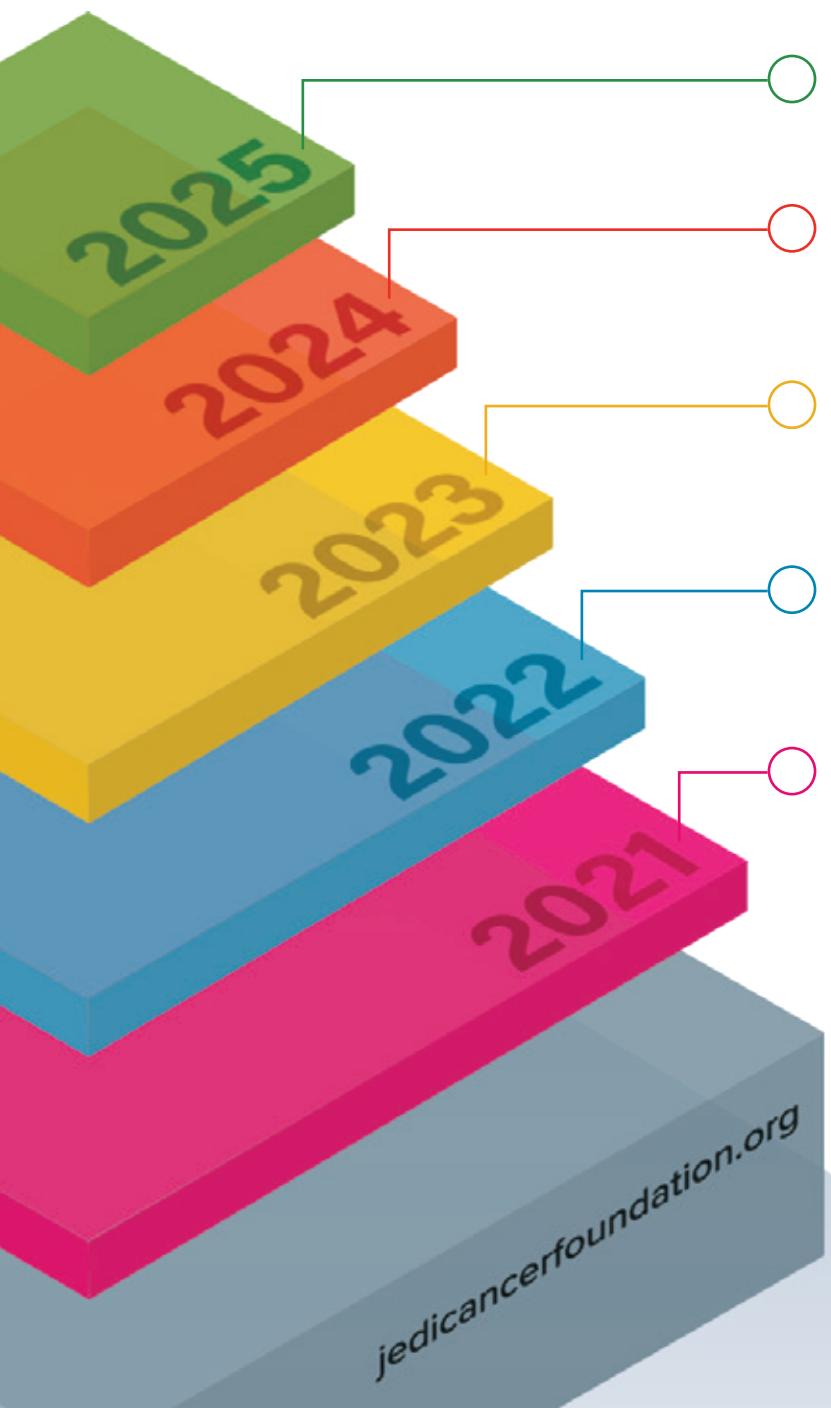
jedi rare cancer foundation

Our Years of Progress



- Lead Alliance for Rare Cancer (ARC) initiatives. The Vision: Every patient deserves to benefit from latest advances in cancer treatment.

- Co-Founded Alliance for Rare Cancer (ARC).
- Sponsored Sarcoma Research Paper Published in AACR *Clinical Cancer Research*.

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- Commissioned Rare Cancer Landscape Study.

- Funded Rare Cancer Research at Memorial Sloan Kettering Cancer Center (2022-2023).
- Co-Sponsored Rare Cancer Conference at Columbia University.

- "What will be my Legacy" –Jed Taxel
- Established Jedi Rare Cancer Research Foundation, October 24, 2021.

Together, We Can End Rare Cancer

A Message of Hope from Mark Taxel

Chairman and Founder, Jedi Rare Cancer Foundation
Chair, Alliance for Rare Cancers

Our foundation's journey began...

Just 4 short years ago, driven by passionate, talented people and organizations representing medical institutions, academia, philanthropy, and government, we launched the Jedi Rare Cancer Foundation. Today, we are actively leading a movement dedicated to uniting the entire rare cancer community at unprecedented scale to accelerate research, treatment, and cures for all rare cancers, the hidden unmet need in our modern era.

Why is this mission important?

While every rare cancer is individually rare, **rare cancers represent 1 in 4 cancers diagnosed annually in the U.S.**, including every type of pediatric cancer.

Despite these numbers, rare cancer has been left behind in the fight against cancer. There is a mismatch between the level of investment and the scale of the challenge.

Cancer science and treatment has advanced dramatically in the past 25 years, as government, industry, and academia focused (with great results) on major common cancers such as breast, lung, colon, and prostate. However, there is no such standard of care or suggested set of treatment options for rare cancer.

The 5-year survival rate for most common cancers has gone from 50% to more than 70% but rare cancer patients have seen little to no progress in survival rates because there is little to no investment for rare cancer research, treatment, and cures–for reasons documented in *The U.S. Rare Cancer Landscape: A 2023 Report,* the study our foundation commissioned last year.

What would it mean to end rare cancer?

Rare cancer patients would have the same opportunity for treatment or cure as common cancer patients.

The Jedi Rare Cancer Foundation, with the support of our donor community and in partnership with Case Comprehensive Cancer Center, the Rare Cancer Research Foundation, and other leaders in academia, philanthropy, patient advocacy and government, has formed the **Alliance for Rare Cancers (ARC)**.

The process we are engaged in with ARC has resulted in a strategic plan and implementation model that represents a comprehensive approach to accelerate rare cancer progress from bed to bench and back again. This model will be designed with the goal of attracting funding from major government and private sources.

