jedis FOR SURVIVAL

OUR YEAR OF PROGRESS 2022

Jed Ian Taxel Foundation for
Rare Cancer Research

jedicancerfoundation.org

jedi rare cancer foundation

JEDIs for Survival Achievement Awards
Sunday, October 16, 2022

Program

Cocktails and Hors d'oeuvres

First Course

Welcome - Mark Taxel

"Our Year of Progress" Video

Main Course

Presenting our JEDIs for Survival Achievement Award Honorees

- Innovator in Rare Cancer Science, Dr. Gary Schwartz
- Agent for Change, Greg Simon, J.D.

Introducing REACT - Mark Taxel and Dr. Benjamin Izar

Gratitude, Recognition and Donor Support

Dessert and Coffee

Wines by David Milligan Selections, compliments of Alex & Julie Milligan
davidmilliganselections.com

Design by Christie Mansfield
cmansfielddesign.com

Photography by Lukas Greyson
greysonimages.com

All recognition gifts compliments of Positive Promotions, Inc.
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The Jed Ian Taxel Foundation
for Rare Cancer Research
P.O. Box 683501 Park City, Utah 84068

The Jed Ian Taxel Foundation for Rare Cancer Research, Inc. is a 501(c)(3) Non-Profit Organization, accepting tax-deductible donations from individuals, corporations, family advised funds and foundations. **Federal Tax ID 86-2610819**

Making a difference.

Helping defeat rare cancer as we know it.

Rare cancers are not rare. 25% of cancers diagnosed annually are rare cancers.

Over 200,000 patients are diagnosed with a rare cancer each year in the U.S. alone. This diagnosis is usually a death sentence because there are no established treatment protocols that lead to durable remission or cures.

With 190 rare cancer forms, government agencies and the pharmaceutical companies cite "not enough bang for our buck" as rationale for low levels of research funding, leaving rare cancer patients without good options. This foundation's purpose is to help change that.

Rare cancer patients and their families need our help.

The Jed Ian Taxel Foundation for Rare Cancer Research's sole commitment is to accelerate scientific discovery … science that translates into breakthrough treatments and maybe even cures for rare cancers.

Jed's untimely death at age 39 exemplifies the heartbreak and loss associated with a rare cancer diagnosis. He lived six short months after his initial diagnosis. By the time doctors realized that Jed had metastatic cancer, after months of treatment for a sports injury, it was too late. This is typical of rare cancers; they don't present like most common cancers. Even with consultations with doctors in leading cancer centers, Jed's outlook was bleak. One night a few weeks before he died, after he learned that his latest treatment was ineffective, he asked "What will be my legacy?"

The Jed Ian Taxel Foundation for Rare Cancer Research is Jed's legacy.

A legacy that contributes to the betterment of mankind. A legacy he would want … one not defined by cancer but defined by better outcomes. This foundation is the vehicle to help others from experiencing our heartbreak … This is something we can and must do. With gratitude and respect,

Mark Taxel
Founder, Father & CEO

Innovator in Rare Cancer Science

Dr. Gary Schwartz

Our JEDI Innovator in Rare Cancer Science, Gary Schwartz, MD is a recognized leader in the field of translational research and has been able to bridge the clinical and basic science elements of drug development.

Dr. Schwartz is a Professor of Medicine and current Chief of Hematology and Oncology and Deputy Director of the Herbert Irving Comprehensive Cancer Center at Columbia UniversityVagelos College of Physicians and Surgeons. Previously, he was Attending Physician and Member at Memorial Sloan Kettering Cancer Center and Chief of the Melanoma Sarcoma Oncology Service. His clinical focus is melanoma and sarcoma.

As Principal Investigator of a series of phase I and II trials based on his laboratory studies, his work has been extensively supported by his peer-reviewed grants. This has included an R01 to develop cyclin dependent kinase inhibitors with chemotherapy, an R01 and a SPORE grant to evaluate combinations of receptor tyrosine kinase inhibitors of IGF-1R and PDGFR with inhibitors of mTOR in sarcomas, a RAID and an R21 grant to develop the sphingosine kinase inhibitor safingol with cisplatin, a DOD grant to develop the botanical herb huanglian, and an FDA-R01 to develop imatinib for the treatment of patients with c-kit mutant melanomas.

Dr. Schwartz is Principal Investigator of the Columbia University Minority/Underserved Site NCI Community Oncology Research Program. In addition, he was recently awarded the Team Science Award by the Melanoma Research Alliance to lead a national effort in developing new therapies for patients with ocular melanoma.

Gary Schwartz, MD. Division Chief, Hematology/Oncology; Deputy Director, Herbert Irving Comprehensive Cancer Center.

Dr. Schwartz has authored or co-authored over 200 manuscripts in the fields of basic and clinical cancer research. His contributions to teaching and mentoring have been recognized by his former fellows, who have awarded him the annual Teaching Award on multiple occasions and by junior faculty for the Excellence in Mentoring Award. In 2000 and 2006, he received NCI K24 and K12 Clinical Oncology Research Career Development Awards aimed at the mentoring of medical trainees in translational research.

