

# MARY FRANCES HARMON

## Going the Extra Mile for Rare Disease Patients

In everything she does, Mary Frances Harmon has a clear objective: making a difference in the lives of patients living with rare diseases.

As senior VP, corporate and patient relations, at PTC Therapeutics, Mary Frances plays an integral role in establishing new connections with patients, advocacy groups, and caregivers so that PTC can better understand their specific situations and conditions.

Her industry background and her extensive experience in patient advocacy enable her to engage and motivate patients and stakeholders. Not only does her work help drug developers personalize the medicine to what patients actually need, it also helps to bridge the communication gap between patients and the rest of the healthcare community.

What most excites Mary Frances is the opportunity to build teams, strategies, and programs that directly support rare disease patients and families. “Engagement is instrumental in helping to empower them to advocate for the appropriate care and treatments,” she says.

Her passion for helping rare diseases patients and their caregivers is so deep that she seeks to make a difference in the space beyond her career.

“I believe the best way to do this is through developing, leading, and mentoring our future leadership,” Mary Frances says. “Mentoring is the best way for an organization to be better than the day before and drive innovation. It ensures that our colleagues and future leaders have the growth and development to drive future achievements.”

Most recently, Mary Frances received the Annual Heart of BioNJ award at BioNJ’s Annual Dinner Meeting and Innovation Celebration, for her commitment to creating a unified vision for patients and implementing programs with patient groups.

Additionally, in her first year at PTC Therapeutics, Mary Frances implemented the Strategies to Realize Innovation, Vision, and Empowerment (STRIVE) awards, which supports initiatives benefitting the Duchenne muscular dystrophy (DMD) patient community. Duchenne is a devastating rare neuromuscular disease affecting mainly boys and young men that is ultimately fatal, and STRIVE has an impact by raising awareness, diagnosis, and

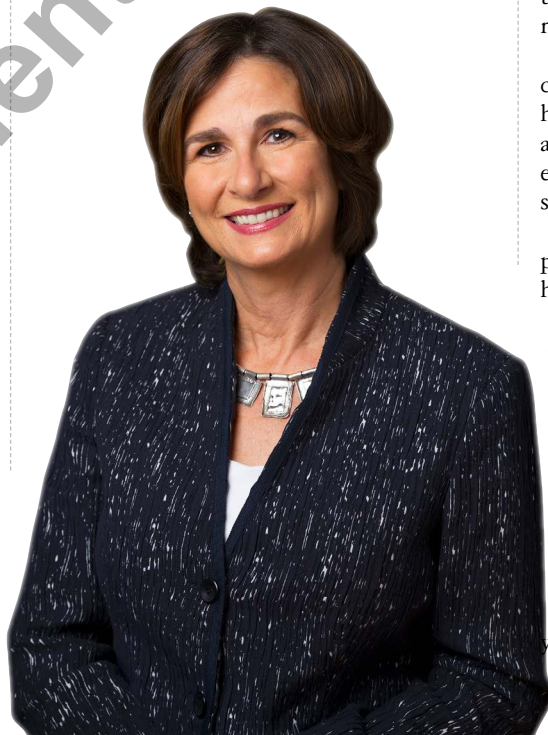
### *Raising the bar... to be better than the day before*

Mentoring is the best way for an organization to be better than the day before and drive innovation. It ensures that our colleagues and future leaders have the growth and development to drive future achievements.

education, and fostering the development of future patient advocates, which is crucial in the rare disease community space. STRIVE has awarded funding to 28 patient advocacy organizations worldwide.

As an innovator, Mary Frances says her role is to help incorporate agile methodologies into PTC Therapeutics projects and programs

## INSPIRE CHANGE



INNOVATIVE. CHAMPION.

### Mary Frances Harmon

**TITLE:** Senior VP, Corporate and Patient Relations

**COMPANY:** PTC Therapeutics

**INDUSTRY AWARDS:** Heart of NJ, BioNJ, 2020

**COMPANY AWARDS:** Multiple Sales and team player awards; MVP of business unit

**ASSOCIATIONS:** SE Guide Dog Puppy Raisers

to improve the impact and speed in bringing innovation to patients.

“What keeps me up at night is the political climate and the impact on innovation within the pharmaceutical and biotech industries,” she says.

To Mary Frances, success is measured by the time that those working for patients can give to patients and their families. “Whether it is hours, days, or years — my goal is to give them the time to experience the special moments that are important to them,” she says.

Mary Frances views herself as not just a coach and manager but also as someone who her team can count on to remove obstacles and barriers. “I lead by example and trust and empower each person to do their best work,” she says.

She says working with smart, talented people who are as much family as colleagues is a huge motivator.

“We are collaborating for the same cause — to improve the lives of people living with rare diseases,” she says. “It is this common goal or mission of helping families that motivates me each day.”

If she could change one aspect of her career path it would be to have been more proactive early on.

“In the 1980s when I joined the industry, there were not many women in leadership and at that time, I didn’t think you could do it all,” Mary Frances says. “As a result, I did not strive for advancement and let my career come to me, rather than pursuing it.” **PV**

Please join us  
in congratulating  
**Mary Frances Harmon**  
and all of this year's

# PharmaVOICE 100 Most Inspiring People



**Rare diseases, real strides to treat  
them—this is why we're here.**

No matter how uncommon the disorder, the life-limiting effects are a daily reality for those affected.

**That's why we're creating life-changing treatments every day.**



*measured by moments*

# DR. ELLIOT BARNATHAN

## A Commitment to Patients

### Elliot Barnathan, M.D.

**TITLE:** Senior Director, Cardiovascular Clinical Development

**COMPANY:** Janssen Research and Development

**INDUSTRY AWARDS:** Flex Champion, Working Mother Magazine

**COMPANY AWARDS:** Multiple Johnson & Johnson Standards of Leadership Awards; Inspire Awards, and Encore Awards; President's Club Award; Immunology Therapeutic Innovation Award; Johnson & Johnson Volunteer Service Award; Artist in Residence TEDxJNJ2015

**COMMUNITY AWARDS:** American Heart Association Outstanding Leadership Award; American Heart Association Distinguished Volunteer Achievement Award

**ASSOCIATIONS:** Board of Directors, American Heart Association (former President of the Board); Fellow of American College of Cardiology; Fellow of the American Heart Association; Alpha Omega Alpha; Phi Beta Kappa

**TWITTER:** @barnathanes

Elliot Barnathan, M.D.'s ultimate goal is to lead teams to develop drugs that create meaningful improvements in the lives of patients in need. "My recent work to develop new therapies to prevent complications from COVID-19 has been particularly challenging, but extremely rewarding," he says, "It has required rethinking how to do research, create new solutions, and lead a team to bring solutions to patients."

With a commitment to patients and evolving standards of care, Dr. Barnathan is working tirelessly with regulators, public health organizations, and specialty societies to ensure the best care for patients affected by the coronavirus.

