and management of genetic cancer risk.

POS2-2

## *CDH1* CASCADE GENETIC TESTING IN AT-RISK RELATIVES: AN ASSESSMENT OF THE IMPACT OF PROBAND CHARACTERISTICS ON UPTAKE

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**Objective:** To determine whether proband characteristics impact uptake of cascade genetic testing among first-degree relatives (FDR) and second-degree relatives (SDR). **Method:** Between January 2017 and March 2022 individuals with a *CDH1* pathogenic or likely pathogenic variant (P/LPV) were enrolled onto a hereditary gastric cancer study. At the time of enrollment participant demographics, genetic test report, family history, *CDH1* relative testing status, and proband (first person testing positive for *CDH1*) information were collected. Total FDR and SDR and those tested for *CDH1* were manually counted twice per pedigree. Comparative statistical analyses (unpaired, independent sample t-test and one-way ANOVA) were performed to evaluate differences in mean rates of *CDH1* cascade testing based on proband characteristics. **Results:** The analysis included 100 probands with *CDH1* P/LPV and their FDR (n=427) and SDR (n=436). The majority of probands were White (79%), female (78%) and median age was 49 years (range 23-84). Proband's cancer history included 24% with gastric cancer and 47% of female probands with breast cancer. Overall, 57% (248/427) of FDR and 31% (135/436) of SDR underwent *CDH1* cascade testing. There were statistically significant ($p<0.05$) higher mean rates of FDR and SDR who had *CDH1* genetic testing if the proband was male. Proband's with a personal history of gastric cancer also had higher rates of cascade genetic testing in FDR and SDR. Among FDR, there was also a significant difference in mean uptake rates by length of time since proband was tested, but not among SDR. A family history of breast cancer was not correlated with higher rates of *CDH1* testing in both FDR ($p=0.543$) and SDR ($p=0.266$) of probands. **Conclusions**: Male probands and probands with a personal history of gastric cancer had higher rates of FDR and SDR who underwent *CDH1* cascade testing. Several factors, such a proband's comfort level in explaining the implications of *CDH1* cascade genetic testing, communication style, and emotional closeness to at-risk relatives may impact testing uptake rates. Additional studies are needed to determine how these factors and others, such as at-risk relatives' perceived threat of gastric cancer versus breast cancer, impact genetic testing cascade test rates in *CDH1* families. Diversity in *CDH1* research is necessary, as most probands in this study were female and White.

POS2-3

## EVALUATION OF THE BREAST CANCER MAINSTREAM GENETIC TESTING PROGRAM AT THE PARKVILLE FAMILIAL CANCER CENTRE, VICTORIA, AUSTRALIA: PATIENTS AND CLINICIANS' EXPERIENCES AND HEALTH SERVICE OUTCOMES

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**Objective**: Increasing demand for genetic testing as standard for many breast cancer patients has necessitated new models of care for clinical genetics services. To improve accessibility the Parkville Familial Cancer Centre (PFCC) established a program of mainstream breast cancer genetic testing in surgical and oncology clinics. A comprehensive program evaluation was undertaken after two years to examine the impact and outcomes of this model. Aim: Evaluate patient experiences and outcomes, clinician impact, and the health service implications of mainstreaming breast cancer genetic testing. **Method:** Data were collected via a clinical audit, patient survey and semi-structured interviews, and breast specialist survey. Descriptive analysis was undertaken for quantitative measures and content analysis for qualitative data. **Results:** Between 2017 and 2019, 72 breast specialists from 9 hospitals facilitated genetic testing for 230 patients, resulting in changes to treatment for most patients (87%). Forty-seven patients (20.4%) attended a PFCC appointment after mainstream testing, with 413 PFCC appointments saved over the 2-year period. Sixty-eight patients (30%) completed the survey with most satisfied with the information provided by their breast specialist before testing (94%) and after results (86%). Twenty patients were interviewed and most preferred testing via mainstreaming rather than an FCC due to the existing relationship with their trusted breast specialist and feeling overwhelmed by many treatment-related appointments. Forty-five breast specialists responded (63%); most had discussed (87%) and consented (80%) patients for mainstream genetic testing. The majority (89%) believed mainstream genetic testing should be part of their role and felt well supported by the PFCC (90%). **Conclusions:** The mainstreaming model implemented by the PFCC has met patient and clinician needs. The findings of the evaluation have provided valuable insight from which the PFCC mainstream program can be further developed with the potential to scale to other sites and for other cancer types.