Dr. Schwartz has served on numerous committees for the American Society of Clinical Oncology, the American Association of Cancer Research and for the NCI including the NExT committee established to assist NCI in identifying new agents for drug development. He is Co-Chair of the Experimental Therapeutic Committee of the Alliance, which has provided a platform for Columbia junior faculty to take leadership positions on national clinical trials.

Agent of Change

Greg Simon, JD

Greg Simon, JD. Former President of the Biden Cancer Initiative; Executive Director of the White House Cancer Moonshot Task Force.

Our JEDI Agent of Change, Greg Simon, JD is a visionary strategist, a dynamic speaker and writer, and an expert analyst of emerging trends in health-care, information technology, innovative drug research and development, and patient advocacy.

Mr. Simon has held senior positions in both chambers of Congress, served two Presidential administrations, was a senior strategy consultant to a variety of international technology CEOs, co-founded and led Faster Cures with Michael Milken, co-founded and led the Melanoma Research Alliance, was the Senior Vice President at Pfizer for Worldwide Policy and Patient Engagement, and was the CEO of Poliwogg, a financial services company creating unique capital market opportunities and indexes in healthcare and life sciences. He is currently CEO/CFO of Intelligent Medicine Acquisition Corp. (IQMD) a SPAC focused on AI-based drug discovery companies.

As the President of the Biden Cancer Initiative, a nonprofit formed by Vice President Joe Biden and Dr. Jill Biden, Mr. Simon and his team continued the work of the White House Cancer Moonshot Task Force to double the rate of progress in preventing, detecting, diagnosing, treating, and surviving cancer. He came to that position after serving as the Executive Director of the White House Cancer Moonshot Task Force established by President Barack Obama and led by Vice President Biden, launching over seventy innovative private and public-private collaborations and numerous novel inter-agency and international initiatives that helped support the successful effort to secure $1.8 billion in new funding for the Cancer Moonshot.

Mr. Simon served as Senator Al Gore`s Legislative Director from 1991 to 1993 before joining him in the White House in 1993 as his Chief Domestic Policy Advisor. He was the lead staffer for the Clinton-Gore Administration for development and passage of the Telecommunications Reform Act of 1996 and the development of the National and Global Information Infrastructure initiatives. He represented the Vice President on the National Economic Council, helped negotiate the US-Russia agreement on the International Space Station and oversaw a number of key health and science initiatives, including programs at the National Institutes of Health, the National Cancer Institute, the Food and Drug Administration, and the Human Genome Project. He was also instrumental in crafting the regulatory framework that is now the foundation for the biotechnology industry.

The journal *Nature Medicine* named Mr. Simon one of “Ten People to Watch” in healthcare policy, noting that he was among “a handful of influential people who quietly keep the wheels of biomedical science turning.”

Columbia University Comprehensive Cancer Center's
Rare Cancers Consortium:
REACT PROJECT
will bring new hope to cancer patients.

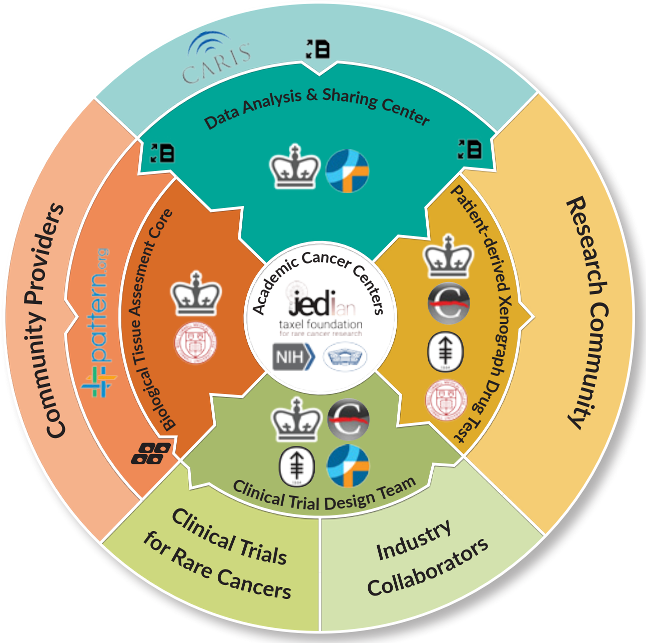
It's a Game Changer:

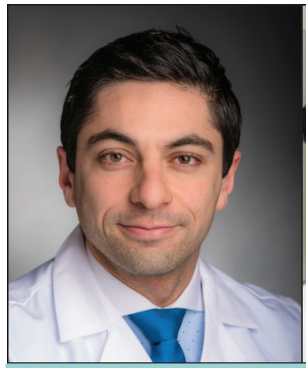
The REACT Project is a comprehensive, innovative effort incorporating leading edge technology. It will drive a paradigm shift in cancer research that transforms the field of cancer medicine, elevating the standard of care with the goal of saving lives around the world.

- The REACT Project is an unprecedented opportunity to extract major insights from thousands of rare cancer tissues currently stored in different institutions.

- This new technology, molecular edge science, allows us to analyze every individual cell in the tumor, providing new pathways for rare cancer research.

