ANNUAL
REPORT

CROWDCARE ®
FOUNDATION

2018

IMPROVING PATIENT OUTCOMES BY
REMOVING BARRIERS TO A CURE.

WE BELIEVE THAT CURES FOR TERMINAL DISEASES WILL COME FASTER THROUGH DIRECT PATIENT INVOLVEMENT.

CONTENTS

OUR MISSION

To provide education, support, and data to accelerate cures for terminal diseases.

The mission of the CrowdCare Foundation is to improve patient outcomes by removing barriers to a cure. As patient advocates, we use new approaches, online communities and technology to provide education, support and data solutions to accelerate cures for patients with terminal diseases.

Founded in 2012 by multiple myeloma patient Jenny Ahlstrom, The CrowdCare Foundation is a Utah-based patient-driven, 501(c)3 non-profit organization that empowers patients with rare diseases at each step of their disease journey - from diagnosis, through education, care and on to a cure.

We help patients become their own best advocates by providing simplified information using online tools and providing key research funding. In all we do, we strive to simplify information for patients and encourage them to participate in clinical trials and to proactively support gaps in existing research funding.

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WHAT WE DO

The CrowdCare Foundation is a Utah-based non-profit founded by terminally ill patients and their caregivers with the belief that our healthcare system can be improved through direct patient involvement. Our mission is to improve patient outcomes by removing barriers to a cure through implementing three major strategic programs:

1. Compile Patient Data for Research

Through a new tool called HealthTree® we combine research data with patient reported outcomes data to help patients and doctors better navigate a patient's treatment plan while inspiring the research community with new insights. "Without patient reported outcomes data, all of our fancy AI algorithms are open loop. For AI to be successful in healthcare, patient reported outcome measures are fundamentally important." said Dales Sanders, President of Technology at Health Catalyst.

2. Support Research-Driven Shared Decision Making

We support the collaboration of patients and experts to make better treatment decisions and focus on increased collaboration to fund the best academic research by crowdsourcing and crowdfunding potential cures.

3. Support Education for Better Self-Advocacy

We provide simplified patient education, offering the latest research news in language patients can understand.

Each program is created in collaboration with the patient and research community with a patient-first focus including the voice of the patient as a key stakeholder in healthcare conversations.

A PATIENT-FIRST APPROACH TO NAVIGATE TREATMENT AND ACCELERATE A MYELOMA CURE.

HEALTHTREE

Launched in June 2018, HealthTree is an online tool myeloma patients can use to navigate their care while also helping advance a cure. HealthTree empowers patients with myeloma knowledge, connects them to peers in similar situations and identifies personalized treatment options. At the same time it helps the research community develop new hypotheses about optimal treatment strategies and identifies best practices in myeloma care. Today HealthTree supports improved shared decision making between patients and doctors and powers the artificial intelligence-enabled healthcare of tomorrow.

Patients don't have the luxury of time and need to access the skill of myeloma specialists as soon as they begin. care. As patients enter their myeloma data into the web-based system, HealthTree educates them on personally relevant clinical trial and treatment options they can discuss with their doctors. Over time, the collective data of many patients provides more context for patient / doctor collaboration. The two main objectives of the HealthTree product are:

1. Help Patients Find Personally Relevant Treatment Options

In order to achieve a cure in myeloma, patients must be treated with personally optimal therapies administered in the most advantageous order. The complexity of treatment options is beyond the ability of most patients to understand, and data shows it is also beyond the ability of most general oncologists to deliver optimal treatment. HealthTree allows patients to understand personally relevant clinal trials and treatment options.

2. Help Researchers Accelerate a Cure Through Aggregated Patient Data

As patients continue to add their myeloma data over time based on questions presented by researchers, patient profiles can be expanded and completed. Eventually, a patient's profile could include myeloma markers, lab values and electronic health records, patient reported outcomes and the full gamut of the patient experience. Both patients and researchers can then have access to this data in reports to accelerate a cure for myeloma.

