



# 2019 Annual Report

**We've started  
a revolutionary  
patient  
movement  
because patients  
are the key in  
accelerating a  
cure for terminal  
diseases.**

# Contents

## **04** CrowdCare Mission

Our mission and a message from our CrowdCare founder.

## **07** What We Do

Improving patient outcomes by removing barriers to a cure.

## **08** HealthTree

An online tool for myeloma patients to help make treat decisions and improve outcomes.

## **12** Myeloma Crowd Programs

Educating patients, supporting research, and leading the way on patient-first healthcare data.

## **16** ALS Crowd Programs

Working on big data initiatives to find foundational insights into ALS.

## **18** Financials

Using precious resources to serve patients.

**Our mission:**  
**To provide  
education,  
support, & data  
to accelerate  
cures for terminal  
diseases.**





## A Message From our Founder

This year was one of exciting growth for the CrowdCare Foundation as we expanded our programs to reach more patients, fund more research and expand our HealthTree platform.

The new Myeloma Coach program expanded to over 100 Coaches this year. These Coaches are dedicated to helping their myeloma peers navigate the disease successfully.

We gave additional funding to our Myeloma Crowd Research Initiative recipients and laid the groundwork to perform more observational studies inside of HealthTree, which we plan to open in 2020. Our goal for the platform is to speed academic research for myeloma at no cost to the research community.

Our HealthTree platform grew to over 5,000 myeloma patients in 2019 and we paused our expansion efforts while we grew our in-house development team to create even more patient benefits in the platform, like our beta of the Twin Machine.

ALS Crowd made plans this year to expand HealthTree to ALS and significant global research was performed to identify key ALS data sets. This and a new website will be an exciting addition for ALS Crowd followers.

We are so intensely grateful for your support this year in making these programs a reality! Working with patients like you brings us incredible joy and we will continue in 2020 with our obsession to find cures for these terminal diseases.

Gratefully,

Jenny Ahlstrom



# 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 by 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. Educated patients are better equipped to navigate the many decisions around their care and self-advocates live longer and have higher patient satisfaction.

# 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.

In 2019, HealthTree grew from 860 myeloma patients to over 5,000 myeloma patients. We added a new design, new features and a new educational platform called HealthTree University, which will become the largest online resource for multiple myeloma education. In 2019 we launched the Twin Machine beta for a subset of patients and produced over 50 reports on the aggregated content. Our continuous interviews with myeloma patients and caregivers are helping us identify new features that will make a meaningful difference in the lives of myeloma patients in 2020 and beyond.



## Moving Myeloma Research Forward Faster at Lower Cost

*“What would have taken me years through traditional survey methods, only took me a couple of months through HealthTree (for free).”*

Dr. Michael Thompson, Aurora Healthcare

## Creating New Myeloma Research Hypotheses

*“HealthTree is a wonderful hypothesis generation tool.”*

Dr. Sandy Wong, University of California at San Francisco

HealthTree Featured on the

# TODAY SHOW

In March 2019, Jenny and Paul Ahlstrom were featured on the Today Show to share the reasons behind the creation of HealthTree. Their main message was that patients are the key. Patients have the freedom to not only aggregate their data, but to freely share their story to help drive new, faster insights.



# HealthTree was made by myeloma patients for myeloma patients

We know how hard it is to navigate multiple myeloma, so we built Healthtree from the perspective of the patient. HealthTree is a tool myeloma patients can use to navigate their disease. At the same time, HealthTree help aggregate data that provides insights for researchers to a potential cure. HealthTree is valuable to help you manage your myeloma alone, but with over 5,000 registered users, our collective myeloma story will help us identify new and exciting hypotheses and bring new personal connections and insights. Our relentless goal behind HealthTree is finding a myeloma cure.

# HealthTree helps you:



## Track Your Disease

Keep everything about your myeloma in one place and update it regularly to make doctor visits easier. Use the HealthTree Connect app to pull your labs automatically for facilities who support Apple Health.



## Find Treatment Options

See personally relevant treatments and clinical trials you could consider for your stage of disease, based on expert opinion from dozens of multiple myeloma specialists.



## Learn about Myeloma with HealthTree University

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.



