

**DIRECTORY**  
**OF**  
**SARCOMA PATIENT ADVOCACY**  
**ORGANIZATIONS AND FOUNDATIONS**

**September 2011**

*"Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has."*

*-- Margaret Mead (1901 to 1978) quote from U.S./World news)*

## **BACKGROUND AND HISTORY OF iSPAN**

*In the summer of 2005 Sharon Anderson, LMS Advocate, Arthur Beckert, The Sarcoma Alliance, Jody Cummings, The Sarcoma Foundation of America and Gilles Frydman, ACOR met to talk about how sarcoma advocacy organizations could become more effective. From this meeting the first ever summit of advocacy organizations was held in conjunction with the Connective Tissue Oncology Society annual conference in Boca Raton, Florida, November 2005. Twenty-seven individuals representing 14 organizations agreed to collaborate on issues affecting all sarcoma patients. The International Sarcoma Patient Advocacy Network (iSPAN) was founded to increase effectiveness and coordination of activities to improve care for all sarcoma survivors. This directory was a result of this meeting.*

---

*iSPAN – International Sarcoma Patient Advocate Network  
- One Unified Voice for Sarcoma*

*Every day, new sarcoma foundations are springing up. iSPAN's mission is to support and strengthen all our mutual efforts & effectiveness. iSPAN was launched as a collaboration summit with the directors of sarcoma patient advocate organizations.*

*For the first time, the directors and key leaders of sarcoma advocate foundations and organizations came together to:*

- *Learn about each organization's unique role, efforts and contributions;*
- *Establish a communication network between all groups;*
- *Discuss current developments, issues and needs for sarcoma advocates;*
- *Define mutual goals and collaborative strategies.*

### *iSPAN Discussion Group*

*iSPAN also has a private discussion group for sarcoma foundation representatives. We use this forum to keep ourselves aware, educated and mobilized by sharing legislative alerts, research & patient resources. We also work together in task force committees on mutual goals and strategies, which will maximize our efforts & benefit us all.*

*To join the iSPAN discussion group go to:*

<http://health.groups.yahoo.com/group/iSPAN-SarcomaPatientAdvocateNetwork/>



*Novartis Oncology played an important role by providing funding for the meeting and the subsequent publication of this directory; for this, everyone in the sarcoma community extends their most heartfelt thanks.*

## Directory of Sarcoma Patient Advocacy Organizations and Foundations

*Note: Organizations with changes since last publication are listed on the last page of the directory*

	<u>Page</u>
<b>Amschwand Sarcoma Cancer Foundation</b>	5
<b>Association of Cancer Online Resources</b>	7
<b>BeatSarcoma</b>	8
<b>Brian Morden Foundation</b>	9
<b>Central Wisconsin Sarcoma Support</b>	11
<b>Chordoma Foundation</b>	12
<b>Conticanet</b>	14
<b>Cure Alveolar Soft Part Sarcoma International (iCureASPS)</b>	17
<b>Cure Our Children Foundation</b>	18
<b>CureSearch (Children’s Oncology Group/National Childhood Cancer Foundation)</b>	20
<b>Dani’s Foundation</b>	22
<b>Desmoid Tumor Research Foundation</b>	25
<b>Ellen C. McCullough Golf Classic</b>	26
<b>Ensemble contre le GIST</b>	27
<b>Foster Foundation</b>	29
<b>Gift to Cure</b>	30
<b>GIST Cancer Research Fund</b>	31
<b>GIST Support International</b>	32
<b>Go4theGoal Foundation</b>	33
<b>Hope Fund for Sarcoma Research</b>	35
<b>Jared’s Juggernaut</b>	36
<b>Jennifer Hunter Yates Sarcoma Foundation</b>	37
<b>Karen Wyckoff Rein Sarcoma Fund</b>	38
<b>Kristen Ann Carr Fund</b>	40
<b>Liddy Shriver Sarcoma Initiative</b>	42
<b>Life Raft Group</b>	43
<b>Link to Beat</b>	44
<b>LMSarcoma Direct Research Foundation</b>	45
<b>The National Leiomyosarcoma Foundation</b>	46
<b>Northwest Sarcoma Foundation</b>	48
<b>Sarcoma Alliance</b>	50
<b>Sarcoma Alliance for Research through Collaboration</b>	51
<b>Sarcoma Foundation of American</b>	52
<b>Sarcoma Patients EuroNet Association</b>	53
<b>Sarcoma UK</b>	55
<b>Southeastern Sarcoma Foundation</b>	56
<b>sPECial Fund</b>	59
<b>Stowazyszenie Pomocy Chorym na Mięsaki “Sarcoma”</b>	60
<b>Swingaway</b>	61
<b>WWWW Foundation</b>	62
<b>Appendix – Other Organizations</b>	63
<b>The Alliance Against Alveolar Soft Part Sarcoma</b>	
<b>Adam Dealey Foundation for Ewing Sarcoma</b>	
<b>Amandalee Fund</b>	
<b>Anthony Pilcher Bone Cancer Trust</b>	
<b>Backmayer / Hetherington Fund</b>	
<b>Carlene Paris Fund for Sarcoma Research</b>	
<b>Cure Sarcoma, Japan</b>	

**GIST Cancer Research Fund**  
**GIST Support UK**  
**Grind for Life Benefit / Mike Rogers Fund**  
**In Memory of Beverly Cohn Fund**  
**In Memory of Vicki Bundock Dowdeswell / Leiomyosarcoma Cancer Research Fund**  
**Jake's Reindeer Race**  
**Janice and Michael Burk Leiomyosarcoma Research Fund**  
**Jeanette S Moor Leiomyosarcoma Fund**  
**Joanna C Marino Foundation**  
**Joshua Gilbert Rhabdomyosarcoma Appeal**  
**PMC Pan Mass Challenge**  
**Reid R Sacco Memorial Foundation**  
**Richard's Run for Life**  
**Seth A Bailey Sarcoma Cancer Fund**  
**SOS Desmoid Association**  
**Shawn Thomas Memorial Foundation**  
**The Robert and Heather Urich Sarcoma Foundation**  
**The Shelly Glaspell Schiellerd Ewing's Sarcoma Fund**  
**The Terry Fox Foundation**

**Changes Since Last Directory Publication**

**67**

*For additions, corrections, or changes to this directory, please email Arthur Beckert at the Sarcoma Alliance, [abeckert@sarcomaalliance.org](mailto:abeckert@sarcomaalliance.org)*

# AMSCHWAND SARCOMA CANCER FOUNDATION

Non-profit status since: February 2001

Website: [www.sarcomacancer.org](http://www.sarcomacancer.org)

## **Public Contact**

Name/title: Amschwand Sarcoma Cancer Foundation  
Address: 2260 West Holcombe, Suite 174, Houston, Texas 77030  
Phone: 832- 367-WISH (9474)  
Email: [info@sarcomacancer.org](mailto:info@sarcomacancer.org)

## **Executive Director**

Name/Title: Melissa Amschwand Bellinger, Director of External Relations & Programs  
Address: 2260 West Holcombe, Suite 174, Houston, Texas 77030  
Phone: 832- 367-WISH (9474)  
Email: [missy@amschwand.com](mailto:missy@amschwand.com)

## **Services Provided**

- Patient/caregiver education website; includes sarcoma survivor starter notebook for newly diagnosed.
- Patient/caregiver bulletin board; rather than duplicate efforts; ASCF provides funding to ACOR annually to ensure continuation of the various sarcoma lists Sarcoma research advocacy.
- Drug development and/or availability advocacy
- Other: ASCF provides tangible support to patients and families affected by sarcoma in the form of its shared families program (A temporary short-term housing program offered in Houston, Texas for patients who seek treatment in the Texas Medical Center). ASCF also works to ensure a greater community awareness of sarcoma and the needs of those affected by it. Finally ASCF provides funding (in the form of grants) annually to support your sarcoma researchers in their work.

## **Description of Organization's Mission, Goals and Focus:**

The Amschwand Sarcoma Cancer Foundation's mission is to ensure the development of effective strategies for the treatment of sarcoma, the provision of tangible support for these patients, and a greater awareness of sarcoma and the needs of those affected by it.

## **Description of Organization's Accomplishments:**

- § ASCF's physician scientist's grants have resulted in the RO1 funding for some of its researchers.
- § Increased awareness of sarcoma and the needs of those affected by it. ASCF has successfully and consistently earned media coverage of its events all of which have included the definition of sarcoma and information regarding the needs of those affected by this deadly orphan disease. Thousands of persons new to the cause are reached annually as a result of ASCF related events and activities.
- § Ensured annual funding to ACOR since 2001.
- § Development of Sarcoma Survivor Starter Notebook and other resources for the newly diagnosed.
- § Achieved lasting corporate, clinical and philanthropic partnerships that have enabled ASCF to maximize its resources and influence.
- § Development of the Shared Families program – a Houston-based hospitality house concept providing short-term temporary housing to patients seeking treatment, follow-up or consultation for sarcoma within the Texas Medical Center.
- § Maintained a high level of focus and financial responsibility. Development of a long-term strategic plan and oversight by the ASCF board of directors has ensured the organization remains true to its mission and is fiscally responsible.

## **Description Organization's Events**

Various. ASCF's annual signature event is Catwalk for a Cure -- an awareness event, fashion show and luncheon attended annually by approximately 500 local business leaders, clinicians, patients and philanthropic groups.

**Recipients of Organization's Funds**

Directly, researchers and indirectly, patients via the organization's tangible support programs.

## ASSOCIATION OF CANCER RESOURCES (ACOR)

Non-profit status since: 1996

Website: <http://acor.org>

### **Public Contact**

Name/title: Gilles Frydman, President  
Address: 173 Duane St N.Y., N.Y. 10013  
Phone: 212-226-5525 Fax: 646-827-9190  
Email: [gfrydman@acor.org](mailto:gfrydman@acor.org)

**Director** Same as above

### **Services Provided**

- Patient/caregiver education website
- Patient/caregiver doctor and/or clinical trial referrals
- Patient/caregiver counseling
- Patient/caregiver bulletin board online community

### **Description of Organization's Mission, Goals and Focus:**

ACOR is an Internet-based public charity dedicated to improve the quality of care provided to cancer patients and the quality of life of patients, survivors and their caregivers.

ACOR leverages its wide technological and biomedical resource expertise to be a reliable source of knowledge, support and community in a relentless worldwide campaign to empower those suffering from the disease.

ACOR achieves its mission by constantly investing in advanced technologies and improving them to:

- Provide uninterrupted open access to a large nexus of online peer support groups (Health eCommunities) it creates and manages,
- Host a number of exceptional patient-centered websites.
- Conduct breakthrough research.

### **Description of Organization's Accomplishments:**

- One of the largest Internet systems of online medical communities
- Recipient of a Robert Wood Johnson Foundation research grant to study the value of its communities
- Very well known and respected in the cancer communication research community. ACOR is now becoming a partner for various research projects with prime academic institutions.

# BeatSarcoma Inc.

Non-profit status since: August 13, 2007

Website: [www.beatsarcoma.org](http://www.beatsarcoma.org)

## **Public Contact**

Name/title: Nathalie Criou, President  
Address: 76 Ellsworth Street, San Francisco, CA 94110  
Phone: 415-826-0474  
Email: [nat@beatsarcoma.org](mailto:nat@beatsarcoma.org)

## **Services Provided**

- Patient/caregiver education website
- Patient/caregiver counseling
- Newsletter (mail or email.) Frequency: Annual at this time
- Sarcoma research advocacy and fundraising

## **Description of Organization's Mission, Goals and Focus**

BeatSarcoma is a volunteer initiative to help increase awareness about sarcomas, raise funds for research and assist with survivorship issues.

We raise funds to sponsor specific research projects or patient initiatives.

- a) We work closely with the medical community to select un-funded high impact projects.
- b) Currently 100% of funds raised support sarcoma efforts. As we grow, we will be transparent about our expenses.
- c) We fund programs hosted by leading non-profit research institutions.
- d) We favor fundamental, translational and early clinical research as opposed to late clinical trials. The funding needs there are greater and the benefits far-reaching.

## **Description of Organization's Accomplishments**

BeatSarcoma is in its first year of operation. We have set up a website, produced a video about fertility preservation for cancer patients raised about \$10,000 with our BeatSarcoma 5k Fun Run, and donated 15 books to children with sarcoma in hospitals.

## **Description Organization's Events (see website for information)**

BeatSarcoma Annual Fun Run: March 29, 2009 -  
[http://www.beatsarcoma.org/BeatSarcoma\\_Fun\\_Run\\_2009.html](http://www.beatsarcoma.org/BeatSarcoma_Fun_Run_2009.html)

Sarcoma Cup – a 2day regatta on San Francisco Bay, August 22 and 23 -  
[http://www.beatsarcoma.org/Sarcoma\\_Cup.html](http://www.beatsarcoma.org/Sarcoma_Cup.html)

Sarcom' Art - <http://stories.beatsarcoma.org/2008/11/beatsarcoma-announces-beatsarcomart.html>

Online photostore: <http://photo.beatsarcoma.org/>



# BRIAN MORDEN FOUNDATION

Non-profit status since: March 2003

Website: <http://brianmordenfoundation.org>

## **Public Contact**

Name/title: Dawn Morden  
Address: 2809 Columbia Dr., Altoona, PA 16602  
Phone: 814-946-9369  
Email: [fdj@brianmordenfoundation.org](mailto:fdj@brianmordenfoundation.org)

## **Services Provided**

- Patient/caregiver education website
- Newsletter (mail or email.) Frequency: 2-3 times yearly
- Sarcoma research advocacy

## **Description of Organization's Mission, Goals and Focus**

- Fund research for the express purpose of finding a cure and/or better treatment for Ewing's Sarcoma.
- Support patients, family, and staff of pediatric oncology units\*
- Provide funding for "Brian Morden Memorial" higher education scholarships

\*Brian was lovingly cared for at Children's Hospital in Pittsburgh, the initial focus of the second BMF goal. We still plan to contribute in important ways to the oncology unit there, however, we have expanded our outreach with Brian Baskets and "Issy" bears, sending them to other pediatric cancer patients especially to those in the Altoona Area, Janet Weis Children's Hospital in Geisinger, and Penn State Children's Hospital in Hershey where some of our area children are being treated. We have also tried to brighten up the day for some children from the Ewing's Sarcoma list serve. If you know a child with cancer who could use a "pick-me-up," please contact us at [fdj@brianmordenfoundation.org](mailto:fdj@brianmordenfoundation.org). We hope to be able to help as many pediatric oncology patients as possible.