Our foundation is also the early-stage primary funder and organizer for a transformative research program **CURE: The Rare Cancer Initiative** at Cleveland University's Case Comprehensive Cancer Center (Case CCC), led by Dr. Gary Schwartz. We have committed to raise $5 million dollars over five years; Case CCC estimates program costs to exceed $12 million dollars, of which the University has committed to raise the balance of funds. This rare cancer initiative will be a collaboration with scientists from other leading institutions.

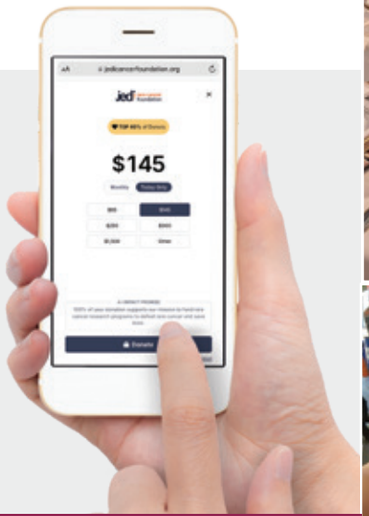
Now is the time to make rare cancer progress.

In the past five years, new science is poised to deliver lifesaving precision medicine and even cures to some cancer patients, making it possible to invest in rare cancer. It is our strong belief that transformative breakthroughs—not just in science but in the ability to deliver better treatments to rare cancer patients–are now possible. Advancements in genome sequencing combined with molecular analysis powered by AI are providing precision medicine with the potential to impact rare cancer patients heretofore condemned.

Of course, this will take time and money. That's why our foundation and ARC partners are engaged in planning and building the framework that will end rare cancer.

New discovery is one of the outputs of this process. While pharma and industry are not inclined to fund early stages of development, we anticipate they will join the fold as measurable progress becomes evident. We are putting the infrastructure in place that can make that happen.

As the front pages of the news recently documented ... cancer is not selective, it is random. Today, a young adult like our Jed or the Princess of Wales is going about a normal and healthy life ... until BOOM ... their lives are turned upside down and they and their families are left struggling for the hope that today's medical science will cure them, or at least give them time for new science to deliver effective treatments.



Your generous donation is an investment in ending rare cancer as we know it.

While I can't give you a definitive timeline today, we won't have a chance if we don't act now. Jed would have given anything for having the chance to live. He and we are not alone because rare cancer is not rare.

DONATE

Please scan the code to donate.
You can also donate at support.jedicancerfoundation.org/donatetocure
Contact me directly at mark@jedcancerfoundation.org or call 914-671-4766.

Thank you in advance for your generous support!

You Make a Difference!

jedi rare cancer foundation

Our Years of Progress

2025

Unite national rare cancer leadership

- Lead Alliance for Rare Cancer (ARC) initiatives. The Vision: Every patient deserves to benefit from latest advances in cancer treatment.

2024

Define resources and national policy needs

- Co-Founded Alliance for Rare Cancer (ARC).
- Sponsored Sarcoma Research Paper Published in AACR *Clinical Cancer Research*.

2023

Accelerate discovery that can save lives

- Announced $5 Million Funding Commitment for CURE: The Rare Cancer Initiative at Case Comprehensive Cancer Center.
- Co-Sponsored National Rare Cancer Workshop.
- Commissioned Rare Cancer Landscape Study.

2022

Collaborate with leading cancer centers

- Funded Rare Cancer Research at Memorial Sloan Kettering Cancer Center (2022-2023).
- Co-Sponsered Rare Cancer Conference at Columbia University.

2021

"What will be my legacy?"

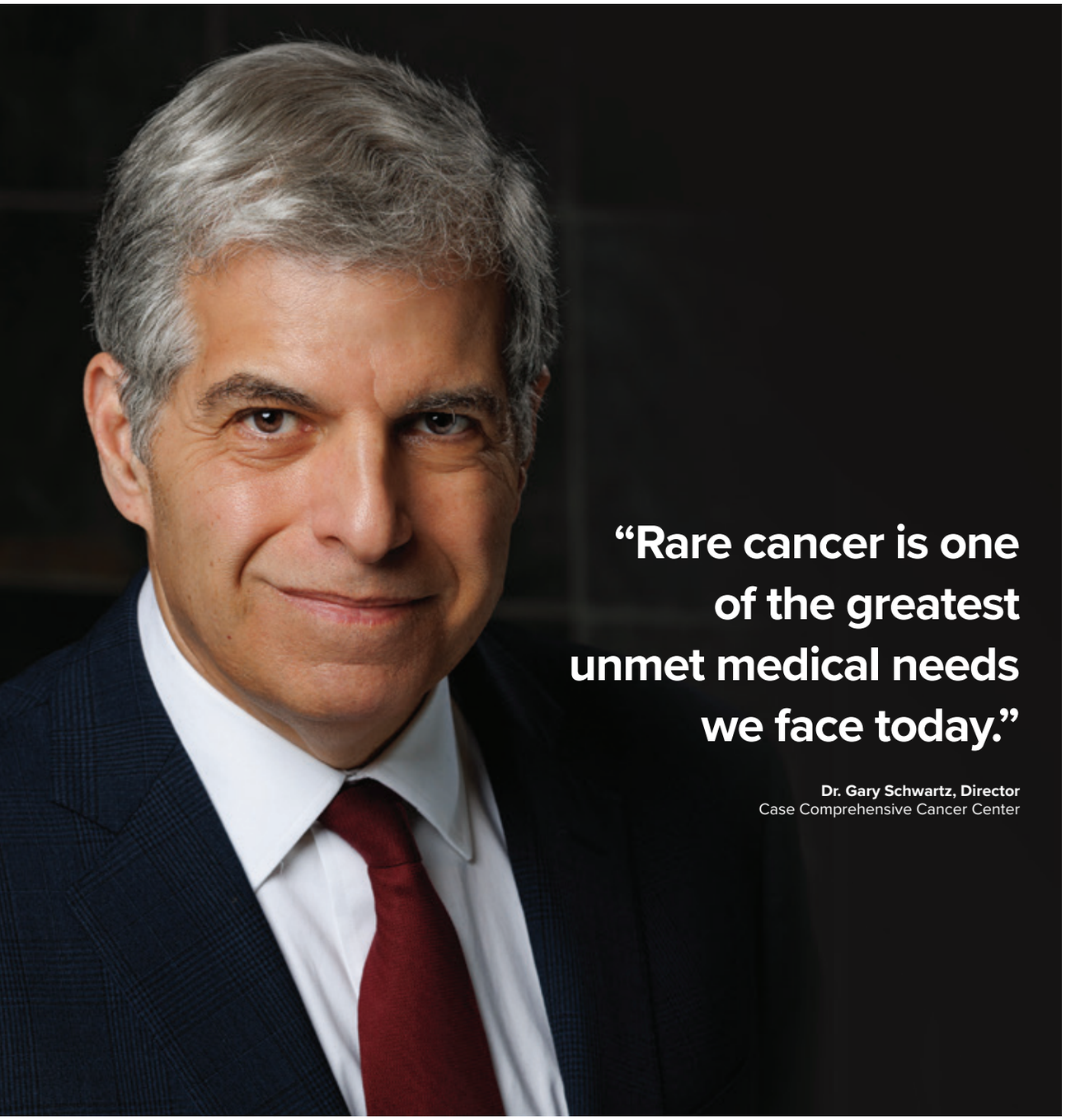
—Jed Ian Taxel

- Established Jedi Rare Cancer Research Foundation, October 24, 2021.