- Bedside to Bench to Bedside research will result in highly impactful clinical, translational research for treatment and ultimately cures for rare cancers.




Dr. Benjamin Izar


Dr. Gary Schwartz

COLUMBIA | Columbia University Herbert Irving Comprehensive Cancer Center

The Rare Cancers Consortium at Columbia University has the potential to be the most comprehensive and innovative effort in rare cancer research.

Under the leadership of Dr. Benjamin Izar and Dr. Gary Schwartz:

- Columbia will lead collaboration among major academic cancer centers including but not limited to Dana Farber Cancer Institute, Memorial Sloan Kettering Cancer Center, MD Anderson Cancer Center and Weill Cornell University.
- Research involves biospecimen coordination (collect patient specimens)
- Data generation and analysis (identify and share potential drug targets)
- Preclinical research (develop patient-specific disease models to test drug candidates)
- Clinical Trials

REACT: LEVERAGES MOLECULAR SINGLE-CELL TECHNOLOGY THAT PROVIDES NEW HOPE TO RARE CANCER PATIENTS

REACT: MEETS THE CHALLENGE OF MODELING A SYSTEMIC, COLLABORATIVE APPROACH TO RARE CANCER RESEARCH

WE, THE JEDI FOUNDATION'S DONOR COMMUNITY, HAVE AN OPPORTUNITY TO ACT NOW TO ACCELERATE THE DISCOVERY OF NEW PATHWAYS FOR BETTER OUTCOMES FOR RARE CANCER PATIENTS

BY SUPPORTING REACT, WE CAN MAKE AN IMPACT WE NEED TO ACT NOW

Rare cancers remain one of the most persistent challenges in oncology today.

Rare cancers receive significantly less funding compared to more common cancers, even though they account for a quarter of all cancer cases and cancer-related deaths in the United States.Phsycian-scientistsremain committeed to the cause but are in need of philathropy to suport their inititives.

Rare tumors are defined as cancer diagnosed in less than 15 out of 100,000 people each year. The 200 types of rare cancer types affect virtually every lineage, and when combined, make up 25% of all cancers and cancer-related deaths in the United States.

While patient survival rates of many common cancer types have significantly improved in the last few years, there has been little progress in the care of many patients with rare cancers in the last 30 years.

With limited access to rare cancer patients and patient samples, cancer physicians and researchers have found it challenging to get a comprehensive cellular ‘big picture’ perspective on these diseases.

Advancements in genomic sequencing and experimental disease models have led to breakthroughs for many common cancers, but these techniques have yet to be broadly applied to rare cancers. These challenges have hampered therapeutic development for these patients.

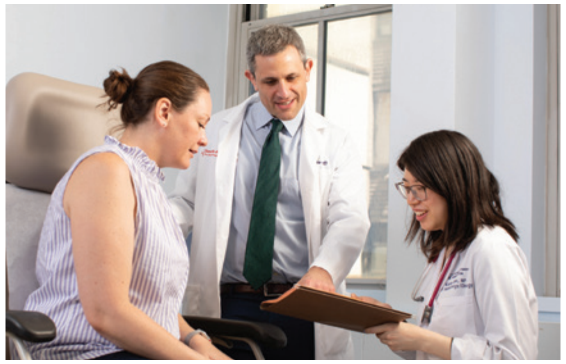
Why Columbia?

Established Institutional Leadership

The Herbert Irving Comprehensive Cancer Center (HICCC) has spent decades building an outstanding translational research infastructire dedicated to advancing basic scientific discoveries into new cancer treatments that improve patient survivorship and quality of life.

Under the leadership of Gary Schwartz, MD, deputy director of the Columbia Cancer Center and chief of the Division of Hematology and Oncology, Columbia has demonstrated that the scientific discoveries it is making right now have the potential to change the standard of care. Dr. Schwartz is a world-renowned oncologist and cancer researcher whose lab specializes in identifying new targeted agents for cancer therapy. Preclinical research conducted at his lab has helped identify new treatment approaches for rare cancers that are currently showing strong promise in patients.

This and other Columbia research has attracted significant NIH and federal support, philanthropic partnerships and pharmaceutical industry investment. With a world-class team of cancer research scientists, clinicians, technicians, radiation therapists, and pathologists with expertise in rare cancer, Columbia is well positioned to be the focal point of a multi-institutional rare diseases initiative that transforms the field of rare cancer research.



State-of-the-Art Science

Reshaping the Future of Rare Cancer Research

Columbia is pursuing an exciting new direction in cancer research. Dr. Izar’s lab has developed approaches to perform these new single-cell genomic technologies on previously collected, frozen archival tissues. Because several large academic centers, such as Columbia University Irving Medical Center, have been collecting such tissues for decades, there is a unique opportunity to study existing tissues. These studies, done at exponential scale, speed, and precision, offer an unprecedented opportunity to propel our knowledge of rare cancers.

Building on these studies, Dr. Izar and his lab are now able to identify not only individual cells, but multiple layers of information for each cell. They are also employing artificial intelligence (AI) tools to predict novel new drug targets and experimentally test combination therapies that will eliminate otherwise drug-resistant cancer cells.

