











jedicancerfoundation.org































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

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

Love never dies.

Linda, Tiffany and Mark Taxel WE ARE ALL JEDIS







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 Cancer is 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

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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 University Vagelos 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 healthcare, 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 Al-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."

>>>CYCLE

MEMORIAL SLOAN KETTERING I EQUINOX



JEDIs for Survival Teams

Rider-Fundraisers

Generous Donors Average Donation

\$158,805 RAISED FOR RARE **CANCER RESEARCH**

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

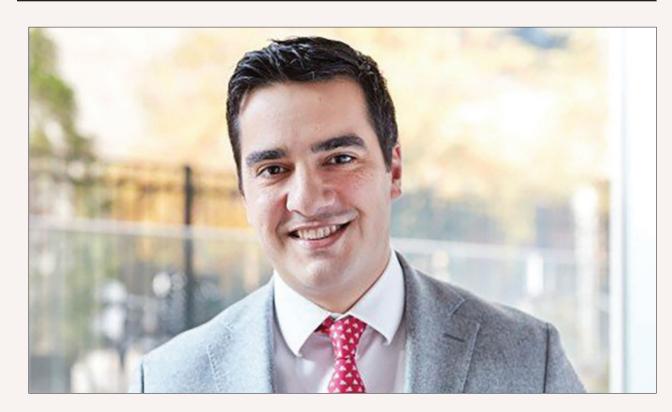
Congratulations to our JEDIs for Survival national team members and all the generous donors who helped make our foundation's inaugural Cycle for Survival fundraising effort a success.

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 for children 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), I everaging 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. Debbie, one of Tiffany Taxel's friends from middle and high school, and her husband Kevin have been dear friends for many years. 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.

JEDIs for Survival | 2022 JEDIs for Survival | 2022

Testimonials of two families whose daughters survived rare cancers



Caroline with Mom & Dad at Cycle for Survival 2018



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 and Dr. Ortiz with Nurse Talia

Alexandra: 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!

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We are all Jedis



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 verv 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

People Who Make a Difference

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.

By Mark Taxel, with deepest appreciation





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's Cycle 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.

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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.



"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 Cancer

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

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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Michael Weiner, MD

Hetttinger Professor and Vice Chair, Pediatrics Columbia University Herbert Irving Medical Center

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



To donate online, scan me or visit **jedicancerfoundation.org**

Or send your donation by check to:

Jed Ian Taxel Foundation for Rare Cancer Research P.O Box 683501 Park City, UT 84068-3501

Thank you in advance for your generous support!

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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 Chappagua, 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.

The Jed Ian Taxel Foundation for Rare Cancer Research

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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

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