"From the very first day of working from home, I have been motivated by working to bring new therapies to COVID-19 patients and to reduce death and disability from this devastating pandemic," he says. "For the last two months that has gotten me up and working around the clock."

Dr. Barnathan inspires colleagues within

### *Raising the bar... by doing faster, low-touch drug development*

his company, co-development partners, and academic leaders with his logical thinking, deep understanding of clinical trial data and analysis, and his work ethic.

This was exemplified when he took over the clinical lead for the ongoing Mariner trial, a 12,000-plus patient trial that tested extended thromboprophylaxis with rivaroxaban in acutely ill patients.

"I worked with a talented team who used the information from this and a previous 8,000 patient trial to figure out the proper population with an optimal benefit-risk profile," he says. "This led to an approval in October 2019 of Xarelto. While this was a great accomplishment given the challenges faced, it was particularly fortuitous in that just a few months later, the COVID-19 pandemic hit the United States, causing the hospitalization of numerous patients for whom thromboprophylaxis has turned out to be very important to prevent thrombotic complications."


He remains focused on working with partners to set up prospective studies of anticoagulants for COVID-19 patients using real world data. "My recent work to develop new therapies to prevent complications from COVID-19 has been particularly challenging, but extremely rewarding," he says. "It has required rethinking how to do research, create new solutions, and lead a team to bring solutions to patients."

Dr. Barnathan's greatest concern is that large pharmaceutical companies tend not to be nimble and are rigidly resistant to risk. "What keeps me up at night these days is that people are dying every day from a disease where I think we can help, but we need approvals and we need to do things differently," he says. "My challenge is to convince leaders of the vision, and to back the vision and the team to realize the dream of bringing new solutions to patients as fast and as safely as humanly possible."

Dr. Barnathan, who spent almost 10 years on the faculty at the University of Pennsylvania, has no regrets moving into the pharmaceutical industry. "If I hadn't left, I would never have had the opportunity to make real differences in the lives of patients," he says. "That has

been the single greatest reward of the change to a career in the pharmaceutical industry. I've never regretted the change for a minute. I have had several offers to move out of R&D and to switch companies, but I have never regretted staying at Centocor and Johnson & Johnson, which has provided rewarding opportunities for me to grow and lead."

Dr. Barnathan's pharmaceutical research career has spanned a range of diseases in cardiology, immunology, and pulmonology. One of his most challenging assignments was as the clinical lead on the acquisition of Actelion, which was the largest ever done by Johnson & Johnson. "I spent almost two years learning all about pulmonary hypertension, about the company, and about how best to develop the company's assets to maximize the opportunities for patients," Dr. Barnathan says.

Beyond his deep clinical expertise, what makes Dr. Barnathan stand out are his interpersonal skills. He believes the greatest legacy that one can leave is to train a new generation of successful researchers. "Throughout my career my greatest goals have been to mentor young scientists and physicians to become the best investigators and to maximize their potential," he says. "I measure success by the success of the people I have helped train." 



CREATIVE. INSPIRATIONAL.

## CREATE, INSPIRE, AND APPRECIATE

Throughout his career, Matt Flesch has been a champion for patients who are overlooked and underserved. As Horizon Therapeutics' VP, patient advocacy and communications, he led the creation of Horizon's #RAREis program, which aims to elevate the faces and stories of people living with rare diseases. Now in its third year, #RAREis has featured hundreds of stories and continues to grow with the addition of the #RAREis Playlist, a partnership with the Sing Me a Story Foundation to transform the stories of children living with rare diseases into song.

Matt counts working with his team at Horizon and rare disease patients and advocacy groups to create the #RAREis program as his biggest career highlight to date.

"What began as a social media campaign has evolved into a full-blown program with a website, Instagram page, and Facebook page where hundreds of people have shared their stories and where resources from leading patient advocacy groups are made available," he says. "It's a great example of how Horizon supports communities in ways that go far beyond our medicines."

Matt learned first-hand the challenges and isolation facing families touched by a rare disease when his younger brother was diagnosed with Focal Segmental Glomerulosclerosis (FSG) at the age of 9. Matt donated his kidney to help his brother and went on to help found the Chicago chapter of NephCure Kidney International, to provide the support and resources to help families like his navigate FSG.

Today, Matt remains just as passionate about supporting patients with rare diseases and their families and caregivers. He is still connected with NephCure, and he serves as a board member for The Brain Recovery Project, a foundation that aims to help children reach their full potential after brain surgery to stop seizures.

Colleagues say Matt is a force for good at Horizon as well as in his community. He places a high priority on getting to know, talk with, and form relationships with everyone he meets.

Matt says his goal at Horizon is "to foster an environment that breeds collaboration and creativity, resulting in great things for our patient communities — whether it's a new medicine, a new educational resource, or a new partnership program that makes a real impact on lives."

# MATT FLESCH

## A Rare Advocate

EMPOWERING. VERSATILE.

### Matt Flesch

**TITLE:** VP, Patient Advocacy and Communications

**COMPANY:** Horizon Therapeutics

**COMPANY AWARDS:** 2019 Horizon People Leader of the Year Award; 2018 Horizon Collaboration Award

**ASSOCIATIONS:** The Brain Recovery Project, board member; Chicago chapter of NephCure Kidney International, co-founder

**TWITTER:** @MattFlesch2

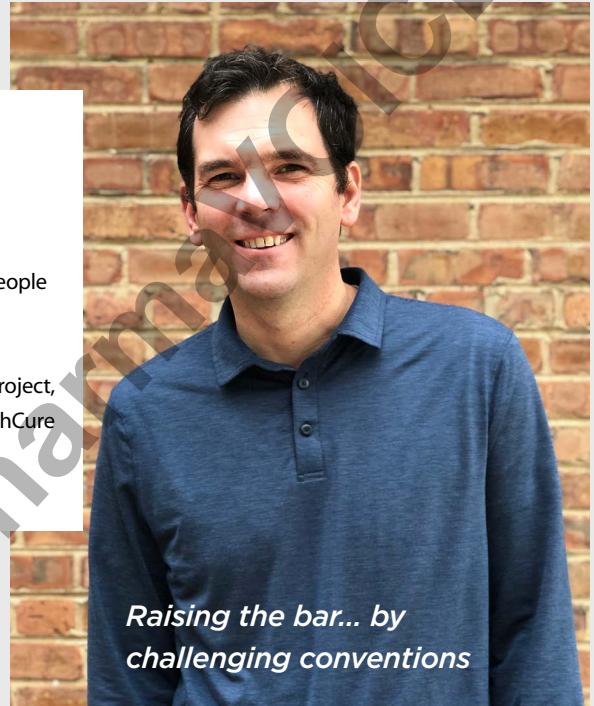
"Together with our advocacy and communications teams, we bring the patient voice into our company," he continues. "We seek to understand where there are needs and identify innovative ways to solve problems for people living with rare and rheumatic diseases."