POS2-4

## "MIRACLE OF TECHNOLOGY" OR "PLAYING GOD"? A QUALITATIVE EXPLORATION INTO THE ROLE OF JUDAISM IN OBSERVANT JEWISH WOMEN'S PATIENT DECISION-MAKING ABOUT PGD FOR BRCA

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**Objective:** Given the relatively high prevalence of *BRCA1/2* gene mutations among individuals of Ashkenazi Jewish descent, and the autosomal dominant nature of the mutation, Jewish *BRCA1/2* carriers' potential risk becomes two-fold: In addition to their own health risk, individuals with *BRCA1/2* mutations often express concerns about transmitting said mutations to their biogenetically related children. Assisted reproductive technologies (ARTs) provide an option to identify the BRCA status of an embryo prior to implantation. Preimplantation genetic diagnosis (PGD), also known as preimplantation genetic testing for monoploidy (PGT-M), is one such reproductive technology. PGD allows for genetic sequencing of an embryo to determine whether it carries a genetic mutation—namely, the *BRCA* mutation. While previous studies have explored patient decision-making in the context of PGD, this qualitative study is novel in its specific focus on observant Jewish-American women. Our research was guided by the following questions: What is the role of Judaism in an individual's experience of deciding on PGD for the *BRCA1/2* mutations? How do Jewish principles bear on decision-making for BRCA? **Method:** Reproductive-age *BRCA1/2* mutation carriers were recruited from 2 medical centers in NYC for a qualitative study of attitudes and decision-making about PGD. Among the participants (N=39; 34 female), 62% identified as Jewish; 6 identified as Jewish and observant, all female. Transcripts were analyzed using reflexive thematic analysis (TA), a qualitative practice in which themes are developed from data content (Braun & Clark, 2006). **Results:** The following 5 themes across transcripts were identified: God's Will, Be Fruitful & Multiply, Stigma & Secrecy, Rabbinic Consultation, and Ethical Dilemmas. Results exemplify the interconnectedness between an individual's relationship to Judaism and their navigation of the decision to use PGD. **Conclusions:** Judaism as a religion and culture places value on reproduction; however, the weight of reproduction and childbearing presents unique challenges for individuals faced with *BRCA*-linked hereditary cancer risk. The results suggest each participant's relationship to Judaism was a defining feature in their consideration of whether they would use PGD for *BRCA*. Future research and clinical practice should consider the sociocultural and religious elements that bear on cancer adjacent choices.

POS2-5

## COMMUNICATION ABOUT HEREDITARY CANCER RISK TO OFFSPRING: A SYSTEMATIC REVIEW OF CHILDREN'S PERSPECTIVE

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**Objective:** The present review describes how children experience hereditary cancer risk communication within the family. **Method:** Searches for studies between 1990 and 2020 on PubMed and EBSCO were undertaken, and 15 studies met the inclusion criteria, following PRISMA guidelines. The findings informed: 1) how, when, and what is discussed about hereditary cancer risk in the family; 2) how does family communication about hereditary cancer risk impact children on psychosocial and behavioral outcomes; 3) what are the child's preferences regarding hereditary cancer risk communication within the family. **Results:** Disclosure is done mostly by both parents, or mothers only, which is in accordance with the children's preferences. Children value open communication about cancer risk with their parents, although they report experiences of fear, surprise, feeling unhappy, and concern about the increased risk of cancer. Regardless of the method of disclosure, children may be particularly sensitive to their parent's emotional state at the time of disclosure, and they learn from their parents' experiences the potential implications of cancer risk. Children also report that it would be helpful to learn more about genetic cancer syndromes via written materials and/or meet a genetic counselor. **Conclusions**: Children rely on their parents as the primary models of the hereditary cancer experience. Therefore, parents play a central role in the psychological adjustment of children. Findings point to the relevance of family-centered care in hereditary cancer risk that targets not only the mutation carrier individually but also their children and partners.

