DIRECTORY

OF

SARCOMA PATIENT ADVOCACY

ORGANIZATIONS AND FOUNDATIONS

January 2014

"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.
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For additions, corrections, or changes to this directory, please email Arthur Beckert at the Sarcoma Alliance, abeckert@sarcomaalliance.org
1 Million 4 Anna Foundation
Non-profit status since: January 2012  Website: http://1million4anna.org

Public Contact
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Phone: 214-986-0009
Email: carol.basso@1million4anna.org

Services Provided
- Patient/caregiver education/support
- Patient/caregiver doctor and/or clinical trial referrals
- Newsletter (mail or email.) Frequency: TBD
- Ewing’s Sarcoma Research funding
- Ewing’s Sarcoma Community Awareness
- Foundation Facebook Fan Page for Awareness/Sharing
- College Scholarships for Ewing’s Sarcoma Warriors/Survivors
- Anna’s Closet – stocking with adolescent/teen prizes in several hem/onc clinics

Description of Organization’s Mission, Goals and Focus
Our mission is to eradicate Ewing’s Sarcoma. We will remain vigilant to the needs of suffering adolescents and their families. We will provide university scholarships for students who have battled, or continue to battle, the disease. We will fund promising Ewing’s research. Our commitment is to empower young cancer survivors and warriors in varying stages of their journeys through inspiration, education, and eradication.

Description of Organization’s Accomplishments
Establishment and upkeep of three “Anna’s Closets” providing adolescent/teen gifts to patients in hem/onc clinic. Successful Book Drive for five libraries in facilities of Children’s Medical Center Dallas and Plano. Dallas Mavericks Night for Ewing’s patients and survivors. Sponsorship of Blood Drive. 100% of activities accomplished with 100% volunteer support.

Description Organization’s Events
Scholarship Dinner (May). Awarded 5 college scholarships to five Ewing’s Sarcoma survivors. Golf Tournament planned for October 2012.

Recipients of Organization’s Funds
College Scholarship Recipients, Ewing’s families, and currently evaluating promising research projects with the help of our Medical Advisory Board.
Non-profit status since: February 2001

Website:  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

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

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 ONLINE RESOURCES (ACOR)

Non-profit status since: 1996
Website: http://acor.org

Public Contact
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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

Public Contact
Name/title:   Nathalie Criou, President  
Address:  76 Ellsworth Street, San Francisco, CA 94110  
Phone:  415-826-0474  
Email:   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 -  

Sarcoma Cup – a 2day regatta on San Francisco Bay, August 22 and 23 -  
http://www.beatsarcoma.org/Sarcoma_Cup.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
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Phone: 814-946-9369
Email: 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. 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 – 3rd Annual $1000 Brian Morden Memorial Scholarship
- Danica Myers (Ewing’s survivor) – 2nd Annual $1000 Brian Morden Memorial Scholarship
- Josh Applas – 2nd Annual $1000 Brian Morden Memorial Scholarship
- Geo Horvath - 1st $1000 Brian Morden Memorial Scholarship
- Brian Johnson – 1st $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
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Email: nesbit@charter.net or 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.
**Public Contact**

Name/title: Joan Darling, Ph.D., Patient Advocate Committee for Soft Tissue Sarcomas  
Address: 611 Hazelwood Drive, Lincoln, NE 68511  
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Email: yesak@inetnebr.com or JDarling@oaconsulting.com  

Name/title: Beryl Gantt, Patient Advocate Committee for Bone Sarcomas  
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Columbia, Maryland 21044  
Phone: Tel 301-596-6756  
Email: bgantt7@comcast.net  

**Director**

Peter C. Adamson, MD, Chairman, Children’s Oncology Group  
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The Children's Hospital of Philadelphia  
3501 Civic Center Blvd, CTRB 10060  
Philadelphia, PA 19104  
Phone: Tel: (215) 590-6359  
Email: adamson@email.chop.edu  

**Services Provided**

- Patient/caregiver education website  
- Patient/caregiver doctor and/or clinical trial referrals  
- Patient/caregiver counseling  
- Sarcoma research advocacy (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  

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

The Children’s Oncology Group (COG), a National Cancer Institute supported clinical trials group, is the world’s largest organization devoted exclusively to childhood and adolescent cancer research. The COG unites more than 8,000 experts in childhood cancer at more than 200 leading children’s hospitals, universities, and cancer centers across North America, Australia, New Zealand, and Europe in the fight against childhood cancer.  

Today, more than 90% of 13,500 children and adolescents diagnosed with cancer each year in the United States are cared for at Children’s Oncology Group member institutions. COG’s unparalleled collaborative efforts provide the information and support needed to answer important clinical questions in the fight against cancer.
The Children’s Oncology Group has nearly 100 active clinical trials open at any given time. These trials include front-line treatment for many types of childhood cancers, studies aimed at determining the underlying biology of these diseases, and trials involving new and emerging treatments, supportive care, and survivorship.

The Children’s Oncology Group research has turned children’s cancer from a virtually incurable disease 50 years ago to one with a combined 5-year survival rate of 80% today. Our goal is to cure all children and adolescents with cancer, reduce the short and long-term complications of cancer treatments, and determine the causes and find ways to prevent childhood cancer.

