# Showcasing New Strides in Rare Cancer Research

Fred Hutch 4th Rare Cancers Symposium features experts in research areas including immunotherapy, clinical trial design and biobanking.

November 11, 2025 By Fred Hutch News Service and N. G. Boeck

---

A cancer diagnosis always brings challenges and uncertainty.

But for those diagnosed with so-called “rare” cancers — traditionally described as diseases that affect 40,000 or fewer Americans every year — even getting an accurate diagnosis can be a challenge.

With fewer patients and research resources, rare cancers are harder to diagnose, which can lead to uncertain treatment plans and unclear prognoses. And there are many different types of rare cancers including choriocarcinoma, periosteal osteosarcoma, translocation renal cell carcinoma and many more. The American Cancer Society, or ACS, in fact, lists over 200 types of rare cancers, cancer subtypes and pre-cancerous conditions that could lead to cancer in the future.

And while navigating one of these rare illnesses can be fraught and confusing, there is reason for hope.

The 4th Rare Cancers Symposium on October 17, hosted by Fred Hutch Cancer Center’s Transformative Rare Cancer Initiative, or TRACER, brought together researchers, clinicians and patient advocates from Fred Hutch, the University of Washington, Seattle Children’s, the National Institutes of Health and Stanford University to showcase new strides in rare cancer research and patient care.

The brainchild of Taran Gujral, PhD, associate professor in the Human Biology Division and founder of TRACER, established in early 2024 to increase awareness and visibility around the challenges of treating and curing these cancers, the twice-yearly Rare Cancers Symposia are designed to help connect researchers, clinicians, philanthropy partners and patients in the rare cancer community.

“It’s exciting to see the growing momentum around rare cancer research at this symposium,” Gujral said. “The panel discussions reaffirmed the importance of collaboration among scientists, clinicians and patient advocates. Programs like TRACER bring these groups together to make rare cancer research faster, more connected and more impactful.”

## A patient's inspiration

Gujral credits one of the symposium's sponsors, the Minneapolis-based Brave Like Gabe Foundation, for the inspiration to create TRACER.

The non-profit was founded by elite middle-distance runner Gabriele "Gabe" Grunewald, who received a diagnosis of adenoid cystic carcinoma, a rare cancer that can start in the salivary glands, the night before a collegiate race in 2009.

"We were in the lobby of a hotel in Arizona doing homework when Gabe got the call that the lump in her neck was cancerous," said Ladia Albertson-Junkans, a college teammate and close friend who is now a board member for Brave Like Gabe. "She started to Google the diagnosis and read what was online, which was not optimistic or inherently encouraging. That's when she first saw that word 'rare.'"

The next morning, Grunewald awoke and raced anyway. She ran faster than she had ever run before. And then she got to work learning more about her disease.

Over the next decade, Grunewald became a spokesperson for the rare cancer community as she went through treatments for her original diagnosis, and then a metastatic recurrence.

Though Grunewald died in 2019, ten years after her initial diagnosis, her Seattle-based sponsor, Brooks Running, and the Brave Like Gabe organization have funded rare cancer research at Fred Hutch since 2020.

## Research, collaboration and progress in treating rare cancers

Symposium participants learned about an innovative tissue banking project at Stanford University that collects and distributes samples of rare tumors to facilitate research; leading-edge techniques in genomics that can match rare tumors with potential drug candidates; and advances in difficult-to-treat cancers such as fused brain cancer (where two or more genes "fuse" during cell division to create a mutant gene that can incite uncontrollable cell growth).

Jing Wu, MD, PhD, a neuro-oncologist who leads the Translational Research Program at the Neuro-Oncology Branch of the National Cancer Institute, discussed hard-to-treat brain cancers and the challenge of designing and carrying out clinical trials for rare cancers. Wu noted that most brain tumors are considered to be rare, based on the incidence rate of both malignant (cancerous) and non-malignant tumors found in all age groups in the United States.

Wu presented research on several clinical trials, including a Phase 1 study of a combination drug therapy for recurrent high-grade astrocytoma, a type of cancer that begins in brain cells called astrocytes (for their star-like appearance). The study indicated that the drug zotiraciclib (also known as TG02) could be used in combination with the common brain tumor drug temozolomide

(also known as TMZ) for certain types of tumors. Based on the strong supportive preclinical evidence for this multifaceted early-phase clinical trial and the findings from other clinical trials, zotiraciclib was granted orphan drug designation by the U.S. Food and Drug Administration (FDA) for the treatment of malignant glioma to expedite the development of a therapy for brain tumors.