Matt loves having his mind changed about something he thought was obvious. "Our assumptions about the patient journey are constantly proven wrong when we actually take the time to sit down and talk with our patient communities," he says. "I find this fascinating, and it motivates me to always see the other perspective and to adapt based on feedback from experts, which is almost always the person living with the disease."

As a leader, Matt says he relies on his team's diversity of experience and expertise and ensures everyone has a voice at the table.

"I see people most inspired when they see the difference their work does for others," he says. "I try to create an environment where ideas are encouraged, where people can push the boundaries of expectation, and work on things that make a difference for patients."

During the COVID-19 pandemic, Matt has spearheaded efforts to ensure advocacy partners are aware of key support programs



*Raising the bar... by challenging conventions*

and Horizon's commitment to patient safety. He also has made sure they know that Horizon is still providing one-on-one support for families by transitioning to an all-virtual team. He personally has reached out to people living with rare diseases who are isolated to ensure they are okay and feel connected to the community.

"The COVID-19 situation is difficult," Matt says. "Across our teams, we're trying to understand where the greatest patient needs are and find ways to work together and help with the situation. On the patient advocacy side, we thrive on meeting with patient groups and individual patients in person, and we're now constantly looking for ways to stay connected and help in this new environment."

Matt says the best professional advice he ever received was: "Learn to embrace the rocky waters."

"Truly rewarding work can't be accomplished from smooth sailing, but by taking risks and managing the challenges that come with true collaboration," he says. <sup>PV</sup>

DO THE VERY BEST YOU CAN, CHALLENGE YOUR ASSUMPTIONS, AND STRIVE FOR MEANING IN YOUR WORK

VISIONARY. DYNAMIC.



### Anita Gupta, D.O., Pharm.D.

**TITLE:** Senior VP, Medical Strategy and Government Affairs

**COMPANY:** Heron Therapeutics Inc.

**COMPANY AWARDS:** Women in Leadership, 2020

**COMMUNITY AWARDS:** Association of American Medical Colleges Learner Award; Compassionate Physician Award; Shining Star Award from Georgetown University for Patient Care; Top Healthcare Professional in Philadelphia, Cover of Philly Biz Magazine

**ASSOCIATIONS:** Fmr. FDA Advisor; National Quality Forum Leadership Coalition Member; Forbes Contributor; Milken Institute Faster Cures Advisory Member; National Academies of Science, Engineering, and Medicine Appointment to the Global Forum

**TWITTER:** @DocAnitaGupta

As one of the nation's leading anesthesiologists and pain physicians, Anita Gupta, D.O., Pharm.D., is taking a significant role in addressing the opioid crisis. She is also a pharmacist, author, transformational patient advocate, healthcare leader, and medical strategist. And she is using all of her skills to combat a national health epidemic. "One of my most challenging assignments has been to build a coalition of alliances to address national emergencies both in the public and private sector to improve the state of healthcare," she says.

As a former FDA advisor, Dr. Gupta is working with the agency's advisory board to

## DR. ANITA GUPTA

### Patients First

lead the American Society of Anesthesiology (ASA) ad hoc Committee on Prescription Opioid Abuse.

"I have been fortunate to align with senior federal officials such as the U.S. Surgeon General and the former Associate Commissioner of the FDA of Women's Health to ensure we achieve optimal outcomes to address the pain and opioid crisis," she says. "One of my proudest moments was being one of the first women anesthesiologists to lead the expansion of naloxone as an opioid overdose antidote through the ASA and be part of the first non-opioid product to receive accelerated approval after the national emergency was announced regarding the opioid crisis."

A committed patient advocate, when she was presented with an opportunity to build a pain clinic in a hospital system in Philadelphia that had limited resources, Dr. Gupta was one of the very few to step up and spend a considerable amount of time in establishing the center.

She says the greatest challenges involve maintaining equitable access to the most important healthcare innovations in the 21st century. "Addressing policy issues that focus on pricing, equitable access, and the rise in chronic diseases are critical to the future of the industry," Dr. Gupta says.

As senior VP of medical strategy and government affairs at Heron Therapeutics, she has fulfilled one of her long-term goals, which is to become an executive leader and advance innovation and policy for patients in pain and with serious illnesses.

"I made great strides in achieving these goals and plan to continue to serve this community through executive leadership in innovation, clinical care, and policy," she says.

Dr. Gupta truly enjoys mentoring, leading a team, and building collaborative coalitions to drive value and innovative solutions for society. She sees it as her role to inspire, enable, and motivate others so they can be their best.

As part of her desire to positively impact the future of healthcare, Dr. Gupta leads Her-

*Raising the bar... by inspiring excellence in innovation, policy, and patient-centricity*

on's Women in Leadership Council, which regularly convenes more than 80 individuals from 12 different organizations to discuss leadership options for women featuring guest speakers from the FDA, HHS, and the industry.

"I like to lead by example," she says. "Taking action, demonstrating what needs to be done, and keeping everyone organized ensures we're all on the same page to drive value for our shared core mission."

Described by colleagues as a dynamic, visionary, and positive leader, Dr. Gupta enjoys working in an environment focused on improving patients' lives. "I inspire others by being authentic in my conversations, remain-

## BE THE CHANGE YOU WANT TO SEE IN THE WORLD

ing positive through challenges, and being an active listener during difficult situations," she says. "In addition, I reflect enthusiasm every day to the people I am in contact with and ensure I surround myself with genuine and positive energy."

A believer in lifelong learning, Dr. Gupta says the more you learn, the more you grow, the better the outcomes.

"I like challenging myself and advancing on a personal level," she says. "It has allowed me to develop new skills that I never would have attempted on my own. It's changed my confidence and this continues to keep me motivated and gets me through tough days, or days where things don't go my way. Success, for me, will always be about making an improvement in other people's lives. If I know that at the end of the day my work has helped an individual's condition improve, then I wake up eager to start work all over again the next day." PV

# RHONDA HENRY

## Creating Greater Access to Clinical Trials

**R**honda Henry, VP of patient centered trials at PPD, says losing a friend and colleague to metastatic breast cancer at the age of 39 was one of her biggest professional challenges and motivators to create change. Despite her best efforts, Rhonda was unable to help her friend find a trial, much less one that would not require her to travel away from her two young boys.

Given this experience, and as a breast cancer survivor herself, Rhonda is deeply passionate about creating greater access to clinical trials and removing potential barriers to participation. She says she has turned her colleague's tragic story and her own heartbreak into a personal mission to ally with stakeholders across the industry to make it easier for all individuals to access clinical trials.

"By doing so, we will provide individuals with more care options," she says. "We will provide the industry with greater access to the volunteers we desperately need to complete our trials, and as a result we are able to accelerate the speed in which drugs are developed."

Rhonda is equally committed to increasing the diversity of patients in clinical trials so that drug approvals and subsequent labels are supported by patient data that represents the profile of the end users.

