The Ewing Sarcoma Institute (ESI) — a catalyst to improve outcomes for patients with Ewing sarcoma globally

Background

Ewing sarcoma is an aggressive bone and soft-tissue cancer that mainly affects children, adolescents, and young adults. While current multi-modal treatments offer a 70–80% survival rate for patients with localized tumors, the prognosis remains poor for patients with metastatic or relapsed disease and survivors suffer from late effects and life-long morbidity.

Mission

ESI is dedicated to radically improving outcomes for Ewing sarcoma patients by uniting the global community to accelerate collaborative scientific discovery and development of breakthrough treatments.

ESI's History

ESI is a new global institute, crystallized through the generosity of Charles Nearburg.

Founded in 2000

The Rett Nearburg International Ewing Sarcoma Research Symposia, launched in 2000, brought together leading researchers and clinicians across seven global convenings. Hosted at institutions such as the Children's Hospital of Los Angeles, Dartmouth College, and the Children's Hospital of Philadelphia, these events laid the foundation for ESI.

7 Symposiums from 2000–2023

The highly interactive format of the seven symposiums convened leading Ewing sarcoma experts from around the world to openly discuss unpublished data, removing competitive barriers and building an atmosphere of trust and collaboration that formed the basis for the conception of ESI at the 7th symposium.

ESI — 2023

The Ewing Sarcoma Institute was conceived at the 7th Rett Nearburg International Ewing Sarcoma Symposium in 2023. At this convening, it was determined that a more structured and sustained effort to promote and support collaborative research involving all stakeholders was needed to substantially improve outcomes for Ewing Sarcoma patients.



Rett Nearburg (1983–2005) lived each day to the fullest throughout his eleven-year battle with Ewing Sarcoma — strengthened by his love of life, family, and friends. He was passionate about art, music, motorcycles, and civil liberties. Courageous and selfless, Rett volunteered for experimental trials and treatments, always pushing forward despite pain and setbacks. His spirit, humor, and resilience continue to inspire everything we do at the Ewing Sarcoma Institute.

Approach

Preclinical Research

Drive scientific discovery to unlock new treatment pathways: Unite the global research community to establish a strategic, high-impact research agenda

Clinical Advancement

Accelerate clinical trial development and access to new therapies: Accelerate the development, launch, and accessibility of better and newer therapeutic options for patients with Ewing Sarcoma

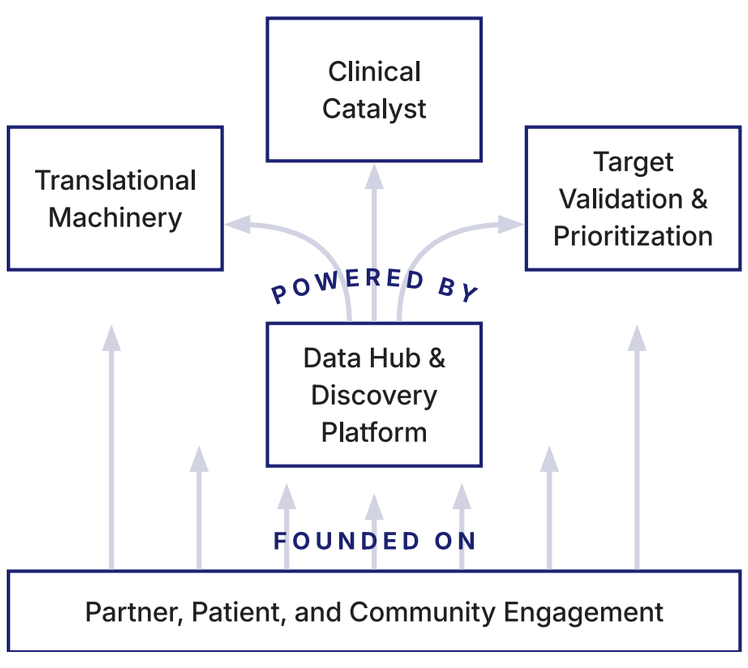
Collaboration & Data Sharing

Build a global research community and data ecosystem: Establish an efficient, shared infrastructure that accelerates progress across the Ewing sarcoma research community through collaboration, streamlined resources, and cutting-edge tools

Patient Advocacy & Resources

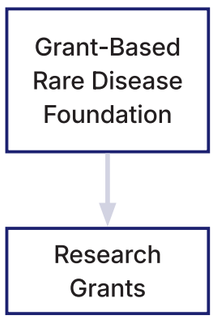
Empower patients and families with knowledge and support: Build a deeply connected, welcoming community where patients, families, researchers, and advocates come together to support one another, share knowledge, and take action