## **Description of Organization's Accomplishments**

- Donated \$25,000 to Dr. James Geiger and his research team at the University of Michigan for a pilot vaccine study
- Sent "Brian Baskets" to Pennsylvania Children's hospitals every major holiday (Thanksgiving, Christmas, New Year's, Valentine's Day, Easter, Fourth of July and Halloween) since Thanksgiving 2003
- Earned National Recognition for our 2004 Make a Difference Day project "Brian Bags for Halloween"
- <http://brianmordenfoundation.org/MakeADifference/MakeADifference.html>
- Created a Ewing's Sarcoma Charity Bear – Issy <http://brianmordenfoundation.org/IssyBear.htm>
- Developed other BMF products to raise funds and awareness – please see: <http://brianmordenfoundation.org/support.html>
- Secured a donation of 20 laptops for Children's Hospital in Pittsburgh – oncology unit

## **Description Organization's Events**

- Please see: <http://brianmordenfoundation.org/activities.html>

## **Recipients of Organization's Funds**

- Dr. James Geiger and his research team at the University of Michigan - \$25,000
- Sarah Connelly – 3<sup>rd</sup> Annual \$1000 Brian Morden Memorial Scholarship

- Danica Myers (Ewing's survivor) – 2<sup>nd</sup> Annual \$1000 Brian Morden Memorial Scholarship
- Josh Applas – 2<sup>nd</sup> Annual \$1000 Brian Morden Memorial Scholarship
- Geo Horvath - 1<sup>st</sup> \$1000 Brian Morden Memorial Scholarship
- Brian Johnson – 1<sup>st</sup> \$1000 Brian Morden Memorial Scholarship
- Pediatric cancer patients at Children's Hospital in Pittsburgh, PA
- Pediatric cancer patients at Janet Weis Children's Hospital in Geisinger
- Pediatric cancer patients Penn State Children's Hospital in Hershey
- Children from Ewing's Sarcoma list serve

## CENTRAL WISCONSIN SARCOMA SUPPORT

Non-profit status since: 2004

Website: [www.sarcomasupport.com](http://www.sarcomasupport.com)

### **Public Contact**

Name/title: Richard Nesbitt

Address: 400 Columbus Dr., Marshfield, WI 54449

Phone: 715-384-3489(h) 800-847-0016 ext 73390(w) Fax: 715-847-3580

Email: [nesbit@charter.net](mailto:nesbit@charter.net) or [nesbitt.richard@marshfieldclinic.org](mailto:nesbitt.richard@marshfieldclinic.org)

### **Director**

Same

### **Services Provided**

- Patient/caregiver education website
- Patient/caregiver counseling

### **Description of Organization's Mission, Goals and Focus**

Provide education and support for people newly diagnosed with sarcoma

### **Description Organization's Events**

Walk for Sarcoma Awareness Events August 28, 2004 and June 11, 2005

### **Recipients of Organization's Funds**

Sarcoma Alliance and Sarcoma Foundation of America

Next year I will include Rare Cancer Alliance as a recipient of the fund raising efforts.

# CHORDOMA FOUNDATION

Non-profit status since: 2007

Website: [www.chordoma.org](http://www.chordoma.org)

## **Public Contact**

Name/title: Josh Sommer  
Address: PO Box 4562, Greensboro, NC 27404  
Phone: 919-809-6779  
Email: [info@chordoma.org](mailto:info@chordoma.org)

## **Director**

Name: Josh Sommer  
Address: PO Box 4562, Greensboro, NC 27404  
Phone: 919-794-8506  
Email: [joshsummer@chordoma.org](mailto:joshsummer@chordoma.org)

## **Services Provided**

- Patient/caregiver education website
- Patient/caregiver doctor and/or clinical trial referrals
- Newsletter (mail or email.) Frequency: quarterly
- Legislative advocacy.
- Sarcoma research advocacy
- Drug development and/or availability advocacy
- Other : Chordoma Biobank, initiate, manage, and fund research

## **Description of Organization's Mission, Goals and Focus**

**Our Mission** is to improve the lives of chordoma patients by rapidly developing effective treatments and ultimately a cure for this devastating disease. We lead a coordinated international research effort to accelerate a cure, while improving the diagnosis, treatment, and quality of life for people affected by chordoma.

We take a big-picture approach to the problem of curing chordoma, ensuring that time and resources are focused to achieve maximum results as quickly as possible. With the input of a diverse group of experts from around the world, we have created a roadmap for developing new effective treatments for chordoma, and serve as the engine to drive this plan forward. Beyond awarding grants, we take an active role in every aspect of the research process by formulating research priorities, recruiting the best researchers, initiating new projects, brokering collaborations, and breaking down barriers to progress.

## **Description of Organization's Accomplishments**

- Sparked scientific interest in chordoma, and united the chordoma research community through international chordoma research workshops, co-hosted with NIH
- Connected chordoma patients, family, and friends, through national community conferences
- Launched over a dozen new research projects
- Developed important new scientific tools such as cell lines and animal models
- Creating a chordoma biobank and patient registry

## **Description Organization's Events**

Hosts yearly research meetings, and patient conferences

## **Recipients of Organization's Funds**

Johns Hopkins University  
Duke University  
University of Florida  
Massachusetts General Hospital  
University College London  
Istituto di Tumori, Milan

# CONTICANET: Connective Tissue Cancer Network

Non-profit status since: European Funded Project launched in Feb. 2006 Website: [www.conticanet.eu](http://www.conticanet.eu)

## **Public Contact**

Name/title: Dr. Simon Baconnier  
Address: Hopital Edouard Herriot  
Oncologie Medicale, Pavillon E  
5 place d'Arsonval  
69437 Lyon  
FRANCE  
Phone: +33 (0)6 32 04 67 76  
Email: [simon.baconnier@conticanet.eu](mailto:simon.baconnier@conticanet.eu)

## **Director**

Name: Pr. Jean-Yves BLAY  
Address: Hopital Edouard Herriot  
Oncologie Medicale, Pavillon E  
5 place d'Arsonval  
69437 Lyon  
FRANCE  
Phone: +33 (0)4 72 11 73 98  
Email: [blay@lyon.fnclcc.fr](mailto:blay@lyon.fnclcc.fr)

## **Services Provided**

- Patient/caregiver education website
- Patient/caregiver doctor and/or clinical trial referrals
- Patient/caregiver counseling
- Newsletter (mail or email.) Frequency: 2-3 times a year
- CTOS conference participation. Other conference participation

## **Description of Organization's Mission, Goals and Focus**

The CONTICANET consortium currently consists of 19 organizations and plans to become a world leader in the understanding, diagnosis and management of connective tissue cancers. This will be achieved by gathering a critical mass of resources and knowledge. In addition it is the objective of the consortium to develop new therapeutic options for connective tissue cancers.

An improvement in our understanding of the epidemiology and biology of these tumors will facilitate the identification of new targets for treatment and generate better prognostic parameters. CONTICANET will improve the diagnosis and treatment of these tumors, not only in the highly specialized centers involved in CONTICANET but also through training of medical doctors - in sufficiently large and adequately equipped hospitals.

Thanks to the participation of patient advocacy groups, patients will also be able to find relevant and useful information for the management of their disease.

Finally, Conticanet will liaise with Regulatory bodies and Health Organizations to ensure that new diagnostic and therapeutic tools are rapidly distributed all over Europe so that equal access to diagnosis and treatment is ensured

## **Conticanet PAG support activities**

PAGs are organized in very variable modalities, in their structures, goals, organisations and means, ranging from small national or even regional organisation, up to international multi language organisations intervening in a large number of countries.

Physicians and researchers are becoming increasingly involved with these patients groups on a daily basis in many aspects of patient management. Because of their increasing role, it is becoming more important to identify precisely their exact contributions and needs. A precise definition of what is a PAG, their role,

function and expected contribution would be important in order to increase the potential benefits of PAG involvement in patient management.

CONTICANET intends to work closely with patient's advocacy groups  
The goal of CONTICANET is to increase efficient interactions between PAGs and researchers in the field of connective tumours, through communication, definition of common goals and strategies.

## **Description of Organization's Accomplishments**

### **Conticanet PAG support activities:**

Integration of 18 European Patients Advocacy Groups (PAG)

<b>Country</b>	<b>Name</b>	<b>Contact Person</b>	<b>Mail</b>
France	<b>SOS Desmoide</b>	Marie Podevin - LeMarchand	<a href="mailto:mpodevin@aol.com">mpodevin@aol.com</a>
United Kingdom	<b>Sarcoma UK</b>	Roger Wilson	<a href="mailto:roger@dflair.demon.co.uk">roger@dflair.demon.co.uk</a>
Switzerland	<b>GIST</b>	Ulrich Schnorf	<a href="mailto:ulrich.schnorf@bluewin.ch">ulrich.schnorf@bluewin.ch</a>
France	<b>Jeunes Solidarité Cancer</b>	Damien Dubois	<a href="mailto:president@jeunes-solidarite-cancer.org">president@jeunes-solidarite-cancer.org</a>
		Keren Borensztajn	
France	<b>Globules Roses d'Any France Sarcome</b>	Vicent-Olivier Beldon	<a href="mailto:gbranya@wanadoo.fr">gbranya@wanadoo.fr</a>
Germany	<b>Life Raft Europe</b>	Markus Wartenberg	<a href="mailto:wartenberg@lebenshauspost.org">wartenberg@lebenshauspost.org</a>
France	<b>AFPG - Ensemble Contre le GIST</b>	Estelle Lecointe	<a href="mailto:ensemblecontrelegist@yahoo.fr">ensemblecontrelegist@yahoo.fr</a>
United Kingdom	<b>Gistsupport UK</b>	Judith Robinson	<a href="mailto:judith@ndrobinson.plus.com">judith@ndrobinson.plus.com</a>
		Dave Cook	<a href="mailto:d.cook@sheffield.ac.uk">d.cook@sheffield.ac.uk</a>
Netherlands	<b>Life Raft Group Nederlands</b>	Hilbrand Bruinsma	<a href="mailto:hb@contactgroepgist.nl">hb@contactgroepgist.nl</a>
		Carolien Verhoogt de Vries	<a href="mailto:cv@liferaftgroup.nl">cv@liferaftgroup.nl</a>
Poland	<b>Stowarzyszenie Pomocy Chorym Na GIST</b>	Stan Kulisz	<a href="mailto:stowarzyszenie@gist.pl">stowarzyszenie@gist.pl</a>
Hungary	<b>Gastrointestinalis Stroma Tumor</b>	Vadnai Agnes	<a href="mailto:gyogyulasazstivel@mailbox.hu">gyogyulasazstivel@mailbox.hu</a>
Italy	<b>A.I.G. - Associazione Italiana GIST</b>	Ana Costato	<a href="mailto:info@gistonline.it">info@gistonline.it</a>
Romania	<b>Romania GIST-Network</b>	Simona Ene	<a href="mailto:si_mi_ene@yahoo.com">si_mi_ene@yahoo.com</a>
Germany	<b>Selbsthilfe Desmoid (sos-desmoid.de)</b>	Christina Baumgarten	<a href="mailto:christina.baumgarten@stud-mail.uni-wuerzburg.de">christina.baumgarten@stud-mail.uni-wuerzburg.de</a>
Israel	<b>Israeli GIST Support group</b>	Shtang Benjamin	<a href="mailto:ehuds@merkavim.co.il">ehuds@merkavim.co.il</a>
Norway	<b>Life Raft Group Norway</b>	Jan-Einar Moe	<a href="mailto:jeinmoe@online.no">jeinmoe@online.no</a>
Belgium	<b>Contact Groep GIST</b>	Krys Heyman	<a href="mailto:kris.heyman1@telenet.be">kris.heyman1@telenet.be</a>
Poland	<b>Sarcoma PL</b>	Kamil Dolecki	<a href="mailto:kamil.dolecki@sarcoma.pl">kamil.dolecki@sarcoma.pl</a>

Annual Patient Advocacy Group Workshop gathering PAG, Physician and researchers.  
Creation of a Core PAG team (Das Lebenshaus, Sarcoma UK, AFPG – Ensemble contre le GIST, GIST Support UK)

Development of a European wide initiative called ESPN (European Sarcoma Patient Network)

### **Description Organization's Events**

Annual European PAG workshop.

Define and develop strategic area of collaboration between PAG and clinical research word

- Clinical Trial accrual
- Informed consent improvement
- First diagnosed patient follow up
- Expert patients and centers

### **Recipients of Organization's Funds**

Project partners:

- Research institutions
- Industrial partners
- Clinical centers
- Hospitals
- Further targeted support (event co funding, PAGs travel expenses for Conticanet events)



<b>CURE ALVEOLAR SOFT PART SARCOMA INTERNATIONAL</b> <b>iCureASPS</b>
--

Non-profit status since: not yet

Website: <http://cureasps.org/>

**Public Contact**

Name/title: Yosef Landesman, PhD  
Address: 260 Tappan St., Brookline MA 02445  
Phone: 781-466 4411 Fax:  
Email: [landesmany@yahoo.com](mailto:landesmany@yahoo.com)

**Director**

Yosef Landesman, PhD : President and Cancer Research Director

**Services provided**

- Patient/caregiver education website
- Patient/caregiver doctor and/or clinical trial referrals
- Patient/caregiver bulletin board \_ chat Room, \_ online support group\_\_yes\_
- Newsletter (mail or email.) Frequency: \_not constant\_\_\_\_\_
- Sarcoma research advocacy
- Drug development and/or availability advocacy

**Description of Organization's Mission, Goals and Focus**

Our organization aims to bring together Alveolar Soft Part Sarcoma (ASPS) patients, their families and friends who have a shared interest to find a cure for ASPS. We actively look for institutions and laboratories that are engaged in research aimed to find a cure for ASPS and support them by funds and shipments of fresh or frozen ASPS tumors from patients who agree to donate their tumors for research. Our website serves as a platform that provides updated information about the research and therapies for ASPS patients and their medical caregivers. Using this knowledge, patients can make better decisions regarding their ASPS treatments. Using our online Forum, members can share their experiences and get information and group support from the ASPS community all over the world. The information network thus generated through patients' communication helps to collect valuable information about this very rare disease and is a key to the success of finding the best available treatments and ultimately to finding a cure.

**Description of Organization's Accomplishments**

1. Efficient fundraiser
2. Active involvement in opening the first clinical trial for Alveolar Soft Part Sarcoma at the Dana Farber Cancer Institute in Boston
3. Initiating additional studies that may result in more clinical trials at the Dana Farber Cancer Institute, or in other institutions.
4. Creating international support group through our website

**Description Organization's Events**

We have a Team of bike riders: "Team ASPS". The team participates in the PMC bike ride of the Jimmy Fund once a year.

**Recipients of Organization's Funds**

1. Dana Faber Cancer Institute, Boston MA
2. Volcani Center, Israel

# THE CURE OUR CHILDREN FOUNDATION

Non-profit status since: 1999

website: [www.cureourchildren.org](http://www.cureourchildren.org)

## **Public Contact**

Name/title: Barry Sugerman, President  
Address: 711 S Carson, Street, Suite 4, Carson City, NV 89701-5299  
Phone: 310-355-6046 Fax: 310-454-9592  
Email: [barry@cureourchildren.org](mailto:barry@cureourchildren.org)

## **Director**

Name: Barry Sugerman  
Address: 1730 Michael Lane, Pacific Palisades, CA 90272-2037  
Phone: 310-355-6046 Fax: 310-454-9592  
Email: [barry@cureourchildren.org](mailto:barry@cureourchildren.org)

## **Services Provided**

- Patient/caregiver education website
- Patient/caregiver doctor and/or clinical trials referral
- Patient/caregiver counseling
- Drug development and/or availability advocacy

## **Description of Organization's Mission, Goals and Focus**

To educate the general public by providing a centralized internet information site to assist parents, families and caregivers of children who have cancer and other life threatening diseases. This information site will assist in learning about the child's disease, current treatments, new and developing treatments, and holistic and complimentary treatment options. The site will also direct the readers to doctors, hospitals and other experts specializing in particular disease treatment. The web site is located at <http://www.cureourchildren.org>.