New Hope for Rare Cancer Patients

CURE: The Rare Cancer Initiative

Jedi Foundation has Anchored the Launch Phase with a $5M Commitment.



Rare cancer is one of the greatest unmet medical needs we face today. One in four cancer patients are diagnosed with a rare cancer. The bottom line is that for most of these rare cancers, no protocol for treatment or cure exists. While there continues to be obstacles, new technology and science models make it possible to envision a path forward.

CURE is a major rare cancer research initiative that will help END rare cancer as we know it. CURE (Conducting Unprecedented Research and Exploration) is a new strategic initiative of the Case Comprehensive Cancer Center (Case CCC) under Director Dr. Gary Schwartz.

CURE: The Rare Cancer Initiative and Case CCC Director Dr. Schwartz’s groundbreaking science are built on the understanding that tumors are complex ecosystems composed of not only cancer cells, but also “healthy” cells that can be co-opted by cancer to fuel its growth, or immune cells that actively attempt to kill cancer cells. Within each of the cellular compartments of a tumor, there exists further heterogeneity, such that cancer cells differ among each other, and immune cells have varying functions and cell-to-cell interactions. Novel cutting-edge technologies, called single-cell genomics, enable deep molecular characterization of tens of thousands of cells, one cell at a time, thus providing the required resolution to dissect the complex tumor ecosystem. Linking single-cell genomics analyses with drug predictions and response data offers a unique opportunity for informing therapies in patients.

The Jedi Rare Cancer Foundation has anchored the launch phase of CURE with a $5M commitment. CURE will establish the Case CCC as a premier destination for innovation and excellence in rare cancers. This effort represents the most comprehensive bedside-to-bench-to-bedside effort in rare cancer research to date and will catalyze innovation among research institutions to accelerate scientific discovery and transform cancer treatment.

Our foundation has committed to raise $5 million dollars over five years alongside the University’s commitment to raise the balance of the projected $12 million initiative at Case Comprehensive Cancer Center. Additional philanthropic support is critical for transforming CURE from concept to reality and collecting vitally important early-stage research results that will position it for large-scale funding from the National Institutes of Health, National Cancer Institute, and more, which will accelerate our progress toward the ultimate shared goal of lifesaving cures.

By supporting CURE, we can make an impact. Join Us! Your generous gift will help accelerate scientific discovery to improve diagnostics, treatments, and therapies for rare cancer that will extend lives and result in healthier survivors.

DONATE

Please scan the code to donate or visit support.jedicancerfoundation.org/donatetocure

Thank you in advance for your generous support! Together, we can END rare cancer.

Alliance for Rare Cancers

An unprecedented alliance of rare cancer organizations

The hidden unmet need

Rare cancer patients have been left behind in the fight against cancer.

The Alliance for Rare Cancers (ARC) is an unprecedented national collaboration among rare cancer organizations.

The Mission: To unite the entire rare cancer community at unprecedented scale to accelerate cures for all rare cancers.

The Vision: Every rare cancer patient deserves access to the latest advances in cancer.

We envision a world where every patient diagnosed with any cancer will quickly have access to a data-driven, clinically proven approach to treatment. The promise of data-driven cancer therapy has engendered hope that, at the time of diagnosis, the molecular profile of a patient's tumor will reliably reveal a tumor's vulnerabilities and guide a patient's options for treatment. Data-driven therapy can and should be available for every rare cancer patient, no matter where they live and no matter how rare their specific cancer diagnosis.

We must transform the fractured landscape of rare cancer research into a coordinated, galvanized effort to directly improve outcomes and treatment options. We will do this by creating a strategic and coordinated alliance of rare cancer stakeholders capable of solving the key challenges that impede innovation in rare cancer treatment. Every patient deserves the right to understand and make data-informed choices in partnership with a medical and scientific community that encourages patient voices and active participation. Technological innovations have made data-driven approaches for rare cancer possible. By centering equity and inclusion of rare cancer patients, we can usher in a new era of hope for rare cancer patients everywhere.

The Problem: Rare cancer patients have been left behind in the fight against cancer.

While individually rare, rare cancers represent 1 in 4 cancer diagnoses in the U.S. and include every type of pediatric cancer. However, rare cancers commonly have no standard

Founding Leadership

We are proud to join with key opinion leaders from leading cancer centers and organizations in founding ARC with a common vision that every rare cancer patient deserves access to the latest advances in cancer.

jedi rare cancer foundation
Case Western Reserve University Case Comprehensive Cancer Center
Break Through Cancer Collaborating for Cures
CANCollaborate
RCRF The Rare Cancer Research Foundation
TargetCancer Foundation
ORIEN Oncology Research Information Exchange Network
Northwell Health
SARC collaborating to cure sarcoma
Children's Tumor Foundation Ending NF Through Research
The University of Texas MD Anderson Cancer Center Making Cancer History
Siteman Cancer Center Washington University in St. Louis School of Medicine BJC HealthCare
NCI MyPART My Pediatric and Adult Rare Tumor Network
pattern.org
PAIR

Every cancer patient
deserves to benefit from the latest advances in cancer treatment.

of care or suggested set of treatment options. While there is some debate over which cancer types qualify as rare cancers, it is certain that the combined group of patients facing a rare cancer diagnosis represent one of today's greatest unmet medical needs.

Why does this disparity exist?
Extensive research investments over the past 25 years have led to considerable progress in overall outcomes for "common cancers," the other three quarters of annual cancer diagnoses, and in some select cases, durable remissions. But rare cancer patients have not meaningfully shared in these improvements, with 5-year survival rates for people diagnosed with rare cancers stagnant with an average around 55-60%. In the race for better cancer treatments, rare cancer patients have been left behind despite comprising 25% of cancer patients.

The good news is, scientifically, there is no reason to believe that rare tumor types are inherently untreatable. The problem is a human systems issue: the current landscape for basic rare cancer research, therapeutic development and patient care in the U.S. presents fundamental, compounding challenges that negatively impact progress in rare cancer treatment.

