

jedis^{FOR} SURVIVAL news

Launching a transformational, systemic approach to END rare cancer

Why

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 continue to be obstacles, new technology and science models make it possible to envision a path forward.

What

A new rare cancer collaborative initiative that will END rare cancer as we know it.



The JEDI Rare Cancer Foundation together with Dr. Gary Schwartz and other leaders at the Case Comprehensive Cancer Center (Case CCC) and the Rare Cancer Research Foundation (RCRF) have committed to forming a rare cancer initiative to unite the entire rare cancer community at unprecedented scale to accelerate cures for all rare cancers.

Our Foundation is the key supporter of CURE: The Rare Cancer Initiative at the Case CCC and has anchored the launch phase with a **\$5M commitment**.

When and How

November 2023: we convened a rare cancer workshop at Case CCC in Cleveland. We began with a stakeholder meeting for a national workshop building a systemic approach to defeat rare cancer. At the November workshop in Cleveland, Ohio, 40 rare cancer academics, patient advocates, rare cancer philanthropies, and government (NCI and FDA) leaders including the former head of Obama's Cancer Moon Shot met for a two-day workshop that examined the issues and opportunities for rare cancer, resulting in a shared vision for carrying this important mission forward.



Prior to the workshop, we commissioned a Rare Cancer Landscape Study. Our researcher interviewed a number of experts representing rare cancer constituencies. The goal of the study was to assess the current state of rare cancer research, identify a consensus of unmet needs, understand the challenges that have prevented progress to date, and identify areas of progress that could form models for a scaled approach to defeat rare cancers. You can read the complete Rare Cancer Landscape Study here.

The Jedi Rare Cancer Foundation is leading this transformational initiative.

We hired **Director of Special Projects, Shelby Doyle PhD**, to facilitate the research and strategic planning process, and after the workshop, a Steering Group was formed. We have formulated a timeline to develop an actionable strategic plan, which will be presented and reviewed at a rare cancer summit in late September 2024. The Steering Group produced a strategic vision, which will form the underlying rationale, mission, and goals for building a scalable, transformative, and sustainable system capable of addressing rare cancer's unique challenges from bench and back again.



[READ MORE ABOUT THIS INITIATIVE](#)

1 in 4 cancer patients have incurable rare cancer. We are determined to change that. Thanks to the guidance and generosity of our donor community, the JEDI Rare Cancer Foundation has assumed a key role where we can effectively impact change. Together, we will END rare cancer.

We invite you to support the Foundation's innovative approach to rare cancers. You can directly enable leading researchers and clinicians to enact the most innovative and integrated approach to cancer research, wholly focused on better outcomes for rare cancer patients.

[DONATE TODAY](#)

What your generosity funds:

- The Rare Cancer Landscape Study and ongoing rare cancer research
- CURE: The Rare Cancer Initiative
- A national rare cancer initiative to END rare cancer.

With gratitude

Mark Taxel, Founder & CEO
JEDI Rare Cancer Foundation



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