POS2-6

## CAREGIVER EXPERIENCES NAVIGATING TELOMERE BIOLOGY DISORDER-RELATED SOCIAL SUPPORT WITH FAMILY AND FRIENDS

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**Objective:** Telomere biology disorders (TBDs) are inherited cancer-prone syndromes caused by germline pathogenic variants in telomere maintenance genes. TBDs are associated with high risk of bone marrow failure, cancer, pulmonary fibrosis, and other complications. Caregivers of children with TBDs may have extensive social support needs given the heterogeneity, chronicity, and potential severity of illness. The aim of this qualitative-descriptive study was to explore caregiver experiences navigating TBD-related social support with family and friends. **Method:** Participants were enrolled in the National Cancer Institute TBD needs assessment study. The analytic sample included 10 caregivers of ≥1 child with a TBD. In interviews, participants were invited to describe TBD-related social support received by or provided to family or friends. We thematically analyzed transcripts using qualitative content analysis. **Results:** Participants were mostly female (n=8) and caregivers of ≥1 adolescent/young adult (n=8). Several reported caregiving for >1 family member with a TBD (n=4) and/or managing their own TBD (n=4). Caregivers described receiving multiple types of helpful support from family and friends; however, some reported that the support offered did not always meet their needs or was upsetting. Caregivers coped by turning to other supports or by setting boundaries to emotionally protect themselves. Caregivers also reported providing substantial support to family beyond their caregiving role. They described feeling responsible for ongoing provision of emotional and informational support to family at genetic risk, but also feeling burdened by this responsibility due to their own complex emotions and the need to tailor communication for developmental readiness or family dynamics. Caregivers reported concerns and uncertainty about their role in supporting children as they developed independence and formed romantic partnerships. **Conclusions:** Findings suggest caregivers often provide considerable support to generations of family members, which is burdensome. Moreover, caregivers may receive support from family or friends that is perceived negatively, potentially having harmful effects on psychosocial health. Interventions that use a family systems approach to address complex and dynamic support needs of caregivers are needed. In health care encounters, clinicians could assess caregivers' social support needs and recommend sources of support that may fulfill these needs.

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POS2-7

## IMPACT OF AMBIGUITY AVERSION ON GENETIC TESTING CONCERNS FOLLOWING "MAINSTREAMING" HEREDITARY CANCER MULTIGENE PANEL TESTING

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**Objective:** Germline multigene panel testing (MGPT) can aid cancer patients' screening and treatment decisions, yet MGPT may also raise feelings of ambiguity. In response to ambiguity, some people consistently have pessimistic judgements of risk and decisional avoidance, a reaction known as "ambiguity aversion." One's predisposition to ambiguity aversion may shape their emotional responses after MGPT. We examined how patients' ambiguity aversion, as well as demographic and clinical factors, are associated with genetic testing concerns following MGPT. We hypothesized that greater ambiguity aversion will be associated with greater genetic testing concerns after MGPT result return. **Method:** Data were collected through a larger study of a "mainstreaming" clinical genetic cancer care delivery model, wherein participants received standardized education and consented to hereditary cancer MGPT with their oncologist and received MGPT results and post-test counseling from a genetic counselor via telephone. Analyzed data came from participant surveys collected at consent (including the Ambiguity Aversion in Medicine Scale, higher scores equal greater ambiguity aversion), and 3 weeks after result return (including the Multidimensional Impact of Cancer Risk Assessment, a measure of genetic testing concerns where higher scores equal greater distress, uncertainty, and lack of positive experiences). We used regression modeling to examine the association between ambiguity aversion with genetic testing concerns, controlling for any demographic and clinical covariates (age, cancer type, gender, family cancer history, MGPT result, race). **Results:** Participants (n=514; age: M=67.2, SD=9.5) were diagnosed with ovarian (20%), prostate (51%), or pancreatic cancer (28%), and were mostly White (87%) and male (67%). MGPT found that 12% had pathogenic variants, 14% had variants of uncertain significance (VUS), and 74% had no variants identified. Among possible covariates, only MGPT result was related to genetic testing concerns ($p<0.001$) and thus included in the model. As predicted, greater ambiguity aversion was associated with greater genetic testing concerns ($B=0.50$, $p<0.001$). MGPT result was also significantly associated with genetic testing concerns; participants with pathogenic variants had greater genetic testing concerns than those with VUS ($B=-8.8$, $p<0.001$) or no variants ($B=-9.08$, $p<0.001$). Exploratory analyses found no significant interaction between ambiguity aversion with MGPT results in predicting genetic testing concerns ($p>0.05$). **Conclusions**: Ambiguity aversion at consent was positively related to genetic testing concerns, suggesting that ambiguity aversion is a predictor of poorer outcomes. Future research should examine how ambiguity aversion may relate to behavioral outcomes and treatment decisions.