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HEALTHTREE

When Jenny Ahlstrom was diagnosed with multiple myeloma, she and her husband Paul wanted to see data showing which treatment plan would help her live the longest. Such a resource didn't exist. They realized that tech, insurance and pharma companies, hospital networks and research communities each had their data silos, HIPAA restrictions, regulatory concerns or liability issues that prevented them from building a solution in an integrated, patient-centric way. Patients are the key. They have the freedom to not only aggregate their data, but to freely share their story to help drive new, faster insights.

WHY USE HEALTHTREE?

As a patient, it's hard to navigate multiple myeloma. How do you get up-to-speed quickly on a disease you've never heard of before? Myeloma is also a complex cancer. Each patient can have several types of myeloma at diagnosis and the disease can change genetically over time. Add to that the fact that 80% ofpatients are treated by general oncologists, but specialists help patients live longer because of their sophisticated approach to treatment. So what gets us closer to better personalized treatment and a cure?

HealthTree gives you the information you need to make critical treatment decisions at every stage of disease. HealthTree gives you a way to track your disease in a single place, so getting a second opinion is easier. HealthTree helps you connect with other myeloma patients in similar situations so you can share insights. HealthTree shows you personalized treatment options you could consider at every stage of disease, and then shows you more detail behind each option. HealthTree identifies all clinical trials you are eligible to join based on your most recent labs. HealthTree University provides classes to quickly educate you about your disease so you can ask better questions in the clinic.

HealthTree is also a tool that can gather long-term anonymous data from thousands of patients, so both patients and researchers can see real world relationships between subtypes of patients, the care they receive and their outcomes. With that information doctors can better personalize therapy and optimize outcomes for each patient.

Many myeloma doctors believe that 10-15% of patients may be already cured but don't know who, how or why. This collective data will feed machine learning engines that will identify the right treatment for the right patient at the right time to accelerate a cure.

BECOME A PART OF A GROWING COMMUNITY OF PHYSICIANS, RESEARCHERS, AND PATIENTS COLLABORATING FOR A CURE.

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HOW HEALTHTREE BENEFITS YOU:

TRACK YOUR DISEASE

Keep everything about your myeloma in one place and update it regularly to make doctor visits easier. Print a summary of your history and get a second opinion. Pulling your labs and prior therapies from many hospitals is now automatic with our Apple Health parthership.

FIND & CONNECT

Find and message other patients in similar situations using our "Twin Machine Technology." Communicate with patients in your area, with similar genetic features or those who are experiencing the same side effects.

FIND HELP & RESOURCES

Find financial assistance and other key myeloma resources with links to the best help available. HealthTree can match you to financial aid you might qualify for, help you find online support groups, or show you the best online sites for myeloma information.

FIND TREATMENT OPTIONS

See personally relevant treatments and clinical trials you could consider for your stage of disease. These treatment options are individualized based on your disease genetics, fitness status, current health, recent lab values and expert opinion from dozens of multiple myeloma specialists.

VIEW REPORTS & DATA

View anonymous reports of patients using HealthTree such as common side effects, outcomes by myeloma genetics and impact of treatment. Reporting will help identify new hypotheses for researchers and will provide practical help for better shared decision-making with your doctor.

LEARN ABOUT MYELOMA

Join HealthTree University with classes on every myeloma topic from the basics to the most complex. Learn more about myeloma at home from our expert "faculty" so you can spend valuable clinic time discussing your individual treatment plan with your doctor.

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Following the launch, we took HealthTree on the road to validate the platform in meetings in 50 cities across the United States with more than 800 patients. We gathered what we learned, updated the software, and created a video to share the idea on the internet. Within four weeks of launching the video, more than 2,500 patients had signed up for HealthTree and over 3.5 million people had watched the video. Many began asking us to bring this idea to more than 50 different deadly diseases.