These formidable challenges can be reduced to key, intersecting themes that impact each individual rare cancer type and, if overcome, would clear the way for rapid progress across rare cancers.

The current formidable challenges are:

Geographical dispersion and relative scarcity of patients, resources, and researchers. Low numbers of patients in any one geographical location makes it difficult to conduct traditional clinical trials and exacerbates challenges to accessing care for patients. Further, no single study or institution can collect the amount of patient samples and data needed to mount a data-driven treatment program at scale. Without concentrated resources, there is no coordinated cohort of researchers committed to rare cancer.

Lack of knowledge needed to identify and deliver new therapies. Without a critical mass of patients, many rare cancers have been woefully understudied such that the information and biospecimens necessary to develop data-driven therapies are not available.

Further, clinicians with rare cancer expertise are limited to major academic medical centers, with some rare cancers having no clinical champions. Where investments have been made for rare cancer research, institutional resistance to "real time" collaboration (sharing biospecimens, disease models, and data) has impeded the scientific progress that patients deserve and expect when they participate.

Mismatch between the level of investment and the scale of the challenge. Government funding focused on rare cancers has historically not been scaled or sustained to overcome rare cancer-specific obstacles. While structural challenges remain unaddressed, private pharmaceutical companies have not been incentivized to invest in rare cancer patients that are seen as outside of a serviceable addressable market for innovative oncology products.

The Opportunity: A chance to collectively propel rare cancers to the forefront of therapeutic advances.

New transformative science is poised to deliver life-saving treatment and even cures for some cancer patients. Key technologies such as organoid models, single-cell genomics, CRISPR tools, and machine-learning are now fully ripe for fundamentally changing our understanding of what drives cancers and transforming our strategies for treatment development.

The organizations that fully seize this opportunity, at the needed scale, will become world leaders for ushering in the full promise of data-driven therapy for all cancer patients.

Together, the rare cancer community is now able to seize such a moment. The ability to perform distributed research and clinical science to overcome challenges of geographic dispersion are finally addressable thanks to the widespread adoption of telecommunication platforms and the digital transformation of many sectors.

Further, the precedent for fast-paced nationally and internationally coordinated team science set in the response to the COVID-19 pandemic has whetted the appetite of researchers for overcoming logistical hurdles to real-time, multi-institutional collaboration in order to make a tangible impact.

Today, the rare cancer community is uniquely positioned to lead the transformation to data-driven cancer treatment and rapidly bring it into existence. Rare cancer patients are highly engaged and responsive to calls for partnership in co-creating solutions for the challenges they face, and rare cancer foundations and advocacy groups are increasingly collaborative in coordinating their efforts.

Institutions across the discovery, development, and care delivery ecosystem currently lack infrastructure for rare cancers, presenting an opportunity to rapidly build novel infrastructure for data-driven approaches in rare cancers without the friction of large-scale change management.

The lack of progress for rare cancer patients to date presents a wide range of opportunities for accelerating the clinical development and regulatory approval of novel, data-driven treatment approaches focused on breakthroughs for rare cancers.

If we act today, we can propel rare cancer patients to the forefront of scientific advancement and ensure they finally have access to the life-saving treatments they deserve. With an organized, systematic approach we can ensure these emerging technologies are optimized for rare cancers, ensuring that patients facing rare cancers are not left behind.common challenges for rare cancers and amplify the efforts of each unique rare cancer community.

Join Us. Never before has this level of collaboration been undertaken in rare cancers, but the promise of data-driven therapies finally reaching our patients has galvanized this community into action. We invite you to learn more about this unprecedented opportunity to forge a direct path to ending rare cancer as we know it.
allianceforrarecancers.org

Rare Cancers are Not Rare

One in four cancers are considered a ‘rare cancer.’

Benjamin Izar, MD, PhD
Columbia Vagelos College of Physicians and Surgeons

Jesse Boehm, PhD
Chief Science Officer
Break Through Cancer

Tyler Jacks, PhD
President, Break Through Cancer; Founding Director, MIT’s Koch Institute for Integrative Cancer Research; David H. Koch Professor of Biology

Cutting-Edge Rare Cancer Research Needs Our Support

While each type of rare cancer occurs relatively infrequently, collectively rare cancers are not rare at all, and all pediatric cancers are considered rare. National Cancer Institute funding allocations, however, are primarily focused on “common cancers” and fail to sufficiently fund rare cancer research. Therefore, we aim to shine a light on important studies such as the two research papers highlighted here. Articles available online.

Columbia Rare Cancer Study Funded by Jedi Rare Cancer Foundation

The study recently published in *Clinical Cancer Research*, “Single-cell profiling of sarcomas from archival tissue reveals programs associated with resistance to immune checkpoint blockade,” by Columbia University medical scientists, corresponding author Dr. Benjamin Izar, Columbia Vagelos College of Physicians and Surgeons (2024), was supported by our $100,000 donation to Columbia University Herbert Irving Comprehensive Cancer Center in 2022.

Purpose: Sarcoma encompasses a diverse group of cancers and underlying mechanisms are poorly understood. The contexture of sarcomas limits generation of high-quality data using cutting-edge molecular profiling methods, such as single-cell RNA-seq, thus hampering progress in understanding these understudied cancers.

In exploring why sarcomas often resist immune checkpoint blockade (ICB) therapy, understanding genomic and transcriptional heterogeneity across and within sarcomas at baseline and during therapy may provide insights into development of future therapies.

Design: The researchers used advanced single-cell RNA sequencing and whole-genome sequencing on frozen tissue samples from eight sarcoma patients (five with undifferentiated pleomorphic sarcomas and three with intimal sarcomas), including paired samples from two patients who received ICB treatment.

Key findings: Genomic diversity decreases in patients with response to ICB, and, in unbiased analyses, identify cancer cell programs associated with therapy resistance. Although interactions of tumor-infiltrating T lymphocytes within the tumor ecosystem increase in ICB responders, clonal expansion of CD8+ T cells alone was insufficient to predict drug responses.

Conclusion: *This study provides a framework for studying rare tumors and identifies salient and treatment-associated cancer cell intrinsic and tumor-microenvironmental features in sarcomas.*

Reimagining Cancer Team Science as Radical Collaboration

We’re excited to share another research paper published in the American Association for Cancer Research journal *Cancer Discovery* that establishes a playbook for cancer team science that we believe can be readily adopted to further the goals of CURE: The Rare Cancer Initiative and the Alliance for Rare Cancers.