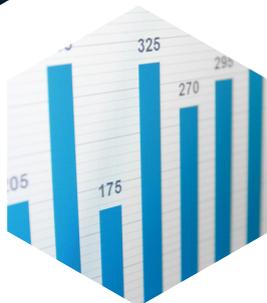
## Accelerate Research

Answer myeloma researcher survey questions and join studies to accelerate a myeloma cure.



## Find Help & Resources

Find financial assistance, a Myeloma Coach, a myeloma specialist and other helpful resources.



## View Reports & Data

View anonymous reports of HealthTree patients using HealthTree such as family incidence of myeloma or heavy/light chain myeloma type. Reports will help identify new hypotheses for researchers and provides better information for patients.



## 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. The Twin Machine is now in beta.

# Myeloma Crowd

The Myeloma Crowd has built a wide number of programs to support multiple myeloma patients and caregivers.

As patients ourselves, we know how challenging a myeloma diagnosis can be. Each of our programs was built to support their needs and we will continue to listen to the myeloma patient community to provide needed programs and services.



## 1 Myeloma Crowd Website

The Myeloma Crowd website continues to be a frequently visited site that provides news and information to myeloma patients and caregivers. The site reaches over 700,000 unique visitors annually with myeloma news, "life with myeloma" articles, clinical trials, radio program transcripts, Coach articles and Myeloma 101 information and resources.

Because finding a myeloma specialist is one of the most important things a myeloma patient can do, we have a directory of myeloma specialists who treat myeloma exclusively. Including a myeloma specialist on your team can provide additional years of life for myeloma patients, according to data from the Mayo Clinic and University of North Carolina.

*Special thanks to key website sponsor Takeda Oncology.*

## 2 Round Tables

Myeloma Crowd Round Tables continue to be one of our most popular programs. In 2019 we hosted meetings in Austin, TX, Buffalo, NY, Atlanta, GA, Chicago, IL, Seattle, WA and St. Louis, MO.

*Special thanks to key sponsor Amgen Oncology.*

## 3 Myeloma Crowd Radio

The enduring Myeloma Crowd Radio program continued in 2019 where we hosted a dialogue between myeloma patients and myeloma researchers discussing topics such as: new innovations in 2019, weighing cancer cells to personalize myeloma therapy, new treatments like CLR-131, Selinexor, isatuximab and CAR T therapy, the world's largest myeloma screening study (PROMISE), creating a new myeloma center of excellence from scratch, immunotherapies in myeloma and cost considerations in myeloma treatment. This beloved program has reached over 1.5 million listeners and readers since its inception in 2013.

## 4 Myeloma Coach

The Myeloma Coach program grew significantly in 2019 with the addition of over 100 Coaches who are trained and determined to provide support and resources to their fellow myeloma peers. We applaud these patients and caregivers who give of their time so willingly to help others. For the first time, five of our Myeloma Coaches attended the ASH 2019 conference.

*Special thanks to key sponsors Amgen, Takeda Oncology and Celgene.*

## Deer Valley Myeloma Coach Summit 2019

We hosted our first Myeloma Coach Summit in Deer Valley, Utah in the summer of 2019. Coaches from all across the United States attended to become more educated about myeloma in order to help the patients they coach. Our gratitude goes to Dr. Gareth Morgan, Dr. Rafael Fonseca and Dr. Doug Sborov for our expert sessions.