**Description of Organization’s Accomplishments**
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

**Recipients of Organization’s Funds**
The Children’s Oncology Group is primarily funded by the National Cancer Institute and also receives additional funding from other granting agencies and from philanthropic sources (cog-foundation.org). Two major NCI grants provide core funding: the primary or Chair’s grant supports research operations and funds personnel at member institutions conducting research, and the statistics and data center grant supports these essential research functions. Other key grants include the COG Phase 1 Consortium grant, supporting 21 COG institutions charged with early phase clinical trials, and the Community Cancer Oncology Program (CCOP) grant.

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CHORDOMA FOUNDATION

Non-profit status since: 2007
Website: www.chordoma.org

Public Contact
Name/title: Josh Sommer
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Phone: 919-809-6779
Email: info@chordoma.org

Director
Name: Josh Sommer
Address: PO Box 4562, Greensboro, NC 27404
Phone: 919-794-8506
Email: joshsommer@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
CURE ALVEOLAR SOFT PART SARCOMA INTERNATIONAL
iCureASPS

Non-profit status since: not yet
Website: http://cureasps.org/

Public Contact
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Phone: 781-466 4411    Fax:
Email: 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.cureourochildren.org

Public Contact
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Address:   711 S Carson, Street, Suite 4, Carson City, NV 89701-5299
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Director
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Address:  1730 Michael Lane, Pacific Palisades, CA  90272-2037
Phone:  310-355-6046  Fax:  310-454-9592
Email:  barry@cureourochildren.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.cureourochildren.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.
Non-profit status since: 1999
Website: www.danisfoundation.org

Public Contact
Name/title: Michele Ashby, Founder & President
Address: 216 16th Street, Suite 1600, Denver, CO 80202
Phone: 303/601-1881
Email: michele@minellc.com

Director
Name: Martha Simmons, Executive Director
Address: 216 16th Street, Suite 1600, Denver, CO 80202
Phone: 303/601-1881
Email: Martha@danisfoundation.org

Services Provided
- Patient Assistance - Dani’s Foundation offers information, resources and financial assistance grants to US pediatric sarcoma patients to assist with finding the most current information available and to assist with paying for human welfare needs. For guidelines and application, email to 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 1 time 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 pediatric cancer patients;
- Implementing community education programs that will inform the public-at-large on the symptoms of sarcomas;
- Providing valuable resource information and financial support for sarcoma patients.

Description of Organization’s Accomplishments

Dani’s Foundation Year By Year Overview

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 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 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 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. Dani’s Foundation provided funding for Dr. Toretsky’s lab to create novel peptides to
Thanks to the above outreach, our Foundation's patient assistance program is lending support to those who need us most.

**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 Fund.

**2008** - Dani’s Foundation awarded $10,000 to Dr. Jeffrey Toretsky to continue his research on Ewing’s Sarcoma. In addition, Dani’s Foundation hired its first full-time Executive Director and hosted the first annual EWS Medical Forum in Denver. This meeting brought together medical and professional advisors, from throughout the nation, to address immediate and long-term research needs that will lead to the eradication of Ewing’s Sarcoma and the Ewing’s Family of Tumors.

**2009** - Dani’s Foundation awarded $10,000 to Dr. Jeffrey Toretsky to continue his research on novel treatments for Ewing’s Sarcoma.

**2010** - Dani's Foundation Awarded $100,000 to Dr. Jeffrey Toretsky to continue his research on novel treatments for Ewing's Sarcoma and awarded a $25,000 seed research grant to the Colorado State University Animal Cancer Center for their study of Stereotactic Radiation Therapy (SRT) for local control of bone tumors.

The Foundation also adopted the development of a Patient Assistance Grant Program that will now be available to provide financial assistance to pediatric sarcoma patients and their family members who are financially struggling to pay those bills that are mounting up due to their cancer diagnosis and treatment.

The Foundation officially launched their much-anticipated **STOP LOOK & LIVE** community education program that has been designed to provide pediatric sarcoma symptom information to those individuals who are on the frontlines in dealing with the health and well-being of our children including school nurses, physical education instructors, coaches, athletic directors and sport trainers with the intent on educating each on the symptoms of these diseases and encouraging their intervention should any symptom persist for an extended period of time. Initially the **FREE** posters and brochures were sent out to all school personnel in Colorado and to any other individual and/or group who would like to assist us in spreading the word on the symptoms of pediatric sarcomas.

**2011** - Dani’s Foundation continued to work on its effort to connect with even more pediatric sarcoma advocates with the goal of improving the delivery of our information and resources via our re-designed website (www.danisfoundation.org).

Our patient assistance grant program proved successful in financially assisting even more pediatric sarcoma patients and, because of this program, our foundation has become professionally connected with many medical centers throughout the country.

During 2011, Dani’s Foundation continued to push for even greater distribution of our pediatric sarcoma educational supplies in all schools throughout Colorado and we continue to be aggressive in an effort to connect with pediatric sarcoma advocates from throughout the nation in an effort to provide each and every advocate with the necessary supplies to take to their local schools and community organizations.

Thanks to the development of two new auxiliary groups which have been created during the past year, the **Mothers & Others: Working to End Pediatric Sarcoma** and the **Pet Pals**. These groups have been established with the intent to raise awareness and funding opportunities for our Foundation’s research programs.

Most importantly, thanks to the generosity of many during 2011, we have been successful in raising the funding necessary to continue our Ewing’s Sarcoma research grant program and have also raised additional funding to begin an organized effort to fund osteosarcoma research in the coming years.