Under Rhonda's leadership, PPD has established a patient diversity working group and task force to foster greater awareness of and access to clinical trials among traditionally underrepresented patient groups. In December, Rhonda teamed up with a colleague to meet with various members of Congress to discuss the importance of representative trials and present them with tangible ways they can be supportive.

"In an industry with so much to offer and so many trials needing volunteers, we should be collaborating on easier and more effective ways for patients to find out about trials that may be right for them," she says. "Instead, we are often competing against each other for the same pool of patients across our known research sites."

Colleagues say Rhonda is adept at creating interpersonal connections. She will always take time to send a message or congratulate a team member, whether they are a clinical

manager in Australia or a feasibility site liaison in Ukraine.

"I try to inspire others through my actions," Rhonda says. "I share my beliefs and convictions with passion and endeavor to listen to and respect the beliefs of others."

In her 28 years at PPD, Rhonda has become a subject matter expert on patient-centered

trial services, developing and implementing solutions to help customers and project teams design better trials and reach more patients with information that makes it easier for them to consider participation.

"The strong desire to make a difference in the lives of others is my motivation," Rhonda says. "When I can see that my actions are having a positive impact on those around me, whether it be patients, our sponsors, my colleagues, or my friends, I am able to approach the next day with even more enthusiasm than the previous one."

Rhonda has a collaborative leadership style. "I enjoy working with others to solve a problem or toward a goal," she says. "I am comfortable developing a strategy but welcome feedback from others, both positive and constructive. I am direct and to the point, and recognize the need to adapt my communication style to meet the needs of others."

Rhonda serves as a mentor for several of her colleagues, as well as a resource for undergraduates of UNCW's clinical research program. She takes both of these roles very seriously.

"I have had the great fortune of being mentored throughout my career by some really exceptional people," she says. "I am truly grateful for that experience and believe strongly it is my turn to pay it forward. I enjoy listening to others who are earlier in their careers and sharing with them the benefit of my experience and lessons learned."

In the face of difficulties, Rhonda always seeks to inspire. "When challenges arise, I remind those around me what we have accomplished to this point, and I look for a way to break down the challenge ahead into small activities to tackle, a little bit at a time," she says.

Rhonda believes her long and rich career at PPD has been a blessing filled with highlights and achievements she never thought possible.

"I am very proud of the totality of my accomplishments during my 28 years at PPD, but my biggest accomplishment by far is to have had a challenging and demanding job that I love and still have managed to raise three amazing children with my husband of 27 years," she says. "That seems to be the epitome of 'having your cake and eating it too.'" <sup>PV</sup>

### HOW CAN I HELP?



#### Rhonda Henry

**TITLE:** VP, Patient Centered Trials

**COMPANY:** PPD

**COMPANY AWARDS:** Lead Vision Nominee, 2015; Key Account Leader of the Year, 2011; Strategic Alliance Leader of the Year, 2006; Global Leadership Program Graduate, 2004

**ASSOCIATIONS:** Oncology Nurses Association; AVOCA Quality Consortium Advisory Panel; Society of Clinical Research Sites; Women in Leadership Alumni; The Carousel Center; Flunk Cancer; Family Promises of the Lower Cape Fear; Impact Club

*Raising the bar... by helping others to be patient-centric.*

**B**arby Ingle is a natural born cheerleader. Starting at the age of 4, she began dancing and cheering, eventually making this her career. She was living her dream as the head spirit program coach at Washington State University, when her battle with chronic pain took her down. Among other conditions, Barby was diagnosed with reflex sympathetic dystrophy (RSD), a progressive neuro-autoimmune condition that affects multiple systems in the body. For nearly seven years, Barby, the once active athlete, was wheelchair bound.

However, she was still the cheerleader on the inside and her fighting spirit would not let her give up. She interacted with at least 100 healthcare professionals; had major surgeries; endured complications such as internal bleeding, medication interactions, kidney stones, and tumors — all without much help from the healthcare system.

So, she decided to pick up the gauntlet and become her own healthcare boss. Once she found her way, she wanted to share her knowledge so other patients would not have to struggle as she had.

“I believe it is important to be a mentor to assist with overcoming the challenges that patients face every day with activities of daily living,” she says. “I had to learn the hard way and now I want to pass on my knowledge to give hope and answers to all patients, caregivers, and healthcare professionals. I hope by speaking out about my journey and sharing my knowledge I can help others avoid what happened to me.”

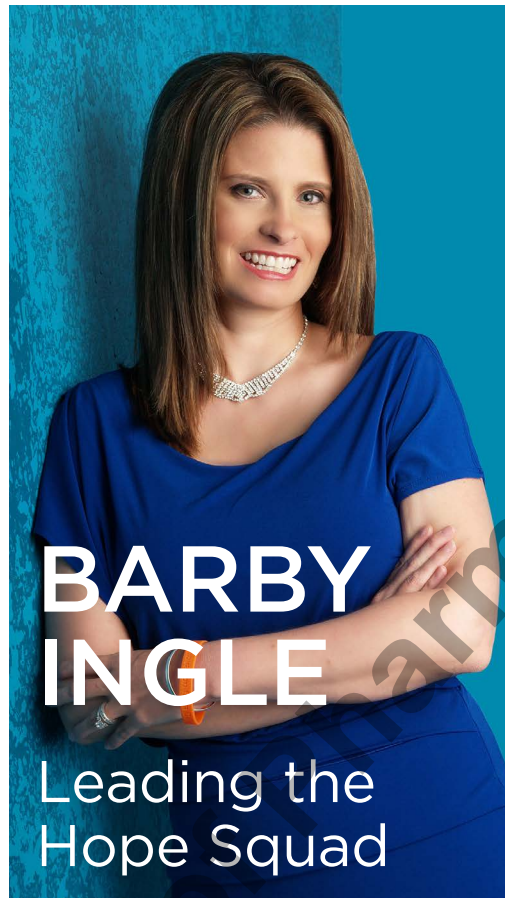
Over the past 15 years or so, Barby has won so many healthcare and advocacy awards that we could only list her most recent accolades. Her efforts have influenced a broad range of audiences, organizations, and patients. She is a strong champion for others, and her resume is filled with glowing accolades and testimonies that speak to her powerful ability to make things happen. “I use my cheerleading skills — responsibility, positivity, doing over being — to accomplish what needs to be done,” she says. “Others connect with these attributes of strength and competitiveness to help amplify their stories and voices.”

Barby is president of the International Pain Foundation (iPain), an Amazon bestselling author, and a reality TV personality. Her

## CHEERLEADER OF HOPE

book, *Wheels to Heals*, demonstrates that it is possible for pain patients facing many chronic pain diseases and health challenges to find treatment options that can restore a quality of life. “My biggest highlight to date has been creating and growing projects that reach

## HOPEFUL. CHEERLEADER.



*Raising the bar...  
by helping the world find hope*

around the world such as NERVErember,” she says. “Last year we had more than 45 million interactions on social media platforms. I love advocating, mentoring patients/caregivers, working on legislation that improves access to care, educating medical professionals, and working on iPain Living Magazine.”