To provide the latest educational material to the general public and to health care professionals about early diagnosis of life threatening diseases affecting children through the internet site, in printed material, and through public speaking engagements and phone conferences.

To form, operate and maintain a committee of expert doctors and other health care professionals that have demonstrated outstanding achievement in treatment of children's life threatening diseases, and have those experts available to counsel children and their families about treatment options.

To provide social, emotional and financial support for children that have life threatening diseases and for their families and caregivers. This will be in the form of toys, gifts, and grants directly to children, their families or caregivers.

To support research into new and upcoming cures and remedies for diseases that are life threatening to children by providing information resources, suggested study protocol comments, and other resources for worthy research projects.

To support free distribution of a flavoring agent to be added to oral medicines to improve taste so children will not hesitate taking their medicine.

## **Description of Organization's Accomplishments**

Numerous original research publications including "Preparing the home for the chemotherapy patient", "Disabled sports" and other topics

## **Description Organization's Events**

Press releases to the national news media when new research is available.

**Recipients of Organization's Funds**

We use our fund for internal research purposes and periodically for family assistance programs.

**CURESEARCH**  
**CHILDREN'S ONCOLOGY GROUP / NATIONAL CHILDHOOD CANCER FOUNDATION**

Website: [www.curesearch.org](http://www.curesearch.org)

**Public Contact**

Name/title: Joan Darling, Ph.D., Patient Advocate Committee for Soft Tissue Sarcomas  
Address: 611 Hazelwood Drive, Lincoln, NE 68511  
Phone: Tel: 402-423-1353 Fax: 402-474-5160  
Email: [yesak@inetnebr.com](mailto:yesak@inetnebr.com) or [JDarling@oaconsulting.com](mailto:JDarling@oaconsulting.com)

Name/title: Angie Pemberton, Patient Advocate Committee for Bone Sarcomas  
Address: 6518 Tavern Creek Road  
Phone: 573-498-3394  
Email: [angiebadge@aol.com](mailto:angiebadge@aol.com)

**Director**

Paul T. Burke, President, CureSearch National Childhood Cancer Foundation  
Gregory H. Reaman, MD, Chairman, Children's Oncology Group  
Address: HEADQUARTERS OFFICE  
4600 East West Highway, #600  
Bethesda, MD 20814-3457  
Phone: (800) 458-6223  
Email: [info@curesearch.org](mailto:info@curesearch.org)

**Services Provided**

- Patient/caregiver education website
- Patient/caregiver doctor and/or clinical trial referrals
- Patient/caregiver counseling
- Patient/caregiver bulletin board \_\_ chat Room, \_\_online support group
- Newsletter (mail or email.)
- Legislative advocacy (NCCF). Issues: Pediatric cancer research
- Sarcoma research advocacy (COG – for pediatric cases)
- Drug development and/or availability advocacy
- NCI committee participation.
- CTOS conference participation.
- Other: Clinical trial development, research and treatment of children and adolescents with cancer, advocacy events

**Description of Organization's Mission, Goals and Focus**

The shared vision of the CureSearch National Childhood Cancer Foundation and the Children's Oncology Group is to reach the day when every child with cancer can be guaranteed a cure.

The CureSearch National Childhood Cancer Foundation (NCCF) raises funds and awareness to conquer childhood cancer. These funds support the work of the CureSearch Children's Oncology Group (COG), the leading organization of doctors and scientists dedicated to discovery and compassionate cures for infants, children, teens and young adults with cancer at over 200 institutions throughout North America and abroad.

The mission of the CureSearch COG is to eliminate the personal, family and societal burden of cancer in children and adolescents by:

- Preventing and curing childhood and adolescent cancer through scientific discovery and compassionate care.
- Performing clinical and research trials.
- Conducting laboratory research.
- Identifying the causes of childhood cancer.

### **Description of Organization's Accomplishments**

The CureSearch COG has treated more children with cancer than any other organization in history and has been responsible for many of the improvements in the treatment and cure rates during the past 40 years. But its most lasting legacy may be in developing a model of cooperative research.

### **Description Organization's Events**

COG: Semi-annual meetings (not open to the public); publications including scientific research as well as educational information for patients, families and survivors. For one example, see:

[www.survivorshipguidelines.org](http://www.survivorshipguidelines.org)

NCCF: Childhood Cancer Advocacy Network, Gold Ribbon Days, Childhood Cancerline Newsletter; many other activities. For more information see:

<http://www.curesearch.org/howtohelp/>

### **Recipients of Organization's Funds**

93.5% of total funds expended by CureSearch NCCF in 2003 were used to support research and for advocacy programs to benefit children with cancer and their families.

88.9% of funds were used to support COG clinical and biological research.

4.6% funded CureSearch NCCF initiatives to raise public awareness and advocate for children with cancer and their families.

6.5% of total expenses were spent on fundraising and administration.

85.3% of total annual revenue was secured through research awards from the National Cancer Institute in response to grant applications; remaining revenue came from charitable support, investment income and non-federal grant support.

# DANI'S FOUNDATION

Non-profit status since: 1999

Website: [www.danisfoundation.org](http://www.danisfoundation.org)

## **Public Contact**

Name/title: Michele Ashby, Founder & President  
Address: 1600 Broadway, Suite 2400, Denver, CO 80202  
Phone: 303/601-1881  
Email: [michele@minellc.com](mailto:michele@minellc.com)

## **Director**

Name: Martha Simmons, Executive Director  
Address: 1600 Broadway, Suite 2400, Denver, CO 80202  
Phone: 303/601-1881  
Email: [Martha@danisfoundation.org](mailto:Martha@danisfoundation.org)

## **Services Provided**

- Patient Assistance - Dani's Foundation offers patients assistance grant funding to pediatric sarcoma patients throughout the United States to assist in paying for outstanding medical and human need. For guidelines and application, email to [martha@danisfoundation.org](mailto:martha@danisfoundation.org)
- Patient/caregiver education website
- Patient/caregiver doctor and/or clinical trial referrals
- Patient/caregiver counseling (instituting and continuing to support the Teen Clinic at The Children's Hospital in Denver, CO)
- Newsletter (mail or email.) Frequency: mail Sarcoma Quarterly 4 times per year. Send out electronic newsletters twice per month.
- Legislative advocacy. Issues: Patient Assistance, Education & Research
- Member of the CO Kids Cancer Association.
- CTOS conference participation.
- Other conference participation: Targeted Therapy for Childhood Cancers (Spring 2009) at Georgetown – Michele Ashby presented.

## **Description of Organization's Mission, Goals and Focus**

*The mission of Dani's Foundation, a charitable organization that was formed in 1999, is to find the cause and the cure for sarcomas affecting children and young adults.*

*Dani's Foundation is dedicated to advancing a global initiative that will be aimed at:*

- *Funding research that will find the cause and the cure for sarcomas including Ewing's Sarcoma (EWS), osteosarcoma and other forms of sarcomas that affect children and young adults;*
- *Funding studies that will target improved treatment protocols for all sarcoma patients;*
- *Implementing community education programs that will inform the public-at-large on the varieties of sarcomas;*
- *Providing valuable resource information and financial support for sarcoma patients.*

## **Description of Organization's Accomplishments**

Since its inception, Dani's Foundation has provided funding to the following grants and awards:

**1999** - A memorial fund at The Children's Hospital (TCH) in Denver received approximately \$30,000, which was used to fund two Dani's Dine In Kiosks.

*Dani's Dine In Kiosks help families and staff order food from nearby restaurants while they are in the hospital.*

**2000** - Dani's Foundation awarded \$18,000 to the Denver Cancer Center at The Children's Hospital in Denver for research aimed at Ewing's Sarcoma and other pediatric cancers.

**2001** - Dani's Foundation awarded \$20,000 to Dr. Jeffrey Toretsky, at the Lombardi Comprehensive Cancer Center, providing pilot funding to extend his research on Ewing's Sarcoma; \$10,000 to the new Teen Clinic at The Children's Hospital in Denver; \$5,000 to Dr. Edythe Albano's research at The Children's Hospital in Denver; \$1,000 to the Marchello Scholarship Fund, a scholarship fund for young cancer survivors.

**2002** - Dani's Foundation awarded \$5,000 to Dr. Jeffrey Toretsky to extend his research on Ewing's Sarcoma; \$5,000 to Dr. Edythe Albano's research at The Children's Hospital in Denver; \$1,000 to the Marchello Scholarship Fund.

**2003** - Dani's Foundation awarded \$5,000 for the continuation of the Teen Clinic at The Children's Hospital in Denver; \$5,000 to Dr. Jeffrey Toretsky to continue his research on Ewing's Sarcoma; \$2,000 to the Marchello Scholarship Fund.

**2004** - Thanks to funding support from Dani's Foundation, Dr. Jeffrey Toretsky's lab discovered a key combination of two proteins in Ewing's Sarcoma.

*By preventing these two proteins from interacting, the research scientists believe the effect could be similar to removing the spark plug wires from the spark plugs in a car: without spark plugs, a car cannot run. Similarly, without this protein interaction, Ewing's Sarcoma cells cannot survive.*

Dani's Foundation was instrumental in providing funding for Dr. Toretsky's lab to create novel peptides to prevent this interaction.

**2004** - Dani's Foundation awarded \$10,000 to Dr. Larry Wiese, at Therapherisis Inc., for research into new treatments for cancer patients; \$5,000 for the continuation of the Teen Clinic at The Children's Hospital in Denver.

**2005** - Dani's Foundation awarded \$5,000 to Dr. Jeffrey Toretsky to continue his research on Ewing's Sarcoma.

**2006** - Dani's Foundation awarded \$2,500 in funding to The Children's Hospital in Denver for the purchase of new DVD players for all patient rooms in the oncology ward; \$5,000 to Dr. Jeffrey Toretsky to continue his research on Ewing's Sarcoma; \$5,000 for the continuation of the Teen Clinic at The Children's Hospital in Denver; \$1,000 to the Marchello Fund.

**2007** - Dani's Foundation awarded \$10,000 to Dr. Jeffrey Toretsky to continue his research on Ewing's Sarcoma; \$5,000 for the continuation of the Teen Clinic at The Children's Hospital in Denver; \$1,000 to the Marchello Scholarship Fund.

**2008** - Dani's Foundation awarded \$10,000 to Dr. Jeffrey Toretsky to continue his research on Ewing's Sarcoma, host its first annual EWS Medical Forum in Denver, CO and hired a full time Executive Director to assist in the continued growth of the Foundation.

**2009** - Dani's Foundation awarded \$10,000 to Dr. Jeffrey Toretsky to continue his research on Ewing's Sarcoma. Hosted the first joint meeting of Ewing's advocates and organization with the goal of uniting to advocate, educate and jointly develop and fund research opportunities.

**2010** - Thanks to the generosity of many during FY 2010, Dani's Foundation was successful in raising the funding to award two major research grants: \$100,000 is being awarded to Dr. Jeffrey Toretsky to continue his research on novel treatments for Ewing's Sarcoma and, in addition to this annual research grant, a \$25,000 grant has also been awarded to the Colorado State University Animal Cancer Center for their study

of Stereotactic Radiation Therapy (SRT) for local control of bone tumors. In addition to funding amazing research, the Foundation was successful in adopting the development of a Patient Assistance Grant Program that will launch in March 2011. That program will provide financial assistance to pediatric sarcoma patients and their family members who are financially struggling to pay the bills associated with their cancer diagnosis and treatment. 2010 also marked the inauguration of the **STOP LOOK & LIVE** community education program. Since August 2010, over 8,000 brochures and posters have been distributed to educators throughout the State of Colorado.

#### **Description Organization's Events**

- Annual Benefit (Spring)
- Purses With A Purpose On Line Auction (Summer)
- CO Step Up For Cancer (Summer)
- STEPS (Stride To End Pediatric Sarcoma) Walk (Fall)
- Year End Campaign (November)

#### **Recipients of Organization's Funds**

- Dr. Jeffrey Toretzky, at the Lombardi Comprehensive Cancer Center at Georgetown
- Dr. Larry Wiese, at Therapherisis Inc
- Dr. Stewart Ryan and Dr. James Custis, at the Colorado State University Animal Cancer Center, Fort Collins, CO
- The Children's Hospital (TCH) in Denver
- Denver Cancer Center at The Children's Hospital in Denver
- Teen Clinic at The Children's Hospital in Denver
- Marchello Scholarship Fund



# THE DESMOID TUMOR RESEARCH FOUNDATION

Non-profit status: 2005

Website: [www.desmoidtumorresearchfoundation.org](http://www.desmoidtumorresearchfoundation.org)  
[www.dtrf.org](http://www.dtrf.org)

## **Public Contact**

Name: Marlene Portnoy  
Address: 16 Marget Ann Lane Suffern, NY 10901  
Phone: (845) 357-2338  
Email: [marleneportnoy@gmail.com](mailto:marleneportnoy@gmail.com)

Name: Jeanne Whiting  
Phone: (203) 966-7240  
Email: [jgwhiting@aol.com](mailto:jgwhiting@aol.com)

## **Description of Organization's Mission, Goals and Focus**

Our Mission is to advance the science related to the diagnosis, treatment and prevention of desmoid tumors, by:

- Increasing funding and support of research into the biological mechanisms and clinical strategies related to the diagnosis, treatment and prevention of desmoids tumors
- Facilitating and enhancing the dialog among members of the medical and scientific communities about basic and clinical research efforts that relate to desmoid tumors.
- Heightening the public's awareness of desmoid diagnosis and treatment and providing informational support for patients, their families and friends.

## **Description Organization's Events**

- November 2009 Cirque du Survivor Fundraiser, San Francisco, California
- Oct 2009 Patient Support Meeting and Gala Fundraiser, Westchester, New York
- May 2008 Patient Support Meeting and Fundraiser
- May 2007 Second Annual Dinner Fundraiser
- Golf Tournament in memory of Joan Holman
- July 2007 Photo Exhibit and Fundraiser
- May 2006 First Annual Dinner Fundraiser
- DTRF 5k Run in Tampa, FL.
- November 2010 Patient Support Meeting and Walk/Run in Philadelphia, PA
- May 2011 Wine Tasting in Piermont, NY
- October 2011 Patient Support Meeting and Walk/Run in Philadelphia, PA

## **Recipients of Organization's Funds**

- [The Hospital for Sick Children in Toronto](#), Benjamin A. Alman, MD: Identifying the Desmoid Initiating Cell.
- [Huntsman Cancer Center-](#), David E. Joyner, PhD: Do growth factors mediate desmoid tumor invasiveness and drug sensitivity?
- [MD Anderson Cancer Center-](#), Dina Lev, MD: Molecular determinants of desmoids tumor development and progression.
- [Stanford University](#), Matt van de Rijn, MD, PhD: ROR2, a potential novel therapeutic target in desmoids tumors.
- [University of Pennsylvania](#), Richard D. Lackman, MD: The role of hydroxyurea as first line treatment for primary and recurrent/refractory desmoids tumors.
- [The University of Chicago](#), Dr. Stephen Skapek, MD: Deregulated mTor in desmoid type fibromatosis: identification and validation of a new therapeutic agent.