2011 will also be noted as the year that launched our Community Education Breakfast. This most important event is our opportunity to showcase the work of our Foundation to those assembled and to formally request participation with us via our patient programs, education and research endeavors. During our first one-hour breakfast meeting, we were able to present real life pediatric sarcoma stories coupled with presentations from our current research award recipients. Following these presentations, most guests in attendance made personal commitments to support our Foundation via personal financial gifts, volunteer service or by offering other resources to help in other areas of the Foundation’s operation.

**2012** is being logged as a landmark year for Dani’s Foundation.

Our overall outreach to the pediatric sarcoma community has doubled during the past year thanks in part to our re-designed website which features a daily blog of information for the pediatric sarcoma community and our continuation of an organized effort in connecting via social networking opportunities. Dani’s Foundation now has a presence via Facebook, Google+, LinkedIn, Tumblr, Network for Good, Twitter, Pinterest and YouTube. We continue to develop outreach via each new opportunity with the goal of connecting with others within the pediatric sarcoma community and offering support where needed.

Thanks to the above outreach, our Foundation’s patient assistance program is lending support to those who need us most.
In 2012, Dani’s Foundation connected with hundreds of pediatric sarcoma patients, family members and medical professionals from around the globe.

We provided 200 patients/patient advocates with requested information and resources. In addition to those connects, our patient assistance grant program provided 16 financial assistance grants to those pediatric sarcoma patients who needed support with such items as fuel cards in order to assist with those expenses associated with traveling to and from doctor and hospital visits; the payment of utility bills due to the patient not having enough funding to pay for both medical expenses and their escalating utility bills; and the payment of a portion of some patient’s rent or mortgage with the hope of easing their financial burden for a short period of time.

The Foundation’s patient assistance programs are vital to lending immediate assistance to those patients and family members who are most in need of support and we are committed to working to continually expand the scope and reach of this program in the coming years with the intent of becoming “The Number One Resource” for the pediatric sarcoma community.

In 2012, Dani’s Foundation was successful in connecting with pediatric sarcoma advocates in 26 states and 7 countries; each of whom are working with us to distribute our community education supplies to their school personnel, medical communities and community networks. Going forward, we are working to obtain support from others who will assist us in our effort to educate the public at large on the symptoms of pediatric sarcoma with the intent of seeking earlier diagnosis and improved outcomes for our children and young adult patients.

The Dani’s Foundation research effort continues to grow thanks to the support of so many patients, patient family members and other supporters who are truly committed to putting an end to pediatric sarcoma. Our Ewing’s Sarcoma research effort continues to thrive and now our designated funds for the study of osteosarcoma offer even greater opportunities in the future. Thanks to our most recent connection with the Mary Crowley Cancer Research Center in Dallas, TX; we are now available to connect Ewing’s Sarcoma patients with a Phase I Clinical Trial that is aimed at providing a targeted therapy opportunity. This is most exciting news for the Ewing’s community and we are looking forward to working with the researchers at Mary Crowley via our recent grant award to them and working together to expand upon this promising science which is aimed at providing greater support to the Ewing’s Sarcoma community.

In addition to the above, we would like to recognize the amazing new support from the Osteosarcoma community, who are now joining with us to follow our Ewing’s research model and seek out those scientific investigators who show promise in finding better treatment protocols for this disease and ultimately the cause and the cure for this dreadful disease. Thanks to this new level of support, Dani’s Foundation is thrilled to be able to support Dr. Aykut Uren and his scientific team at the Lombardi Comprehensive Cancer Center, as he embarks on his research toward a targeted therapy for osteosarcoma.

Our Osteosarcoma network is already looking into other research opportunities for funding during 2013 and Dani’s Foundation will look forward to announcing those new research grant opportunities during the coming months.

Description Organization’s Events
- Annual Benefit (Spring)
- STEPS WITH PETS WALK (Spring)
- GOLF FORE A KID Golf Tournament (Summer)
- FriendRaising Breakfast (Fall)
- Year End Campaign (November)

Recipients of Organization’s Funds
- Mary Crowley Cancer Research Center
- Dr. Aykut Uren, Lombardi Comprehensive Cancer Center at Georgetown University
- Dr. Jeffrey Toretsky, Lombardi Comprehensive Cancer Center at Georgetown University
- 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
                              www.dtrf.org

Public Contact

Name: Marlene Portnoy
Address 16 Marget Ann Lane Suffern, NY 10901
Phone 914-262-6595
Email marlene@dtrf.org

Name: Jeanne Whiting
Phone (203) 966-7240

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
• 2012 Patient meeting; Running for Answers Walk/Run; Wine Tasting
• 2013 Rosie O'Donnell Comedy Show
• 2013 Patient Symposium and Running for Answers Walk
• 2013 Golf Outing

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, Stephen Skapek, MD: Deregulated mTor in desmoid type fibromatosis: identification and validation of a new therapeutic agent.
• Memorial Sloan Kettering Cancer Center, Mrinal Gounder MD: Phase III, double blind, randomized, placebo-controlled trial of sorafenib in desmoid tumors or aggressive fibromatosis (DT/DF).
• Aaron Weiss, DO, Main Medical Center, Portland, Maine; Deregulated mTOR in desmoid-type fibromatosis: identification and validation of a new therapeutic target.
• 2012 Grant Awards -Mrinal Gounder, MD –Memorial Sloan-Kettering Cancer Center; A Phase III, double blind, randomized, placebo-controlled trial of sorafenib in desmoid tumors or aggressive fibromatosis (DT/DF)
Public Contact
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Address: c/o Hall Court Park Ridge NJ 07656
Phone: 201-391-4757
Email: 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

Public Contact
Name/title: Estelle LECOINTE
Address: Maison des associations, 6 cours des allies – 35000 Rennes (France)
Phone: None
Email: ensemblecontrelegist@yahoo.fr

Director
Name: Estelle LECOINTE
Address: Maison des associations, 6 cours des allies – 35000 Rennes (France)
Phone: None
Email: ensemblecontrelegist@yahoo.fr

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:

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

Current projects:

Since 2011, A.F.P.G. “Ensemble contre le GIST” organize an annual call for project in order to select the best GIST research project driven by a French team and then orientate 100% of our donations to its funding.