# Myeloma Crowd Research Initiative

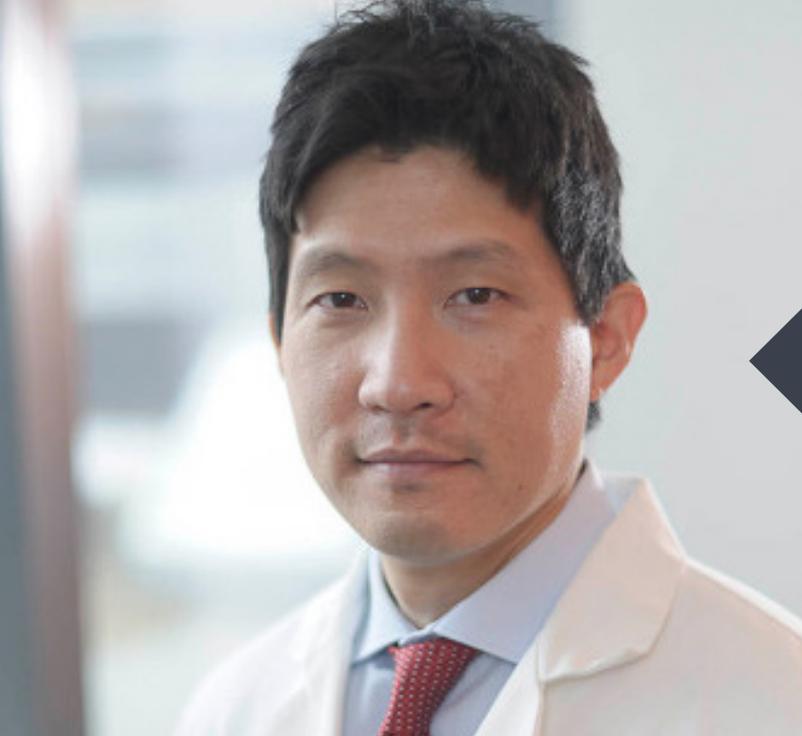
The Myeloma Crowd Research Initiative (MCRI) is a patient-driven effort to accelerate the pace of research for patients who need it the most. In 2019 we continued to fund the three projects selected for our second MCRI campaign through your generous donations.

Although many immunotherapy technologies have been in development for many years, we are just now seeing the practical application of those new treatments and a greater focus on personalizing therapy for each individual patient.

New areas beyond just genomics are now being explored. Researchers are working to identify the role and status of the immune system and how that relates to myeloma progression, relapse and outcomes. Because myeloma changes over time, work is also being done to identify the “best”

myeloma treatments for an individual patient at every stage of disease. This is especially helpful to prevent unnecessary or ineffective treatment and to provide each patient with the most effective therapies at each stage of disease. Myeloma stem cells are an ever growing focus with the goal of preventing myeloma from relapsing.

We are intensely grateful to our generous donors who supported these three projects at <http://give.crowdcare.org/mcri>.



## Creating an Immune System Signature

David Chung, MD, PHD

The role of the immune system is key to myeloma progression and relapse. Dr. Chung is working to identify an immune system “panel” of key indicators and then match that with traditional genetic testing to help determine the likely response to therapy or relapse.

## 3D Tumor Modeling with Organoids

Cesar Rodriguez, MD

Dr. Rodriguez aims to determine which myeloma therapies will be the most effective for each individual patient, based on their myeloma at specific time points of treatment. Using a new technology called organoids, he can test the same sample across 50+ different myeloma therapy combinations.



## Targeting CD24 to Prevent Myeloma Relapse

Fenghuang (Frank) Zhan, PhD

Myeloma remains an incurable cancer, possibly because residual stem cells are not killed by today's therapies and cause regrowth. Dr. Zhan is studying the role of CD24 cells in the cause of relapse and potential CD24 targeted therapies.





# ALS Crowd

In 2019, ALS Crowd performed global research into ALS data sets. Founder Seth Christensen visited with key ALS investigators in the United States and Europe.

The visits included King's College Translational Neuroscience Department in London where Ammar Al-Chalabi leads a lab and team of geneticists and data scientists. They have the ability, staff, and US and European partnerships to do everything from bench science to clinical trials and their focus is subdividing ALS into genomic groups he believes are driven by different causes.

In Brussels, Belgium, Seth met with IMI, a €5B EU initiative to make EU pharma companies more competitive, and to bring innovative therapies to rare disease communities. They do this by matching EU funds with those of industry and nonprofit consortia. IMI is considering sponsoring a

global ALS biomarker validation project and is a potential partner for ALS Crowd.

At the University of Lisbon's ALS Multidisciplinary Clinic Professor Mamede de Cavalho founded a 30-year-old ALS clinic that treats 25% of ALS patients in Portugal. They are doing research, with multiple PhD candidates in the pipeline, but this research is limited in scope, or done in conjunction with larger clinics or with groups like Project MinE. We believe that linking the capabilities of small or medium sized clinics could provide faster, more flexible research in ALS.

At UMC Utrecht in the Netherlands, Professor Jan Veldink and Evelijn Zeijdner are aggregating over 1 petabyte of ALS genomic data from around the world. Many of the recent ALS linked genes were discovered using their data.



In 2019 ALS Crowd began research and planning to expand the HealthTree platform to ALS Crowd patients. While there are key differences between ALS and multiple myeloma, ALS patients share an urgent need to remove roadblocks from researchers' paths and accelerate progress.