POS2-8

## PEDIATRIC ONCOLOGY, TUMOR MOLECULAR PROFILING, AND PAIRED GENETIC TESTING: PARENTS' EXPERIENCES AND IMPLICATIONS FOR HEALTHCARE DELIVERY

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**Objective:** Pediatric tumor molecular profiling (TMP), paired with germline genetic testing, is rapidly becoming a well-established research and clinical practice in children's cancer care. Little is known about parents' experiences with testing their children's DNA, or how it may ultimately influence children's healthcare delivery. To inform the field, we are conducting a mixed-methods, multi-institutional pilot study across 5 National Cancer Institute-designated comprehensive cancer centers to examine patient outcomes. **Method:** Caregivers of children with cancer (n=11, M age=46, 91% female, 72% White, 55% Hispanic, 55% partnered) were invited to complete a brief, online self-report behavioral survey. This assessed their comprehension about and the implications of TMP and germline genetic testing, including preferences for family education. A subset of parents and children (n=6) were also invited to complete key informant interviews. **Results:** Within this sample, 64% could not accurately recall their/their child's participation in TMP (despite having done so). Of the participants who recalled TMP, 25% strongly identified with emotional responses to more than 80% of survey items relating to the implications of testing/results on future healthcare management. Similar themes emerged during qualitative interviews, where participants who recalled pediatric TMP expressed relief upon disclosure, as the results helped to guide treatment. Regarding the return of results, 73% endorsed preferences for learning about health conditions with genetic risk, and 64% for adult-onset cancers with prevention/treatment implications. Qualitatively, all caregivers voiced interest in knowing the results of all tests, while children preferred limiting results to those impacting their immediate care. All participants felt overwhelmed when speaking with the pediatric oncology team; only 1 parent reported cascade testing in response to actionable germline genetic findings. The need for cascade testing assistance (91%) and literature on TMP (i.e., beyond informed consent; 82%) was reflected across both data collection methods (in 7/8 thematic domains). Literature and conversations with healthcare professionals (45%) were viewed as effective means of family education and endorsed as the most preferred methods during qualitative interviews (92%). **Conclusions:** Parents and children with cancer value TMP, its results, and health implications: knowledge of TMP is increasingly an integral component of healthcare decision-making. Both tumor and germline genetic testing could be guided by healthcare professionals, and new resources could be developed to support family education.