50 CITIES

850 PATIENTS

2,200 NEW USERS

With internal resources, the CrowdCare Foundation has been able to validate the need for HealthTree, build out the platform, and recruit over 2.5% of the US myeloma patients to join. We are excited to add additional resources to scale the HealthTree platform to the majority of US patients in 2019 and add support for additional cancers and diseases in the future. As the success of HealthTree grows, it will provide a powerful patient voice alongside other key stakeholders to improve the quality of care and positive outcomes for patients.

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HEALTHTREE LAUNCH TOUR

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MYELOMA CROWD

The Myeloma Crowd programs offer education and support for our myeloma community of patients, family members and caregivers. The Myeloma Crowd offers three areas of support.

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1. Simplified Patient Education

We aggregate and share the latest research in patient-friendly language on each disease website and provide social media groups where patients can exchange information. We also host live patient meetings and seminars, especially for relapsed and high-risk patients.

2. Support Research Driven by Patient Needs

We connect patients with top researchers in the field to explore gaps in current research funding. We then select specific projects that solve the most urgently needed

answers to pressing treatment questions. The two current Myeloma Crowd Research Initiative projects were carefully selected by both an expert Scientific Advisory Board and Patient Advisory Board and were targeted toward the most promising progress toward a cure.

3. Use Data to Solve Patient and Research Problems

For rare diseases like multiple myeloma, the secret to a cure may be found in patient lab values and disease genetics. Our data solutions will offer immediate help for patients searching for treatment answers. Collecting and aggregating all available patient data into formats that researchers can use is also an extremely important and efficient way to accelerate research.

1 WEB SITE

The Myeloma Crowd website features a host of resources for multiple myeloma patients and caregivers, including general information on myeloma, research articles, a clinical trial finder, and "life with myeloma" articles to help patients become self-advocates.

2 RADIO PROGRAM

Myeloma Crowd Radio features extended audio interviews with top myeloma experts to help patients understand open clinical trials and current myeloma research. By the end of 2018, over 122 experts had been interviewed, and the audio files have been made available on the website.

3 ROUND TABLE DISCUSSIONS

Myeloma Crowd Round Tables are live meetings for high-risk and relapsed patients. In 2018, we successfully hosted five round table discussions in the following locations: Baltimore, St. Louis, Charlotte, New York City, and Buffalo.

4 MEETUPS

Myeloma Meetups are ways for myeloma patients to get together with other patients in their local area to talk about topics ranging from Myeloma 101 to the very latest in research, join a Myeloma Crowd Round Table, or just meet for lunch to share experiences.

ROUND TABLE
DISCUSSIONS

Myeloma Crowd Round Tables on High-Risk Disease are day-long patient education meetings featuring world-class experts to assist patients and caregivers to make decisions about their treatment and care. The presentations and panels help make the most difficult issues in myeloma research and treatment - high-risk, relapsed and refractory disease - undertandable in plain language.

In 2018, we successfully hosted five such meetings in various locations throughout the U.S., including New York City, NY, where on May 5th, presentations and panels featuring six myeloma experts covered topics from bone disease, therapies, and transplants to CAR-T cells, imaging, and the history of myeloma.

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MYELOMA CROWD
RESEARCH INITIATIVE

The Myeloma Crowd Research Initiative (MCRI) is a patient-driven effort to accelerate the pace of research for patients who need it the most. With an expert Scientific Advisory Board and Patient Advisory Board, we ran our second crowdsourcing effort to find the most promising research being performed for high-risk myeloma patients. These patients are not benefitting from the latest advances and still have a 2-4 year life expectancy.

Our global search rendered 36 proposal submissions that were vetted by our Scientific Advisory Board.The 10 finalists submitted full proposals and were hosted on Myeloma Crowd Radio to share their idea with the patient community.