## ELLEN C. MCCULLOUGH GOLF CLASSIC

### **Public Contact**

Name/title: Kathy McCullough, Karen Dell' Aglio, Kelly Huber, Co-Presidents  
Address: c/o Hall Court Park Ridge NJ 07656  
Phone: 201-391-4757  
Email: [KathyOT@aol.com](mailto:KathyOT@aol.com)

### **Services Provided**

- Leiomyosarcoma (LMS) research fund raising

### **Description of your Organization's Mission, Goals and Focus**

- To raise money for the genetic aspects of LMS
- To educate and increase awareness about sarcoma and where one should receive treatment with a focus on LMS

### **Description of organization's Accomplishments**

- Have held two successful fund raising events

### **Description Organization's Events**

- We have held golf tournaments in June 2004 and 2005.

### **Recipients of Organization's Funds**

- Funds raised are distributed to researchers in New York, New York for LMS genetic research.

# Ensemble contre le GIST

Non-profit status since: October 11<sup>th</sup>, 2005

Website: [www.ensemblecontrelegist.org](http://www.ensemblecontrelegist.org)

## **Public Contact**

Name/title: Estelle LECOINTE

Address: 4, avenue des acquêts – 35650 Le Rheu (France)

Phone: None

Email: [info@ensemblecontrelegist.org](mailto:info@ensemblecontrelegist.org)

## **Director**

Name : Estelle LECOINTE

Address: 4, avenue des acquêts – 35650 Le Rheu (France)

Phone: None

Email: [info@ensemblecontrelegist.org](mailto:info@ensemblecontrelegist.org)

## **Services Provided**

- Patient/caregiver education website
- Patient/caregiver doctor and/or clinical trial referrals
- Patient/caregiver counseling
- Patient/caregiver bulletin board ; chat Room, online support group
- Newsletter (mail or email.) Frequency : Monthly
- Sarcoma research advocacy
- Drug development and/or availability advocacy
- CTOS conference participation
- Other conference participation: Novartis annual GIST patient summit ; ECCO14 (Barcelona)

## **Description of Organization's Mission, Goals and Focus**

The missions of “Ensemble contre le GIST” are the following ones :

- 1 **Providing information about GIST and treatments to patients and caregivers.**
- 1 **Gathering French speaking GIST patients and caregivers in order to create a support network.**
- 1 **Promoting the knowledge of GIST within the French medical and scientific community so as to improve the management and care of this disease.**
- 1 **Supporting French GIST scientific and medical research.**

We actually support three different studies about GIST :

- 1 **“MolecGIST”** : French GIST molecular epidemiological study.
- 1 **“EndoGIST”** : Prospective survey focusing on small oesogastroduodenal GIST tumors monitored by endoscopy.
- 1 **“IMAIL2”** : Phase I clinical trial which aim is to identify IKDCs in the human body and to assess the efficacy of the “Gleevec+Interleukine2” combination in the treatment of GIST cancer.

As GIST is a very rare cancer, we are also willing to inform doctors on its peculiarities to optimize GIST patients' follow-up and survival. In order to reach this point, we work hard to set up a strong collaboration with French and European scientific groups and networks such as the “French Sarcoma Group” and the “CONTICANET” network.

Our group also tries to be represented in most of the major French and international events dealing with GIST or Cancer.

Furthermore, we've recently applied to join the French NCI patient committee.

## Description of Organization's Accomplishments

- 1 Brochure about GIST : **“Mieux connaître sa maladie”** (Updated in january 2008)
- 1 Brochure about compliance in French : **“L'observance au traitement : devenir acteur de sa prise en charge thérapeutique au quotidien”**.
- 1 PDF English version of the brochure : **“Compliance with treatment : be an active partner in your GIST care everyday”** (Soon online on the CONTICANET website : [www.conticanet.eu](http://www.conticanet.eu)).
- 1 Brochure about “SUTENT” (in partnership with Pfizer).
- 1 English version of our website : [www.ensemblecontrelegist.org](http://www.ensemblecontrelegist.org) (March 2008).

## Description Organization's Events

- 1 French National Information Campaign dealing with Cancer : In 2007, Estelle LECOINTE participated in the biggest national information campaign that had ever been made in France and embodied the image of GIST in France.
- 1 General assembly : Annual event occurring in november.
- 1 **“The Race of hope”**: Healthy people, GIST patients, caregivers, and doctors are going to run for a day in order to collect funds for the French GIST research. This event will occur in Fougères (35) on june, 1<sup>st</sup> 2008.
- 1 **“The GIST Patients day”** : Scientific sessions specifically made for GIST patients and caregivers. This event will occur in November, 22<sup>nd</sup> 2008 in Lyon.

## Source of Organization's Funds

- 1 **Public and private Donations**
- 1 **Conticanet**
- 1 **Novartis**
- 1 **Pfizer**

# Foster Foundation

Non-profit status since: 2002

Website: [www.fosterfoundation.com](http://www.fosterfoundation.com)

## **Public Contact**

Name/title: Joseph Leondis, Trustee  
Address: 25 Rockaway Ave, Garden City, NY 11530  
Phone: 516-746-6516  
Email: [info@fosterfoundation.com](mailto:info@fosterfoundation.com)

## **Services Provided**

- Sarcoma research advocacy
- Drug development and/or availability advocacy

## **Description of Organization's Mission, Goals and Focus**

- Osteosarcoma Research

## **Description of Organization's Accomplishments**

- Funded basic research for a targeted therapy

## **Description Organization's Events**

- Various Fund Raisers

## **Recipients of Organization's Funds**

- Medical Researchers

<b>Gift To Cure Corporation</b>
---------------------------------

Non-profit status status: applied July 28, 2010

Website: [www.gifttocure.org](http://www.gifttocure.org)

**Public Contact**

Name: Stacie Hubbard (Director)  
Address: 3733 Sheridan Road, Cameron Park CA 95682  
Phone: 530-244-5428  
Email: [staciehubbard@gifttocure.org](mailto:staciehubbard@gifttocure.org)

**Director**

Name/title: Salome E Klopper (President/Founder)  
Address: PO Box 825, El Dorado, CA 95623  
Phone: 714-600-2509  
Email: [sallyklopper@gifttocure.org](mailto:sallyklopper@gifttocure.org)

**Services Provided**

- Patient/caregiver DSRCT education website
- Patient/caregiver DSRCT doctor and/or clinical trial referrals
- Patient/caregiver chat room link
- Newsletter email monthly
- DSRCT research advocacy
- NCI committee participation
- CTOS conference participation
- Patient/caregiver financial support
- List of all DSRCT patients and link to DSRCT statistics

**Description of Organization's Mission, Goals and Focus**

The mission of GiftToCure is to:

- Support individuals with DSRCT and their immediate families by providing information, as well as emotional and financial support;
- Raise public awareness; and
- Sponsor research toward more-effective treatment and, ultimately, a cure for DSRCT.

We achieve our mission through the support of many volunteers and our Board of Directors. Our activities include:

- Providing support to, and exchanging information with, other professional cancer programs;
- Selling awareness merchandise;
- Hosting public fundraisers and community awareness events;
- Requesting corporate grants and private donations.

**Description of Organization's Accomplishments**

- Various fundraisers to fund DSRCT research for a cure and improved treatment at Stehlin Institute in Houston TX
- Brought the DSRCT community closer to each other
- Provide valuable information for DSRCT community about treatments, doctors, and treatment centers

**Description Organization's Events**

- Online Fundraisers
- DSRCT Public Fundraisers and Community Events (walk/run/cycling),
- Poker Run and fund raisers with the Biker Community
- Cycling events together with Team-Will
- Planned for the future – More of the above
- Raising awareness and funds through Facebook/Twitter
- Annual DSRCT Summit
- Public fundraisers with help of Special Speakers/ Entertainers
- Combined events with other non-profits, etc.

**Recipients of Organization's Funds**

- DSRCT patients and family (hardship)
- Stehlin Institute (DSRCT Research)
- Educational events to raise awareness

# GIST CANCER RESEARCH FUND

Non-profit status since: December 3, 2002

Website: [www.gistinfo.org](http://www.gistinfo.org)

## **Public Contact**

Name/title: Tania Stutman Chairperson  
Address: 55 Sawmill Rd., New City, NY 10956  
Phone: 845 634-1174  
Email: tania5kids@aol.com

## **Director**

Name: Tania Stutman  
Address: 55 Sawmill Rd., New City, NY 10956  
Phone: 845 634-1174  
Email: tania5kids@aol.com

## **Services Provided**

- 1 Patient/caregiver education website
- 2 Patient/caregiver doctor and/or clinical trial referrals
- 3 Sarcoma research advocacy
- 4 Drug development and/or availability advocacy
- 5 NCI committee participation.
- 6 CTOS conference participation.

## **Organization's Mission, Goals and Focus**

To raise money for GIST research

## **Organization's Accomplishments**

Raised \$1,500,000.00 in the past 2 years for GIST research

## **Organization's Events**

Annual Walks for a Cure: NY, California, Oregon, Washington.  
Silent Auction and Dinners: Atlanta, Ga. and Long Island, NY

## **Recipients of Organization's Funds**

Memorial Sloan Kettering  
Fox Chase  
Dana Farber  
OHSU-Coreless and Heinrich Lab  
University of Pittsburg

## GIST SUPPORT INTERNATIONAL

Non-profit status since: March 2005

Web site: [www.gistsupport.org](http://www.gistsupport.org)

### **Public Contact**

Name/title: Marina Symcox, PhD Co-manager  
Address: 209 West 10 Avenue Bristow, OK 74010  
Phone: 918-367-9279  
Email: [gsi@gistsupport.org](mailto:gsi@gistsupport.org)

Name/title: Lee Ann Lamb, Co-manager  
Address: 12 Bomaca Dr Doylestown PA 18901  
Phone: 215-340-9374 Fax: 215 340-1630  
Email: [gsi@gistsupport.org](mailto:gsi@gistsupport.org)

Julie Royster, PhD  
Title: Science Coordinator  
Email: [julie\\_royster@bellsouth.net](mailto:julie_royster@bellsouth.net)

### **Services provided**

- Patient/caregiver education website-yes
- Patient/caregiver bulletin board \_yes\_ chat Room, yes -online support group yes
- Attend GIST relevant medical conferences to gather up to date educational information for our group.
- Volunteer network of Phone Pals to talk with those in need of personal contact
- Separate Grief and Loss support list for those facing the loss of a loved one
- Offer a clinical trials referral service through EmergingMed Clinical Trials Service direct link on GSI web site

### **Description of Organization's Mission, Goals and Focus:**

GIST Support International (GSI) is an all-volunteer, non-profit organization dedicated to outreach, education and support of GIST patients and their families and friends. GIST Support International is committed to the concept of free communication and open membership. Communication with our members is through LISTSERV mailing list which is donated to GSI by LSoft and our frequently updated website.

### **Description of Organization's Accomplishments:**

Our website currently uses a blog format to update our science information with the most comprehensive GIST relevant publications and abstracts found in one place. We have almost 600 members in 25 countries world wide.



# Go4theGoal Foundation

Non-profit status since: July 2006

Website: [www.go4thegoal.org](http://www.go4thegoal.org)

## **Public Contact**

Name/title: Beth Stefanacci  
Address: 300 West Maple Ave., Merchantville, NJ 08109  
Phone: 609-313-0912  
Email: [bethstefanacci@aol.com](mailto:bethstefanacci@aol.com)

## **Director**

Name: Charla Lewis  
Address: 43 E. Cedar Ave., Merchantville, NJ 08109  
Phone: 609-636-7184  
Email: [g4theg@gmail.com](mailto:g4theg@gmail.com)

## **Services Provided**

- Patient/caregiver education website
- Newsletter (mail or email.) Frequency: quarterly
- Legislative advocacy. Issues: Research funding
- Sarcoma research advocacy – Ewing’s sarcoma
- Drug development and/or availability advocacy
- Other : Support for children with cancer, gift baskets, wish granting, working with Companions in Courage and Dream Street camp for kids with life threatening diseases – we support cancer patients going to the camp.

## **Description of Organization’s Mission, Goals and Focus**

Go4theGoal Foundation is a not-for-profit corporation that was formed in 2006 by Dr. Richard & Beth Stefanacci when their oldest son Richard (13) was diagnosed with Ewing’s Sarcoma, a form of bone cancer. At this time, we saw the great need that existed for research in this field, as well as social support for patients and their families.

It became evident very early on in Richard’s treatment that many other children suffering from childhood cancer do not have the emotional, financial and logistical support that they are fortunate enough to have for Richard. With the outpouring of support from family, friends, and neighbors far outstripping their needs, Richard & Beth did what came naturally to them which was to bring together the surplus of resources with the great need to improve the lives of children and their families affected with cancer.

Go4theGoal Foundation is a public charity whose funds will be used to provide supportive services to children with cancer and their families with the goal to provide a sense of “normalcy” in their lives while they “Go4theGoal” of being healthy again soon.

Go4theGoal Foundation is a dedicated to finding a cure for Ewing’s Sarcoma. We are also involved with helping children and their families affected by pediatric cancer.

## **Research Funding**

At this time, our research funding is going to Dr. Jeffrey Toretsky, MD and his team of researchers at the Lombardi Comprehensive Cancer Center at Georgetown University, who are dedicated to finding a cure for Ewing’s Sarcoma. Besides the cutting edge research happening in his lab, we were inspired by Dr. Toretsky’s personal dedication since his first patient was diagnosed with Ewing’s Sarcoma in 1981. He has also been affiliated with the National Cancer Institute and the University of Maryland.

## **Social Giving**

In our mission to help pediatric cancer patients and their families, we are able to provide financial assistance for day to day expenses as well as special requests. Annual holiday gift baskets are given to pediatric cancer patients at area hospitals. We also work with local schools developing volunteer programs for community service projects.

Since Richard’s death in June 2007, the Go4theGoal Foundation has increased our efforts towards accomplishing our goals. Along with your support, we can achieve these goals and our dream of finding a cure for Ewing’s and other sarcomas

## **Description of Organization’s Accomplishments**

We are a small grassroots organization founded when the Stefanacci’s son, Richard, was diagnosed with Ewing’s sarcoma. We started slowly with a few events in the year of Richard’s treatment but since his death, have grown with additional events and reaching out to more hospitals each year. We began funding research and have continued to stay involved with the advancement of a cure for Ewing’s sarcoma. Our goal is to continue to grow to reach more children reach year and not stop until we find a cure for Ewing’s.