In “Radical Collaboration: Reimagining Cancer Team Science,” co-authors Jesse Boehm and Tyler Jacks (2024) define six “Hallmarks of Cancer Collaboration” (illustrated in the graphic at right) that underpin next-generation cancer team science experiments underway in the U.S. and abroad. Radical collaboration’s six ingredients can propel cancer teams to reach new levels of productivity and impact in the modern era.

Defining Radical Collaboration

Collaboration is a general term, including any form of interaction among multiple researchers receiving joint funding.

Radical collaboration refers to a new form of collaborative team science that champions the six Hallmarks of Cancer Collaboration: common vision, leaders as catalysts, aligned incentives, shared culture, resource sharing, and operational groundwork.

Team science is a larger number of investigators working together toward a common goal, typically leveraging organizational structures that currently exist.

Boehm and Jacks suggest radical collaboration’s approach builds on the collaborative success of the Cancer Genome Atlas (TCGA), which revolutionized cancer understanding by pooling efforts from thousands of scientists across multiple institutions. Their organization, Break Through Cancer, works with foundation and biopharma partners to create virtual shared laboratories across institutions, called TeamLabs, that centrally manage resources to tackle ambitious cancer challenges. Each TeamLab shares data and discoveries in real time.

We agree with the authors that this is an unprecedented moment for oncology.

- After decades of steady progress, now nearly 30% of patients with cancer benefit from recent medicines developed from our improved understanding of the molecular biology and genetics of cancer.
- Unparalleled breakthroughs in single-cell and spatial genomics, machine learning and data science, and novel therapeutic modalities provide fundamentally new opportunities for impact.
- Within the next five years, national and international cancer data generation and aggregation initiatives will achieve the necessary scale and precision to drive diagnosis and intervention earlier than ever before.

But, unless the cancer community takes fundamentally new steps to work together, competition and fragmentation threaten the pace of progress.

We have the opportunity to take stock of this type of team science enterprise and optimize it as we move forward with CURE and ARC. There is work for all of us to do, and it has just begun.

The U.S. Rare Cancer Landscape: A 2023 Report

By Laura Taxel

Commissioned by The Jedi Rare Cancer Foundation

Prior to a national rare cancer workshop the Jedi Rare Cancer Foundation convened at the Case Comprehensive Cancer Center in November 2023, our foundation commissioned a landscape study and report to explore the state of research and discovery for rare cancer in the United States.

Approximately one in four of the 1.9 million people in the United States who had or will receive a new cancer diagnosis in 2023 will have a 'rare cancer,' defined as an incidence of fewer than six cases per 100,000 people per year. The bottom line is that for most of these rare cancers, no protocol for treatment or cure exists. While there continues to be obstacles, new technology and science models make it possible to envision a path forward.

The aim of The U.S. Rare Cancer Landscape Study:

- To learn why progress in developing therapeutics for rare cancer has not kept pace with advances in treating the more common cancers;
- To determine what is currently being done to address this need and what would be required to expand upon and integrate these efforts; and
- To integrate the information discussed into a comprehensive systemic approach to improve outcomes for every person diagnosed with a rare cancer.

***The U.S. Rare Cancer Landscape: A 2023 Report* contains qualitative data obtained from experts** with specialized relevant knowledge to inform this inquiry, answer questions, and pose new ones. These individuals represent multiple organizations, multiple diseases, and multiple points of view with insights gained from real-world medical science experience in the rare cancer space.

The report also identifies a chain of issues related to rare cancer, including insufficient numbers of patients at any single location, difficulty enrolling enough patients in clinical trials, and a lack of localized biospecimens. These issues slow down data collection and research, leading to a lag in the development of therapeutics to treat rare cancer.

Findings suggest a more holistic, interconnected approach encompassing rare cancer research, public policy, education, and advocacy is required. It breaks down the factors discussed into four broad categories: Research; Biospecimens and Data; Patient-Centered Pathways; and Funding, Management, and Government.

Highlighted within the report is the need for a consensus on what defines a cancer as rare; it finds that the field of oncology is moving away from classifying cancers by site of origin in the body to delineating tumor types based on molecular aberrations, vulnerabilities, and drivers.

The report concludes by emphasizing the importance of multi-year funding commitments for basic research for rare cancer and the need for institutional leadership to support and participate in pioneering projects. It also highlights the potential of drug repurposing and the need for innovative research models.

Read *The U.S. Rare Cancer Landscape: A 2023 Report at jedicancerfoundation.org/landscape-study*

Laura Taxel is a Cleveland-based researcher, award-winning journalist, and author.

Kamron Khan Photography 2023

In her 48-year career, Laura Taxel has covered a wide variety of subjects and produced commissioned works for the Ohio Department of Mental Health, the Carnegie Foundation for the Advancement of Teaching, the John D. and Catherine T. MacArthur Foundation, the Lake View Cemetery Foundation, and Ohio End of Life Options, a nonprofit education and advocacy organization. Her articles have appeared in local, regional, and national magazines and newspapers. She has written four nonfiction books, among them "University Hospitals: 150 Years of Advancing the Science of Health and the Art of Compassion" and has contributed to eight others. Laura is married to photographer Barney Taxel, brother of Mark Taxel, Chairman and Founder of the Jed Ian Taxel Foundation for Rare Cancer Research.

In Pursuit of the Facts:

Taking a Close Look at the Rare Cancer Landscape

Laura Taxel

My brother-in-law, Mark Taxel, Chairman and Founder of the Jedi Foundation recruited me in March 2023 to write a report that would provide an overview of the work being done in rare cancer research and a nuanced examination of what was inhibiting the development of appropriate drugs and protocols to test them.

Like the Foundation's mission to accelerate discovery and get effective, desperately needed treatments to people diagnosed with rare cancers, the task was ambitious and initially seemed near impossible to achieve. While I have authored a book about the 150-year history of Cleveland's University Hospitals and have a 40-year career as a researcher and writer, I felt ill-equipped to take this on. I had little familiarity with medical science and healthcare in general and no background in this specific field. The stakes were high and the pressure real; the assignment had to be completed in just seven months because the document was intended to provide structure and direction for a November 2023 meeting.

To jumpstart the process and find the right questions, I searched the relevant scientific, medical, academic, governmental and nonprofit arenas, reading extensively to determine what was being done–and not done—to address the lack of viable options for rare cancer patients. Mark Taxel and Harmony Knutson, edi Foundation President and CEO, shared what they had already learned early on by attending various cancer conferences and speaking with people who had a long history of engagement with healthcare delivery and rare cancer in particular. It seemed that a few fundamental problems led to a number of major obstacles. The quantity of quality data available was insufficient and the data that did exist was not being shared. There were no means to easily link efforts or strategize as a community about how to address the issues impeding progress. Incentivizing and sustainable financial support was lacking or extremely hard to get, especially for early stage, groundbreaking research and initiatives that reflected out-of-the-box approaches.

