Sarcoma Knows No Borders

Sarcoma knows no borders. It can occur anywhere in the body. It doesn't discriminate based on age, gender or race, and it is diagnosed in countries all over the world. Yet...



...sarcoma is the forgotten cancer.

What is sarcoma?

- Sarcoma is a very dangerous cancer that affects the connective tissues, such as nerves, muscles, cartilage, joints, bone, or blood vessels.
- It can arise anywhere in the body, frequently hidden deep in the limbs.

How prevalent are sarcomas?

- About 1% of all adult cancers are sarcomas.
- About 15% of all children's cancers are sarcomas.
- There are hundreds of thousands of patients and their families struggling with sarcoma worldwide.

How are sarcomas treated?

- When possible, sarcoma patients have surgery to remove the cancer.
- Surgery is often combined with chemotherapy and/or radiation.

Why are sarcomas dangerous?

- They are often misdiagnosed. Sometimes they are thought to be sports injuries.
- When they are diagnosed, they may be large and difficult to remove surgically, and they may have metastasized.
- Many sarcomas resist current treatments.

Learn more and do something to help! SarcomaHelp.org

Become a Part of the Liddy Shriver Sarcoma Initiative!

The Faces of Sarcoma

More than 500 people have contributed to this beautiful collection of photographs that honors patients, survivors, and those who have lost their lives to sarcoma. Send us a photo today. You can help by resizing your photo to 600 pixels wide (or less) and cropping it to focus on one person's face.



Sarcoma Support and Resources

Volunteers from the Liddy Shriver Sarcoma Initiative are available to support patients, families, physicians and nurses by e-mail and telephone. We maintain a growing Team Sarcoma Facebook Group, where patients, survivors and advocates can connect for meaningful discussion. We also publish a comprehensive list of support resources (including sources of financial and travel assistance, support groups, and sarcoma centers) that are available to sarcoma patients and their families.

"Sarcoma Knows No Borders" Bracelets



Thousands of people around the world wear these bracelets as a sign of support and solidarity. The background color of the bracelet is a swirl of a pathology slide of a sarcoma patient. The bracelet is reversible. "Sarcoma Knows No Borders" is printed on one side, and the word "sarcoma" is printed in 13 languages on the other side. Each bracelet is individually packaged. Many boys, girls and teenagers wear them as ankle bracelets.

We suggest a \$5 donation for each wristband, plus shipping costs. All of the donations for wristbands go directly to sarcoma research.

Additional Ways to Get Involved

We have worked with hundreds of families, advocacy groups and medical teams to promote sarcoma awareness, education and research. Whether you'd like to publish an online tribute to a loved one, plan an event in your community, or support promising sarcoma research, we would love to work with you! Physicians and advocates can help by writing and reviewing articles for ESUN, sharing our resources with patients, and providing feedback about our activities.

Contact Us

Contact us at support@sarcomahelp.org or by telephone in the U.S. at (914) 762-3251.

The Initiative's Research Grants Program

The Liddy Shriver Sarcoma Initiative supports research that is targeted at finding a cure for sarcoma, as well as research that attempts to develop more effective treatment regimens than those currently available. Specifically, the Initiative funds seed grants for basic and translational research on sarcomas. We anticipate that the results of these "starter grants" will allow researchers to apply for funding for larger studies.

Our Research Grants Program is highly selective: applications are accepted throughout the year and are reviewed by sarcoma experts. Only the most promising studies are approved through this process, and our goal is to ensure that funds are available for every approved study.

The Initiative has funded more than \$1.7 million in sarcoma research studies by respected investigators around the world.

At the Initiative, we believe that quality research should be funded wherever it is done, and we encourage collaborative efforts between departments, institutions and countries. We hope that such collaborative studies will bring more effective and less invasive treatments from the research lab to the patient quicker than has been possible in the past. We also hope that such grants provide a mechanism and incentive for other sarcoma researchers to undertake similar international collaborative efforts.

"I have been very impressed by your grant funding program. You have done an excellent job engaging the best minds in the sarcoma research field to act as peer reviewers, thus assuring that grant applications are fairly reviewed and only the best proposals are funded."