## **Description Organization’s Events**

Richard's Run – 5K in HoHoKus, NJ held each fall, Oct. 2009 will be the 4<sup>th</sup> annual  
Bowling the Goal- bowling event held in Feb. – 3<sup>rd</sup> annual planned for Feb. 2010  
Richard's River Run – 5K in Pennsauken, NJ – 3<sup>rd</sup> annual May 3, 2009  
Richard's Drive 4 a Cure – Golf Outing, Horsham, PA 2<sup>nd</sup> to be held in June 2009  
Casino Night – Cherry Hill Health and Racquet Club held annually in April.

**Recipients of Organization's Funds**

Dr. Jeff Toretsky's lab at Georgetown University – Annual research support since Dec. 2007  
Various hospitals that receive the gift baskets at the December holidays include Children's Hospital of Philadelphia, Hackensack Hospital, Georgetown University, St. Christopher's in Philadelphia, Seattle Children's Hospital, Cooper Hospital in Camden, NJ.

## THE HOPE FUND FOR SARCOMA RESEARCH

Non-profit status since: **2006, Donor-advised fund through NFCR (www.nfcr.org)**

Website: n/a

### **Public Contact**

Name/title: Marianne Bouldin  
Address: 304 Charlesgate Place Nashville, Tn. 37215  
Phone: 615 298-7798 or 202 333-6867  
Email: mariannebouldin@mac.com

### **Director**

Name/Title: Marianne Bouldin / Kenneth A. Bouldin co-directors  
Address: Same as above

### **Services provided**

- Newsletter
- Legislative advocacy. Issue: - Funding/Access
- Sarcoma research advocacy: Awareness/Funding/Access
- 15 years experience as health issues/cancer professional lobbyist/advocate

### **Description of organization's mission, goals and focus**

To increase understanding of sarcoma, to raise level of funding for sarcoma research, especially seed funding for "adventure pilot programs"

### **Description of organization's accomplishments**

Collaboration with National Foundation of Cancer Research in US and China  
Collaboration with Wellness Centers and various other organizations

### **Description your organization's events**

We will participate as Team Sarcoma – Tennessee for the first time this year with the Liddy Shriver Cancer Initiative. Organizing educational seminars at Vanderbilt

Recipients of your organization's funds:  
To be determined

# JARED'S JUGGERNAUT

Non-profit status since: 2010

Website: [www.jaredsjuggernaut.org](http://www.jaredsjuggernaut.org)

## **Public Contact**

Name/title: Robyn Grossman

Address: 112 Sandringham Road, Cherry Hill, NJ 08003

Phone: 856-424-5345

Email: [admin@jaredsjuggernaut.org](mailto:admin@jaredsjuggernaut.org)

## **Director**

Name: Raymond Grossman

Address: 112 Sandringham Road, Cherry Hill, NJ 08003

Phone: 856-424-5345

Email: [admin@jaredsjuggernaut.org](mailto:admin@jaredsjuggernaut.org)

## **Services Provided**

- Patient/caregiver education website
- Patient/caregiver doctor and/or clinical trial referrals
- Patient/caregiver counseling
- Sarcoma research advocacy
- Current body sparing research information

## **Description of Organization's Mission, Goals and Focus**

- Help fund research into new and novel non-chemotherapy treatments for various types of Sarcoma cancers with emphasis on Rhabdomyosarcoma
- Raise money for this purpose through sponsorship of various fundraising events and activities
- Increase public awareness and knowledge of the various types of Sarcoma and current research by maintaining a website which contains definitive information on forms of the disease, current treatment methods, diagnostic tools and current clinical trials.
- Write grants to aid worthy researchers in finding innovative methods of treating Sarcomas without harming healthy cells and tissues.
- Maintain a physicians referral list containing hospitals and doctors along with their specific area of expertise in specific forms of Sarcoma treatment and research

## **Description of Organization's Accomplishments**

- Have associated ourselves with a doctor and hospital to which we hope to donate funds as soon as we raise some more funds.

## **Description Organization's Events**

- Teamed with the Peter Skelton Sarcoma Research Fund to announce our upcoming events
- Two fundraising events at Campbell's field, Camden, NJ-Aug. 28 and Sept. 18

## **Recipients of Organization's Funds**

- Comer Children's Hospital @ University of Chicago-Dr. Skapak

# JENNIFER HUNTER YATES SARCOMA FOUNDATION

Non-profit status since: September 2004

Website: [www.jenniferhunteryatessarcomafoundation.org](http://www.jenniferhunteryatessarcomafoundation.org)

## **Public Contact**

Name/title: Susan Erickson, Secretary  
Address: 467 Laws Brook Road, Concord, MA 01742  
Phone: 978-371-7351  
Email: [Sarcomasteps@yahoo.com](mailto:Sarcomasteps@yahoo.com)

## **Director**

See above

## **Services Provided**

- General information about the JHYSF and fundraisers

## **Description of Organization's Mission, Goals and Focus**

The goal of the JHYSF is to raise funds to provide sarcoma research, sarcoma education, and sarcoma family support at Massachusetts General Hospital (MGH). Our focus is to support sarcoma patients and doctors at MGH who receive little if nothing in terms of research funding. Our other goals are to provide sarcoma patients and families with education and support. Another goal is to provide patients and families who have traveled a far way to be treated at MGH with financial support.

## **Description of Organization's Accomplishments**

Our first fundraiser, *12,402 Steps to Cure Sarcoma Walk*, held on May 7, 2005 resulted in our donating \$75,000.00 to MGH to help with our goals.

In three years of fundraising, JHYSF has donated \$319,000 to the Massachusetts General Hospital Cancer Center. Funds have been used to increase participation in clinical trials, fund a Jennifer Yates Sarcoma Scholar, provide patients with resources for wigs, prescriptions, and transportation to and from treatment, and to sponsor a three hour long Sarcoma Seminar that is held each year in the month of November. JHYSF is also responsible for increasing awareness by creating a Sarcoma Awareness Week in Massachusetts."

## **Description Organization's Events**

*12,402 Steps to Cure Sarcoma Walk* is an event to honor the memory of Jennifer Hunter Yates, who was 33 years old when she died. She had battled Malignant Peripheral Nerve Sheath Tumor and Osteosarcoma for 17 months. The 12,402 steps signify the number of days of Jennifer's life.

## **Recipients of Organization's Funds**

The Jennifer Hunter Yates Sarcoma Fund at Massachusetts General Hospital Cancer Center

## KAREN WYCKOFF REIN IN SARCOMA FUND

Non-profit status since: 2004

Website: [www.reininsarcoma.org](http://www.reininsarcoma.org)

(Worked as fund of University of Minnesota Cancer Center from 2001 until March of 2004)

### **Public Contact**

Name/title: Peter T. Wyckoff, President  
Address: 3312 Richmond Avenue, Shoreview, MN 55126  
Phone: 651-486-9114  
Email: [ptwyckoff@msn.com](mailto:ptwyckoff@msn.com) or [ptwyckoff@reininsarcoma.org](mailto:ptwyckoff@reininsarcoma.org)

### **Director**

Name/Title: Mike Trucano, Board Member  
Address: 11 Thompson Lane, North Oaks, MN  
Phone: 651-484-9332  
Email: [mdtrucano@comcast.net](mailto:mdtrucano@comcast.net)

### **Services Provided**

- Patient/caregiver education website
- Patient/caregiver counseling
- Newsletter (mail or email.) Frequency: as needed
- Sarcoma research advocacy

### **Description of Organization's Mission, Goals and Focus**

The Karen Wyckoff Rein In Sarcoma Fund is a Minnesota non-profit Foundation created to carry out the vision of its founder. Karen Wyckoff at the age of twenty-five created the fund shortly before her death from Synovial Sarcoma in 2001. Its mission then as now is to:

- **Find a cure** for sarcoma cancers (raise funds for research)
- **Educate** physicians and public about sarcomas
- **Support** sarcoma survivors and their families.

### **Description of Organization's Accomplishments**

- Annual Rein in Sarcoma Event last Monday of each July (since 2001)
- Annual free picnic for sarcoma patients, survivors and loved ones (since 2004)
- The Fund's support of University of Minnesota Sarcoma Researchers coalesced groups from both the Veterinary School and Medical School into an increased emphasis and excitement about Sarcoma research.
- Increased public awareness of sarcoma cancers
- The major support system for sarcoma patients in the upper Midwest
- Have begun education of the medical community about sarcomas

### **Description Organization's Events**

#### **Rein in Sarcoma**

Rein In Sarcoma has been held annually in late July in St. Paul's Como Park since 2001. From the beginning, unlimited free rides on the historic Cafesjian's Carousel have been a major draw for the event. Over the last four years the event has expanded to the Marjorie McNeely Conservatory and its adjacent grounds.

Rein in Sarcoma currently consists of continuous entertainment for the whole family, unlimited carousel rides, special Conservatory tours, and a massive silent auction.

Totally run by volunteers, the 2005 event attracted over 600 attendees from throughout Minnesota as well as Wisconsin and Iowa. Over fifty sarcoma survivors most of whom never had met other sarcoma patients joined in this celebration of life.

Three stages of continuous entertainment highlighted the event. Included were magicians, vocal groups, jazz, dancers, and a Beatles tribute band. All performers donated their time. In addition entertainment for children included a book walk, face painting and a moonwalk. Chair massages were also offered by professional massage therapists throughout the evening.

Over 200 items were on the 2005 Silent Auction raising over \$12,000. Items generously donated included: restaurant and hotel gift certificates, art work, vacation condos, airplane rides, fine wine, music, books, retail gift certificates, food baskets, spas, entertainment, gourmet dinners, clothing, jewelry and much more. An Internet auction preceded the event that helped spur interest and set the opening bids for the actual live silent auction. Internet bidding came from throughout the country.

Through RIS we have raised over \$160,000 toward research and perhaps most importantly, we brought patients, families and their doctors together for an evening of fun. The 2005 event netted about \$40,000.

One of major strengths of the event is its appeal to people of all ages and resources. Over 100 volunteers handled all aspects of Rein In Sarcoma. There is no paid staff.

### **Sarcoma Family Picnic**

For many families touched by Sarcoma, the centerpiece of Rein in Sarcoma is the pre-event picnic. The picnic is for survivors, their families and families who have lost someone to sarcoma. This year's picnic was attended by over 300 people who have been directly touched by sarcoma. The University of Minnesota sarcoma physicians joined the celebration of life. There were reunions of survivors with the doctor who saved their lives up to 30 years ago and whom they hadn't seen since. Some attendees were patients who were operated on the week before and were glad to eat with their doctor without a mask. People shared their sarcoma successes and also celebrated the lives of those lost to sarcoma. Many of the picnickers told us that the shared stories make the sarcoma experience easier. The picnic was made possible by the generous sponsorship of American Family Insurance Company.

### **Recipients of Organization's Funds:**

The primary recipient of the Fund is the Karen Wyckoff Sarcoma Research Fund at the University of Minnesota Medical Foundation.

## KRISTEN ANN CARR FUND

Non-profit status since: 1993

Website: [www.sarcoma.com](http://www.sarcoma.com)

### **Public Contact**

Name/title: David Marsh, Trustee  
Michael Solomon and Rishon Blumberg, administrators  
Address: 39 West 32<sup>nd</sup> Street, Suite 1403  
NY, NY 10001

Phone: (203) 846-9033; (212) 501-0748

Fax: (212) 268-3544

Email: [marsh6@optonline.net](mailto:marsh6@optonline.net)  
[info@sarcoma.com](mailto:info@sarcoma.com)

### **Services Provided**

- Patient/caregiver education website
- Newsletter (mail or email.) Frequency: Biannual (Sarcoma Update, published with Memorial Sloan Kettering Cancer Center)
- Sarcoma research advocacy

### **Description of Organization's Mission, Goals and Focus**

Our mission is to raise funds and make grants to find treatments and cures for sarcoma. Also, to improve the living conditions of patients with sarcoma or other teenage and young adult cancers.

### **Description of Organization's Accomplishments**

Surgical fellowship at Memorial Sloan Kettering Cancer Center; Sarcoma Laboratory at MSKCC; Sarcoma Update newsletter; small grants to several other groups including Musicians on Call, Planet Cancer, SARC and NY Lifelab

### **Description Organization's Events**

We hold one large annual event in NY in the spring. There is an annual Halloween party. We also sponsor pediatric holiday events with MSKCC Pediatric Dept. but that is not a fundraiser.

### **Recipients of Organization's Funds**

MSKCC Dept of Surgery; MSKCC Sarcoma Laboratory; MSKCC Department of Pediatrics; Planet Cancer; Musicians on Call; NY Lifelab; SARC are the main ones.



## LIDDY SHRIVER SARCOMA INITIATIVE

Non-profit status since: November 2003, a Collective Giving Fund within FJC, a 501(c)(3) Not-for-Profit Public Charity and a Foundation of Philanthropic Funds

Website: [www.sarcomahelp.org](http://www.sarcomahelp.org)

### **Public Contact**

Name/title: Bruce Shriver  
Address: 17 Bethea Drive, Ossining, NY 10562  
Phone: 914 762 3251 Fax: 914 941 9181  
Email: [shriver@genesis2.com](mailto:shriver@genesis2.com)

### **Co-Directors**

Names: Bruce Shriver/Beverly Shriver  
Address: same as above  
Email: [beverly@genesis2.com](mailto:beverly@genesis2.com)

### **Services Provided**

- Patient/caregiver education website
- Electronic Sarcoma Update Newsletter (ESUN) Frequency: bi-monthly
- Detailed, searchable clinical trial information on website
- Research grants program
- Patient/caregiver counseling
- Legislative, sarcoma research, and drug development & availability advocacy
- CTOS conference participation

### **Description of Organization's Mission, Goals and Focus**

The mission of the Liddy Shriver Sarcoma Initiative is to improve the quality of life for people dealing with sarcoma. The Initiative increases public awareness of sarcoma, raises funds to award research grants, and provides support and timely information to sarcoma patients, their families, and medical professionals. These efforts are achieved through collaboration with numerous individuals and organizations that share a similar vision. To address the challenges presented by sarcomas, the Liddy Shriver Sarcoma Initiative:

- Publishes the Electronic Sarcoma Update Newsletter (ESUN) which is accessed by physicians, nurses, patients and caregivers worldwide. Much of this information has been organized in the Sarcoma Learning Center for our website visitors;
- Funds sarcoma research targeted at finding a cure for sarcoma and research that attempts to develop more effective treatments than those currently available;
- Provides support for patients and families. The Initiative compiles relevant and timely online resources for patients and medical professionals. We provide personal responses to questions from patients and their families. And we coordinate the Team Sarcoma Initiative to bring communities together in support and awareness.