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POS2-9

## CARE PRIORITIES AMONG BRCA MUTATION CARRIERS: A PILOT SURVEY

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**Objective:** There is a dearth of literature on patient-reported needs and preferences of BRCA mutation carriers with regards to preventative healthcare services, psychosocial and financial or logistic support. We conducted a patient-advocate led pilot survey to address this gap. **Method**: People self-identifying as having *BRCA1* or *BRCA2* mutations completed an anonymous online survey focusing on care preferences. The 20-question survey was distributed via email through patient advocate and survivor networks. **Results:** Twenty-seven self-identifying BRCA mutation carriers completed our survey. Median age of respondents was 45 years (IQR 39-67.5); 23 (85%) identified as non-Hispanic White, 3 (11%) as Hispanic White, and 1 (4%) as non-Hispanic Black. All were women; 13 (48%) reported a history of breast or ovarian cancer. Most respondents valued the following components of medical care: access to physicians specializing in *BRCA* (26, 96%), a single provider managing all *BRCA* related needs (26, 96%), centralized care at a single institution (26, 96%), short appointment wait time (26, 96%), streamlined care with scheduling of several appointments on a single day (25, 93%), access to clinical trials (24, 89%), and access to providers specializing in the psychological needs of people with BRCA mutations (24, 89%). Respondents reported prioritizing that the specialists who managed the following aspects of care had expertise in BRCA: ovarian and breast cancer screening (27, 100%), menopause symptoms (25, 100%), risk-reducing breast or pelvic surgery (22, 96%), and interpretation of breast imaging (25, 93%). Twenty-one responders (77%) reported they would be interested in receiving care at a comprehensive hereditary genetic center if the option were available, with one patient offering in a free text response, “It is tedious and time-consuming to schedule all the cancer screening tests around the year. I would prefer to get coordinated care in a specialized center that meets all my *BRCA*-related needs efficiently.” **Conclusions:** A majority of *BRCA* mutation carriers expressed desire for a single provider or center to coordinate *BRCA*-related needs and that providers managing cancer screening, risk-reducing surgery, and menopause symptoms have expertise in treating patients with BRCA mutations. Healthcare centers should strongly consider these needs and preferences to provide comprehensive patient-centered care for this high-risk population.

POS2-10

## FACILITATING RETURN OF GENETIC RESEARCH RESULTS FROM A BIOBANK REPOSITORY: PARTICIPANT UPTAKE AND UTILIZATION OF DIGITAL INTERVENTIONS

**Elizabeth Wood, MS.** University of Pennsylvania, United States

**Coauthors**: Demetrios Ofidis, BA;[1] Lillian Phung, BA;[1] Rajia Mim, MS;[1] Brian Egleston, PhD;[1] Sarah Howe, MS;[1] Lillian Hoffman-Andrews, MS;[1] Anjali Owens, MD;[1] Susan Domcheck, MD;[1] Reed Pyeritz MD, PhD;[1] Bryson Katona MD, PhD;[1] Staci Kallish DO;[1] Giorgio Sirugo MD, PhD;[1] JoEllen Weaver BS;[1] Katherine Nathanson MD;[1] Dan Rader MD;[1] Angela Bradbury MD[1]

Affiliations:[1]University of Pennsylvania, USA; [2]Fox Chase Cancer Center, USA

**Objective**: To evaluate uptake of actionable genetic research results, factors associated with receipt of results, and willingness to complete pre-disclosure education and disclosure through a digital intervention among patients enrolled in the Penn Medicine Biobank. **Method**: A two-step method was used to contact participants with an actionable genetic research result indicating increased risk for cancer or cardiovascular conditions. Step 1 invited participants and controls to digital pre-disclosure education and allowed opt-out of return of results. Step 2 randomized participants to receive results via digital disclosure or genetic counselor (GC). Participants could opt out of results or request to speak to a GC at any point. Clinical confirmation testing was offered after disclosure. Descriptive statistics with Rank Sum and Fisher's Exact tests were used for analyses. **Results:** 130 biobank participants with actionable mutations and 130 controls were contacted. Participants were a mean age of 62.4 years old (SD 14.5), 57.6% male, 37.6% Black, and 3.2% Hispanic. Five (2.0%) participants initially opted out. Of the 125 participants with actionable results, 15.2% completed pre-disclosure education after Step 1 and 41.6% after Step 2. Forty-six percent of cases received results, with a higher rate observed in the GC disclosure arm (55.8% vs. 35.7% in digital arm, p=0.06). Among those who received results, 90.4% completed pre-disclosure education. 5 (4.4%) participants actively declined receiving results, 34 (30.1%) passively declined, and 22 (19.5%) could not be reached. Receiving results was associated with younger age (56.1 vs. 65.9 years old, p<0.001), completion of pre-disclosure education (77% vs. 10%, p<0.001), and randomization to the GC arm (p=0.06). 57.1% of participants who received research results completed confirmation testing (55.6% GC vs. 59.1% digital arm, p=1.00). Five participants (9.6%) actively declined confirmation testing due to lack of interest or concern, and 30.6% passively declined (agreed to confirmation but did not return testing kit). **Conclusions:** Half of biobank participants elected to receive research results, and many completed pre-disclosure education or disclosure by a digital alternative. While digital models may reduce resources needed to return results, further research is necessary to determine if uptake is higher when results are offered with a provider. Understanding barriers to confirmation testing will be needed to ensure clinical use of results.