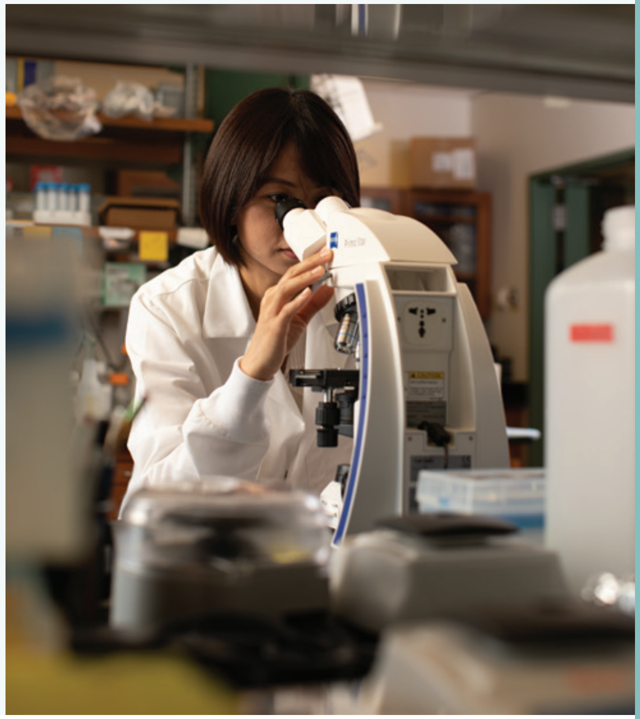
Columbia will take the lead in building a team of top cancer researchers and clinicians who will work together to advance knowledge and care for rare cancers. The REACT project presents a totally unprecedented opportunity to extract major insights from the thousands of rare cancer tissues that are currently being stored across different institutions, and to develop new, targeted treatments for rare cancer patients.

This approach will drive “bedside to bench to beside” research resulting in highly impactful clinical, translational research for the treatment and ultimate cure of rare cancers. With this new technology to analyze every individual cell in the tumor, we anticipate a paradigm shift in cancer research, resulting in “unexpected discoveries” that will transform the field of cancer medicine.

The goal of the Rare Cancers Consortium at Columbia is to assemble a multi-center research coalition that will combine access to patient samples with the expertise and resources needed to support Columbia’s aforementioned sequencing and data analysis capabilities, and to bring their collective discoveries to rare cancer patients. REACT will use clinical samples from rare cancer patients currently in treatment in addition to the decades’ worth of frozen samples, giving researchers the largest data set in history.

The potential of such an initiative is incredible – it represents one of the largest-scale, collaborative efforts in cancer research to make significant scientific and clinical progress in these areas:

- Biospecimen coordination (collect patient specimens and distribute samples to/from partner institutions)
- Data generation and analysis (identify and share potential drug targets)
- Preclinical research (develop patient-specific disease models and use them to test drug candidates)