## **Description of Organization's Accomplishments**

- The ongoing publication of the bi-monthly, peer-reviewed Electronic Sarcoma Update Newsletter (ESUN, see <http://www.sarcomahelp.org/esun/index.html>). ESUN began its sixth year of publication in February 2009. We have published over 600 pages of peer reviewed information on sarcoma and over 400 pages of Op Ed pieces written by oncologists, nurses, patients, caregivers and survivors, research abstracts, stories of courage and hope, and updates on a wide range of sarcoma advocacy groups. We also provide an extensive amount of detailed, searchable clinical trial information on our website.
- The funding of 23 research studies (see <http://tinyurl.com/dncbqn>). The Liddy Shriver Sarcoma Initiative funds basic research seed grants in sarcoma. We anticipate that results from these demonstration or starter grants will provide results that will allow the researcher to apply for funding for a larger study. We believe that work needs to proceed on many of the subtypes of sarcoma and have supported work in a wide range of sarcomas, including: alveolar soft part sarcoma, chondrosarcoma, chordoma, clear cell sarcoma, Ewing's sarcoma, leiomyosarcoma, liposarcoma, MFH, MPNST, osteosarcoma, and rhabdomyosarcoma. We believe that quality work should be funded wherever it is being done and have awarded grants to institutions in Australia, China, Italy, Germany and the United States. We seek out other sarcoma advocacy groups and individuals to help fund research studies that have been recommended for funding as a result of our peer-reviewed grant application process. By combining our financial resources, our organizations can fund more substantive research studies jointly than we could fund independently. We have co-funded research studies with the Amschwand Sarcoma Cancer Foundation, Bone Cancer International, Brian Morden Foundation, Chordoma Foundation, FOSTER Foundation, LMSarcoma Direct Research Foundation (LMSdr). Additionally, we have funded three Sarcoma Foundation of America (SFA) initiated research studies. The results of some of the studies that we have funded have been used, in part, to secure funding of R01 support for some investigators. A number of research papers have been published citing Liddy Shriver Sarcoma Initiative support.
- The coordination of the annual Team Sarcoma Initiative (a.k.a. the International Sarcoma Awareness Week). This Initiative has grown from 7 people in 2003 to over 8,000 people worldwide in 2008 and involved events organized by 26 medical centers, 26 sarcoma advocacy groups and 26 events organized by sarcoma patients and survivors. Our 2009 goal is to have over 10,000 people involved worldwide helping to raise public awareness of sarcoma and funds to support sarcoma-related research (see <http://www.team-sarcoma.net/>).
- The development of: (a) the video presentation “*A Forgotten Cancer*”, available in 9 languages on YouTube; 4 additional languages will be available in 2009; (b) the “*The Faces of Sarcoma*” project, a gallery of photos of over 355 of sarcoma patients, survivors, and those who have lost their lives to sarcoma representing over 30 countries and 30 types of sarcoma (see <http://tinyurl.com/create.php>); (c) the “*Moments in Sarcoma*” project, short essays written by sarcoma patients, caregivers, and survivors, one of which will be published a daily basis beginning in May 2009; (d) the “*Sarcoma Post-It® Links*” webpages that contain scores of sarcoma related links (see <http://www.protopage.com/sarcoma>); and (e) the “*Sarcoma Knows No Borders*” bracelets; since July 2006, we have distributed over 18,000 of them worldwide.

## **Description Organization's Events:**

See the hyperlinks in the previous response.

## LIFE RAFT GROUP

Non-profit status since: 2002

Website: [www.liferaftgroup.org](http://www.liferaftgroup.org)

### **Public Contact**

Name/title: Life Raft Group  
Address: 155 Route 46 West, Suite 202, Wayne, NJ 07470  
Phone: (973) 837-9092 Fax: (973) 837-9095  
Email: [liferaft@liferaftgroup.org](mailto:liferaft@liferaftgroup.org)

### **Director**

Name/Title Norman J. Scherzer  
Address: 155 Route 46 West, Suite 202, Wayne N.J. 07470  
Phone: (973) 837-9092 x 119 Fax: (973) 837-9095  
Email: [nscherzer@liferaftgroup.org](mailto:nscherzer@liferaftgroup.org)

### **Services Provided**

- Patient/caregiver education website
- Patient/caregiver doctor and/or clinical trial referrals
- Patient/caregiver online support community
- Newsletter (mail and/or email.) Frequency: Every other month
- Legislative advocacy Issues: Medicare drug coverage and clinical trials placebos
- Sarcoma research advocacy; directed to GIST
- Drug development and/or availability advocacy NCI committee participation.
- CTOS conference participation; Presented LRG research paper on resistance & Gleevec dosage in 2004
- Other: Crisis intervention for treatment access; Patient driven research; International outreach; Clinical trial planning and design; Pediatric GIST initiative; New resistance research initiative; Global GIST network

### **Description of Organization's Mission, Goals and Focus**

The mission of the Life Raft Group (LRG) is to ensure the survival of GIST patients while maintaining the quality of their lives. To accomplish this mission, the Life Raft Group devotes its efforts to five major program areas: Research, Treatment Surveillance, Information & Support, Patient Outreach & Assistance, and Advocacy.

### **Description of Organization's Accomplishments**

Each year the LRG reaches a network of over 60,000 people through its newsletters, websites and educational materials. The LRG offers localized support in over 50 countries.

### **Description Organization's Events**

Membership meetings; Research strategy meetings; Special focus meetings (eg. Pediatric GIST); Annual Fundraiser; B.O.D. meetings; etc.

### **Recipients of Organization's Funds**

Research Funding is provided to: Memorial Sloan-Kettering Cancer Center, New York, NY; West German Cancer Center, University of Essen, Germany; Oregon Health & Science University, Portland, OR; Catholic University of Leuven, Belgium; University of Pittsburg Cancer Center, Pittsburg, OH; Brigham and Women's Hospital, Boston, MA; Stanford University Medical Center, Stanford, CA; and The Cleveland Clinic, Cleveland, OH.

**LINK TO BEAT**

Website: [www.linktobeat.com](http://www.linktobeat.com)

**Public Contact**

Name/title: John Link  
Address: 31 Indian Meadow Dr, Northboro, MA 01532-2129  
Phone: 774-258-0860  
Email: [linktobeat@yahoo.com](mailto:linktobeat@yahoo.com)

**Accomplishments**

Published book on experiences from diagnosis to a survivor of Osteosarcoma

**Recipients of Organization's Funds**

University of Massachusetts Medical School "Walk to Cure Cancer"  
<http://www.walktocurecancer.com/>

## LMSarcoma Direct Research Foundation (LMSdr)

Non-profit status since: Applied for 2/06

Website: [www.LMSdr.org](http://www.LMSdr.org)

### **Public Contact:**

Name/title: Ed Kurtz, President  
Address: PO Box 52697, Tulsa, Oklahoma 74152  
Phone: Fax: (413) 502-2241  
Email: [ekurtz@lmsdr.org](mailto:ekurtz@lmsdr.org)

### **Director**

Name/Title: Sharon Anderson, Executive Director  
Address: PO Box 52697, Tulsa, Oklahoma 74152  
Phone: (650)922-8762 Fax: (413) 502-2241  
Email: [2taikomon@gmail.com](mailto:2taikomon@gmail.com)

### **Services provided**

- Patient/caregiver education website
- Patient/caregiver doctor and/or clinical trial referrals
- Newsletter (mail or email.) Frequency: 3 x year
- Legislative advocacy. Issues: funding
- Sarcoma research advocacy
- Drug development and/or availability advocacy
- CTOS conference participation. Other conference participation: ASCO
- Other: LMS Patient Registry

### **Description of Organization's Mission, Goals and Focus:**

The mission of LMSarcoma Direct Research Foundation is to assure the development of the means to cure and control the disease known as Leiomyosarcoma (LMS) and to improve the quality of life for those with this disease until the cure is found.

### **Description of Organization's Accomplishments:**

LMSdr was founded 2/06. We plan to establish a registry for LMS patients, continue to support the LMS tissue collections and bank. We plan to attend all related medical conferences and work in partnership with researchers.

### **Description Organization's Events:**

LMSdr plans to hold an annual conference for both patients & researchers focused on LMS education & developments.

### **Recipients of Organization's Funds:**

LMSarcoma Direct Research Foundation invites investigators to submit grant applications for institutional research studying leiomyosarcomas. The foundation is particularly interested in basic science and translational research aiming for a better understanding of the (molecular) biology of non-uterine as well as uterine leiomyosarcomas eventually leading to improvement of diagnostic tools, discovery of new prognostic markers and novel therapeutic approaches to find a cure for this malignant disease or improve the quality of life for those whose disease cannot be cured.

This funding is intended primarily as seed money for promising new work. It is not for supporting research where funding has either lapsed or has been previously disapproved. Preference will be given to applications where indirect costs are minimal or nonexistent.

## THE NATIONAL LEIOMYOSARCOMA FOUNDATION, INC.

Non-profit status since: July 14, 2001

Website: [www.nlmsf.org](http://www.nlmsf.org) or [www.nlmsf.net](http://www.nlmsf.net)

**Public Contact**

Name/title: Joni M. Fixel- President  
Address: 2843 E. Grand River Ave, #230 East Lansing, MI 48823-5031  
Phone: 1-888-449-6805 Fax: 517-853-0434  
Email: [joni@nlmsf.org](mailto:joni@nlmsf.org)

**Director**

Name/Title: Jane Moulds - Treasurer  
Address: 18623 Co. Rd 12 S, Foley, AL 36535  
Phone: 251-971-3735 Fax: 251-971-3735  
Email: [jane@nlmsf.org](mailto:jane@nlmsf.org)

**Services Provided**

- Patient/caregiver education website
- Patient/caregiver online support group
- Newsletter (mail or email.) Frequency: 3-4 months
- Sarcoma research advocacy
- Other: Funding of LMS research

**Description of Organization's Mission, Goals and Focus**

To raise and spread awareness and education of LMS among patients, the public, and medical field. Also to procure funds for LMS research grants.

**Description of Organization's Accomplishments**

To date we have raised in excess of \$900,000 without government or agency assistance. We have donated over \$642,000 in research grants and made and distributed over 75,000 LMS Awareness Ribbons at NO charge.

**Description Organization's Events**

Annual weekend gathering, "Hugfest" of LMS Survivors, Caregivers, Supporters, and Researchers. Various ongoing fundraisers through our LMS Awareness Products we sell. Attending and supporting various fundraisers for our foundation.

**Recipients of Organization's Funds**

To date we have awarded multiple grants to Pennsylvania Hospital, Tulane University, Mt. Sinai School of Medicine, The Coriell Institute, and Stanford University all for furthering LMS Research.

# NORTHWEST SARCOMA FOUNDATION

Non-profit status since: 1997

Website: [www.nwsarcoma.org](http://www.nwsarcoma.org)

## **Public Contact**

Name/title: Melissa Hill, Executive Director  
Address: 7327 SW Barnes Road, PMB #404, Portland, OR 97225  
Phone: 503-810-3713 Fax: 503-297-6932  
Email: Melissa@nwsarcoma.org

## **Director**

Same as above

## **Services Provided**

- Patient/caregiver education website
- Patient/caregiver bulletin board
- Newsletter (mail or email.) Frequency: 2 x a year
- Sarcoma research advocacy
- Other: Fundraising and social events to connect sarcoma patients/families etc.

## **Description of Organization's Mission, Goals and Focus**

Mission: The NW Sarcoma Foundation is a non-profit organization, committed to providing education and support to patients and families who are living with this cancer.

Values:

**C**ompassion: Provide comfort through a sympathetic awareness.

**A**dvocacy: Promote accurate diagnosis, research and treatment options.

**R**esponsibility: Provide accurate information and reliable resources.

**E**ducation: Teach patients, families and health care providers about this disease and its treatment.

Vision: We will provide support to patients and families through the NW Sarcoma Foundation Website. We will provide support by creating local networks within Washington, Oregon, Alaska, Montana, and Idaho. We will provide timely and accurate information regarding research and treatment options.

## **Description of Organization's Accomplishments**

We became active only in April of 2003. We developed a website and have hosted several social/fundraising events to connect patients, and have acquired a large database of folks in a very short time and space of a few years as a "grass roots" effort. We have gained extraordinary momentum and connected with other foundations over the past three years. We provide an excellent list of resources that cover all phases of care, treatment and after care on our website. We have fully self-sustained with an all volunteer board and practically volunteer director. We have started a quilt called the "Blanket of Honor" to honor survivors and memorialize those who have died

## **Description Organization's Events**

We have hosted several wine receptions as a connecting point. We will call these "Friend raisers" in the future. We have also hosted a walk a thon event this past year, which had a very large attendance, and we connected people from the Washington, Oregon regions together.

## **Recipients of Organization's Funds**

Funding is currently to self sustain, with plans to move toward funding research projects.

We have made a small donation in 2005 to The Alliance Against Alveolar Soft Parts Sarcoma, who is currently advocating and fundraising for clinical trials of a vaccine.



## SARCOMA ALLIANCE

Non-profit status since: 2000

Website: [www.sarcomaalliance.org](http://www.sarcomaalliance.org)

### **Public Contact**

Name/title: Arthur Beckert, Executive Director  
Address: 775 E Blithedale Ave, #334, Mill Valley, CA 94941  
Phone: (415) 381-7236 Fax: (415) 381-7235  
Email: [abeckert@sarcomaalliance.org](mailto:abeckert@sarcomaalliance.org)

### **Director**

Same as above

### **Services Provided**

- Patient/caregiver education website
- Patient/caregiver doctor and/or clinical trial referrals
- Patient/caregiver counseling
- Patient/caregiver bulletin board; Chat room; Online support group
- Peer to Peer support
- Newsletter (mail or email.) Frequency: 2 or 3/year
- Legislative advocacy
- Sarcoma research advocacy
- Drug development and/or availability advocacy
- NCI committee participation.
- CTOS conference participation. Other conference participation: AACR, ASCO, ONS

### **Description of Organization's Mission, Goals and Focus**

The Sarcoma Alliance strives to improve and extend the lives of sarcoma patients through accurate diagnosis, improved access to care, guidance, education and support. This mission statement drives all decisions about our programs and future plans. In order to assure the best possible outcome a sarcoma patient must be seen by a physician expert in the diagnosis and treatment of sarcoma. This includes not only the primary treating medical oncologist but the pathologist, surgeon and radiation therapist.

We refer patients to sarcoma centers throughout the United States and through our Assistance Fund provide financial support to those seeking second opinions from sarcoma specialists. We provide educational information on our website, provide links to other websites and will send up to date diagnosis specific written materials on request. We also have a bulletin board where patients can receive information and support and conduct a twice a week web based support group so that patients, families and caregivers can learn and get support from others with similar experiences. We also have a Peer to Peer program for one on one support.

### **Description of Organization's Accomplishments**

- We have a comprehensive web site, bulletin board, twice a week web based support group, promote face to face support groups, facilitate peer to peer support, a twice per year newsletter, send our patient education materials via email and regular mail.
- We provide grants to individuals so to help pay for second opinions from sarcoma specialists.
- We are developing a booklet for newly diagnosed sarcoma patients

### **Description Organization's Events**

We have four fund raising events each year. We sponsor a 5k/10k walk/run in northern California and New York City; the Ocean of Hope, part of The Catalina Classic, a paddleboard race from Catalina Island to

Manhattan Beach, at the end of August and dinner fund raising event for our Assistance Fund. We promote Sarcoma Awareness Week the second week each June.