There was a sense that the timing was right for this undertaking. Advances in medical science and technology were providing transformative insights into tumor biology at the molecular level, informing and altering the way cancers were understood. People were questioning the traditional means by which drugs were created and brought to market and coming up with alternatives. A growing awareness that patients had an essential role to play at every stage and that their willing participation was a potential gamechanger, necessitating a massive campaign to educate the public about rare cancers, as well as physicians and their patients.

The Jedi Foundation's operating belief was that it would require a comprehensive, collaborative and integrated approach to address the unique challenges of rare cancers, a catchall term for many different diseases that are by definition uncommon. Essentially my job was to find out if the experts agreed, and if the answer was yes, to hear from them about what made that approach so difficult to put into practice. In addition, I was to identify and examine innovative models and successful projects. I was given a short starter list of thought leaders and key players to call. Each person I interviewed suggested others I should contact.

The people I spoke with were pursuing important productive work in the rare cancer space in a variety of capacities: doing research, caring for patients; running advocacy and support organizations; and leading academic medical centers and federal agencies. They were determined, dedicated, and overextended. Like Mark and Linda Taxel, founders of the Jedi Foundation, who lost their son to rare cancer, a number of these individuals were prompted to get involved because they themselves or someone they loved had been diagnosed with it. The personal stories they shared touched me deeply and clarified both my purpose and the value of what the Jedi Foundation was trying to catalyze. Others told me that a sense of urgency drives them because they see how sick people and their families are harmed by the fractured and incredibly slow approach currently in place for drug development and delivery.

Some of the most experienced people were initially the most skeptical about our ability to actually execute and achieve our aims. They had all been to many conferences where discussion and cooperation ended when the conference did. They were accustomed to the disappointment that followed because despite all the talk, there was little follow-up and less action. The status quo remained intact. As a representative of the Jedi Foundation, I had to convince them it would be different this time, that the commitment to facilitating real change was absolute and that reaching out, listening and identifying challenges and unmet needs was just a first step in this direction.

Their motivation to make tangible progress and actually transform the system to better serve researchers, medical professionals, and patients was clear to me. They saw the possibilities in what I was proposing on behalf of the Foundation, and because hope was essential for the work they engaged in, day after day, year after year they decided to take a chance on us. Despite how busy each person was in meeting the obligations of their own jobs and constituencies, every conversation without exception ended with requests to keep them informed and offers to get involved or contribute in some capacity. Deborah Collyar, founder and President of PAIR (Patient Advocates in Research) echoed the response of many when she said, "There are lots of people with good ideas. The question is how to take those ideas and create a game plan for action. I believe that the Jedi Foundation could do this and make a real difference."

Within that cohort there was a smaller group that were in touch with each other and considered themselves an ad hoc team. But the majority of individuals were functionning in silos unaware of many projects and efforts in adjacent but different work. I came to realize that as a result of my investigations, I had the most wide-ranging and detailed picture of what was actually going on nationwide. I incorporated everything I had found into "The U.S. Rare Cancer Landscape: A 2023 Report." At the time of its completion, there was no other single document that captured the totality of information and ideas from those already involved in rare cancer research, care and advocacy.

I sorted the material into four broad categories: research, data, patients, and funding. These became the organizing framework for the gathering of key stakeholders and activists convened in Cleveland by the Jedi Rare Cancer Foundation in partnership with Gary Schwartz, MD, Director of the Case Comprehensive Cancer Center, and the Rare Cancer Research Foundation.

In combination with a facilitating approach called Appreciative Inquiry that brings people together to talk with each other, not at each other in the usual conference format dominated by speeches and presentations, the 38-page report sparked dynamic and positive conversations. Attendees coalesced around its key points and there was a clear consensus that collaboration was essential. They committed to taking next steps to begin building out a formal, functional network.

When I interviewed Jesse Boehm, Chief Science Officer for Break Through Cancer, in August 2023 he said, "What's missing in this space is a group of people that want to work together in the national interest. In my opinion great communities produce great ideas even though they might have disparate viewpoints. Let me know what role you want me to play and how I can be helpful." He agreed to attend our first meeting, noting that, "if people can come out of it feeling like this is new and unique, and are inspired to work together, and if we can keep the temperature high until we figure out how to do it, that would be a good outcome." That is exactly what has occurred.

A Steering Committee and various working groups subsequently took shape, participating in what I can only describe as pragmatic visioning: dreaming big while thinking practically. They have formulated an agenda for moving ahead that includes articulating strategies for collaboration; actionable initiatives and demonstration projects; and the formation of ARC, the Alliance for Rare Cancers, a non-profit coalition of multiple organizations, institutions, governmental agencies and individuals that can serve as the fundable entity for an array of related but autonomous efforts.

When my nephew, Mark and Linda's son Jed Ian Taxel died in 2017, there was not any standard of care for his rare cancer, nothing specialists could do to slow it down let alone cure his disease. As our conversation wrapped up, Boehm, who is now a member of the committee developing a vision and mission statement to guide ARC's strategic planning process, said something that linked all the exciting things that are happening now on a big scale back to that one painful, personal fact that launched this endeavor and remains its lodestar: *"Thank you for what you and the Jedi Foundation are trying to do. I know it is bittersweet but it's so important and such an amazing and meaningful way of affirming a legacy for Jed."*

2024 Honoree | Jedi Award

Agents of Change

The Rare Cancer Research Foundation

Our 2024 Jedi Agent of Change, The Rare Cancer Research Foundation (RCRF), is dedicated to building the infrastructure to accelerate rare cancer research and save lives. Since 2014, founder Mark Laabs and his team have worked tirelessly with patients, researchers, medical institutions, and patient advocacy foundations to lead a collective mission to find a cure for rare cancers.

Since our inception, the Jedi Rare Cancer Foundation and RCRF have partnered to promote rare cancer awareness and advocacy. They are founding members with our foundation in the newly formed Alliance for Rare Cancers (ARC) and valued partners and collaborators in CURE: The Rare Cancer Initiative at Case Comprehensive Cancer Center. RCRF's Pattern.org initiative is also a crucial part of CURE's national collaboration as a provider of tumor samples and associated clinical data. Their indication-agnostic approach allows them to build scale and efficiencies across cancer communities and act as a force multiplier in the search for a cure.

"We seek to philosophically align only with rare cancer researchers and institutions who agree to share their learning for the greater good," emphasizes Pattern.org President and RCRF Board Member Barbara Van Hare. Following this philosophy, researchers who receive tissue through Pattern.org agree to place any resulting models, along with any associated de-identified clinical, sequencing, CRISPR, and other data into the public domain, helping researchers worldwide accelerate their scientific research.