Strategy

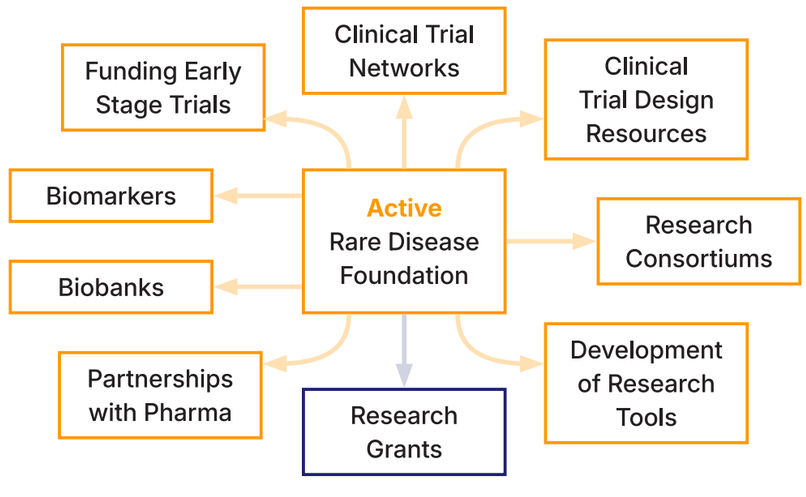


An Active Foundation

Grant-based foundations focus on funding catalytic research



Active foundations like ESI focus on lowering the risk of therapeutic development



Leadership — Executive Board



Patrick Grohar
Russell G. Adderley Professor of Pediatric Oncology at the C.S. Mott Children's Hospital, University of Michigan



Heinrich Kovar
Group leader; Professor at St. Anna Children's Cancer Research Institute



Lee Helman
Director of the Osteosarcoma Institute · Adjunct Clinical Professor of Pediatrics, Cancer and Blood Disease Institute, CHLA, Keck School of Medicine, USC



Charles Nearburg
Owner/President, Nearburg Producing Company



Chad Brown
Chief Investment Officer, Ewing Sarcoma Institute

Connect with ESI

Support ESI

Spread the word: Share ESI's mission and work with your patients, colleagues, and professional networks

Stay connected: We'll be sharing exciting updates and resources at ewingsarcoma.org

Give with purpose: Consider ESI in your end-of-year giving or through your company's charitable match program

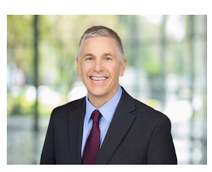
Partner With ESI

When you partner with ESI, you access:

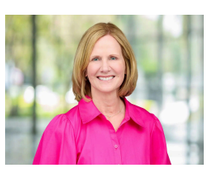
- A seasoned team of Ewing Sarcoma experts, researchers and clinicians
- A rich ecosystem of resources
- Our deep commitment to scientific innovation and agile methodologies that will result in tangible results

You can visit us at **ewingsarcoma.org** or email Pei Pei Ma at **pma@esinst.org**.

Strategic Advisory Board



James Amatruda
Chief, Division of Pediatric Hematology-Oncology; Director, Cancer and Blood Disease Institute, CHLA



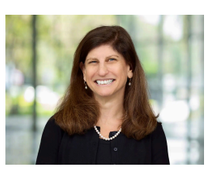
Carol Basso
Patient/Family Advocate, Texas



Rashmi Chugh
Clinical Professor in Hematology and Oncology, University of Michigan



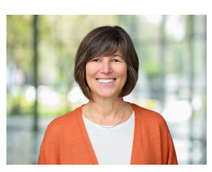
Olivier Delattre
Director of the SIREDO Oncology Center · Research unit director of the Cancer, Heterogeneity, Instability and Plasticity (CHIP) unit, Inserm/Institut Curie (France)



Julia Glade Bender
Pediatric Hematologist-Oncologist, Vice Chair for Pediatric Clinical Research, Memorial Sloan Kettering Cancer Center



Thomas Grünewald
Professor, University of Heidelberg (Germany) · Division Head, German Cancer Research Center (DKFZ) & Hopp Children's Cancer Center (KiTZ) (Germany)



Elizabeth (Beth) R. Lawlor
Associate Director, Ben Towne Center for Childhood Cancer & Blood Disorders Research, Seattle Children's Research Institute



Poul Sorensen
Johal Chair in Childhood Cancer Research, The University of British Columbia



Kim Stegmaier
Chair of Pediatric Oncology at Dana-Farber Cancer Institute · Associate Chief of the Division of Hematology/Oncology at Boston Children's Hospital



Sandra Strauss
Professor of Medical and TYA Oncology and Honorary Consultant Medical Oncologist, University College London



Jeff Toretsky
Professor, Departments of Oncology and Pediatrics; Division Chief, Pediatric Adolescent and Young Adult (AYA) Hematology/Oncology, Georgetown University

Institutions represented by our Strategic Advisory Board:

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