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”, “ESMO”
and “EORTC”. In 2009, we have also co-founded, with several other European GIST Patients organizations, the creation of a European Sarcoma Coalition called “Sarcoma Patients Euro Net”. After seven years of commitment, we are now represented in most of the major French and international events dealing with GIST, sarcoma or Cancer. Since 2008, we are sitting at the Patient committee of the French NCI where we represent at a national level and advocate for patients suffering from rare cancers.

**Description of Organization’s Accomplishments**

- Brochure about GIST : “Mieux connaître sa maladie”
- Brochure about compliance in French : “L’observance au traitement : devenir acteur de sa prise en charge thérapeutique au quotidien”.
- PDF English version of the brochure : “Compliance with treatment : be an active partner in your GIST care everyday” (Now available online in 12 different languages)
- Brochure about “SUTENT” (in partnership with Pfizer).

**Description Organization’s Events**

- 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.
- General assembly : Annual event occurring in November.
- “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, 1st 2008.
- “The GIST Patients day” : Scientific sessions specifically made for GIST patients and caregivers. This event will occur in November, 22nd 2008 in Lyon.

**Source of Organization’s Funds**

- Public and private Donations
- Conticanet
- Novartis
- Pfizer
Foster Foundation

Non-profit status since: 2002
Website: 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

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
Gift To Cure Corporation

Non-profit status: applied July 28, 2010
Website: 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

Director
Name/title: Salome E Klopper (President/Founder)
Address: PO Box 825, El Dorado, CA 95623
Phone: 714-600-2509
Email: 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

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
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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
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

Public Contact
Name/title: Marina Symcox, PhD Co-manager
Address: 209 West 10 Avenue Bristow, OK 74010
Phone: 918-367-9279
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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

Julie Royster, PhD
Title: Science Coordinator
Email: 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

Public Contact
Name/title: Beth Stefanacci
Address: 300 West Maple Ave., Merchantville, NJ 08109
Phone: 609-313-0912
Email: bethstefanacci@aol.com

Director
Name: Charla Lewis
Address: 43 E. Cedar Ave., Merchantville, NJ 08109
Phone: 609-636-7184
Email: 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 each 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 4th annual
Bowl4the Goal- bowling event held in Feb. – 3rd annual planned for Feb. 2010
Richard’s Drive 4 a Cure – Golf Outing, Horsham, PA 2nd 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 Organization’s Funds**
To be determined
INFOSARCOMES

Status: Non-Profit Organisation since May, 2009
Website: www.infosarcomes.org

Public Contact
Name/Title: Estelle LECOINTE – Founder President
Address: Maison des associations – 6, cour des allies, 35000 Rennes (France)
Phone: None
Email: info@sarcomes.org

Service Provided
- Educational website
- Doctor and/or clinical trial referral
- Patients/caregivers support
- Newsletter
- Financial support to French Sarcoma research
- Support for training of health professionals

Description of Mission, Goals, Focus
- Development and dissemination of validated scientific and medical information for patients, caregivers and non specialist doctors
- Optimization of the visibility of the French Sarcoma Group
- Development of sarcoma knowledge and support to dissemination of good practice
- Facilitate patients referral in sarcoma expert centers
- Facilitate patients access to sarcoma clinical trials
- Promote sarcoma scientific and medical research at National and European scales
- Raise public opinion awareness about sarcomas and rare cancers

Description of Organization’s Accomplishments
- Official partnership with the French Sarcoma Group
- Annual call for sarcoma research
- Funding of 4 sarcoma research projects

Description of Organization’s Events
- Annual patient conference
- Partnership in the development of the eSURGE programme

Recipient of Organization’s Funds
- French sarcoma group research projects
JAREDS JUGGERNAUT TO CURE SARCOMAS
Non-profit status since: 2010     Website: www.jaredsjuggernaut.org

Public Contact
Name/title: Robyn Grossman, President
Address: 24001 Muirlands Blvd. #303, Lake Forest, CA. 92630
Phone: 856-424-5345
Email: admin@jaredsjuggernaut.org

Director
Name: Raymond Grossman, Executive Director
Address: 24001 Muirlands Blvd. #303, Lake Forest, CA. 92630
Phone: 856-424-5345
Email: 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
• Children’s Hospital, L.A.
• Oregon Health and Science University
• Texas Children's Hospital SW.
JENNIFER HUNTER YATES SARCOMA FOUNDATION

Non-profit status since: September 2004       Website:  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

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.reinisarcoma.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 or ptwyckoff@reinisarcoma.org

Director
Name/Title: Mike Trucano, Board Member
Address: 11 Thompson Lane, North Oaks, MN
Phone: 651-484-9332
Email: 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.
Non-profit status since: 1993       Website: www.sarcoma.com

Public Contact
Name/title: David Marsh, Trustee
          Michael Solomon and Rishon Blumberg, administrators
Address:  39 West 32nd Street, Suite 1403
          NY, NY  10001
Phone:    (203) 846-9033; (212) 501-0748
Fax:       (212) 268-3544
Email:     marsh6@optonline.net
          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: 2003     Website: www.sarcomahelp.org

Public Contact
Name/title:  Bruce and Beverly Shriver, Co-Founders
Address:  17 Bethea Drive, Ossining, NY 10562
Phone:  914 762 3251       Fax: 914 941 9181
Email:   bruce@sarcomahelp.org
Email:   beverly@sarcomahelp.org

Services Provided
- An educational website for the international patient and medical communities
- Electronic Sarcoma Update Newsletter (ESUN): A bi-monthly, peer-reviewed journal
- Peer-reviewed Research Grants Program
- Patient and caregiver counseling and support
- Advocacy for sarcoma research and drug development

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.