RCRF team members Susan Horrell, Heather Ronshaugen, Katie Coleman, Amber Smith, Barbara Van Hare attending AACR Annual Meeting 2024.

RCRF's Pattern.org initiative enables patient donations of fresh tissue, fluid, and data by coordinating collection and transfer from any U.S. hospital to innovative research projects at world-leading academic institutions. This supports critical rare cancer research including the creation of cell lines, animal models, genomic and single cell sequencing, CRISPR screens and drug testing, all accelerating understanding of rare cancers and reducing the time to new and effective therapies.

"Collaboration Finds Cures." – Mark Laabs

Before Mark Laabs founded RCRF, there was little progress for decades in rare cancer research. Historically, research findings are closely guarded, primarily shared only upon publication intended to help secure funding. With little to no funding, low awareness, and lack of access to the limited patient pool and tissue samples, rare cancer researchers have struggled to find the resources they need. RCRF's Pattern.org fills the gap between rare cancer researchers in need of tissue and rare cancer patients, providing and sharing resources that can result in new treatments or combination of drugs that could be most promising for rare cancer patients' recovery.

"The Jedi Rare Cancer Foundation and RCRF share a very similar vision," Barbara explains. "We are broad-based rare cancer organizations who work with all groups that exist for a particular rare cancer disease type. We both share the hope and vision to put together transformative collaborations and processes that pave a way to evolve the rare cancer eco-system, ensuring every rare cancer patient gets access to a life-saving treatment."

Visionary, Advocate, Mentor, Friend

Celebrating Mark Laabs

Rare Cancer Research Foundation Founder and Chairman of the Board

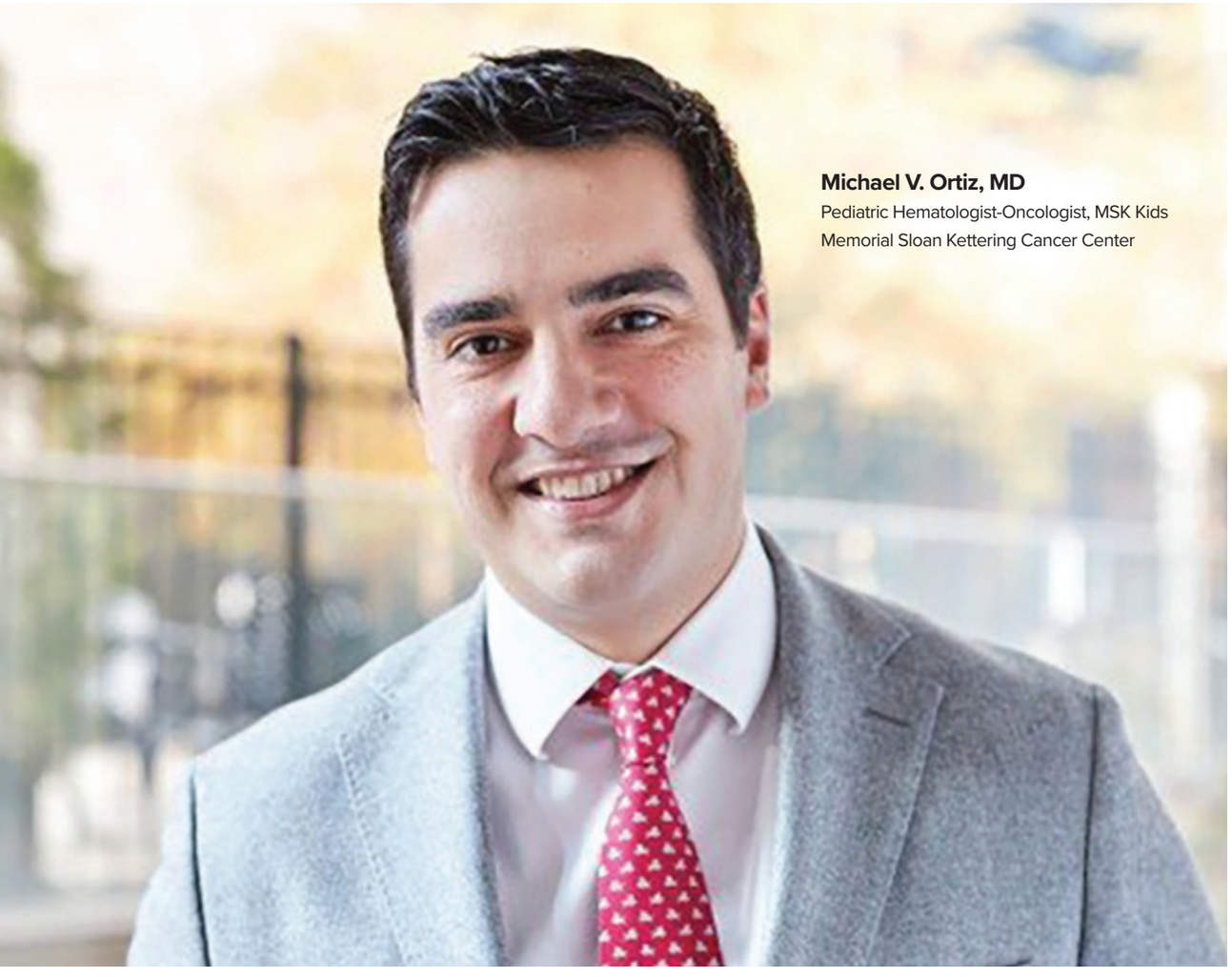
It is with immense sadness that we announce the passing of our dear friend and advisor, RCRF founder and Chairman of the Board Mark Laabs, to metastatic ocular melanoma. We have lost an exceptional individual–an extraordinary leader, visionary, advocate, and mentor. His expert guidance, and generous support of the Jedi Rare Cancer Foundation has been invaluable.

We are especially grateful to Mark's unselfish and zealous commitment to take his own cancer diagnosis and turn it into a platform to help others in similar situations. Early in life, Mark established guiding principles to live by, two of which are "make the greatest contribution you can over the course of your lifetime" and "consider the impact of your decisions on the next seven generations." RCRF's mission to provide infrastructure solutions for all rare cancers, not just the one he was diagnosed with, demonstrates how fully Mark integrated these principles into his values and life.

Mark inspired us immensely, and we know his legacy will live on through the foundation and its amazing team who are continuing his mission to mitigate and potentially eradicate cancer to benefit those most in need. We are honored to share Mark's vision of *"Collaboration Finds Cures"* and will continue his legacy to build a significantly better future for rare cancer patients and their families.