**Recipients of Organization's Funds**

Our funds are used for program operations and to provide grants to patients to receive second opinions from sarcoma specialists (Assistance Fund).

**SARCOMA ALLIANCE for  
RESEARCH through COLLABORATION (SARC)**

Non-profit status since: 2003

Website: [www.sarctrials.org](http://www.sarctrials.org)

**Public Contact**

Name/title: Denise Reinke  
President and COO - SARC  
Address: 24 Frank Lloyd Wright Drive  
Lobby A, Suite 3100  
PO Box 406  
Ann Arbor, MI 48106-0406

Phone: 734-930-7600

Fax: 734-930-7557

Email: SARC Operations Office [Sarc@sarctrials.org](mailto:Sarc@sarctrials.org)

**Director**

SARC is led by a Board of Directors, and McHenry "Mac" Tichenor Chairman

**Services provided**

- Patient/caregiver education website
- Patient/caregiver doctor and/or clinical trial referrals
- Legislative advocacy. Issues: Clinical Trial Funding
- Sarcoma research advocacy
- Drug development and/or availability advocacy
- NCI committee participation.
- CTOS conference participation.
- Other: Medical community education, recruitment of sarcoma-experienced regional hospitals to participate in clinical trials.

**Description of your organization's mission, goals and focus**

To facilitate clinical trials, attract pharmaceutical and government funding, develop compounds that show promise for Sarcomas, make trials available to patients as treatment options, and establish standards of care for Sarcoma.

**Description of your organization's accomplishments**

Has garnered the leadership of Sarcoma specialists with a shared mission; attracted European Sarcoma specialists for guidance regarding their successful creation of cooperative groups, established a collaboration of 31 participating centers to conduct trials, has improved patient accrual into trials, has facilitated the achievement of numerous trials that would not have happened without this infrastructure and patient accrual, has received pharmaceutical funding as well as funding from the Department of Defense and an appropriation within the new Energy bill recently passed. Has ongoing dialogue with and support from NIH.

**Description your organization's events**

General meetings at CTOS and ASCO

**Recipients of your organization's funds**

Funds are used for the conduct of trials and statistical support and education of physicians, patients and caregivers.

# SARCOMA FOUNDATION OF AMERICA

Non-profit status since: 2001

Website: [www.curesarcoma.org](http://www.curesarcoma.org)

## **Public Contact**

Name/title: Matthew Alsante, Executive Director  
Address: 9884 Main Street, Damascus, MD 20872  
Phone: (301) 253-8687 Fax: (301) 253-8690  
Email: [malsante@curesarcoma.org](mailto:malsante@curesarcoma.org)

## **Services Provided**

- Patient/caregiver education website
- Patient/caregiver doctor and/or clinical trial referrals
- Newsletter (mail or email.) Frequency: annually
- Legislative advocacy. Issues: Sarcoma research
- Sarcoma research advocacy
- Drug development and/or availability advocacy
- NCI committee participation.
- CTOS conference participation. Other conference participation: ASCO
- Other: Surgical Oncology (ACOSOG)
- Sarcoma Patient Registry
- SFA State Chapters

## **Description of Organization's Mission, Goals and Focus**

The mission of the Sarcoma Foundation of America (SFA) is to advocate for increased research to find new and better therapies with which to treat patients with Sarcoma. The organization raises money to privately fund grants for Sarcoma researchers and conducts education and advocacy efforts on behalf of Sarcoma patients.

## **Description of Organization's Accomplishments**

Funded 40 SFA Sarcoma Research Grants  
Funded 3 ASCO Young Investigator Awards  
Funded 2 ASCO Advanced Clinical Research Awards  
Participated in the Sarcoma PRG  
Successfully advocated for sarcoma "language" in the NIH/NCI report from Congress.  
Founded the Sarcoma Patient Registry  
Formation of SFA State Chapters

## **Description Organization's Events**

Annual NY Gala event in April/May  
Annual Educational Conference in April/May  
Multiple fundraisers nationwide

## **Recipients of Organization's Funds**

Scientists and physicians throughout the world

# Sarcoma Patients EuroNet Association

Non-profit status since: August 2009

Website: [www.sarcoma-patients.eu](http://www.sarcoma-patients.eu)

## **Public Contact**

Name/title: Michaela Geissler (Project Manager)  
Address: Am Rothenanger 1b, D-85521 Riemerling / Germany  
Phone: + 49 (0)89-62836807  
Email: [info@sarcoma-patients.eu](mailto:info@sarcoma-patients.eu)

## **Director**

Name: Markus Wartenberg (Financial Director)  
Address: Usa-Strasse 1, D-61231 Bad Nauheim / Germany  
Phone: +49-(0)6032-9492438  
Email: [wartenberg@lebenshaus.post](mailto:wartenberg@lebenshaus.post)

## **Services Provided (delete those that do not apply)**

- Patient/caregiver education website
- Patient/caregiver doctor and/or clinical trial referrals
- Patient/caregiver counseling
- Newsletter (email) Frequency: monthly
- Sarcoma research advocacy
- Drug development and/or availability advocacy
- CTOS conference participation. Other conference participation: ECCO, ESMO, ASCO, EMSOS etc.

## **Description of Organization's Mission, Goals and Focus**

**Sarcoma Patients EuroNet Association (SPAEN), the European Network of Sarcoma, GIST and Desmoid Patient Advocacy Groups**, was founded in April 2009 with the aim of extending information services, patient support and advocacy to patient organisations for the benefit of sarcoma patients across the whole of Europe. Acting in partnership with clinical experts, scientific researchers, industry and other stakeholders SPAEN is working to improve the treatment and care of sarcoma patients in Europe through improving information and support, and by increasing the visibility of sarcoma with policymakers and the public.

## **Vision**

- § A Better Future For Patients With A Rare Cancer.
- § *Speaking with one voice, advocating and cooperating professionally and in partnership on a European level to develop a better future for Sarcoma-patients and their families at each national level!"*
- § Acting in partnership with experts, the researching industry and other stakeholders SPAEN will work to improve treatment and care of sarcoma patients in Europe through improving information and support, and by increasing the visibility of sarcoma with policymakers and the public.

## **Core Objectives**

- § Increasing the awareness of sarcoma
- § Providing information and support
- § Improving treatment and care
- § Supporting research
- § Building capacity

## **Core Values**

- § Focused on the needs of the PAGs (patient advocacy groups) and the patients/caregiver
- § Willingness to advocate

- § High quality of information/education/training:  
Correct, up to date, understandable, independent
- § Cooperative and professional
- § Ethical, transparent, behave with integrity
- § Innovative spirit

### **Description of Organization's Accomplishments**

- § Participation ESMO-Guidelines GIST/Sarcomas in Lugano
- § Co-organizer of the "European Sarcoma and GIST surgery masterclass" 2010
- § Organizer of the 2010 CTOS PAG session (co-chaired with Prof. G. Demetri)
- § Different presentations at European platforms: Patient Partner, EPPOSI, ECPC RC-Action Group, RARECARE, CONTICANET, ECCO Policy Forum, etc.
- § Presence on different important conferences:  
(DGHO, CTOS, Trinat. GIST-Meet., DKK, EMSOS, ECCO, ESMO, Swiss Cancer League, etc.)
- § GIST "Compliance Brochure" in 12 languages
- § 1st Annual Conference 2010 Madrid
- § Launch of website at [www.sarcoma-patients.eu](http://www.sarcoma-patients.eu)

### **Description Organization's Events**

The 2nd SPAEN Annual Conference for Organizations Representing Patients with Sarcomas, GIST or Desmoid Tumours will be held on 17 – 19 November in Berlin/Germany. The conference aims to provide Sarcoma, GIST and Desmoid patient advocates with an opportunity to share experience and best practice, as well as to learn about advances and challenges in the treatment of rare cancers. The three day conference will focus on research, treatment and advocacy/capacity building. Leading European Sarcoma Experts will join us to present the latest news and answer questions.

The 1st SPAEN Conference 2010 in Madrid was attended by 65 participants from 16 countries covering Patient Advocates, Medical Experts and Members of the Healthcare Industry.

### **Recipients of Organization's Funds**

Funds raised are used to cover external costs for projects (e.g. annual conference, educational materials) and internal costs of the Associations (human resources, administrative costs etc.)

# SARCOMA UK

Founded in 2003 as non-profit company. Now also UK registered charity 1139869.

Website: [www.sarcoma.org.uk](http://www.sarcoma.org.uk)

## **Public Contact**

Name/title: Ms Lindsey Bennister - CEO  
Address: 49-51 East Road, London N1 6AH  
Phone: +44 207 7250 827  
Email: [info@sarcoma.org.uk](mailto:info@sarcoma.org.uk)

## **Services Provided**

- Patient/caregiver education website and printed leaflets
- Patient/caregiver doctor and/or clinical trial referral information
- Patient/caregiver counseling on an ad hoc basis usually through contact with other patients/carers. We also recommend patients to use one of the specialist support/counseling cancer charities (there are two in UK).
- Patient/caregiver email lists
- Newsletter (mail or email.) Frequency: \_\_twice a year
- Legislative advocacy. We are allied with other UK and European cancer patient groups on a whole range of issues involving representation to national and European governments. Main aim is to ensure that cancer is properly prioritized in healthcare funding programs and that awareness of sarcoma is maximised.
- Regulatory advocacy. We work with NHS regulators nationally, regionally and locally, and lobby them too. We have developed a reputation for holding NHS bodies to account for sarcoma related issues which are not addressed appropriately.
- Sarcoma research advocacy – working with the UK’s National Cancer Research Institute and the association of the UK’s specialist clinicians, the British Sarcoma Group.
- We are a founder member of Sarcoma Patients Euronet which works closely with pan-European sarcoma research collaborations (EORTC, EuroSarc, Conticanet)
- Drug development and/or availability advocacy – this is more at the trials-to-treatment end of the chain, rather than at the lab bench end.
- NCI committee participation. We have three representatives on the NCRI (National Cancer Research Institute) Sarcoma Studies Group and two on the National Cancer Information Initiative (NCIN)
- CTOS conference participation. Have attended and spoken at CTOS when in Europe. Other conference participation: NCRI Conference, BSG Conference and ECCO/ESMO (the pan-European version of ASCO)
- Other: we work with GIST Support UK, the Bone Cancer Research Trust and we support local sarcoma support groups practically and financially. We also advise small charities fund raising for sarcoma research.

## **Description of Organization’s Mission, Goals and Focus**

- To provide information and support to sarcoma patients, their caregivers and families
- To support the development of a coherent national network of specialist centers to treat sarcoma in line with the best identified clinical practice
- To support research which leads to better treatment and better outcomes for sarcoma patients
- To raise awareness of sarcoma

## **Description of Organization’s Accomplishments**

We have dragged sarcoma over the horizon in the UK; the forgotten cancer is now noticed. The specialist treatment centers distribute our print materials. We have helped the clinicians create the British Sarcoma Group. The NHS is now in the final stages of developing 'Improving Outcomes' guidance for sarcoma with our help. There is now a body, which can represent sarcoma patients, based on the fact that over 700 patients/caregivers have now registered with us. (All sarcomas, including GIST, account for about 3200 diagnoses in UK annually).

#### **Description Organization's Events**

With a full-time staff team in post from early 2011 we now have the capacity to arrange events which may be for support, for developing our services, or for fund-raising.

#### **Recipients of Organization's Funds**

Our research strategy is being finalized although in 2009 we committed over £250,000 into four projects at The Institute of Cancer Research, the Royal Marsden Hospital, and Sheffield University. Recipients of support funding include regional/local support groups.



# Southeastern Sarcoma Foundation

Non-profit status since:

Website: <http://www.facebook.com/group.php?gid=55631987050>

## **Public Contact**

Name/title: Ned Crystal, Founder

Email: [nedcrystal@kw.com](mailto:nedcrystal@kw.com)

## **Services Provided**

- Raise money for research

# The sPECIAL Fund

Non-profit status since: 2008

Website: <http://www.thespecialfund.org>

## **Public Contact**

Name/title: Malcolm J. Itkin, Patient Services Coordinator

Phone: 866-881-3203

Email: [Malcolm.Itkin@thespecialfund.org](mailto:Malcolm.Itkin@thespecialfund.org)

## **Director**

Name: Phyllis Domm

Address: 6038 SE Horseshoe Point PL | Stuart FL 34997

Email: [Phyllis.domm@thespecialfund.org](mailto:Phyllis.domm@thespecialfund.org)

## **Services Provided**

- Patient/caregiver education website
- Patient/caregiver doctor and/or clinical trial referrals
- Newsletter (mail or email.) Frequency: Quarterly
- Sarcoma research advocacy
- Drug development and/or availability advocacy
- CTOS conference participation.
- Speakers Available
- Patient Stories

## **Description of Organization's Mission, Goals and Focus**

The sPECIAL Fund - Sarcoma and PEComa Investigation and Action Leadership

Our organization is committed to research, education, advocacy, and support for those diagnosed with sarcoma cancer. We're focused on the unique problems and challenges presented by a rare and heterogeneous disease.

### Goals

1. Research focused at the biology of several rare sarcoma and their shared molecular pathway links to other cancers (melanoma, lung and breast seem to be promising connects)
2. Support only research which fosters best in class collaborations among major institutions
3. Provide new Sarcoma patients and their caregivers support through web resource information access and direct support. The focus is patient personal accountability and advocacy

## **Description of Organization's Accomplishments**

1. The volunteer effort is already serving patients across the country who are newly diagnosed or seeking new direction for their Sarcomas
2. Our Director has an article published in [Women & Cancer, "Managing a Rare Cancer Diagnosis"](#). The article is about managing a rare cancer diagnosis, and how it presents unique challenges. This survivor shares her tips for navigating the sometimes murky waters.
3. November, 2008: The sPECIAL Fund's research focus was presented at the CTOS Society Meeting in London.

## **Description Organization's Events**

- Our trained volunteers work with new patients and caregivers regarding how to overcome barriers to find most relevant resources.
- Our outreach services include availability of speakers (Phyllis Domm and others) to be available to groups for education and cancer patients to provide inspirational messages and train patients on best advocacy strategies.
- July 18-26, 2009: Team sPECial Forces will sponsor an event in Maine to support International Sarcoma week. Co-Sponsorship by Dana-Farber Cancer Institute.

### **Recipients of Organization's Funds**

The sPECial Fund supports significant research in the area of rare sarcoma. The research is being conducted by a unique collaboration of full professors, researchers and clinicians at Dana-Farber Cancer Institute (DFCI), Massachusetts General Hospital (MGH) and the Harvard Teaching Consortium.