- David Loeb, MD, PhD; Director of the Musculoskeletal Tumor Program; Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins

The Initiative has awarded grants to investigators in Australia, Canada, China, Germany, France, Italy, the Netherlands, Norway and the USA. These grants have focused on several types of sarcoma, including alveolar soft part sarcoma, carcinosarcoma, chondrosarcoma, chordoma, clear cell sarcoma, Ewing's sarcoma, GIST, leiomyosarcoma, liposarcoma, malignant peripheral nerve sheath tumor, osteosarcoma, rhabdomyosarcoma and unclassified pleomorphic sarcoma (MFH).

Recipients of the Initiative's grants agree to publish both an experimental plan and a study report in ESUN.

These reports allow physicians and researchers worldwide to benefit from learning about the research we have funded. We are proud of this level of transparency and accountability, and we believe that donors have a right to know how their money is used. In keeping with our donors' wishes, the Initiative's grants may not be used for salaries, overhead or indirect costs of the investigators' institutations.

Learn more about the Research Grants Program at SarcomaHelp.org.

Physicians and Researchers Support the Initiative's International Efforts

"The Liddy Shriver Sarcoma Initiative is the most important non-governmental organization, surpassing the patient advocacy mission and supporting research and collaboration in the sarcoma field. **The Initiative's collaborating partners belong to the most reliable sarcoma specialists in the world**. -- *Piotr Rutkowski*, *MD*, *PhD*; *Head of the Department of Soft Tissue/Bone Sarcoma and Melanoma at the Maria Sklodowska-Curie Memorial Cancer Center and Institute of Oncology in Warsaw*, *Poland*



"The vision of the Initiative in promoting international collaborating has already proven important in our understanding of sarcoma by allowing researchers to pool critical resources, especially clinical specimens, to generate information that has sufficient statistical power. I think the projects supported by the Initiative and the successes we have had are the best testimony for the critical role of international collaboration. **We look forward to making sarcoma history with Liddy Shriver Sarcoma Initiative.**" *-- Wei Zhang, PhD; Director, Cancer Genomics Core Lab at MD Anderson Cancer Center*

International cooperation among the entire spectrum of sarcoma experts, from dedicated laboratory researchers to diagnostic and treating physicians of all specialties, is critical to achieve the best results for individual patients. No one country has all the answers, and we can only improve by being open to ideas developed by experts elsewhere. -- Raphael Pollock, MD, PhD; Senator A. M. Aiken, Jr. Distinguished Chair; University of Texas MD Anderson Cancer Center

"The Liddy Shriver Sarcoma Initiative is a focus for the brain, heart and soul of the sarcoma community, providing essential resources for scientists, physicians, caregivers, patients and advocates. **The Initiative breaks barriers to cooperation and communication with open access to their authoritative reviews, extensive translations, and funding of joint research projects emanating from transcontinental and transnational collaboration.**" -- *Crystal Mackall, MD; Chief of the Pediatric Oncology Branch of the National Cancer Institute*

Moving from bench to bed-side will be the most successful way to improve patient treatment and management. The Liddy Shriver Sarcoma Initiative fosters this type of collaboration by bringing together leading basic biologists, pathologists and translational oncologists in common research projects - ultimately accelerating sarcoma research." -- Leonardo A. Meza-Zepeda, PhD; Head of the Microarray and Sequencing Core Facility at the Norwegian Radium Hospital

"The Initiative's successful fundraising efforts have led to numerous seed-funded projects; in our case, that seed sprouted a fruit-bearing tree." -- Jeffery Toretsky, MD; Georgetown University Lombardi Cancer Center in Washington, DC



Learn more about the Initiative's Global Research Grants Program at SarcomaHelp.org.

The Electronic Sarcoma Update Newsletter

ESUN is an online, peer-reviewed newsletter that contains articles of interest to patients, caregivers, physicians and nurses. ESUN has published detailed review articles for nineteen types of sarcoma, as well as more than 100 articles on current sarcoma-related topics. In addition, ESUN's regular columns cover clinical trials, recent research findings, community news and patient stories.