JEDIs for Survival funds

Dr. Michael Ortiz at MSK Kids



Michael V. Ortiz, MD
Pediatric Hematologist-Oncologist, MSK Kids
Memorial Sloan Kettering Cancer Center

Since 2022, the Jedi Rare Cancer Research Foundation's JEDIs for Survival teams and community of donors have supported Cycle for Survival's annual fundraiser. We ride to accelerate progress in rare cancer research and lifesaving clinical trials at Memorial Sloan Kettering Cancer Center, bringing new and better treatments to people worldwide Thanks to your incredible contributions, we successfully raised an astounding $258,805 directed to the research of Memorial Sloan Kettering's MSK Kids pediatric oncologist Dr. Michael Ortiz.

Dr. Julia Glade Bender, Vice Chair for Pediatric Clinical Research at Memorial Sloan Kettering Cancer Center and a Jedi foundation Medical Advisor, recommended the work of Dr. Michael Ortiz who specializes in caring for young adults and children with rare and high-risk childhood solid tumors, particularly cancers of the kidney and liver including Wilms Tumor.

The Jedi Rare Cancer Foundation's funds supported the multi-center phase 2 clinical trial of Selinexor in children, adolescents, and adults with advanced solid tumors, specifically evaluating how well Selinexor treats cases of advanced WT, MRT, MPNST, and other rare solid tumors that we believe may benefit from XPO1 inhibition.

Selinexor is the first drug developed to block Exportin 1 (XPO1), a protein pump on the surface of the cell's nucleus, a unique weakness in several rare and generally childhood-onset solid tumors, including Wilms tumors (WT), malignant rhabdoid tumors (MRT), and malignant peripheral nerve sheath tumors (MPNST).

Prior trials did not offer a liquid option for young children; therefore, they were not able to be treated with Selinexor since they could not swallow tablets and tablets could not be crushed. Selinexor has now been studied in several thousand cancer patients, including multiple studies in children with cancer, so a safe dose to administer to children has been established. Plans–contingent upon sufficient funding–are to expand into a multicenter format with four large programs in Atlanta, Boston, Cincinnati, and Los Angeles.

Foundation funds also supported the research paper "Advances in the clinical management of high-risk Wilms tumors" published in *Pediatric Blood & Cancer* (January 10, 2023), of which Dr. Michael Ortiz and Dr. Christa Koenig are first co-authors. DOI: 10.1002/pbc.30153

11 JEDIs for Survival Teams
93 Rider- Fundraisers
778 Generous Donors
$332 Average Donation
$258,805
RAISED FOR RARE CANCER RESEARCH

Abstract
Outcomes are excellent for the majority of patients with Wilms tumors (WT). However, there remain WT subgroups for which the survival rate is approximately 50% or lower. Acknowledging that the composition of this high-risk group has changed over time reflecting improvements in therapy, we introduce the authors' view of the historical and current approach to the classification and treatment of high-risk WT. For this review, we consider high-risk WT to include patients with newly diagnosed metastatic blastemal-type or diffuse anaplastic histology, those who relapse after having been initially treated with three or more different chemotherapeutics, or those who relapse more than once. In certain low- or low middle-income settings, socio-economic factors expand the definition of what constitutes a high-risk WT. As conventional therapies are inadequate to cure the majority of high-risk WT patients, advancement of laboratory and early-phase clinical investigations to identify active agents is urgently needed.

Together, we are making progress possible, and every single gift makes a difference.

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Dr. Schwartz is a recognized leader in the field of translational and clinical research. His vision is to establish highly innovative clinical translational research programs in the field of cancer therapy. As Director of Case CCC and former Deputy Director of the Herbert Irving Comprehensive Cancer Center and Chief of Hematology and Oncology at Columbia University Irving Medical Center, he has worked extensively in bench-top to bedside research for early drug development, successfully bridging clinical and basic science elements and focusing on the identification of new targeted agents for cancer therapy; many drugs that originated in his labs are now being evaluated in clinical trials.

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and all of its employees, and the Nelson and Susan Taxel family for their continued support of the **The Jed Ian Taxel Foundation for the Rare Cancer Research** and its work to find new treatments and pathways to cures for rare cancer.

jedi rare cancer foundation *is Jed's legacy*

The Jedi Rare Cancer Foundation is a living memorial to Jed Ian Taxel, who died in 2017 of a rare cancer. He was 39 years old. A few weeks before he died, Jed asked, *"What will be my legacy?"*

This is our answer, a rare cancer research foundation that can change lives and enable better outcomes for rare cancer patients and their families. Although 1 in 4 cancers diagnosed annually are considered rare cancers, rare cancer patients have been left out in terms of cancer research and treatment.

We know Jed would be proud of the work we have done and will continue to do in his memory. Jed cared about humanity and social justice, and by advancing our goal to give every person diagnosed with a rare cancer the same opportunity for effective treatment and cures, our commitment to this community speaks to the democratization of cancer care at the highest level.

We wholeheartedly welcome you and are grateful for your support.
Whether you stand as a triumphant survivor, a dedicated caregiver, or a passionate advocate, you hold the strength to kindle inspiration, extend solace, and empower those who seek it most.

More healthy survivors, less family heartbreak.

Your generous donations are an investment in ending rare cancer as we know it. Together, we can defeat rare cancer.

Together, we can END rare cancer.

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Join us! Your gift will help accelerate scientific discovery to improve diagnostics, treatments, and therapies for rare cancer that will extend lives and result in healthier survivors.

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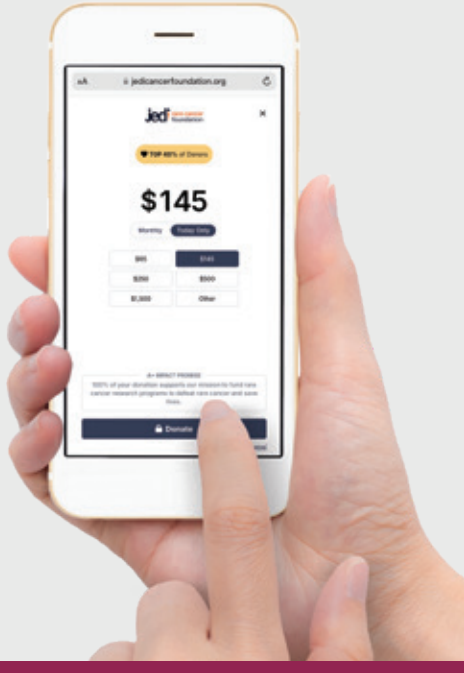
To learn more about the Jed Ian Taxel Foundation for Rare Cancer Research, visit **jedicancerfoundation.org.**



Thank you in advance for your generous support!

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