Both the Scientific and Patient Advisory Boards selected the three final and promising projects. The MCRI ran a crowdfunding campaign and enabled the Myeloma Crowd patient community to advance exciting research. More information on this exciting initiative can be found at http://give.crowdcare.org/mcri.
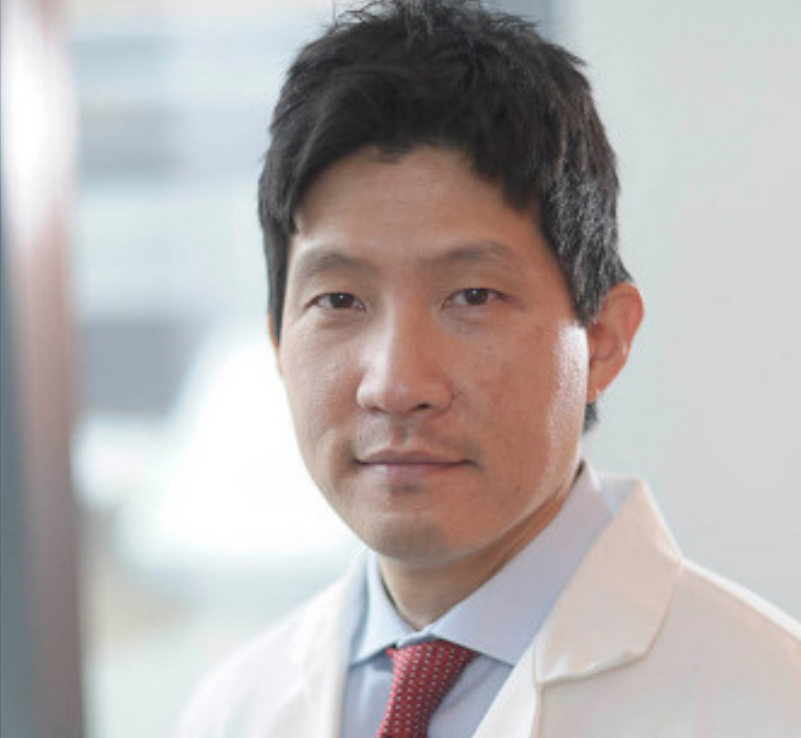
CREATING AN IMMUNE SYSTEM SIGNATURE - DAVID CHUNG, MD, PHD

Why do some multiple myeloma patients relapse early after stem cell transplant while others stay in remission for many years? The patient's immune system may be a key factor. Dr. Chung's research will review patients who have undergone stem cell transplant. He will study three different parts of their immune system after transplant – T cells, lymphocytes and myeloid derived suppressor cells (MDSCs) and will compare patients with early vs. late relapse. He will then combine that immune system signature with the myeloma genetics of each patient to understand the impact they have together.

TESTING YOUR INDIVIDUAL MYELOMA TUMOR AGAINST AVAILABLE MYELOMA THERAPIES - CESAR RODRIGUEZ, MD

Each myeloma patient's tumor is unique and can change over time. Dr. Rodriguez is using a new 3D organoid tumor modeling platform which allows the testing of over 50 myeloma treatment combinations against your specific tumor (including your bone marrow microenvironment) to identify which treatments will work best for your type of myeloma. This personalized approach will help you find useful drug combinations that will have the most impact and avoid treatments that will be ineffective.

TARGETING CD24 TO ELIMINATE MYELOMA STEM CELLS - FENGHUANG (FRANK) ZHAN, PHD

Myeloma stem cells (or early progenitor cells before they become plasma cells) may not be killed with current myeloma therapies and could be the cause of relapse. Dr. Zhan has identified the presence of CD24 as a strong candidate as a cancer stem cell marker and believes that high CD24 levels lead to more aggressive myeloma and earlier death. His work will test patient samples for the presence of CD24 and assess outcomes while also identifying CD24 monoclonal antibodies that could impact this target.

ALS CROWD

ALS is a terminal illness with an unknown cause and no treatment to stop its effects. It is robbing an estimated 300,000 people of the ability to move, eat and breathe.