Description of Organization's Accomplishments
- We have published more than 100 peer-reviewed articles and Op-Ed pieces by sarcoma specialists around the world. Many of these articles have been translated by physicians and advocates into several languages.
- We have funded more than $2.2 million in sarcoma research grants, including several large International Collaborative Grants.
- We have worked with dozens of individuals, communities and organizations to host sarcoma awareness events and to fund sarcoma research grants.
- We offer opportunities for personal sharing and support in the Faces of Sarcoma Gallery, the Sarcoma Survivors Project, and the Team Sarcoma Facebook Group.

Description Organization's Events:
Events vary based on the needs and goals of our supporters and partners. Many events focus on increasing awareness and support for specific subtypes of sarcoma.

Recipients of Organization’s Funds
The Liddy Shriver Sarcoma Initiative funds a wide range of basic and translational research that is targeted at finding cures for sarcomas, as well as research that attempts to develop more effective treatment regimens than those currently available. Our Research Grants Program is highly selective: study proposals are accepted throughout the year and are reviewed by sarcoma experts. Only the most promising studies are approved through this process, and our goal is to ensure that funds are available for every approved study. Grant recipients publish their experimental plan and a report of their research findings in ESUN. Past grant recipients include:
• Cedars-Sinai Medical Center
• Dana Farber Cancer Institute
• Fondazione IRCCS Istituto dei Tumori (Italy)
• Johns Hopkins Medical School
• Georgetown University
• Huntsman Cancer Institute
• Leiden University Medical Center (Netherlands)
• M. D. Anderson Cancer Center
• Mother & Child Hospital (France)
• New York University School of Medicine
• Peter MacCallum Cancer Centre (Australia)
• Stanford University School of Medicine
• Tianjin Cancer Hospital and Institute (China)
• University of Toronto (Canada)
LIFE RAFT GROUP

Non-profit status since: 2002
Website: 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

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

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.
Public Contact
Name/title: John Link
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Phone: 774-258-0860
Email: 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

Public Contact:
Name/title: Ed Kurtz, President
Address: PO Box 52697, Tulsa, Oklahoma 74152
Phone: (413) 502-2241
Email: 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

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 or 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

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

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.
**Public Contact**

Name/title: Jeffrey Sweeney, President, Board of Directors  
Address: P.O. Box 91460, Portland, OR 97291  
Phone: (425) 829-3829  
Email: jeffrey.r.sweeney@jci.com

**Director**

Name/title: Tammy Wilhoite  
Phone: (503) 781-0921  
Address: P.O. Box 91460, Portland, OR 97291  
Email: tammy@nwsarcoma.org

**Services Provided**

- Patient/caregiver education website
- Peer support
- Referrals to physicians/clinics with experience treating sarcoma
- Sarcoma research advocacy
- Financial assistance through the HELP$ program to patients undergoing treatment for sarcoma
- Research

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

**Mission:** Northwest Sarcoma Foundation is a non-profit organization committed to improving cure rates for sarcomas, making the Pacific Northwest a research and clinical care leader through academic and community initiatives to serve as the paradigm for sarcoma research.

**Compassion:** Provide comfort through a sympathetic awareness.

**Advocacy:** Promote accurate diagnosis, research and treatment options.

**Responsibility:** Provide accurate information and reliable resources.

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

**Vision:**

Develop better treatments for patients with sarcomas through research and institutional collaboration.

**Description of Organization’s Accomplishments**

- Co-Recipient of National Cancer Institute grant to raise awareness about sarcoma treatment and research in the Pacific Northwest.
● Patient Packet – Packets distributed to physician offices and hospital social workers with information.
● HELP$ Financial Assistance Program – A need-based financial assistance program for adult patients currently undergoing treatment; Jenna Westerholm Pediatric HELP$ Program -- A need-based financial assistance program for pediatric patients currently undergoing treatment.
● Research Fund – Development and continued growth of a fund from which monies can be withdrawn for research or research-based purposes.
● Legacy Gifts – In partnership with Oregon Health & Sciences University (OHSU)/Doernbecker Children’s Hospital a program has been established to collect pediatric tumor tissue for research into a cure for sarcoma.
● OHSU Lectureship Series – Sponsorship of a research lecture in conjunction with OHSU.
● Support Groups
  ○ Solidarity in Sarcoma: an in-person support group held monthly in the Seattle area
  ○ Online Support Group through private Facebook page Solidarity in Sarcoma

Description Organization’s Events
● Dragonslayer Bike, Hike, or Trike is an annual walk to raise awareness of sarcoma, and support for sarcoma patients and their families. Held in Seattle, WA and Portland, OR.
● Stories from the Vineyard is an annual benefit dinner featuring wine tasting and silent/live auctions and a paddle raise that funds the HELP$ programs.
● Community events are held from time to time by individuals or groups in support of the foundation’s programs.

