

jedis^{FOR} SURVIVAL news

Dear Friend,

Rare cancer patients, who've been overlooked for decades, demand our full and most urgent attention. Nothing less will meet the unprecedented opportunity we have before us.

In 2024, our foundation launched Alliance for Rare Cancers (ARC), a consortium of rare cancer leaders from across the U.S. who are committed to radical collaboration at unprecedented scale to make data-driven approaches in rare cancer a reality.

Today is Rare Disease Day, and I'm excited to announce the ARC Board of Directors and Leadership Council. These esteemed participants are marked not only by extraordinary expertise and accomplishment, but by an uncommon spirit of collaboration.

ARC Chief of Staff, VP & Secretary Shelby Doyle, PhD tells us, "The founding members of ARC are committed to building a new future for rare cancer patients and are willing to break with the status quo to make it happen." Shelby is also Jedi Rare Cancer Foundation Director of Special Projects.

ARC Board Member Jane Wilkinson, CANCollaborate President and Co-Founder, emphasizes the importance of this alliance when she states, "We have the bold and disruptive opportunity to bring the entire rare cancer community together to create collaborative initiatives that will bring us closer to understanding rare cancers."

There is much to do and we must work together. Modern advances in cancer have given so many families the gift of more time and more life after diagnosis. Rare cancer patients deserve that same chance at life. By coming together to show the scale of their common challenges, rare cancer patients can finally gain the level of investment needed to bring modern advances in cancer to their care.

ARC Board of Directors

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ARC Vice Chair of the Board
Case Comprehensive Cancer Center Director

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Jesse Boehm, PhD

MIT Principal Investigator
Break Through Cancer Chief Science Officer

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Abby Sandler, PhD (Retired)

Formerly at National Cancer Institute
MyPART Executive Director

Erin Siegel, PhD, MPH

National Cancer Institute Epidemiology

Your support will help fund research, provide critical resources, and drive awareness for rare cancers, bringing us closer to the cures that so many need.

With gratitude,



Mark Taxel,
Jedi Rare Cancer Foundation Founder &
Chair; ARC CEO & Chairman of the Board

& Genomics Research Program Associate Director

Marshall Thompson, PhD
Rare Cancer Research Foundation, President

Brian Van Tine, MD, PhD
Washington University in St. Louis Professor of Medicine
& Pediatrics

Steven Young
Sarcoma Alliance for Research through Collaboration
President & CEO

Renew Your Support



Jesse Boehm, PhD, Chief Science Officer of Break Through Cancer

Experts share challenges and opportunities for treating rare cancers.

In honor of Rare Disease Day, the *Trends in Cancer* journal published [“Think zebras: challenges and opportunities for treating rare cancers.”](#) a series of new interviews with experts in the field of rare cancer research.

ARC Board Member Jesse S. Boehm, PhD emphasizes that rare cancer patients have been left behind in the fight against cancer and this is unacceptable. When asked why does this disparity exist? Dr. Boehm replied, “Shockingly, it’s not a scientific barrier—it’s a systems challenge. The geographical dispersion and relative scarcity of patients, resources, and researchers at any one institution leads to a lack of clarity about cellular targets to hit when developing therapies. And a mismatch between the level of investment needed and the scale of the challenge is clear.”

“The Alliance for Rare Cancers (ARC),” Dr. Boehm explained, “has galvanized an unprecedented coalition of stakeholders to capitalize on these opportunities and work collaboratively to implement a coordinated national rare cancer plan for the USA and beyond.” Dr. Boehm believes the confluence of new technologies, such as organoid culture, genome engineering and machine learning, patient-partnered

platforms for data and living tissue donation, and social media-driven patient communities will enable any researcher to hunt for rare cancer drug targets.

[Read the Article](#)



Case Comprehensive Cancer Center recognized by the National Cancer Institute

Congratulations to our partner Case Comprehensive Cancer Center (Case CCC), recognized by the National Cancer Institute (NCI) with a merit award of outstanding 19 months after transitioning to a new director [Dr. Gary Schwartz](#), who is also Chair of our foundation's Medical Advisory Board. Case Western Reserve University President Eric W. Kaler stated, "We are grateful for the steady and strong leadership of the Center's director Dr. Gary Schwartz, and his commitment to producing high-quality research and programming that builds upon Case CCC's national reputation for excellence." He added, "The collaborative efforts of our partnering institutions at Case CCC have led to improved outcomes for people whose lives are affected by cancer—around the country and, importantly, right here in Northeast Ohio."

[Read the Announcement](#)



Rare Cancer Breaking News

We thought you'd be interested in two important articles published recently: [this Newsweek story](#) about the power of genetic sequencing in cancer treatment provides an overview of the promise of precision oncology—an approach that identifies and targets the gene mutations that drive each person's cancer.

[This Cleveland.com article](#) underscores the severity of a proposed policy change recently announced by the National Institutes of Health that would cut its funding for “indirect costs” tied to biomedical research. For Northeast Ohio’s research institutions alone, the result of Trump’s plan would be a reduction of billions of dollars. A federal judge, however, has ordered the Trump administration to hold off [on a plan that would cut billions](#) in federal funding for research at the nation’s universities, cancer centers and hospitals.

Rare cancer research is already underfunded. Now, indiscriminate cuts are putting life saving research and potential therapies at risk. Your donations are more important than ever to sustaining research that can bring hope to rare cancer patients and their families.

Donate Today



jedi rare cancer
foundation

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