Also known as Lou Gehrig's Disease, ALS gained global attention in 2014 during the phenomenon known as the Ice Bucket Challenge. Though millions participated in the challenge, the ALS community still finds itself grappling to discover a cause and a cure.

Utah native Seth Christensen was diagnosed with ALS in 2010. A director of venture integration at Microsoft and ALS Crowd Founder, he began work to bring the latest in computer technology to the fight to develop a cure. Partnering with other leaders he is a top national voice

in the ALS "Big Data" movement--the movement to allow ALS patients to control and donate their medical data for wider use.

1 WEB SITE

We aggregate and share the latest research in patient-friendly language and provide social media groups where patients can exchange information.
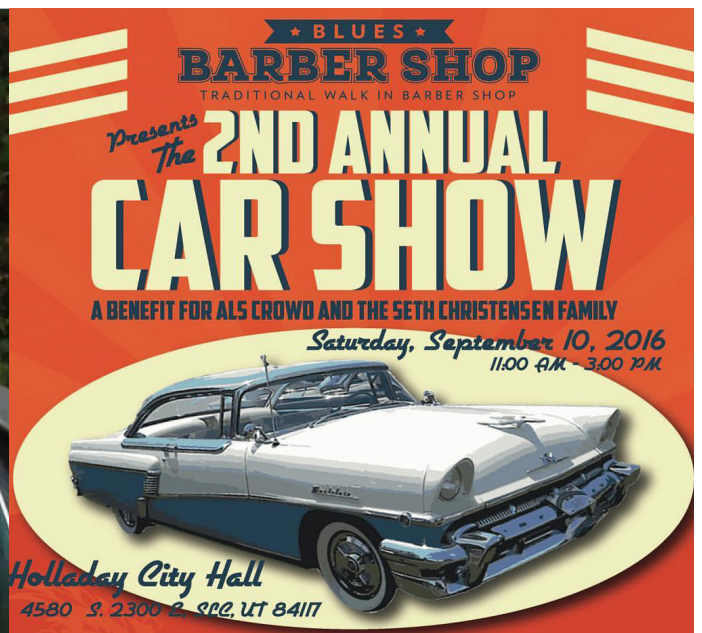
2 BIG DATA INITIATIVE

Aggregating available patient data into formats that researchers can use is an extremely important way to accelerate research. Our data solutions offer immediate help for patients searching for treatment answers. In the future, HealthTree will be applied to ALS to understand optimal strategies to reverse ALS progression.