Recipients of Organization’s Funds
● The Foundation HELP$ programs provide financial assistance to patients undergoing treatment for sarcoma.
● OHSU and UW Lectureship Program
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

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; Facebook
• 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, AOSW

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. Finally, we help to promote July as Sarcoma Awareness Month.

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.
Description Organization’s Events
Our primary fundraising campaign is the Ocean of Hope. We have paddleboarders and outrigger teams who participate in events in California and Hawaii. The Sarcoma Alliance has a tent at these events. Additionally, individuals regularly hold events around the United States to raise awareness about sarcoma and to raise funds for the Alliance. Check our events page for the latest listing of events, locations, times, etc.

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

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

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 Cancer Foundation of Canada

Non-profit status since: 2010
Website: www.sarcomacancer.ca

Public Contact
Name/title: Sarcoma Cancer Foundation of Canada
Address: 1 Yonge Street, Suite 1801, Toronto, Ontario, M5E 1W7
Phone: 416-214-7584
Email: info@sarcomacancer.ca

Director
Name: Diana Arajs, Founder and Chair
Address: 374 Lippincott St, Toronto, Ontario, M5S 2P7
Phone: 416-214-7584
Email: Diana@poisecommunications.com

Services Provided
- Patient/caregiver education website
- Newsletter (mail or email.)
- Sarcoma research advocacy
- Sarcoma research funding
- Sarcoma community awareness
- Facebook/Twitter/Website for awareness/sharing

Description of Organization’s Mission, Goals and Focus
The SCFC was founded in 2010 in memory of Vera Arajs and other Canadians who have lost their lives to Sarcoma cancers. We are a volunteer-run national organization supporting patients and their families, while working with Canada's leading research institutions in their efforts to eradicate Sarcoma cancers.

It is our mission to connect patients and their families with the best medical information and community resources, to ease the process of dealing with a sarcoma cancer diagnosis and treatment.

Description of Organization’s Accomplishments
- Establishment of the Vera Arajs Clinical Research Fellowship in Sarcoma at Mount Sinai Hospital, Toronto. The fellowship is on-going and provides important sub-specialty physician training and clinical research.
- 100% of activities and events accomplished with total volunteer support, with all funds raised going directly to sarcoma efforts.

Description Organization’s Events
- August 2010 - Earth Salon fundraiser, Toronto, Ontario.
- August 2010 - Inaugural Scratch Sarcoma Shindig, Toronto, Ontario.
- October 2011 - Scotiabank Toronto Waterfront Marathon, Toronto, Ontario.
- September 2012 – Sarcoma Step and Fetch, Trenton, Ontario.
- Jigsaw for Hair: Champagne Charity Event, Edmonton, Alberta.

**Recipients of Organization’s Funds**

Donations are used for priority projects that support sarcoma cancer patients and their families across Canada. SCFC also works with Canada’s leading research institutions to develop life-saving treatments.
SARCOMA FOUNDATION OF AMERICA

Non-profit status since: 2001
Website: www.curesarcoma.org

Public Contact
Name/title: Tony Ferlenda, Executive Director
Address: 9899 Main Street, Suite 204, Damascus, MD 20872
Phone: (301) 253-8687 Fax: (301) 253-8690
Email: @curesarcoma.org

Services Provided
• Patient/caregiver education website
• Patient/caregiver doctor and/or clinical trial referrals
• Newsletter (mail or email.) Frequency: quarterly
• 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: SARC
• 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. The SFA has a national Sarcoma Patient Registry and also provided a Clinical Trial Navigator Service.

Description of Organization’s Accomplishments
Funded 65 SFA Sarcoma Research Grants
Funded 6 ASCO Young Investigator Awards
Funded 2 ASCO Advanced Clinical Research Awards
Funded 1 ASCO Career Development Award
Participant 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 of 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

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

Director
Name: Markus Wartenberg (Financial Director)
Address: Usa-Strasse 1, D-61231 Bad Nauheim / Germany
Phone: +49-(0)6032-9492438
Email: 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

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

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

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?gis=55631987050

Public Contact
Name/title: Ned Crystal, Founder
Email: 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

Director
Name: Phyllis Domm
Address: 6038 SE Horseshoe Point PL | Stuart FL 34997
Email: 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.
STEEL LILLIES FOUNDATION

Non-profit status since: We have non-profit status through University of Rochester
Website: www.steellilies.org

Public Contact
Name/title: Steel Lillies Foundation
Address: 40 Humboldt Street
Rochester, NY 14609
Tel: 585-288-2070
Fax: 585-288-1257
Email: Jlill@industrialfurnace.com

Director
Name: Vivian Santora
Address: 40 Humboldt Street
Rochester, NY 14609
Phone: 917-612-7358
Email: vsantora@nyc.rr.com

Services Provided

• Fund Sarcoma research and research advocacy

Description of Organization’s Mission, Goals and Focus

Steel Lillies was founded in January 2012 with Tiffany Lill’s wish to raise awareness and funding for sarcoma research, a little known cancer. At that time, Tiffany was in the middle of her sixteen month long fight with this disease. The Mother of two young children and lifelong “Flower City” resident would eventually lose her courageous battle on 4/9/12. The Steel Lillies name symbolizes Tiffany’s beauty and toughness. The “Steel” represents Tiffany’s unwavering strength as metal rods were inserted to support her spine after tumors grew around her upper back area. The “Lillies” represents Tiffany’s last name as well as being her favorite flower.