# Abstract Award Recipients

We are delighted to recognize the following abstract award recipients. The selection of award recipients was based on Scientific Committee review of the abstracts, as well as a separate review by the Scientific Committee of student/early career abstracts that were nominated for awards.

## Student Awards

**Giulia Ongaro, MSc.** European Institute of Oncology, Milan, Italy

- *Motivational drives and psychological determinants of men's adherence to cascade screening for BRCA1/2 (PA5-1)*

**Emily Pearce, MPH.** University of North Carolina at Chapel Hill, United States

- *The use of social media to express and manage medical uncertainty in Dyskeratosis Congenita (PA3-1)*

**Caroline Salafia, MA.** University of Connecticut, United States

- *Impact of ambiguity aversion on genetic testing concerns following "mainstreaming" hereditary cancer multigene panel testing (POS2-7)*

## Early Career Investigator Awards

**Chloe Huelsnitz, PhD, MPH.** National Cancer Institute, United States

- *"I told them that they had to get tested, and they did": Sibling social influences on LFS testing, screening, and decision-making (POD5-1)*

**Hernâni Oliveira, PhD.** University of Évora, Portugal

- *PLAY-THE-ODDS: Co-designing a communication tool to help parents talk about genetic cancer risk with their children (PA4-3)*

# Conference Reminders

## IMPAHC Website

For more information about IMPAHC or to view the 2023 Annual Meeting page, please visit www.IMPAHC.org.

## Security

All in-person, non-NIH participants are required to enter the building through security. Please plan for security to take up to a half hour. Processes are similar to airport security; a photo ID is required, you will need to remove shoes and coats and walk through a metal detector, and all bags are x-rayed.

## Filming, Recording, and Photography

- Filming and recording in sessions are strictly prohibited without the consent of the presenter(s)/author(s).
- Photography is only allowed with the explicit permission of individual presenters.

## Lunches

Descriptions of local food options are provided on the IMPAHC website (http://impahc.org/faqs). There are not many food options within walking distance of the NCI but two food trucks will be available on Tuesday, May 23.

- Kuks Tribute food truck: Authentic West African cuisine of jollof rice, meat and fish options, plantains, and greens.
- Crepe Shoppe food truck: A variety of savory and sweet crepes with fresh fruits, veggies, and meats.

A variety of food options will be available from which meals can be purchased on Wednesday, May 24 at the Farmers Market in the NCI parking lot.

## Meeting Feedback

Thank you again for attending the Annual Meeting! We hope you enjoy the sessions. We encourage you to provide any feedback to info@impahc.org.