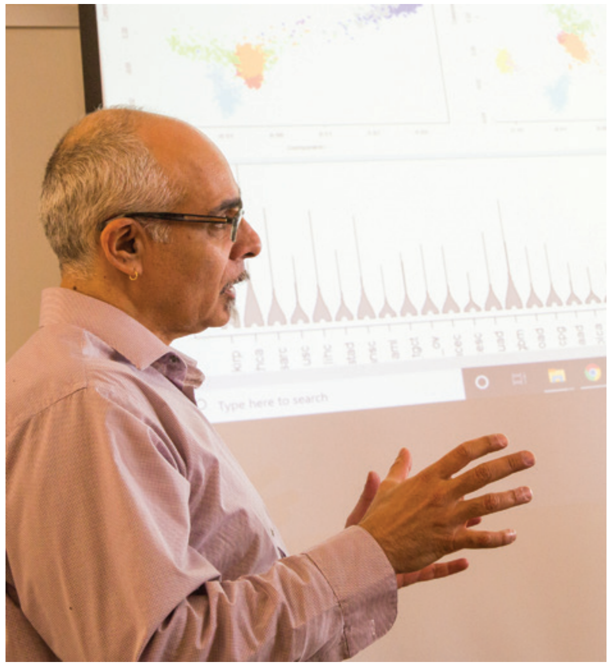
Great Strides

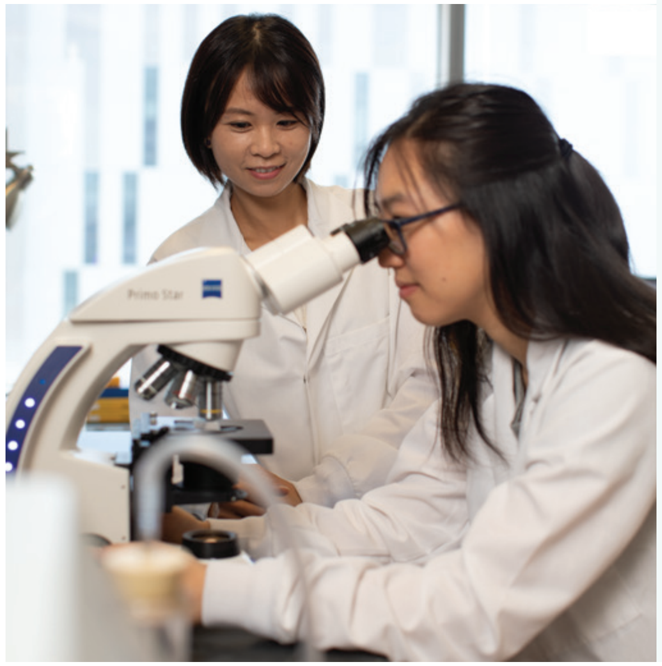
Building a Best-in-Class Consortium

Columbia has already made great strides toward building the rare cancers consortium. In April of 2022, ***Rare Cancers: Great Unmet Medical Needs*** **academic symposium** co-sponsored by Columbia and the Jed Ian Taxel Foundation for Rare Cancer Research featured leading rare cancer experts discussing specific rare cancers medicine research, public policy, and advocacy. Going forward, our foundation and Columbia would like this to be an annual event that will mark our progress and allow us to publicize and share the consortium's scientific findings with the entire rare cancer community. We expect the symposium to become more than an academic conference; we see it as a rallying point: a key opportunity to expand the consortium, build momentum, and continue our fundraising efforts.

In addition to identifying the four major academic comprehensive cancer centers Dana Farber Cancer Institute, Memorial Sloan Kettering Cancer Center, MD Anderson Cancer Center, and Weill Cornell University, Columbia has identified experts in the clinical care of patients with rare cancers and scientists in the field with a proven track record of productive collaborations.

Pattern.org is also a critical partner in this effort. Pattern.org is part of the Rare Cancer Research Foundation, a nonprofit organization dedicated to curing rare cancers. Pattern.org has formed partnerships with other foundations, research institutions, and most importantly, with oncology providers caring for patients in the community. Pattern.org founder Mark Laabs, a survivor of a rare cancer built an infrastructure that enables patient- and local community provider-driven efforts to systematically collect tumor biopsies that are sent to pattern.org where they are distributed to rare cancer research institutions.





REACT Resource Needs

Significant JEDI Support and First-Year Goals

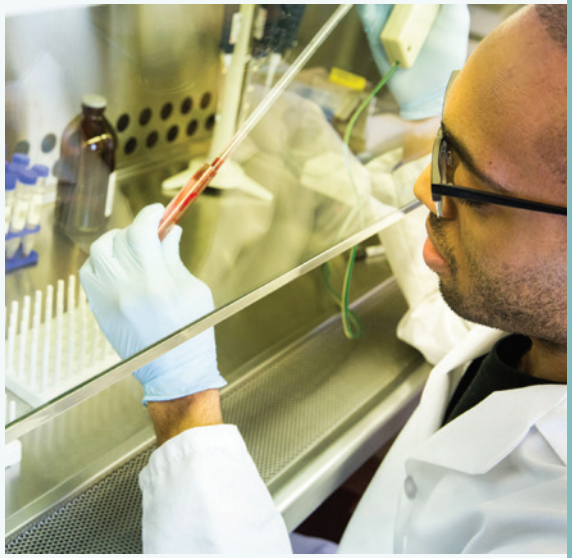
With the long-term goal of making scientific breakthroughs that improve care and quality of life for patients, Columbiais seeking philanthropic partners to raise $17 million in support of its buildout of this major new translational research consortium and projrect devoted specifically to rare cancer. In support, our foundation has committed an initial philanthropic investment of $5 million over the next three years.

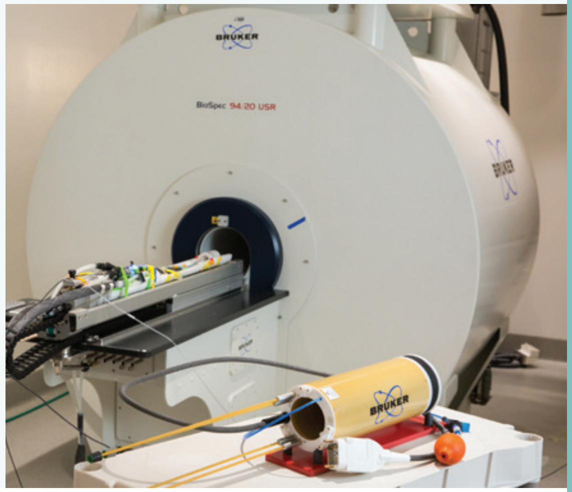
Our foundation's investment will allow Columbia to pursue its REACT research agenda by expanding and strengthening Columbia Cancer Center's resources in the following areas:

- Research/scientific staff
- Technical staff
- Tissues obtained through collaborations
- Laboratory supplies
- Sequencing equipment
- Computational equipment
- Preclinical disease models

We hope that this philanthropic boost can be leveraged to pursue additional funding from both federal and private sources in the near future.

We invite you to learn more and join us in supporting the REACT Project to transform the field of cancer medicine and save lives.