Financial goal is to raise a total of $250,000 for the James P. Wilmot Cancer Center at the University of Rochester.

Description of Organization’s Accomplishments

We are proud to say that the Foundation has raised over $185,000 toward our $250,000 pledge to the James P. Wilmot Cancer Center at the University of Rochester. Contributions will have an immediate impact in the medical community by funding research with the promise of finding a cure for sarcoma cancer. Advancements in the fight against sarcoma cancer will also lead to new treatments and cures for all types of cancer.

In the Fall of 2012, we were notified that EVERY DOLLAR RAISED BY STEEL LILLIES WILL BE MATCHED by the University of Rochester’s Department of Orthopedics. This means every contribution will have double the impact.
The larger portion of our gift was used as a recruitment package for a physician-scientist who is specifically focused on sarcoma cancer. With the match provided by the Orthopedics department, there will be a level of funding necessary to support a new research program over a few years. To be clear, these funds are restricted for research and will not be used for salary support. This is a means to elevate the level of sarcoma-related research as well as the care of patients who face a sarcoma diagnosis.

Through the generous funds raised by the Steel Lillies Group, Dr. Emily Carmody Soni was successfully recruited by the U of R and she began her work this past August.

**Description Organization’s Events**

Two Annual Events:

1. All In For Steel Lillies Gaming and Silent Auction Event Annually in February
2. Steel Lillies 5K Annually in June

**Recipients of Organization’s Funds**

James P. Wilmot Cancer Center at the University of Rochester
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 Mięsaki “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.
Non-profit status since: August of 2003

Website: 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

**Director**
Name/Title: David Cook
Address: Same as above
Phone: (918) 269-6135
Email: 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.
WWW FOUNDATION, INC. (Quad W)

Non-profit status since: 2006  
Website: 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

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

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 but whole-hearted spirit that Willie embodied.

Description Organization’s Events:
Pediatric Cancer Translations Genomics Meeting – February 2012

Recipients of Organization’s Funds
ASCO Conquer Cancer Foundation, 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.
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.