In conjunction with NERVErember, Barby filled her closet with 31 orange outfits, orange being the signature color of the group, to celebrate the initiative on social media.

By sharing her powerful story, she is inspiring legions of others to find their way to a fulfilling life. Drawing on her 20 years of research and navigating the health system as a pain patient, she can provide answers to creating the path that is right for the individual patient. “My leadership style is a combination of coach and pacesetter with a touch of democracy,” she says.

The best professional advice she ever received was also helpful in her personal health struggles. “One of my bosses at Washington State University, Deb Flanagan, taught me to change the word ‘issues’ to ‘challenges,’” she says. “The premise being that people want to

## Barby Ingle

**TITLE:** President

**COMPANY:** International Pain Foundation

**INDUSTRY AWARDS:** 2020 HITMC Patient

Advocate of the Year; Top 10 Healthcare Influencers that every marketer MUST follow, MedicoReach, 2020; Inspirational Luminary 2019, Inspire Me Today; No. 5 of 15 Top Healthcare Influencers Redefining the Industry, GRIN Co., 2019; Best Creative, Health Information Technology Marketing & Communications, 2018; No. 12 on Disruptor Daily’s list of 25 First-Rate Pharma Influencers, Disruptor Daily Blog, 2018

**PERSONAL AWARDS:** iPain Top 100

Rare Disease Advocates, International Pain Foundation, 2020 and 2019

**COMMUNITY AWARDS:** RARE Champion of Hope Nominee, Global Genes, 2019; RareVoice Abbey Award Finalist, EveryLife Foundation for Rare Diseases, 2019

**ASSOCIATIONS:** International Pain Foundation; Creating Patient Access Task Force; Arizona Chronic Care Together Coalition; Arizona Step Therapy Coalition; Breakthrough Crew for Clara Health; Global Genes, 2017, 2018, 2019, Social Media Ambassador; IL Chronic Care Collation; IL Step Therapy Coalition; Kansas Step Therapy Coalition; Rare Disease Legislation Advocacy with EveryLife Foundation; Savvy Coop; WEGO Health

**TWITTER:** @barbyingle, @powerofpain

run away from issues, but challenges — especially to athletes — are to be faced and met.”

Barby says re-framing the situation to something that can be accomplished helps people get beyond mental and physical barriers that make the task seem impossible.

“I have learned that there are millions of ways to accomplish something, so just keep trying,” she says. “Knowledge equals power. My goals are to leave a lasting change for the better when it comes to access to proper and timely care through education and advocacy. I will use the education to increase my new experiences, create new lasting, options for others, and collaborate with teams outside my silo for the best possible chance at lasting positive changes for the health of humans worldwide.”

A little fun fact about Barby? She is married to Ken. And together they have completed nine seasons of the Ken and Barby digital reality show offered on multiple digital platforms. **PV**

# MICHAEL KEENS

## Keeping the Focus on the Why

**M**ichael Keens, VP, site and patient solutions at ICON, has been a leader in the clinical research realm for more than 20 years, during which time he has developed expertise in many different avenues of research, such as clinical operations, business development, and now patient advocacy. The common thread throughout is a passion and dedication to improving processes for patients.

One of Michael's biggest career highlights was the first time he helped establish a connection between a biotech company and a patient advocacy group for a clinical trial initiative, and then helped foster that relationship to benefit patients.

"What was great was introducing two groups that were working alone and then working together successfully," he says. "My favorite part was when the biotech company supported the advocacy group with a dollar-for-dollar match at one of their events, which provided direct supporting for the patient population as well as longer-term advocacy support."

Michael measures success on the personal level as well as on a project level. "You can achieve project success and still be unsuccessful if your team or patients had a horrible experience," he says. "So, keeping both the project and personnel aspects in mind, for me, is the best way to measure overall success."

Michael says he finds the best projects and assignments are those in which everyone is involved regardless of their organization or role, and where everyone is treated as a member of the same team.

"When this type of structure is not in place, it's extremely challenging to continually model positive actions and keep team members aware of their importance and the collective goals," he says.

As a leader, Michael strives to be as collaborative and transparent as possible while also finding opportunities to provide insights into the rationale behind decisions and approaches. "The more everyone understands aspects of the assignments influencing each team member, the more effectively the team operates, and the more fun we have," he says.

Michael inspires his colleagues by reminding them of their "why" and examining ways to incorporate this into their own personal or professional goals. "Communicating why we're

### Michael Keens

**TITLE:** VP, Site and Patient Solutions

**COMPANY:** ICON plc

**INDUSTRY AWARDS:** CenterWatch Top 20 Innovator, 2018

**ASSOCIATIONS:** American Society of Clinical Oncology (ASCO); ACRP; SOCRA; DIA

**TWITTER:** @keensmike

together, why we are part of the team, and why what we are doing is important to leading teams," he says.

In all of his interactions, Michael looks for ways to provide mentorship and guidance. "Too often, people think they need to have a formal sit-down mentoring relationship, and those certainly are helpful, but seeking opportunities to provide mentorship and partnership in each and every interaction you're a part of is more scalable and impactful," he says. "Additionally, as a result you're always mindful to guide your interactions with others to be a great partner."

Colleagues say Michael has always demonstrated a passion for helping companies execute clinical trials with a focus on increasing patient participation. He actively leads to create innovative solutions in patient care and continuously examines ways to enhance the experience of patients in clinical trials.

## CARE ABOUT WHAT YOU DO

"These goals can be achieved with technology, which people classically associate with innovation, as well as a change in process and approach, which many people forget about," he says.

Michael notes that drug development always comes with challenges, regardless of how well companies plan or undertake risk mitigation in advance.

"Keeping motivated during challenges means examining how to be part of the solution rather than someone who just sits at the table; I encourage input and effort from everyone," he says. "Directly contributing,

COLLABORATIVE. CURIOUS.



*Raising the bar... by keeping patients first.*

regardless of title, also demonstrates dedication to one's goals and respect for colleagues. I embrace the philosophy of rolling up your sleeves to help, not just tell others what to do."

One of his biggest challenges is transferring the excitement many people have for new technology into deployment and incorporating that into a better experience or engagement with the patient, not just a more convenient way to gather data. "There's a tendency to sometimes throw new technology at patients and call it patient-centricity," Michael says. "The industry has a lot of great advocates and speakers on being patient-centric, we need to work to continue to turn that talk into action, and develop more people of action, not just speakers."

His goal is to continue to play a lead role in the industry by learning, growing, and applying his vast knowledge to improve the clinical trials experience for patients.