# STOWAZYSZENIE POMOCY CHORYM NA MIESAKI “SARCOMA”

Non-profit status since: 2007

Website: [www.sarcoma.pl](http://www.sarcoma.pl)

## **Public Contact**

Name/title: Stowarzyszenie Pomocy Chorym na Mi saki “SARCOMA”

Address: ul. Malborska 14/5 03-286 Warszaw, Poland

Phone: +48 22 844 89 25

Email: [office@sarcoma.pl](mailto:office@sarcoma.pl)

## **Director**

Name Kamil Dolecki

Address: . Malborska 14/5 03-286 Warsaw, Poland

Phone: +48 608 335 326

Email: [Kamil.Dolecki@sarcoma.pl](mailto:Kamil.Dolecki@sarcoma.pl)

## **Services Provided**

- Patient/caregiver education website
- Patient/caregiver doctor and/or clinical trial referrals
- Newsletter (mail or email.) Frequency: every 4 months
- Sarcoma research advocacy
- NCI committee participation. Other committee participation: in near future
- CTOS conference participation. Other conference participation: in near future Other: ECPC

## **Description of Organization’s Mission, Goals and Focus**

Our Association aims at:

- Support cancer treatment, including sarcoma, in compliance with international standards
- Act in favor of ensuring any medical and legal assistance to patients with sarcoma and their families
- Protect the rights of sarcoma affected people and their families
- Carry out educational/training activities to make the society more aware of cancer-related problems, including sarcoma
- Establish contacts with similar institutions and organizations in Poland and abroad.

## **Description of Organization’s Accomplishments**

On September 2007 the documentation of our organization was been placed in the Polish Court Register ,and the sentence of the Court gave us the status of Association on 28 December 2007

## **Description Organization’s Events**

On the 30 July 2007 first meeting took place of people interested in sarcoma organization activity. We discussed the mission and goals of organization, and we elected members of management board. On the 29 January 2008 the first meeting of members and management board took place.

# SWINGAWAY

Non-profit status since: August of 2003

Website: [www.swingaway.org](http://www.swingaway.org)

## **Public Contact**

Name/title: Scott Dixon, Co-Founder/President  
Address: 10632 S. Memorial Drive, #212, Tulsa OK 74133  
Phone: (210) 825-4401  
Email: [s\\_dixon@swingaway.org](mailto:s_dixon@swingaway.org)

## **Director**

Name/Title: David Cook  
Address: Same as above  
Phone: (918) 269-6135  
Email: [davidcook@swingaway.org](mailto:davidcook@swingaway.org)

## **Services Provided**

- Sarcoma research advocacy

## **Description of Organization's Mission, Goals and Focus**

To provide financial assistance to sarcoma cancer patients and families and to aid in the research of sarcoma cancer.

## **Description of Organization's Accomplishments**

We have raised a little over \$6,000 in the past two years donating the money to two different cancer treatment centers: Sloan Kettering and Washington Tumor Center.

## **Description Organization's Events**

Golf Tournaments

## **Recipients of Organization's Funds**

Stated above.

## WWWW FOUNDATION, INC.

Non-profit status since: 2006

Website: [www.QuadW.org](http://www.QuadW.org)

### **Public Contact**

Name/title: Lisa W. Tichenor, Trustee  
Address: 100 Crescent Court, Suite 700, Dallas, TX 75201  
Phone: 214-459-3330  
Email: [lwtichenor@QuadW.org](mailto:lwtichenor@QuadW.org)

### **Director**

Name/Title: Mac T. Tichenor, Jr., executive director  
Address: 100 Crescent Court, Suite 700, Dallas, TX 75201  
Phone: 214-459-3330  
Email: [mtichenor@QuadW.org](mailto:mtichenor@QuadW.org)

### **Services Provided**

- Sarcoma research advocacy

### **Description of Organization's Mission, Goals and Focus**

The WWWW Foundation provides financial support to people and organizations pursuing innovative ideas and opportunities in the areas of higher education, sarcoma research, personally transforming mission experiences and general philanthropy. Our accomplishments will reflect the light-hearted gbut whole-hearted spirit that Willie embodied.

### **Description Organization's Events:**

AACR sponsored Sarcoma Research Panel – April 2007, Dallas, TX

### **Recipients of Organization's Funds**

ASCO Young Investigator Award in Sarcoma, annually  
Children's Oncology Group for QuadW Sarcoma Biostatistics Office  
SARC (Sarcoma Alliance for Research through Collaboration) for creation of unified data base  
MD Anderson Cancer Center for Willie Tichenor Fellowship in Sarcoma

*On March 15, 2006 Willie Tichenor died of osteosarcoma at age 19. The WWWW Foundation, Inc., or QuadW, was created to honor his desire to make positive changes in the world around him. We will ponder the question "What Would Willie Want?" as we consider ideas to achieve these wishes.*

*Music was Willie's passion throughout his life – he was a glorious singer, whether on stage with his band CloverStreet, at church or in his car. He loved sports, especially basketball, and was an avid snowboarder. Willie was insightful, outrageous and full of good ideas and big plans. He regularly accomplished his goals. Through the end he maintained a strong faith in God. Willie had the remarkable ability to inspire those around him to be better. With his unique zest for life, Willie's personality and actions made an enduring contribution to his family, friends, and community. His unmatched charm and wit are still remembered and emulated by those who encountered him.*

*He brought great joy to his family and friends with his infectious smile and dancing eyes. He always made us laugh. And think.*

## APPENDIX

The following is a list of other organizations, which advocate for sarcoma survivors and/or raise funds for treatment and research. If you wish to be listed, contact Sarcoma Alliance.

Organization/ Foundation	Contact	Grants Given
<b>The Alliance Against Alveolar Soft Part Sarcoma (TAAASPS)</b> <a href="http://www.alveolarspsarcoma.net/">http://www.alveolarspsarcoma.net/</a>	Rose Birtley, President <a href="mailto:info@alveolarspsarcoma.net">info@alveolarspsarcoma.net</a> 141-08 Coolidge Avenue Briarwood, NY 11435 Tel 718 523-7752 Fax 718 657-0516	Dana-Farber's Jimmy Fund: the Pan-Massachusetts Challenge (PMC)
<b>Adam Dealey Foundation for Ewing Sarcoma</b> <a href="http://www.adamdealey.org/default.asp">http://www.adamdealey.org/default.asp</a>	John & Marian Dealey	UKCCSG
<b>Amandalee Fund</b>	Arlynn Haarer, Marketing Specialist <a href="mailto:haarerad@moffitt.usf.edu">haarerad@moffitt.usf.edu</a> H. Lee Moffitt Cancer Center 813- 632-1744 800-972-HOPE x1744	Lee Moffitt Cancer Center
<b>Anthony Pilcher Bone Cancer Trust</b> <a href="http://www.apbonecancertrust.org/">http://www.apbonecancertrust.org/</a>	<a href="mailto:gill@apbonecancertrust.org">gill@apbonecancertrust.org</a> Peacehaven, UK	Royal Marsden Hospital
<b>Backmeyer/Hetherington Fund</b> <a href="mailto:hetheringtonmarylynn@hotmail.com">hetheringtonmarylynn@hotmail.com</a>	Dana-Farber –Contributions Division of Development & The Jimmy Fund 10 Brookline Place West Brookline, MA 02445-7226	LMS research  Dana Farber Cancer Center
<b>Carlene Paris Fund for Sarcoma Research</b>	M.D. Anderson Cancer Center P.O. Box 297153 Houston, Texas 77030	M.D. Anderson Cancer Center
<b>Cure Sarcoma, Japan</b> <a href="http://www.curesarcoma.jp">http://www.curesarcoma.jp</a>	Kaja Onishi <a href="mailto:kajafromvancouver@ybb.ne.jp">kajafromvancouver@ybb.ne.jp</a>	Dr. Takahashi's Calponin Gene research
<b>Ferrin Randall Zeitlin Foundation For Sarcoma Research</b>	Alan Zeitlin 27 Grace Dr. Old Westbury, NY 11568-1228	
<b>GIST Cancer Research Fund (GCRF)</b> <a href="http://www.gistinfo.org">www.gistinfo.org</a>	Tania Stutman, Chairwoman <a href="mailto:Tania5kids@aol.com">Tania5kids@aol.com</a>  Dr. Mark Landesman: Director Ken Schou: Director  GIST Cancer Research Fund 55 Saw Mill Road New City, NY 10956	GIST research  MSKCC, Dana Farber, Fox, OHSU Cancer Centers

	(845) 634-6060	
<b>GIST Support UK</b> <a href="http://www.gistsupportuk.com">www.gistsupportuk.com</a>	David Cook <a href="mailto:D.Cook@SHEFFIELD.AC.UK">D.Cook@SHEFFIELD.AC.UK</a>	
<b>Grind for Life Benefit / Mike Rogers Fund</b> <a href="http://skateboard.about.com/gi/dynamic/offsite.htm?site=http://mr1skateshop.net/M.R.%2520Fund%2520%2D%2520Grind%2520for%2520Life.htm">http://skateboard.about.com/gi/dynamic/offsite.htm?site=http://mr1skateshop.net/M.R.%2520Fund%2520%2D%2520Grind%2520for%2520Life.htm</a>	Mike Rogers <a href="mailto:mrskateshop@aol.com">mrskateshop@aol.com</a> (561) 252-3839	Financial aid for travel to sarcoma centers, Sarcoma Alliance, Miracle House, Sloan Kettering Hospital
<b>In Memory of Beverly Cohn Fund</b>	M.D. Anderson Cancer Center P.O. Box 297153 Houston, Texas 77030	M.D. Anderson Cancer Center
<b>In Memory of Vicki Bundock Dowdeswell Leiomyosarcoma Cancer Research Fund</b>	Royal Marsden Hospital Fulham Road Chelsea, LONDON, England	Royal Marsden Hospital
<b>Jake's Reindeer Race</b> <a href="http://jakesreindeerrace.com/">http://jakesreindeerrace.com/</a>	Cindy Maynard <a href="mailto:jgmaynard@hunton.com">jgmaynard@hunton.com</a> 720 Epsom Downs Court Richmond, Virginia 23229 804-741-3694	CureSearch



<b>Janice and Michael Burke Leiomyosarcoma Research Fund</b>	Dana-Farber –Contributions 10 Brookline Place West Brookline, MA 02445-7226	Dana Farber Cancer Center
<b>Jeanette S Moore Leiomyosarcoma Fund</b> <a href="http://www.lmsfund.org/">http://www.lmsfund.org/</a>	Jacqueline Yencha <a href="mailto:mooreyencha@yahoo.com">mooreyencha@yahoo.com</a>	Georgetown Univ. Hospital
<b>Joanna C. Marino Foundation</b> <a href="http://www.joannacmarinofoundation.org">http://www.joannacmarinofoundation.org</a>	Dave Marino <a href="mailto:jcmfoundation@verizon.net">jcmfoundation@verizon.net</a> 508-380-8304 cell. 508-966-1557 H.	Dana Farber Cancer Center
<b>Joshua Gilbert Rhabdomyosarcoma Appeal</b> <a href="http://www.jg-rabdo.com/">http://www.jg-rabdo.com/</a>	Mr. Robert Berg, c/o Janes Solicitors <a href="mailto:info@jg-rabdo.com">info@jg-rabdo.com</a> 18-21 Jermyn Street London SW1Y 6HP England, UK Tel: 0207 734 3900	Addenbrook Hospital, Cambridge  The Institute of Cancer Research
<b>PMC Pan-Mass Challenge</b> <a href="http://www.pmc.org/">http://www.pmc.org/</a>	Billy Starr, Executive Director <a href="mailto:billy@pmc.org">billy@pmc.org</a> 77 Fourth Ave. Needham, MA 02494 781-449-5800 781-449-5803 fax	Jimmy Fund, Dana Farber
<b>Reid R. Sacco Memorial Foundation</b> <a href="http://reidsaccofoundation.org/index.html">http://reidsaccofoundation.org/index.html</a>	<a href="mailto:gsacco@reidsaccofoundation.org">gsacco@reidsaccofoundation.org</a>	Scholarships for high school graduates
<b>Richard's Run for Life</b> <a href="http://www.richardsrunforlife.com">www.richardsrunforlife.com</a>	Richard Gonzmart <a href="mailto:r.gonzmart@columbiarestaurant.com">r.gonzmart@columbiarestaurant.com</a> Richard's Run For Life Foundation P.O. Box 5027 Tampa, Florida 33605	Pediatric sarcoma research at H. Lee Moffitt Cancer Center

<p><b>Seth A. Bailey Sarcoma Cancer Fund</b>  <a href="http://www.tourtocure.com">www.tourtocure.com</a></p>	<p>Tom Bailey  <a href="mailto:tom.bailey@tourtocure.com">tom.bailey@tourtocure.com</a>  3173 560th St. SW  Riverside, IA 52327  319-679-2629</p>	<p>Sarcoma  Foundation of  America</p>
<p><b>SOS DESMOIDE Association</b>  <a href="http://www.sos-desmoide.asso.fr">http://www.sos-desmoide.asso.fr</a></p>	<p>Marie Podevin  President &amp; Founder  Daniel et Rejane Podevin  1 Rue des Trembles, 17200 Royan,  France  <a href="mailto:podevin@aol.com">podevin@aol.com</a></p>	
<p><b>Shawn Thomas Memorial Foundation</b>  <a href="http://www.shawnthomasfoundation.org">http://www.shawnthomasfoundation.org</a></p>	<p><a href="mailto:mail@shawnthomasfoundation.org">mail@shawnthomasfoundation.org</a></p>	
<p><b>The Robert and Heather Urich Sarcoma Foundation</b>  <a href="http://www.spenser.de/roberturich-com/index.html">http://www.spenser.de/roberturich-com/index.html</a></p>	<p>The Robert and Heather Urich Sarcoma  Foundation  1500 E. Medical Center Drive, Ann  Arbor, MI 48109-0755</p>	<p>U of Michigan  Cancer Center</p>
<p><b>The Shelly Glaspell Schiellerd Ewing's Sarcoma Fund</b>  <a href="http://www.ewingssarcomafund.com">www.ewingssarcomafund.com</a></p>	<p>Sandy Glaspell  <a href="mailto:sandyg@carolina.rr.com">sandyg@carolina.rr.com</a>  PO Box 1174 • Harrisburg, NC 28075  704.795.7010</p>	<p>Financial  assistance for  Ewing's families</p>
<p><b>The Terry Fox Foundation</b>  <a href="http://www.terryfoxrun.org/english/home/default.asp?s=1">http://www.terryfoxrun.org/english/home/default.asp?s=1</a></p>	<p>Darrell Fox Ex Director  <a href="mailto:national@terryfoxrun.org">national@terryfoxrun.org</a>  Canada  (604) 701-0246</p>	<p>National Cancer  Institute of  Canada</p>

**Organizations with changes since last directory publication:**

- Dani's Foundation
- Desmoid Tumor Research Foundation
- National Leiomyosarcoma Foundation
- Sarcoma Alliance for Research through Collaboration (SARC)
- Sarcoma UK
- Sarcoma Patients EuroNet Association (SPAEN)