One of the greatest roadblocks is researchers' limited access to patients and patient data.

Although ALS patient registries exist, the disease's rarity and its pattern of progression make patient communities and patient datasets extremely difficult to build and maintain. None exist that allow patients to upload and share relevant data, including medical records, with the research community.

ALS Crowd is now raising funds to build the pilot model of ALS HealthTree based on Myeloma Crowd's proven 'foundation + platform' and 'patient-enabled data collection' model.



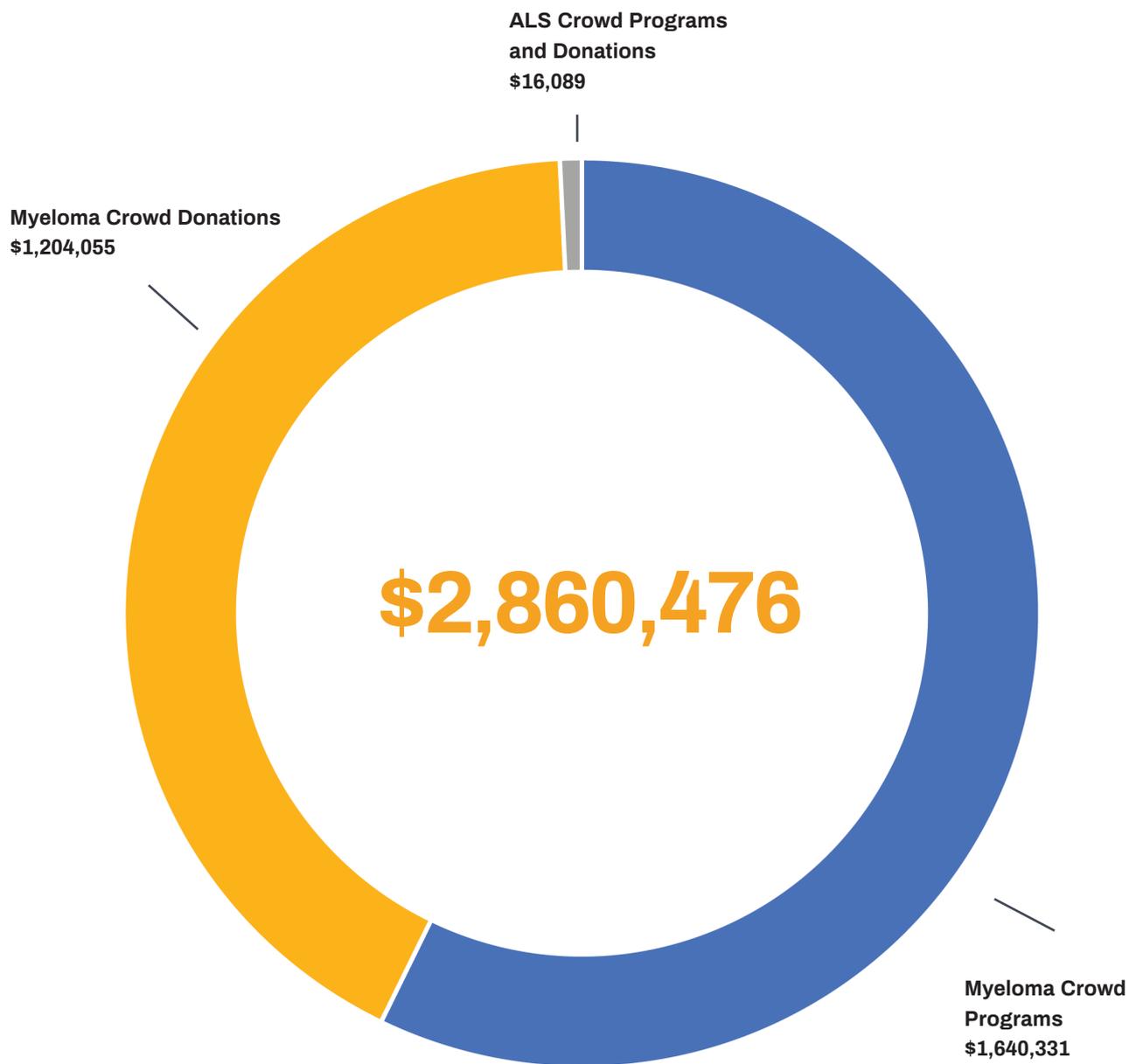
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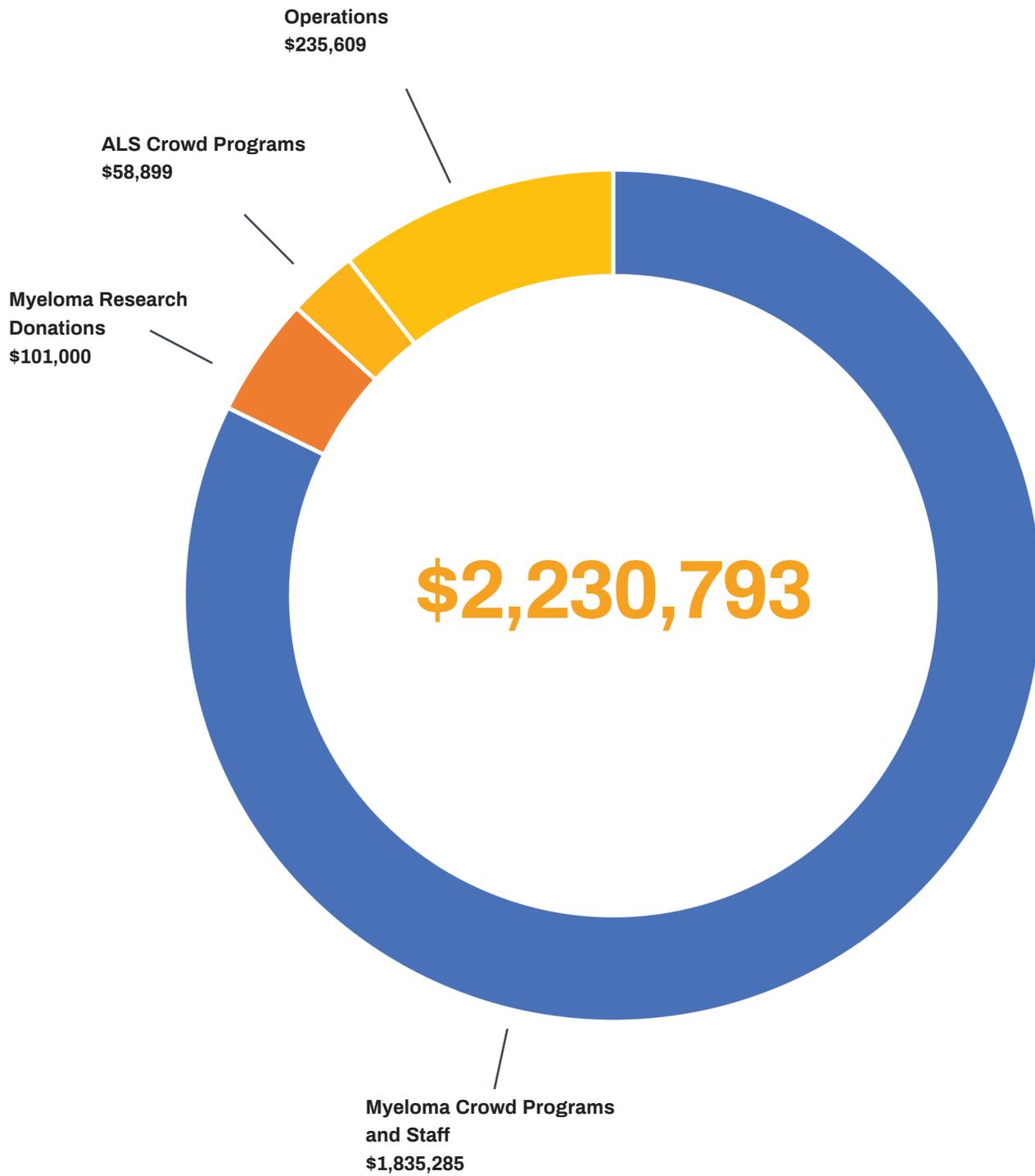
SETH AND AMY  
CHRISTENSEN AT  
PROJECT MINE: UMC  
UTRECHT, NETHERLANDS

# Financials

## 2019 Income



# 2019 Expenses



Special thanks to our key corporate sponsors



Improving patient outcomes by removing barriers to a cure.