"From learning about new diseases and conditions, to integrating technology to finding better methods of supporting patients, I feel fortunate to work in this industry," he says. "Despite the tremendous amount of altruism and good intent of those in this industry, it's easy to focus on only your individual needs or goals. I've found the more you understand what others are trying to accomplish, and how you can collaborate with them, the end result is better for all involved. I've tried to bring that approach to all the positions I've held in this industry. Additionally, we're so fortunate to be in a dynamic and advancing field of work — there are so many opportunities to learn each day. I continue to enjoy the opportunity, on a daily basis to learn and grow while also helping others." <sup>PV</sup>



# JESSICA KIM

## Busting Out of the Patient Engagement Box

As a creative talent, Jessica Kim has long been focused on how she could have the most positive effect on a study participant's experience. This focus led to her being named to the newly created position of creative director of patient experience and engagement at BBK Worldwide.

And she hasn't wasted any time getting down to business. Jessica is helping to evolve the whole concept of the clinical trial patient experience by introducing "Study-Life Balance," a construct that leverages patient-centric solutions to help patients more easily integrate clinical trial participation into their daily lives.

"I was thrilled to introduce this new construct to the marketplace earlier this year, as it reflects my continued commitment to finding ways to help remove barriers to participation while improving the patient's clinical trial journey," Jessica says.

Study-Life Balance lines up with Jessica's goal of helping to contribute to taking down obstacles to clinical trial participation through creative messaging and tactical execution.

"I want to be able to leverage my passion for design to engage and motivate patient, site, and sponsor audiences," she says. "Through my work, I hope to be able to influence and push the industry forward to embrace creative opportunities and creative thought."

### I MAY BE SMALL, BUT I AM FIERCE

Colleagues say Jessica's infectious, creative passion has helped to push the limits of what's possible in patient recruitment and engagement. Whether it's working to conceptualize and develop novel engagement programs for hard-to-reach patient audiences or analyzing granular details that may unlock hidden trends and ideas, her daily goal is always the same: to improve the clinical trial experience for patients, caregivers, site staff, and sponsors.

Her peers also say she is a force of nature in that her energy is enviable. She never wastes a moment, never misses a deadline, and gets it done right.

#### Jessica Kim

**TITLE:** Creative Director, Patient Experience and Engagement

**COMPANY:** BBK Worldwide

Jessica engages in critical, imaginative thinking to help BBK push the limits of innovation with the products and services it provides.

"Are our products the best they can be to truly help enhance the patients' experience, or can we do more?" she says. "Is our technology up to the standards patients need, or do we need to help push the industry more in this area?"

By asking these questions, Jessica adds, BBK has been able to enhance its app platform into a more robust portal, enabling patients to engage within the study through text messaging, gamification, and appointment/medication reminder capabilities.

"We have also been able to find new ways to digitally engage the patient experience by creating smarter and more robust ads to recruit, such as utilizing Snapchat or creating video content for Instagram stories, and then supplementing that with user-friendly study websites and pre-screeners," Jessica says.

She tries to inspire others through positive energy and thinking outside the box, no matter what.

"By bringing positive energy to a challenge, I hope to create an atmosphere that will ultimately help me and those I work with to

**By bringing positive energy to a challenge, I hope to create an atmosphere that will ultimately help me and those I work with to feel more comfortable and confident pursuing outside-of-the-box ideas.**



CREATIVE. RESOURCEFUL.

**Raising the bar... by being bold and pushing what can be in the clinical trial industry**

feel more comfortable and confident pursuing outside-of-the-box ideas," she says.

Jessica says one of her greatest accomplishments to date was her introduction of a very specific strategic philosophy within the agency.

Jessica leads by example and finds new ways to approach things no matter the challenge while remaining calm and unfazed.

"I think that, in our industry, being resourceful is key, especially with all the regulations in place to make sure we are up to the standards of regulatory review," Jessica says.

She also believes it can be useful to pause when hitting a roadblock. "I believe stepping back and taking a breath can not only bring clarity but also inspiration," she says. "Sometimes, we are so distracted by the end goal that we can lose sight of what the patient's journey will be. By encouraging those around me to take a step back, we can ensure a better experience."

When it comes to mentoring others, Jessica feels privileged to guide colleagues through BBK's wide range of services that help a study from startup to providing results to patients upon study's end.

"These things range from site selection and feasibility, cultural adaptation and translation, digital marketing and media, reimbursement and travel programs, and much more," she says. "To be able to mentor someone on all these services and products, to make them understand how important they are within a clinical study — from enhancing the patient experience to helping unburden the site — is quite humbling." **PV**

# KELLY JOHNSTON MCKEE

## Changing the Narrative

**K**elly McKee is passionate and relentless in her pursuit of changing the field of clinical trial participation for patients. She is a resounding voice in support of patients and innovators who are also passionate about breaking down barriers to clinical trial participation. Kelly says one of the biggest challenges to be overcome is that many people think of participating in clinical trials as akin to being a guinea pig rather than a test pilot. “Test pilots are cool, admirable, and fearless,” she says. “Clinical trial participants are all of those things and more. If we can change that image, we can start to make real progress in improving participation rates.”

Kelly has led breakthrough initiatives to complete enrollment for some of the largest patient-centric clinical trial companies in the world. She fully believes in offering patients a choice, whether it is participating in a fully decentralized trial, a remote visit, a hybrid solution, a patient experience measurement, or a community engagement initiative; her philosophy of letting patients select their own experience has moved the needle in the industry.

An advocate for innovation, Kelly makes connections among like-minded people and creates opportunities to improve the patient experience in clinical trials and enhance the operational effectiveness of the clinical team.

“We have a problem in clinical trials today — too few individuals participate in clinical research and it takes too long for new medicines to come to market,” she says. “I believe that if we focus on the patient and improve the clinical trial experience, we can begin to solve these problems.”

While at Lilly, Kelly ran a program called Hero’s Journey Art where her team invited 1,000 individuals from the clinical trial community — patients, investigators/site staff, and caregivers — to decorate wooden “bricks” to commemorate their clinical-trial experiences. “Working with artist John Mangan and documentarian Theo Rigby, we created three large sculptures and a documentary series,” she says. “The sculptures are currently on display in Winston-Salem through the Greater Gift organization and you can see the documentary chapters on YouTube.”

Now, as head of patient recruitment at Vertex, she is driving a cultural shift by ensuring patients’ needs and preferences are at the core of clinical trial design and execution across the portfolio. She is proud of the work her team is doing to include choice in clinical trials — from location, to travel support, to tools.

“As individuals, we all have different preferences, yet we expect clinical trial participants to have the same experience,” she says. “By allowing participants to have options we can improve experiences and make clinical research an option for more people.”

Kelly believes it’s not enough to look at quantitative data, such as whether enrollment goals were met, but qualitative measures such as did participants enjoy their clinical trial experiences also need to be evaluated. One of her goals is to solicit answers to what can be done to improve clinical trials as well as how to make clinical trials an option for more people.