# Thank You

## 2023 Planning Committee Members

- Rowan Forbes Shepherd, PhD, National Cancer Institute, United States
- Jada Hamilton, PhD, MPH, Memorial Sloan Kettering Cancer Center, United States
- Chloe Huelsnitz, PhD, MPH, National Cancer Institute, United States
- William Klein, PhD, National Cancer Institute, United States
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- Sharon Savage, MD, National Cancer Institute, United States
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## 2023 Scientific Committee and Abstract Reviewers

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- Rosalind Eeles, FMedSci, PhD, FRCP, FRCR, The Institute of Cancer Research, United Kingdom
- Mary Jane Esplen, PhD, University of Toronto, Canada
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- June Peters, MS, CGC, LMFT, National Cancer Institute, United States
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## IMPAHC Volunteers

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- Margarita Aryavand, MSN, CFNP, National Cancer Institute, United States
- Soundarya Avantsa, MPH, National Cancer Institute, United States
- Renée Bremer, MS, National Cancer Institute, United States
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- Rachel Hendricks, BS, National Cancer Institute, United States
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- Jennifer Zink, PhD, National Cancer Institute, United States

The Planning Committee would like to thank Kristen Mangold, Sara Owen, and Payal Khincha for their guidance and coordination to host this meeting at the National Cancer Institute (NCI).

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Kim Nichols.....PA4-2, POS2-8
Barbara Norquist.....POS1-1, POS2-1

O

Tracey A. O'Brien .....POD3-2
Kenneth Offit .....POD1, POD3-1, POS1-7, POS2-7

Demetrios Ofidis.....POS2-10
Hernâni Oliveira.....PA4-3
Sabrina Oliveros.....POD1
Kai Ren Ong.....PA6-2
Giulia Ongaro.....PA5-1
Kelly Ormond.....POS2-8
Annastasia Ouma.....PA4-2
Hannah Ovadia.....POD3-1, PA4-1, POS1-7
Anjali Owens.....POS2-10
Elissa Ozanne.....POD5-2

## P

Elizabeth Page.....PA6-2
Tuya Pal.....PA6-1
Maryland Pao .....POD2-3
Emily Pearce.....POD5-4, PA3-1, POS2-6
Bojana Pencheva.....KEY2-1
Susana Pereira.....PA4-3
Beth Peshkin.....PA4-1, POS1-10, POS2-8
Serena Petrocchi.....PA5-1
Lillian Phung.....POS2-10
Mark Pinese .....POD3-2
Jenny Pope.....PA6-2
Christopher Porter.....KEY2-1
Shelby Posen.....POS1-3
Jacqueline Powers.....PA5-2
Gabriella Pravettoni.....PA5-1
Cynthia Prows.....POS2-8
Stacy Pundock.....POS2-7
Reed Pyeritz.....POS2-10
Louise Pyle.....POD1-3

## Q

John Quillin.....PA2-1

## R

Dan Rader.....POS2-10
Michael Raff.....POS1-1
Hannah Raj.....PA3-1
James Ralston.....PA5-3, PA5-4
Huma Q. Rana.....KEY2-1
Jihan Rashed.....KEY2-3
Kim A. Reiss.....POS1-8, POS2-7
Ken Resnicow.....POS1-4
Kurt Ribisl.....PA3-1
Robert Richardville.....PA5-2
Camella Rising.....KEY2-2, INV2, POD2-2, POD5-4, PA6, POS1-3, POS2-6
Mark E. Robson.....POD3-1, POS1-7, POS1-8, POS2-7
Yanete Rodriguez.....POD5-2
Lainie Ross.....PA4-1, POS2-8
Lisa Rubin.....POS2-4

## S

Rosalba Sacca.....PA4-1
Caroline Salafia.....POS2-7
Célia Sales.....PA4-2, POS2-5
Monica Salinas.....PA6-2
Erin E. Salo-Mullen.....POS2-7
Pauleen Sanchez.....POS1-7
Julie Sapp.....POS1-2
Sarah Savage.....KEY2-1
Sharon Savage.....POD5-4, PA3-1, PA2-6
Jaclyn Schienda.....KEY2-1
Joshua Schiffman.....KEY2-1
Elizabeth Schofield.....POD3-1, POS2-7
Kasmintan Schrader.....POD1
Lisa Schwartz.....PA4-4
Aaron Scrol.....POD4-3, PA1-1, PA5-3, PA5-4
Enida Selmani.....POS1-3
Ibrahim Shah.....POS2-7
Payal Shah.....POD4-1, PA5-2
Ravi Sharaf.....POS2-9
Katianne Howard Sharp.....KEY2-3, PA4-2
Rania Sheikh.....POD3-1
Eliza Sherman-Daniels.....POS1-8
Sanjay Shete.....POS1-6
Brian Shirts .....POS1-6, POS2-1
Lucy Side.....PA6-2
Eunice Silva.....PA4-3
João Silva.....PA4-3
Emilie Simmons.....KEY2-1
Giorgio Sirugo.....POS2-10
Alix G. Sleight.....KEY2-2, INV2