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COLUMBIA

COLUMBIA UNIVERSITY
HERBERT IRVING COMPREHENSIVE
CANCER CENTER

CONGRATULATES
2022 HONOREES

GARY SCHWARTZ, MD
JEDI Innovator in Rare Cancer Science

GREG SIMON, JD
JEDI Agent of Change

In support of the Jed Ian Taxel Foundation for Rare Cancer Research

6	JEDIs for Survival Teams
63	Rider-Fundraisers
532	Generous Donors
$299	Average Donation

$158,805

RAISED FOR RARE CANCER RESEARCH

CYCLE
FOR SURVIVAL
MEMORIAL SLOAN KETTERING | EQUINOX

JEDIs for Survival team exceeds their fundraising goal – Thanks to YOU!

Congratulations to our JEDIs for Survival national team members and all the generous donors who helped make our foundation's inaugural Cycle for Survival fundraising effort a success.

Together, our community raised $158,805 for rare cancer research.

Our foundation sponsored 6 JEDIs for Survival team captains who recruited 63 riders and 532 donors – and we matched the first $10K raised by each team. 100% of every dollar raised goes directly to groundbreaking rare cancer research and lifesaving clinical trials for cancer research at Memorial Sloan Kettering Cancer Center (MSK), benefiting people worldwide.

Today and every day, we are grateful for all that your support has helped us accomplish. Your philanthropic support of the foundation's mission allows us to set ambitious goals and fuels us as we work toward a more hopeful future for people with rare cancer and their families.

Introducing Dr. Michael Ortiz and his lifesaving rare cancer research

$158,805 in funds raised by our foundation's JEDIs for Survival team at Cycle for Survival support the work of Memorial Sloan Kettering pediatric oncologist Dr. Michael Ortiz. Before directing our foundation donations, we sought the advice of Julia Glade Bender, MD, Vice Chair for Clinical Research in Pediatrics at Memorial Sloan Kettering Cancer Center (MSK Kids). She recommended the work of Dr. Ortiz who specializes in caring forchildren and young adults with rare and high-risk childhood solid tumors, particularly cancers of the kidney and liver including Wilms Tumor.

Cancer is personal. Science requires creativity. Innovation comes in many forms.

An active member of the MSK Kids pediatric sarcoma team in New York City, Dr. Ortiz has led several early-phase clinical trials of novel agents including the TPO agonist Romiplos-tim (NCT04671901), the GPC3 antibody Codritu-zumab (NCT04928677), and the ATR inhibitor Elimusertib (NCT05071209), leveraging genomics and proteomics to develop safe and effective rationally targeted therapies.

Upon learning of Dr. Ortiz and his research, we also learned of a personal connection to Dr. Ortiz. Tiffany Taxel and Debbie Bhatt went to middle and high school together and have been dear friends for many years including with Jed and Debbie's husband Kevin. When our family was struggling through Jed's battle with cancer, their family faced a similar struggle at the same time. In 2016, at the age of 3, Debbie and Kevin's daughter was diagnosed with Stage 4 bilateral Wilms Tumors (kidney cancer) with lung mets.

Turn the page to read Debbie Bhatt's story of her daughter Caroline's rare cancer and her successful outcome ...

Testimonials of two families whose daughters survived rare cancers

Caroline with Mom & Dad at Cycle for Survival 2018

Debbie Bhatt: Caroline and Dr. Ortiz

Kevin and I are SO grateful that you are allocating the Cycle for Survival funds to Dr. Ortiz. As you know, all pediatric cancer is “rare” even though every day, 43 kids in the U.S. are diagnosed with it. Wilms Tumor (kidney cancer) is unusual even among uncommon cancers - it accounts for only about 5% of all the cancers children face.

Meeting a bright and dedicated doctor like Dr. Ortiz who was focused on Wilms was so encouraging for us when our daughter Caroline was diagnosed with Stage 4 bilateral Wilms Tumors with lung mets. With just 500 to 600 new cases in the United States every year ... it’s not enough for a pharmaceutical company to fund a new targeted drug yet there are a lot of families going through hell. Dr. Ortiz knew no pharmaceutical company would fund a new drug for such a small group, so he focused on finding adult cancer drugs that could be repurposed to fight Wilms. My husband and I immediately appreciated how practical and resourceful he is.

After two years of difficult treatments and four years of periodic scans, Caroline officially became a cancer survivor in February 2022. We are so grateful for her health but also heartbreakingly aware of the range of outcomes for pediatric cancer diagnoses. This is why I am a volunteer at MSK, and why the legacy I want to leave is better outcomes for children with cancer.

Lyyli Zissu and Dr. Ortiz with Nurse Talia

Alexandra Zissu: Lyyli and “Mikey”

There isn’t really a way to describe “Mikey,” as my 9-year-old daughter Lyyli calls him. He might be the kindest man on earth. When he is with you, there is no sense he has any other patients at all. His level of caring, his nuance of emotions, his mind … he really wants all parents and kids to understand the science, what is happening.

Dr. Ortiz’s patience in explaining and then explaining over and over again is amazing. He will answer questions forever. He uses a kidney pin to walk you through everything visually. He would be a most excellent professor. He seems to never go home, as he is there first thing in the morning, late at night, and even on summer weekends of endless chemo when you feel like you’ve been forgotten by the world. He is charming and comforting and deeply human.