A term Kelly is striving to stamp out is “subject” with regard to clinical trial participants, because as she says, individuals who participate in clinical trials are much more than data. “Patients are people who are giving themselves and their time to help make new medicines possible,” she says. “I’ve tried so many things, including writing a song called ‘Don’t call me subject’ to the tune of ‘Daugh-

### Kelly Johnston McKee

**TITLE:** Head, Patient Recruitment

**COMPANY:** Vertex Pharmaceuticals

**INDUSTRY AWARDS:** Top 20 Innovators, Centerwatch, 2018; Clinical Researcher of the Year, Clinical Research Team, Pharma Times, 2012; Co-Creator: Participant Engagement Award (SCOPE); PopUp STAR, Greater Gift

**TWITTER:** @kellyjmckee

### *Raising the bar... by improving clinical trial experiences*

ter’ by Pearl Jam with TJ Sharpe, Michael Mittleman, and Craig Koch. I’ve used a swear jar where individuals using the term are asked to contribute to a fund that I donated to a clinical research charity. I’ve changed patient-facing materials and have respectfully challenged those who continue to use the word. I’m still struggling with this self-imposed assignment. My work is not done, but I won’t stop until we have dissociated the term.”

She seeks to inspire those around her to focus on participants as people, not data, and to recognize the important role they play in making new medicines possible.

She says the best piece of advice she ever received was from Lilly’s Jerry Matczak, who passed away in 2017, who taught her to slow down and take the time to truly understand patients, to listen to their stories, and use the information they share to improve clinical trials for others.

In addition to her work at Lilly and Vertex, Kelly lends her expertise and passion to programs such as PopUp Star, an annual competition organized by Greater Gift, which encourages innovative thinking around how people can be better informed, educated, and engaged in a way that impacts clinical trial advocacy and participation. **PV**

*Editor’s Note: At press time, Kelly was named senior director, patient recruitment and registries at Medidata Solutions.*

## CLINICAL TRIAL PARTICIPANTS MAKE NEW MEDICINES POSSIBLE



INNOVATIVE. INSPIRING.



# TIFFANY A. MURA

## Champion for the Patient

**T**hroughout her career, Tiffany Mura has inspired others by tackling complicated issues while remaining focused on the big picture. Tiffany has a depth of experience in the life-sciences industry that spans agencies and working within health and pharma companies.

Today, as VP client experience and strategy, health, at Mad\*Pow, Tiffany is working to give people the power to better manage their conditions and achieve better health, enabled through technology. Her role is to drive innovation in a variety of areas — from the client experience, to organic client growth, to strategic thought leadership.

Tiffany's passion for improving the patient experience runs through every project she undertakes — as part of a movement that is helping the health industry evolve to be more patient-centric.

Colleagues say Tiffany sees a future health system where the consumer, regardless of background or economic means, is able to get the tools and resources they need to live healthy lives. That doesn't just mean they get treatment when they are sick, it means good health is the default setting for

I want to leverage innovation and design thinking to help drive the shift from a focus on illness to wellness, to help the consumer be at the center of healthcare, and to ensure accessibility of quality healthcare for everyone.

The fact that what I do every day helps people live healthier lives — physically, mentally, and emotionally — gets me out of bed every morning.

daily life. To get there, the health industry needs to look at the whole person, and Tiffany continues to drive the industry in that direction.

"The fact that what I do every day helps people live healthier lives — physically, mentally, and emotionally — gets me out of bed every morning," she says. "I want to leverage innovation and design thinking to help drive the shift from a focus on illness to wellness, to help the consumer be at the center of healthcare, and to ensure accessibility of quality healthcare for everyone."

Tiffany says her career has followed the growth of digital and social marketing within pharma. Among her highlights are founding and running Cadient Group, a leading digital pharma marketing agency in Philadelphia, presenting at the FDA social media hearings in 2009 to be a voice in helping shape policy, and working with Vivitrol during the explosion of the opioid crisis. "The one initiative that has been most meaningful personally is the work that I recently did to help launch the Collaboration to Address the Shortage of Medical Supplies' — CASMS — website platform for CIMIT's initiative to help with the PPE shortage," she says. "There are many aspects of the healthcare system that are fantastic, but the COVID crisis has

*Raising the bar...  
to drive positive change.*

### Tiffany Mura

**TITLE:** VP Client Experience & Strategy, Health

**COMPANY:** Mad\*Pow

**ASSOCIATIONS:** Innovation Women  
Speakers Bureau

**TWITTER:** @tiffanymura

demonstrated there are many areas that still need innovation and evolution."

Colleagues say she is adept at maneuvering around challenges, such as determining how to champion optimal customer experiences within a heavily regulated environment that is slow to adopt to new technology. "Additionally, with the proliferation of digital health, I am continually challenged with how we make this accessible across populations," she says.

Nevertheless, Tiffany says the industry's limitations mean it requires more creativity. "I want to be remembered as someone who brought innovative solutions to this industry that I love," Tiffany says. "I also want to be remembered as an inspiring voice — a senior leader who helped mentor others, who approached her work, colleagues, and clients with passion, creativity, and empathy."

An even-keeled leader, Tiffany seeks to hire the best people and let them flourish. She inspires others through example, empathy, and a mindful energy, exhibiting the behaviors that she wants her team to emulate.

"I always try to look at things from other peoples' perspectives to better understand them and see where my own limitations might be," she says. "I also try to be very

## ANYTHING IS POSSIBLE

mindful as to how I go about my day, particularly how I manage my energy because others are very much impacted by it, particularly in times of crisis such as where we are right now. I can help lift others up, keep them focused, and keep them motivated by ensuring my own energy is in a good spot."

To Tiffany what matters most is the experience others have had working with her. "Whether it's clients, colleagues, or consultants, I want them to have loved the experience — from the quality of work I did for them to the way I treated them," she says. **PV**

# DR. KANCHAN RELWANI

## A Passion for Patients



### GREAT JOB! WHAT'S NEXT?

#### Kanchan Relwani, M.D.

**TITLE:** VP and Head of Medical Affairs

**COMPANY:** Alkermes

**ASSOCIATIONS:** Medical Affairs Professional Society (MAPS), ASCO

The roots of Kanchan Relwani, M.D.'s commitment to improving patients' lives can be traced back to her father's tragic death.

"My father died at the age of 27 from a disease that had no cure," she says. "The opportunity to help people live longer, fuller lives is the driving force behind my work. While I'm constantly trying to learn, grow, and further my career, focusing on what is right for patients with significant unmet needs has always led me to the right places professionally."

A physician with more than 12 years of pharmaceutical experience, Kanchan started her industry career at a medical communications agency. She then quickly moved to biotech, where she rapidly transitioned into leadership positions within medical affairs and clinical development functions.

"I've been fortunate to be part of teams that have seen great success in our efforts to help patients living with complex and hard-to-treat illnesses," Kanchan says. "Early in my career, I served as the medical lead for the launch of a new cystic fibrosis medication, which was

*Raising the bar... by challenging/transforming myself and others to better connect people, reimagine science, and improve patients' lives*

the first protein targeted therapy approved. After that experience I was drawn to Alkermes by the opportunity to focus on neuroscience, oncology, and serious public health issues."