Wu described the challenges of creating clinical trials for rare cancers, a theme echoed by several speakers at the symposium.

“We usually start with the clinical observations, and with those observations, we generate a focused hypothesis that can be tested or partially tested in the laboratory,” Wu explained.

From there, her team designs and implements a clinical trial based on the observations gleaned from both the clinic and the laboratory experiments created from clinical observations. It’s a model of clinical research and patient care that Wu described as “bench to bedside and back,” and it holds the promise of continuing to search for therapies for hard-to-treat rare cancers by combining the best of clinical and research science in a cycle of continued improvement.

Brooke E. Howitt, MD, a gynecologic pathologist at Stanford University School of Medicine, spoke about her institution’s tissue banking program, in which human tissue samples from rare cancer tumors are preserved for future biomedical research.

Howitt, who serves as the faculty director for the program, noted that biobanking of rare cancer tumors can greatly improve rare cancer research simply by giving research labs access to actual tissue samples.

Because rare cancers occur so infrequently, it is often difficult to develop clinical trials based on pre-clinical lab findings. Access to human tissue samples — collected during procedures in which there is excess tumor tissue that would normally be discarded — greatly improves the chances of performing critical lab research that can identify potential therapies.

To date, over 400 rare tumors have been preserved, including those of gastrointestinal, genitourinary, gynecologic and soft tissue cancers. These samples are made available for study at very low cost, both to investigators at Stanford and to Stanford collaborators at other academic institutions.

Howitt also highlighted an initiative inspired by one of her patients, a Washington state resident who initially received three different diagnoses for her rare cancer from three different institutions.

“Rare cancer [patients] often suffer from this sort of experience,” Howitt said. “It was just a very confusing process for [this patient].”

Howitt’s patient’s experience led to the creation of the Uterine Mesenchymal Tumors Alliance (UTMA), a program funded by the Department of Defense Rare Cancer Research Program.

“Having a refined and very reproducible diagnosis is the basis to be able to properly study and

treat these cancers," Howitt said.

The UTMA program collects and characterizes uterine sarcomas using multi-omic techniques and independent expert pathologic diagnoses and develops web-based resources for both medical professionals and patients to help improve the accuracy of diagnosing these tumors. Howitt presented a case study on adenosarcomas, rare uterine tumors whose morphology (or physical characteristics) varied widely, but could be successfully studied and characterized using molecular markers called methylation on the tumors' DNA.

Christopher Kemp, PhD, a professor in the Fred Hutch Human Biology and Public Health Sciences divisions, discussed the promise of a tumor screening test designed to identify the most promising drug candidates for rare tumors.

Known as PARIS (for Personalize, Aimed, Robotic, Informatics, Sequenced), the test measures how a patient's tumor cells respond to different drugs and then matches them to therapies most likely to be effective, applying functional precision medicine principles to hard-to-treat cancers.

"It's a very simple concept," Kemp said. "You take patient tumors, culture them and treat them with drugs. And you also sequence tumor DNA. You correlate these two things to nominate potentially effective drugs."

A report is provided to the patient's physician which ranks the drugs for their potential activity against that patient's particular cancer.

Kemp explained the genesis of the program that produced PARIS: a patient's simple request to Kemp's long-term collaborator, Carla Grandori, MD, PhD: "Can you study my rare tumor?"

That led Kemp and Grandori to identify and overcome roadblocks to these types of studies in the traditional academic setting. Kemp and Grandori, a former principal investigator at Fred Hutch, established non-profit entities including Cure First and the Society for Functional Precision Medicine in their quest to develop a clinically useful assay to help inform therapy selection.

Kemp highlighted results from several patients who showed clinical benefit from drugs identified by the PARIS test.

## Innovations in rare cancer research drive hope

In addition to Wu, Howitt and Kemp, five additional researchers from Fred Hutch, University of Washington and Seattle Children's presented their findings in several critical areas of rare cancer research:

- Jason Carter, MD, PhD, a postdoctoral fellow at the University of Washington working with Fred Hutch and UW Medicine surgeon Venu G. Pillarisetty, MD, discussed his research on

fibrolamellar carcinoma (FLC), a rare and aggressive liver cancer seen in otherwise healthy young adults that afflicts less than 100 new patients a year. Carter reported on research illustrating that a combination therapy targeting two cell mechanisms involving immune checkpoints and chemokines (small molecules that guide immune system cells to specific locations in the body) showed strong evidence in pre-clinical studies that such a therapy could have promise for FLC patients in the future.

