

RARE CANCER RESEARCH FOUNDATION



IMPACT REPORT

2023



THIS YEAR, WE CELEBRATED TEN YEARS OF IMPACT AT THE RARE CANCER RESEARCH FOUNDATION.

The organization works to meet the unmet needs that exist for rare cancer patients in innovative, scalable ways that lead to exceptional outcomes not only for one patient but for all patients. In 2023, the organization experienced significant and exciting growth.

- From a team of 4 in 2022, we ended 2023 more than 20 strong! To learn more about our team [visit our staff page](#). Thank you to our Board of Directors and our Scientific Advisory Board for their leadership, vision and stewardship!
- We worked closely with a pioneering group of patients to further explore the opportunities to expand precision medicine capabilities and learnings to the rare cancer community.
- We told the world about our fiercely patient-centric work in the Boston Globe, on social media platforms and in communities across the country.
- We raised more than \$2.5M from well-respected institutions like the Chan Zuckerberg Initiative and the Parker Institute of Cancer Immunotherapy, as well as individual donors.
- At Pattern.org, we've had more than 370 patients donate tissue samples and we've worked with 5 research institutions to create more than 65 research models. Most notably, 20% of those research models come from underrepresented groups – urgently shifting a landscape that continues to lack diversity and representation.



2024 WILL BE A TRANSFORMATIVE YEAR AS WE EXPAND OUR OFFERINGS IN TWO PRIORITY AREAS.

1

The first is to build the most powerful tools for rare cancer patients to make data-informed decisions about their cancer journey. We are building a patient-directed custodial biobank and other tools to give patients significantly increased agency over their treatment and care, including the capacity to return gene sequencing results to patients to give them actionable information to help them make more targeted treatment decisions.

2

The second is to create the Pattern Data Commons - a shared data platform with clinical annotation that will unify the rare cancer community's data for scientific discovery and rapid progress. Whether it's omics, AI and machine learning, or breakthrough therapies, we will have the tools and the shared platform to make scientific discoveries and progress toward better treatments and cures. We are working together to create a future where every rare cancer patient has options, proven treatments, and promise for better outcomes.



I was just diagnosed with a rare cancer and have been told there's no standard of care to treat it. My options seem limited.



"We don't know a lot about these rare cancers and don't know what treatments to use. There is no database to go to find treatment standards."

- Michael J. Overman, MD
MD Anderson Cancer Center

The status quo leaves rare cancer patients behind the pace of innovation.



Even researchers say it's too difficult to get samples of my type of cancer for them to even begin studying it.



I'm doing everything I can, but there's so much conflicting information out there that I don't know what will work for me or where to start.



RCRF'S INITIATIVES CREATE MEANINGFUL COLLABORATIONS TO PUSH THE FRONTIERS OF ONCOLOGY AND INNOVATE FASTER TO SAVE LIVES.



Pattern.org empowers patients anywhere in America to contribute tissue, genomic data, and clinical data to cutting edge researchers and open source data platforms.

Pattern.org will enable patients and doctors to access genomic data to better inform care and eventually to explore personalized treatment options. This approach accelerates innovation in rare cancer treatment and helps narrow the quality of care gap for patients, whether they're in their local community hospital or a comprehensive cancer center. Pattern.org can help patients access:

- Tumor profiling report with CLIA sequencing
- Insights learned from patients with similar genomic profiles
- Insights from across our patient community

PATTERN DATA COMMONS

The data commons is a technology platform that enables aggregation and analysis of clinical and multi-omic data by patients, researchers, doctors, biotech, and pharma.

OUR WORLD CLASS SET OF ALLIES AND ADVISORS



Raymond Dubois, MD, PhD

Director of MUSC Hollings Cancer Center



Andy Futreal, PhD

Genomic Medicine, MD Anderson Cancer Center



Andy Hong, MD

Assistant Professor, Emory University



Brian McSteen, MD

Internal Medicine Resident at Weill Cornell Medicine



Corrie Painter, PhD

Strategic Advisor, Count Me In; Broad Institute



Marlene Portnoy

Former Executive Director, Desmond Tumor Research Foundation



Kenna Mills Shaw, PhD

Executive Director, Institute for Personalized Cancer Therapy at MD Anderson Cancer Center



Josh Sommer

Co-Founder/Executive Director of The Chordoma Foundation



Tania Simoncelli

VP, Science in Society at Chan Zuckerberg Initiative



Marty Tenenbaum, PhD

Founder and Chairman at Cancer Commons





Our **fiercely patient-centric** vision is to work in collaboration with rare cancer patients to rapidly improve the research and treatment options and find cures for their diseases.

RCRF BY THE NUMBERS

- **65+** models created + more under development (**27** of those models are at ATCC in Virginia, **3** of those models are at DSMZ in Germany, **30** models at the Cancer Cell Line Factory at the Broad Institute in Massachusetts).
- Countless datasets from Pattern samples in the Broad Institute's DepMap Portal, NIH's database of Genotypes and Phenotypes (dbGaP) and cBioPortal for Cancer Genomics.
- First ever publicly available Desmoid Tumor Cell Line now at ATCC, developed from a patient sample donated through Pattern.org.
- Discovery of **37** possible repurposed drugs and **31** new targets for Desmoid Tumors.
- **6** verified Leiomyosarcoma cell lines created from patient samples donated through Pattern. All 6 currently undergoing genome-wide RNAi and CRISPR loss-of-function screens at the Broad Institute's DepMap Initiative.
- Currently have partnerships with **5** research institutions including the Broad Institute, MD Anderson Cancer Center, the Koch Institute, Emory University/Children's Hospital of Atlanta and University of Wisconsin Health with an additional **4** research partnerships to be announced early in 2024.
- Added a number of new patient advocacy foundation partners such as HunterSeven Foundation, Max Vince Foundation, CureASPS, Kidney Cancer Foundation, Judy Nicholson Kidney Cancer Foundation and Chromophobe and Oncocytic Tumor Alliance.