Since joining Alkermes, Kanchan, VP and head of medical affairs, has helped grow the medical affairs organization and expanded the scope and impact of the function within and outside the company.

"My team and I work cross-functionally across the organization to enhance collaboration and foster dialogue that amplifies Alkermes' scientific expertise," she says. "These efforts help ensure medicines that are designed to make a meaningful difference in patients' lives are well understood."

Colleagues say in addition to her professional integrity, Kanchan has strong convictions and is unwavering on the extremely important topics that define and impact the industry: ethics, loyalty, and trust. She embodies her organization's mission of putting patients first and remains steadfast in her commitment to humanity.

Kanchan is an inclusive and decisive leader who approaches all situations and opportunities with a patient-first mentality.

"I understand the eminent value of being empathetic with uncompromising tenacity, and I always strive to elevate the successes and accomplishments of those around me," she says. "I also try to ensure that everyone is having fun along the way by making humor and laughter an integral part of our team culture."

Kanchan inspires others by challenging them to take risks and encouraging them to take on projects that would be considered stretch opportunities. "I'm a firm believer in collaboration, and I find working with others or teams to be motivating," she says. "I also always try to find the positive in every situation. As I like to say to my team, 'I've learned that it doesn't matter if the glass is half full or half empty, either way it needs to be filled and it's up to us to do so.'"

Kanchan prides herself on being a mentor to people at all different levels in a variety of industries and pushes others to do the same.

I see immense value in sharing my knowledge with others so they can learn from my experiences and successes. I believe that everyone has something to teach me.

"My passion for mentorship is fueled by the strong mentors who have guided me at various stages of my career, as well as my spiritual mentor: my mother," she says. "My mother is a fearless, successful, and dynamic entrepreneur, who always prioritized her family. She inspired me to provide support and care for my family and my team, who are my extended family. I am fortunate and blessed that my husband, who has always believed in me, taught me that nothing is impossible. He also has been a strong mentor, always pushing me further and encouraging me to take chances.

"I see immense value in sharing my knowledge with others so they can learn from my experiences and successes," Kanchan adds. "I believe that everyone has something to teach me."

Kanchan believes it is important to never forget your roots and your ability to influence change.

"In India, my family started a school for children in need in memory of my father," she says. Kanchan's family also established charitable clinics to enable access to healthcare for patients in need and supported the farmers in rural areas and villages by improving their housing conditions and providing them with equipment.

"In my professional life, my close collaboration with the patient advocacy team has introduced me to amazing charitable organizations supporting causes in mental health and addiction that have become very dear to my heart," she adds. <sup>PV</sup>

# DR. JESSICA SCOTT

## Shifting the Culture

### *Raising the bar... by including patients in the process of drug development*

**B**ringing the partnership with patients to a whole new level of mutual benefit is what Jessica Scott, M.D., J.D., is all about. She encourages everyone around her to think differently, to collaborate, and rally around a new vision for a patient-focused culture. “I champion patients’ needs and interests, reaching the hearts and minds of colleagues by sharing insights into the patient experience and how and how more deeply understanding their perspective is mutually beneficial for developing medicines of value for patients and the industry,” Dr. Scott says.

As the leader of Takeda’s R&D patient engagement team, Dr. Scott has played a key role in the cultural shift within her company. She has redefined patient engagement in R&D for Takeda and has shaped the strategic priorities for achieving the company’s goal of developing medicines with patients rather than for patients. Under her leadership, Takeda has implemented global R&D patient engagement KPIs to change the culture of Takeda R&D by embedding patient engagement across all global program teams. “However, the patient engagement requirement alone is not enough to change the way of thinking,” she says. “We also empower our teams to employ creativity and innovation to determine where and how patient engagement will

be most valuable to the development of their asset. Patient engagement activities continue to expand as study teams able to connect with patient advisors to obtain feedback and incorporate these perspective into trials which may, for example, lead to reducing the trial burden and increasing patient recruitment and retention. The KPI initiative gained rapid wide support from the corporate executive team and the R&D organization was able to exceed the target by 33%. In addition to informing the development of new medicine, patient engagement has proven to be so valuable that study teams are requesting even more activities.”

Guided by her passionate leadership, Takeda has implemented exciting solutions that have helped study teams improve study timelines, reduce costs, implement more efficient systems, and design and execute trials



INSPIRED. IMPACTFUL.

### Jessica S. Scott, M.D., J.D.

**TITLE:** Head of R&D, Patient Engagement  
**COMPANY:** Takeda Pharmaceuticals

that are more meaningful to patients and caregivers. “In 2019 we also started KPIs requiring all global program teams develop a patient engagement plan — PEP, a proactive road map for how the teams plan to incorporate the patient and patient community in their clinical development programs and continue to scale to 100% in 2020,” Dr. Scott says.

She adds by incorporating the patients’ insights we are able to achieve benefits well beyond those derived from physicians, medical literature, or even social media. “The patient’s world and the researcher’s world are different,” Dr. Scott says. “Yet, as we navigate these differences, we open our minds to a new level of understanding of how a disease affects patients. This information is critical in the development of new medicines.”


This level of collaboration requires humility and a desire to suspend prior beliefs, an open mindedness that results in mutual benefit that is greater than can be achieved on one’s own. “At its core, true collaboration is the belief that we are better together,” she says.

Dr. Scott’s career in medicine was shaped in part through a personal experience. Her sister’s cancer diagnosis gave Dr. Scott additional perspectives about patients’ needs, while her background in law has provided her with the skills needed for collaboration to address complex multi-stakeholder issues.

“I have a personal passion for directly involving patients in the research process as a means to create a deeper more medicines of value and also to inspire and generate a greater sense of purpose for Takeda employees,” she

says. “I remind my team and vendor partners that patient engagement is a two-way dialogue with patients with shared purpose and mutual benefit that result in measurable outcomes.”

One of the ways Dr. Scott motivates others is by developing a deep sense of connection and trust. People know that she cares about them and values who they are and their unique contributions. She serves as a mentor for others, including formally at the law school from which she graduated. She also mentors women in business, particularly healthcare, who are working to find balance between professional and personal lives/pursuits, and for colleagues at Takeda. “I like to bring out the potential in others and to see them connect with their areas of passion, core values, and their own sense of purpose,” she says. “I enjoy providing others with opportunities to grow in ways that align with their interests and talents, and seeing them thrive.”

Dr. Scott is committed to helping her colleagues deal with challenges. “I am a change agent and hold people accountable to think differently,” she says. “I ask questions to understand their point of view, I listen with an open mind, and we collaborate toward solutions. By asking thoughtful and probing questions, people become engaged and invested in the process of creating a solution.” 

## PATIENT PARTNER