- Robert N. Eisenman, PhD, professor in the Basic Sciences Division, presented research from his lab on the relationship between Myc (pronounced “mick”), a transcription factor critical for cell growth that is implicated in various cancers, and the protein known as “Max” in stabilizing the ability of Myc to bind to DNA, an action that contributes to the control of gene expression. Eisenman presented data from his lab’s research, in collaboration with the lab of David MacPherson, PhD, professor in the Human Biology and Public Health Sciences divisions and holder of the Vinh Bui and Tram Le Endowed Chair for Lung Cancer, on mouse models showing how the interaction of these proteins, and their deletion, could lead to a new understanding of the mechanism by which some rare tumors grow, including a marked increase in the progression of small cell lung cancer as well as thyroid and pituitary neuroendocrine cancers when the Max gene is deleted.

- Priya Mahajan, MD, associate professor of Pediatric Hematology and Oncology at Seattle Children’s, discussed her work in managing rare pediatric tumors for which no diagnostic or therapeutic standards have been established, leading to the risk of compromised patient care. She stressed the need for global partnerships and collaborations to both better understand the biology of the tumors, and to care for these patients effectively. She discussed opportunities to optimize care in pediatric patients with advanced papillary thyroid carcinoma, the most common thyroid cancer seen in children and adolescents.

- Soheil Meshinchi, MD, PhD, professor in the Translational Science and Therapeutics Division,

presented research on a novel CAR T-cell treatment for a rare pediatric blood cancer, acute myeloid leukemia, that is much more often seen in adults in their later years.

- Julia Walker, BSc, a research associate in the lab of Eric Holland, MD, PhD, senior vice president and director of the Human Biology Division and holder of the Endowed Chair in Cancer Biology, presented research on pediatric high-grade glioma, a rare brain cancer driven by the fusion of genes involved in the transcription of proteins known as receptor tyrosine kinases (RTKs). The rarity of the cancer and the difficulty of finding patients to enroll in clinical trials led the Holland Lab to create mouse models for this cancer to run a "co-clinical trial" on mice with parallel tumors to speed up the research to identify potential treatments sooner than could be identified in a human trial alone.

The eight speaker sessions were followed by a panel discussion with Gujral, Howitt and Wu, moderated by cancer survivor and Fred Hutch communications consultant Susanna Ray. The day wrapped up with a poster session showcasing research being performed by current Fred Hutch trainees in areas relevant to rare cancer diagnosis and treatment.

## Bringing the patient experience to the forefront of rare cancer awareness

Throughout the day, patient stories of self-advocacy and persistence in the face of sometimes long odds were woven through the experts' research talks.

Gujral announced the 5th Rare Cancers Symposium would be held March 14, 2026, at Fred Hutch, adding that it will be a patient-centered event with topics on the biology of rare cancers, living with rare cancers, and how patients can drive progress through tissue donation and advocacy.

Brave Like Gabe board member Albertson-Junkans was gratified to witness this new emphasis on collaboration, some of which was made possible by her friend's longtime advocacy for rare cancer research. Grunewald's determination to race the day after her initial diagnosis set the stage, she said, for how Gabe came to embrace her role as a patient advocate.

"She really set the tone and buoyed us," Albertson-Junkans said. "We [her teammates] were very concerned and overwhelmed by the news, and she showed us how she wanted to approach [her diagnosis]. And it was really with grit and determination, and I do think courage as well."

For more information about the 5th Rare Cancers Symposium to be held in March 2026, contact

rarecancers@fredhutch.org. To learn more about the projects funded by the Brave Like Gabe Foundation, visit bravelikegabe.org/impact.

Nicole G. Boeck (née Nazzaro) is a science writer based in Edmonds, WA. Her writing has appeared in Immunology and Cell Biology, Sky & Telescope, the New York Times and many other publications. She has a BA from Harvard University, an MJ in journalism from the University of California-Berkeley and a postbaccalaureate BS in biochemistry from the University of Washington. Nicole is a member of the National Association of Science Writers. Reach her at nicole@impactmedianw.com or @mnicolen.bsky.social.

This article was originally published October 31, 2025, by Fred Hutch News Service. It is republished with permission.

---