

The Liddy Shriver Sarcoma Initiative Partners with Experts Worldwide to Cure Sarcomas

Increased global collaboration is the future of sarcoma research and education, offering new hope for everyone affected by these rare cancers.

Chicago, Illinois – October 26, 2011 – The Liddy Shriver Sarcoma Initiative is pleased to announce that it has funded research in nine countries and published resources in six of the world’s languages. These achievements are a part of the Initiative’s unique mission to meet the needs of the global sarcoma community.



Sarcomas are rare and dangerous cancers that affect people all over the world in all parts of the body. They can be difficult to understand and treat, presenting numerous challenges to patients, physicians and researchers.

The communication of experts around the world can affect a single patient – and thousands of patients. According to Dr. Raphael Pollock of MD Anderson Cancer Center, cooperation is the key to success for patients: “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.”

But sharing ideas is only the beginning. There are more than 70 known subtypes of sarcoma, each with its own behavior. A cure for any one of these ultra-rare cancers will only be found when researchers work together. This collaborative effort starts in basic research, as investigators seek to understand sarcomas and their behavior. It continues as new treatments are tested, as Dr. David Thomas of the Peter MacCallum Cancer Centre in Australia explains:

“Putting all sarcomas together, they still meet US and European criteria for rare or orphan diseases! Worse, each subtype is rarer still. For example, alveolar soft part sarcoma has an incidence of considerably less than 1 per million in the population. There are new treatments for this disease, but to test whether these treatments work, we need the combined efforts of the international community to take part in a trial. Such studies are underway, with the pooled support of sarcoma groups across three continents.”

Since its inception in 2003, the Liddy Shriver Sarcoma Initiative has focused on international collaboration. The Initiative encourages sarcoma experts to co-author articles in the peer-reviewed [Electronic Sarcoma Update Newsletter \(ESUN\)](#). Specialists from around the world have stepped forward to translate ESUN articles into several languages, making accurate sarcoma information more available than ever before. And the Initiative has awarded [more than \\$1.7 million for research studies](#) in Australia, Canada, China, Germany, France, Italy, the Netherlands, Norway and the USA. Several of these studies have involved the collaborative efforts of researchers from different departments, institutions and countries.

Dr. Wei Zhang, a researcher at MD Anderson Cancer Center, has seen the effectiveness of the Initiative’s grants firsthand: “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.”

Bruce and Beverly Shriver, founders of the Initiative, are at the joint meeting of the Connective Tissue Oncology Society and the Musculoskeletal Tumor Society in Chicago this week, talking with attendees about their work. The Shrivens are looking to the future, and they have a lot to say about the generous contributions that make their work possible:

"We owe a debt of gratitude to all of those who give so freely of their time, expertise, experience and funds to help support our efforts. Hundreds of oncologists, researchers and advocates, whose schedules are already overflowing with commitments, have graciously contributed their time toward this global initiative. The results of their work are evident in the quality of the articles published in ESUN and the quality of research that we have funded. We also offer our immeasurable thanks to all of those who, believing in our mission and passion, have donated and raised the funds to support our research grants program. What we have accomplished is just the start of what the global sarcoma community can achieve together."

Dr. Crystal Mackall, Chief of the Pediatric Oncology Branch of the National Cancer Institute, summarizes the impact of the organization: "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."

MORE ABOUT THE INITIATIVE'S COLLABORATIVE RESEARCH GRANTS

The Initiative's grants provide a mechanism and incentive for sarcoma researchers to undertake global collaborative efforts. The Initiative's volunteers hope that these studies will bring more effective and less invasive treatments from the research lab to the patient quicker than has been possible in the past.

MORE ABOUT ESUN ARTICLES IN NATIVE LANGUAGES

An increasing number of people throughout the world can read and speak English; however, there are many who cannot. Furthermore, reading medical and technical material in a foreign language can be particularly challenging. With the proper resources, any physician who encounters a sarcoma can be familiar with the disease and its treatment, and any family facing the diagnosis can have a better understanding of the care that they need. Thus, the Initiative has made the following resources available at SarcomaHelp.org for anyone to read, print and share:

- [The Sarcoma Facts](#) in 23 languages
- [Dermatofibrosarcoma Protuberans \(DFSP\)](#) in French and Polish
- [Ewing's Sarcoma Family of Tumors \(ESFT\)](#) in Chinese, French, Italian and Spanish
- [Leiomyosarcoma of the Bone and Soft Tissue](#) in Chinese and Spanish
- [Leiomyosarcoma of the Uterus](#) in Chinese
- [Liposarcoma](#) in Chinese, French and Spanish
- [Malignant Peripheral Nerve Sheath Tumors \(MPNST\)](#) in Chinese
- [Osteosarcoma](#) in Chinese and Spanish
- [Rhabdomyosarcoma](#) in Chinese, French and Spanish
- [Synovial Sarcoma](#) in Chinese, French, Italian and Spanish
- [Psychological Adaptation, Coping, and Distress in Adult-Onset Soft Tissue Sarcomas](#) in Polish
- More than 590 photos in the international [Faces of Sarcoma](#) project