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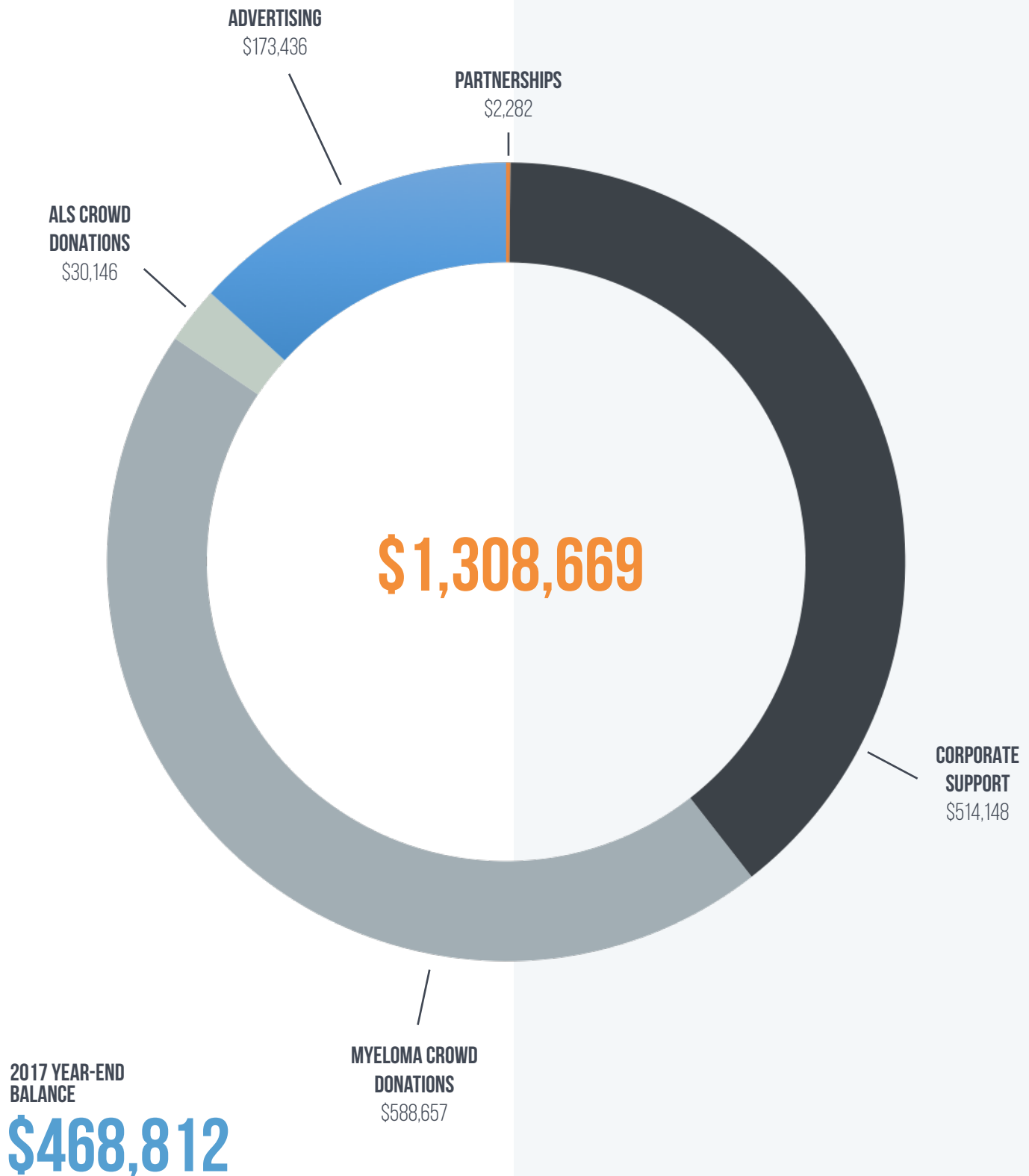
BLUES BARBERSHOP