Dr. Ortiz works hard to understand his kids – Lyyli gave him so much grief at first (feisty girl!) and he seemed to love it, changing tactics and approaches to win her over. He makes sure to match families with a nurse who suits them best. He’s an ace at telling who will go best with whom. Talia, pictured here, is a rock. All of the nurses on 9 adore him and say he is the best. He engages with each child’s life directly to make sure his kids are being taken care of in all ways. Lyyli has come around to him, asking him for a hug at her 6-month scans – all clear!

We are all Jedis

People Who Make a Difference

By Mark Taxel, with deepest appreciation

Alex Wolin

Alex introduced Linda, Tiffany, and I to MSK's Cycle for Survival…it was our first exposure to the issues surrounding rare cancer. Once we started the foundation, Alex was the natural leader for our MSK Cycle for Survival fundraising effort. He led the formation of our six teams, resulting in the $158,000 dollars we raised. Alex and Jed were not just cousins, they were great friends. Alex is our Chief Cycling Officer…our Chief Cycling Jedi.

David Lord

Dave and Jed were friends since they were a little over a year old and remained close. We asked Dave to join our board of directors because as an accomplished senior executive he had the skills to help manage this foundation. Dave's mother Ellen died of a rare cancer. Dave is our Chief Operating Officer and CFO. From day one, he committed his time and heart to the foundation's work, organizing our marketing systems and financial affairs. Living in Park City Utah, he organized a Cycle for Survival event, raising almost $20,000 dollars. Working with Dave inspires me daily. Dave is an original Jedi.

Michael Weiner

Michael, Linda and I were high school classmates. Until very recently he was Vice Chair of Pediatric Oncology at Columbia University's Herbert Irving Comprehensive Cancer Center. We reconnected at our 50th high school reunion. As we were forming the foundation, Michael called me for some marketing assistance on a book project. On that call, I told him about our nascent foundation and asked him if he would be willing to lend his considerable expertise and experience to our "enterprise." He agreed and has been instrumental in introducing us to the cancer research leaders at Columbia and leading our collaboration with them beginning with this past April's Rare Cancer Conference. His unique perspective helped us define a meaningful philanthropic role. Michael is a leader in cancer philanthropy. Michael is a most valued Jedi.

Natasha Jinks

Nothing ever gets done in an organization like ours without a person like Natasha. An early volunteer on the Positive Promotions JEDIs for Survival Cycle team, Natasha tirelessly led fundraising efforts, organized and delivered the design and production of t-shirts, water bottles and hats for the May Cycle ride at Wollman rink. Natasha is a glowing example of the tireless volunteer spirit that makes our work successful. Thank you, Natasha, you are an exemplary Jedi volunteer.

Harmony Knutson

Harmony and Jed first met working on John Kerry's Presidential Campaign. Later they were partners in a lobbying effort. She is an accomplished development and public policy executive. Harmony and I began a conversation about the future of Jed's foundation shortly after last October's fundraising event. It was apparent to me that she was deeply interested in helping the foundation develop into a meaningful philanthropic organization. Early this year, she agreed to become our Chief Development and Advocacy Officer, a full-time volunteer position. As such, she has become my day-to-day partner. Her deep high-level experience in political and nonprofit organizations has added a level of energy, expertise and commitment that has accelerated our work and made us better every day. No words can express how fortunate we are to have Harmony as part of our Senior leadership team. Harmony is a Jedi Leader.

Christie Mansfield

Christie is a very talented graphic designer. I have had the pleasure of working with her for almost 20 years. When I first engaged her to design our branding, website, and other communication graphics she refused to take payment. She put her talent and love into the work. Her work and commitment to the foundation would make Jed proud. Christie, you are a most generous Jedi.

Susan and Nelson Taxel

Nelson is my first cousin. He and his wife Susan are two of our most ardent supporters. When I initially shared the concept of the foundation with Nelson and asked for his support… his response was "anything you want"… his company Positive Promotions has provided unlimited support in terms of people, product and fundraising. Positive'sCycle team led all others in fundraising. Susan is a serious student of the science we support and one of our most effective fundraisers. Susan and Nelson are inspired Jedis.

Laurie Scheinman

Laurie is secretly a marketing genius. She is one of the first people I spoke with about forming Jed's foundation. She became my collaborator in crafting our mission and branding, carefully defining our goals and aspirations word by word. She nicknamed us "the little engine that could," a small group that would accomplish big things. Laurie is an inspiring Jedi.

The OPPORTUNITY to create NEW HOPE for rare cancer progress is NOW.

News from the first annual conference co-sponsored by The Jed Ian Taxel Foundation for Rare Cancer Research and Columbia University Herbert Irving Comprehensive Cancer Center.

COLUMBIA | COLUMBIA UNIVERSITY HERBERT IRVING COMPREHENSIVE CANCER CENTER
PRESENTS
RARE CANCERS
Great Unmet Medical Needs
CME Conference
JOINT PROVIDER
the jedian | the jed ian taxel foundation for rare cancer research

"There needs to be a revolution in government health agencies."