ESUN is in its eighth year of publication. Its articles are accessed more than 30,000 times each month.

Reaching the World

Although an increasing number of people throughout the world can read and speak English, there are many who cannot. Furthermore, reading medical and technical material in a foreign language can be particularly challenging. In order to provide native language access to ESUN material, several sarcoma physicians and researchers have translated a number of ESUN articles. In a few instances, sarcoma patients and survivors have provided initial drafts of the translations. Twenty-five translations have already been published, and more are underway.

"The ESUN articles published by the Liddy Shriver Sarcoma Initiative are authoritative, comprehensive and eminently readable. I consider them on par with reviews found in pubmed indexed journals."

- Crystal Mackall, MD, Chief of the Pediatric Oncology Branch of the National Cancer Institute

The Liddy Shriver Sarcoma Intiative embraces the mantra "Sarcoma Knows No Borders" because sarcoma is a disease that can be found anywhere in the body and everywhere in the world. We want our efforts to include all who are affected by sarcoma and everyone working to help them.

The effort of translating these articles into multiple languages is of great value, delivering quality information to the non-English speaking population, and ultimately leading to a better understanding of this disease. - Leonardo A. Meza-Zepeda, PhD; Head of the Microarray and Sequencing Core Facility at the Norwegian Radium Hospital

Please Join in this Global Initiative!

If you can help with translating, writing or reviewing ESUN articles, or if you have additional ideas for international outreach, let us know.

The Experts Are Talking About ESUN

"ESUN is an outstanding learning resource for patients and professionals alike. The electronics are easy to navigate, the content highly topical and current, and the overall utility factor is exemplary. It is the most reliable web-based source of information of which I am aware; hence my reliance on ESUN as my reading resource top choice, especially for my patients, my trainees, and colleagues who are seeking specific information about sarcoma care." -- Raphael Pollock, MD, PhD; Senator A. M. Aiken, Jr. Distinguished Chair; University of Texas MD Anderson Cancer Center



"I am an incredibly strong supporter of the Liddy Shriver Sarcoma Initiative. I find the Electronic Sarcoma Update Newsletter (ESUN), and the Initiative's website to be critical resources for the entire sarcoma community. I find both resources to be well prepared and managed, free of bias, and very informative. I am a sarcoma researcher, and although I keep up with the literature as best as I can, I always find new and interesting information through ESUN and the website." --Stephen Lessnick, MD, PhD; Huntsman Cancer Institute

"I find ESUN to be a tremendous resource. The review articles are outstanding. Being written by authorities in the field and peer-reviewed prior to publication ensures that the information is accurate and useful. Your use of sidebars is especially helpful, allowing a single article to be useful to both a patient/family and to a clinician. The hyperlinks to additional information and to websites describing clinical trials in detail are an efficient use of the web that cannot be replicated by paper newsletters." --David Loeb, MD, PhD; Director, Musculoskeletal Tumor Program; Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins University

"ESUN is a valuable resource for patients and physicians trying to learn more about sarcoma. **It is comprehensive in its scope, demonstrating true intellectual probity.**" --*R. Lor Randall, MD; L.B. & Olive S. Young Endowed Chair for Cancer Research; Children's Medical Center at the University of Utah*

"ESUN is, in my mind, the most extensive and reliable source of cutting edge information targeting sarcoma-related topics for a non-specialist audience, but it is also valuable to specialists because of the wide range of topics covered. This is thanks both to the dedicated people of the Liddy Shriver Sarcoma Initiative, and to their many equally-dedicated professional contributors." -- Ola Myklebost, PhD; Group Leader at the Department of Tumor Biology at the Institute for Cancer Research in Oslo, Norway

"It is my pleasure to write about the impact of the Liddy Shriver Sarcoma Initiative and the Electronic Sarcoma Update Newsletter (ESUN) upon scientists, physicians, and patients with sarcoma. Your tireless dedication to provide the highest quality of information on-line is critical for patients seeking state-of-the-art information." *Jeffery Toretsky, MD; Georgetown University Lombardi Cancer Center in Washington, DC*



You'll Find ESUN articles published throughout SarcomaHelp.org.