$30K RAISED

through ALS Crowd events and programs in 2018

A few years ago, Seth's 13-year-old son emailed him and said, "Dad, I've decided what car I want; a '68 Camaro." Seth says in a typical life you would blow that off and say, "Yeah, we all do." But Christensen, as an ALS diagnosee himself, doesn't take time or dreams for granted. Father and son immediately started looking around, found a pretty good car and bought it. It did not drive at all and needed a complete restoration. The Utah Auto Body Association partnered with Christensen to help complete this project. Seth also struck up a friendship with Jerone Wedig, owner of Blues Barbershop in Holladay. Their mutual love of classic cars led them to put on their own car show as a fundraiser for ALS Crowd.
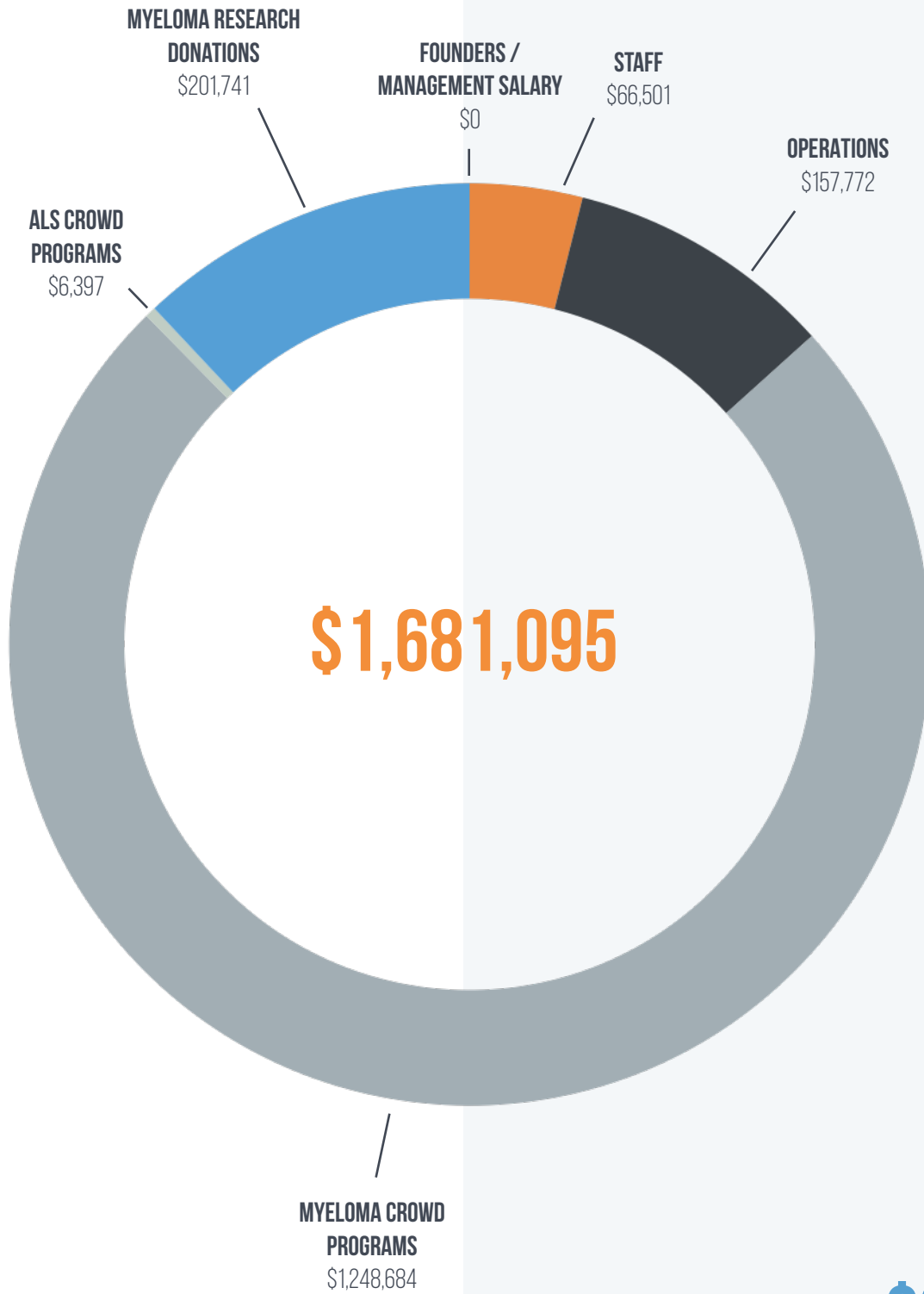
CROWDCARE FOUNDATION

FINANCIALS

2018 Income

ADVERTISING
$173,436

PARTNERSHIPS
$2,282

ALS CROWD DONATIONS
$30,146

$1,308,669

CORPORATE SUPPORT
$514,148

MYELOMA CROWD DONATIONS
$588,657

2017 YEAR-END BALANCE
$468,812

2018 Expenses

MYELOMA RESEARCH
DONATIONS
$201,741

FOUNDERS /
MANAGEMENT SALARY
$0

STAFF
$66,501

OPERATIONS
$157,772

ALS CROWD
PROGRAMS
$6,397

$1,681,095

MYELOMA CROWD
PROGRAMS
$1,248,684

2018 YEAR-END
BALANCE
$96,386

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Improving patient outcomes by removing barriers to a cure.