Catherine G. Young, PhD
Former Executive Director, The SHEPHERD Foundation; Senior Director of Science Policy, Biden Cancer Initiative

Greg Simon, JD
Former President, Biden Cancer Initiative; Executive Director, White House Cancer Moonshot

Catherine Young and Greg Simon are public policy leaders and advocates for solutions to advance rare cancer research at the federal government level. They shared insights into the forces within government agencies that can impede or accelerate rare cancer research. These include sustaining an entrepreneurial, accelerator-like mission at ARPA-H and increasing coverage for the evolution of cancer diagnostics and treatments from the anatomic level to the molecular so that patients can access better treatments more quickly. "Imagine the same people doing the same thing without much results ... for decades," says Mr. Simon. "It's important for advocates like the Taxel Foundation to help others realize that they can be part of the legacy."

Gary Schwartz, MD
Chief, Hematology and Oncology; Deputy Director, Herbert Irving Comprehensive Cancer Center Columbia Vagelos School of Medicine

"We're going to do this together. We're going to win. We have to win."

Conference Co-Chair Dr. Schwartz introduced conference objectives and suggested outcomes that can accelerate discovery and move rare cancer progress forward, emphasizing *"this is something we cannot lose on."*

- Better understanding of rare cancers
- Increase awareness that rare cancers are not "rare"
- Best ways to identify and treat rare cancers
- Opportunities for new drug development
- New paradigms that allow better treatment and cures
- Determine investments to advance the field and engage pharmaceutical and investment communities to promote new drug discovery.

Molecular Science

is a Game Changer for Rare Cancers

On April 26, the *Rare Cancers: Unmet Medical Needs* conference brought attention to the scarce resources and treatment options available to the more than 400,000 Americans diagnosed with a rare cancer each year – and to the major advancements in medical science stemming from the ability to study the genomics of every molecule in tumor tissues. This transformative research is moving from an anatomic (organ based) to molecular understanding of tumors across rare cancers. When the molecular-level mechanisms that drive rare cancers are understood, there's no stopping us. Molecular science can revolutionize the whole field of cancer medicine and bring new hope to rare cancer patients.

Young Scientist Awards

Dr. Gary Schwartz with Early Career Scientists award winners Sara Viragova, PhD, Sminu Bose, MD, and award presenter Tiffany Taxel.

The 2022 Jed Ian Taxel Foundation for Rare Cancer Research Awards for Early Career Scientists were given to the following awardees for their presentations of original research.

1st Prize: Sara Viragova, PhD, Postdoctoral Researcher, Columbia University Medical Center For research on inhibitors of a retinoid signaling as anti-tumor agents in Adenoid Cystic Carcinoma.

2nd Prize: Sminu Bose, MD, Oncology Fellow, Columbia University Medical Center For research demonstrating the feasibility of implementing single-cell genomics from archival tissue to study sarcoma and propel our understanding of drug resistance.

3rd Prize: Alexander Wei, MD, MS, Hematology & Oncology Fellow, Columbia University Medical Center For research on the clinical and disease characteristics of metastatic uveal melanoma patients who develop symptomatic brain metastases.

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Thanks for all you do!

jedi rare cancer foundation

The good and important work of his foundation will advance science and save lives.

We are humbled and grateful for all your love and support of our beloved Jed.

Love never dies.

Linda, Tiffany and Mark

WE ARE ALL JEDIs

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"What will be my legacy?"

In April 2017, 39-year-old Jed Taxel was diagnosed with an occult, metastatic rare cancer. That August, after learning his treatments were ineffective, he rhetorically asked, "What will be my legacy?"

The Jed Ian Taxel Foundation for Rare Cancer Research is his legacy. Its mission is to inspire and empower scientific breakthroughs, clinical trials, and improve treatments that can change lives and enable better outcomes for rare cancer patients and their families.

Jed was born on January 17,1978 in White Plains, New York to Mark and Linda. Raised in Chappaqua, he graduated from Horace Greeley High School and went on to study at NYU, graduating cum laude with a degree in Journalism.

He was Chief Marketing Officer at BeneStream, whose mission was to help companies, unions, and nonprofit organizations obtain government benefits for their lower income workers.

Jed and his wife Tiffany met in 2005, dated for a couple of years and then reconnected in 2012. They married on October 11, 2014, at the National Arts Club in New York. Jed was an avid guitar and tennis player, loved to ski the moguls, was active in politics and AA; he had a wide circle of close friends and family. Jed and Tiffany lived in NYC but spent as much time as possible at Twin Maple Farms, the family's vacation home they shared with Mark and Linda. Jed and Tiffany enjoyed travel, tennis, cooking, tending to a large and diverse garden, but most importantly being together.

Accelerating science that saves lives is Jed's legacy.

In February 2017, Jed became ill, experienced severe pain and had a series of tests and received several treatments directed at alleviating his symptoms. An eventual biopsy of a sternal mass revealed a rare cancer of an unknown etiology; further tests demonstrated metastatic spread to his lungs, liver, and bones. Immunotherapy with Keytruda and chemotherapy were ineffective. He died that October on his 3rd wedding anniversary.

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