Marcelo Sleiman.....PA4-1, POS1-5, POS1-10, POS2-8
SK Smith.....POD1-2
Moran Snir.....KEY2-1
Guy Snir.....KEY2-1
Kelsey Spielman.....PA5-2, POS1-8, POS2-7
Zsofia K. Stadler.....POD3-1, POS2-7
Elena Martinez Stoffel.....POS1-4
Jill Stopfer.....POD3-1
Elizabeth Swisher.....POS1-1, POS2-1
Heather Symecko...POD3-1, POS1-8, POS2-7

## T

Nur Aishah Mohd Taib.....POD1-2, POD5-3
Beth Tarini.....PA4-1
Soo-Hwang Teo.....POD1-2, POD5-3
Kenneth Tercyak.....PA4-1, PA4-2, POS1-5, POS1-10, POS1-8
Ann Tezak.....PA6-1
Tesla Theoryn.....POS1-1
Ashley Thompson..KEY2-2, POD2-2, POD5-1, POD5-4, POD1-9, POS2-6
Meow Keong Thong.....POD1-2, POD5-3
Marc Tischkowitz.....PA6-2
Elise Travis.....POS2-2
Susan Trinidad.....POS1-1, POS2-1
Magan Trottier.....POS2-7
Katherine M. Tucker.....POD3-2
Lesley Turner.....PA3-2
Vanessa Tyrrell .....POD3-2

## V

Susan Vadaparampil.....POD1
Jennie Vagher.....POS1-5
Rachel S. van der Post .....PA2-3
Jolanda M. van Dieren .....PA2-3
Mohini Varughese.....PA6-2
Janine Vetsch.....POD3-2
Sarah Vittone.....PA4-1

## W

Angela Waanders.....POD1-3
Lynne I. Wagner.....POS1-3
Claire E. Wakefield.....POD3-2
Christine Walsh.....POS2-9
Catharine Wang.....POD4, POD4-4, POS1-1, POS2-1
Meera Warby .....POD3-2
JoEllen Weaver.....POS2-10
Emily Webster.....POS2-9
Anne Weidner.....PA6-1
Michelle Weinberg.....POS1-3
Shayna Weiner.....POS1-4
Joanna Weinstein.....POD1-3
Kuang-Yi Wen.....POS1-3
Allison Werner-Lin.....KEY2, KEY2-2, INV2, POD1, POD2, POD2-2, POD5-1, POD5-4, PA4-3, POD1-9, POS1-6
Jax Whitehead.....POD1-3
Lori Wiener.....POD2-3, PA3-3
Rianne A. Wijbenga.....PA2-3
Benjamin Wilfond.....PA4-1, POS2-8
Rachel Williams.....POD1-2, POD5-3
Catherine Wilsnack....KEY2-2, INV2, POD2-2, POD5-4, POS2-6
Catherine Wolf.....POS1-8
Elisabeth Wood.....POS1-3, POS2-10
Yelena Wu.....POS1-5, POS2-8

## Y

Cheng-Har Yip.....POD5-3
Mary Rose Yockel....PA4-1, POS1-5, POS1-10, POS2-8
Sook Yee Yoon.....POD5-3
Jennifer Young.....POD5-1

## Z

Kristin Zelley.....PA4-4
Jamilyn Zepp.....PA1-3, PA5-3, PA5-4
Lingzi Zhong.....POD5-2
David S. Ziegler.....POD3-2