<table>
<thead>
<tr>
<th>Organization/ Foundation</th>
<th>Contact</th>
<th>Grants Given</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Alliance Against Alveolar Soft Part Sarcoma (TAAASPS)</td>
<td>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</td>
<td>Dana-Farber’s Jimmy Fund: the Pan-Massachusetts Challenge (PMC)</td>
</tr>
<tr>
<td>Adam Dealey Foundation for Ewing Sarcoma</td>
<td>John &amp; Marian Dealey</td>
<td>UKCCSG</td>
</tr>
<tr>
<td>Amandalee Fund</td>
<td>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</td>
<td>Lee Moffitt Cancer Center</td>
</tr>
<tr>
<td>Anthony Pilcher Bone Cancer Trust</td>
<td><a href="mailto:gill@apbonecancertrust.org">gill@apbonecancertrust.org</a> Peacehaven, UK</td>
<td>Royal Marsden Hospital</td>
</tr>
<tr>
<td>Backmeyer/Hetherington Fund</td>
<td>Dana-Farber –Contributions Division of Development &amp; The Jimmy Fund 10 Brookline Place West Brookline, MA 02445-7226</td>
<td>LMS research Dana Farber Cancer Center</td>
</tr>
</tbody>
</table>
| **Betsy Project Cure Sarcoma Now**  
http://www.thebetsyproject.myevent.com/ | Mail donation checks payable to MD Anderson with “Marcia Acker” on the memo line to: Tricia Touchstone, 3468 Amherst Avenue, Dallas TX 75225." | MD Anderson |
|---|---|---|
| ** Carlene Paris Fund for Sarcoma Research** | M.D. Anderson Cancer Center  
P.O. Box 297153  
Houston, Texas 77030 | M.D. Anderson Cancer Center |
| **Cure Sarcoma, Japan**  
http://www.curesarcoma.jp | Kaja Onishi  
[kaajfromvancouver@ybb.ne.jp](mailto:kaajfromvancouver@ybb.ne.jp) | Dr. Takahashi’s Calponin Gene research |
| **Ferrin Randall Zeitlin Foundation For Sarcoma Research** | Alan Zeitlin  
27 Grace Dr.  
Old Westbury, NY 11568-1228 |  |
| **GIST Cancer Research Fund (GCRF)**  
www.gistinfo.org | Tania Stutman, Chairwoman  
[Tania5kids@aol.com](mailto:Tania5kids@aol.com)  
Dr. Mark Landesman: Director  
Ken Schou: Director  
GIST Cancer Research Fund  
55 Saw Mill Road  
New City, NY 10956  
(845) 634-6060 | GIST research  
MSKCC, Dana Farber, Fox, OHSU Cancer Centers |
<table>
<thead>
<tr>
<th>Fund Name</th>
<th>Contact Information</th>
<th>Institution</th>
</tr>
</thead>
</table>
| GIST Support UK                               | David Cook  
**D.Cook@SHEFFIELD.AC.UK**                               |                                                  |
| **Grind for Life Benefit / Mike Rogers Fund** | Mike Rogers  
**mrskateshop@aol.com**  
(561) 252-3839                                             | Financial aid for travel to sarcoma centers, Sarcoma Alliance, Miracle House, Sloan Kettering Hospital |
|                                               |                                                               |                                                  |
| **In Memory of Beverly Cohn Fund**            | M.D. Anderson Cancer Center  
P.O. Box 297153  
Houston, Texas 77030                                      | M.D. Anderson Cancer Center                       |
|                                               |                                                               |                                                  |
| **In Memory of Vicki Bundock Dowdeswell**     | Royal Marsden Hospital  
Fulham Road  
Chelsea, LONDON, England                                    | Royal Marsden Hospital                            |
| **Leiomyosarcoma Cancer Research Fund**       |                                                               |                                                  |
|                                               |                                                               |                                                  |
| **Jake’s Reindeer Race**                      | Cindy Maynard  
**jgmaynard@hunton.com**  
720 Epson Downs Court  
Richmond, Virginia 23229  
804-741-3694                                                | CureSearch                                       |
<p>| <strong><a href="http://jakesreindeerrace.com/">http://jakesreindeerrace.com/</a></strong>             |                                                               |                                                  |</p>
<table>
<thead>
<tr>
<th>Organization</th>
<th>Address/Contact Information</th>
<th>Institution/Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Janice and Michael Burke Leiomyosarcoma Research Fund</td>
<td>Dana-Farber – Contributions 10 Brookline Place West Brookline, MA 02445-7226</td>
<td>Dana Farber Cancer Center</td>
</tr>
<tr>
<td>Jeanette S Moore Leiomyosarcoma Fund [<a href="http://www.lmsfund.org/">http://www.lmsfund.org/</a>]</td>
<td>Jacqueline Yencha <a href="mailto:mooreyencha@yahoo.com">mooreyencha@yahoo.com</a></td>
<td>Georgetown Unv. Hospital</td>
</tr>
<tr>
<td>Joanna C. Marino Foundation [<a href="http://www.joannacmarinofoundation.org">http://www.joannacmarinofoundation.org</a>]</td>
<td>Dave Marino <a href="mailto:jcmfoundation@verizon.net">jcmfoundation@verizon.net</a> 508-380-8304 cell. 508-966-1557 H.</td>
<td>Dana Farber Cancer Center</td>
</tr>
<tr>
<td>Joshua Gilbert Rhabdomyosarcoma Appeal [<a href="http://www.jg-rabdo.com/">http://www.jg-rabdo.com/</a>]</td>
<td>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</td>
<td>Addenbrook Hospital, Cambridge The Institute of Cancer Research</td>
</tr>
<tr>
<td>Lola’s Love Sarcoma Cancer Organization [<a href="http://lolaslove.org/">http://lolaslove.org/</a>]</td>
<td>320 East 86th Street Suite 4C New York, NY 10028</td>
<td></td>
</tr>
<tr>
<td>Paula Takacs Foundation for Sarcoma Research [<a href="http://paulatakacsfoundation.org/">http://paulatakacsfoundation.org/</a>]</td>
<td>Paula Takacs-Director Geoffrey Takacs-Assistant Director P.O. Box 78416 Charlotte, NC 28271 (p) 704-287-7733 Email: <a href="mailto:info@paulatakacsfoundation.org">info@paulatakacsfoundation.org</a></td>
<td>Memorial Sloan Kettering</td>
</tr>
<tr>
<td>PMC Pan-Mass Challenge [<a href="http://www.pmc.org/">http://www.pmc.org/</a>]</td>
<td>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</td>
<td>Jimmy Fund, Dana Farber</td>
</tr>
<tr>
<td>Reid R. Sacco Memorial Foundation [<a href="http://reidsaccofoundation.org/index.html">http://reidsaccofoundation.org/index.html</a>]</td>
<td><a href="mailto:gacco@reidsaccofoundation.org">gacco@reidsaccofoundation.org</a></td>
<td>Scholarships for high school graduates</td>
</tr>
<tr>
<td>Richard's Run for Life [<a href="http://www.richardsrunforlife.com">www.richardsrunforlife.com</a>]</td>
<td>Richard Gonzmart <a href="mailto:r.gonzmart@columbiarestaurant.com">r.gonzmart@columbiarestaurant.com</a> Richard’s Run For Life Foundation</td>
<td>Pediatric sarcoma research at H. Lee Moffitt</td>
</tr>
<tr>
<td>Organization</td>
<td>Contact Information</td>
<td>Location</td>
</tr>
<tr>
<td>---------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------</td>
<td>-----------------------------------------------</td>
</tr>
<tr>
<td><strong>Seth A. Bailey Sarcoma Cancer Fund</strong></td>
<td>Tom Bailey <a href="mailto:tom.bailey@tourtocure.com">tom.bailey@tourtocure.com</a> 3173 560th St. SW Riverside, IA 52327 319-679-2629</td>
<td>Sarcoma Foundation of America</td>
</tr>
<tr>
<td><a href="http://www.tourtocure.com">www.tourtocure.com</a></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>SOS DESMOIDE Association</strong></td>
<td>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></td>
<td></td>
</tr>
<tr>
<td><strong>Shawn Thomas Memorial Foundation</strong></td>
<td><a href="mailto:mail@shawnthomasfoundation.org">mail@shawnthomasfoundation.org</a></td>
<td></td>
</tr>
<tr>
<td><a href="http://www.shawnthomasfoundation.org">http://www.shawnthomasfoundation.org</a></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>The Robert and Heather Urich Sarcoma Foundation</strong></td>
<td>The Robert and Heather Urich Sarcoma Foundation 1500 E. Medical Center Drive, Ann Arbor, MI 48109-0755</td>
<td>U of Michigan Cancer Center</td>
</tr>
<tr>
<td><strong>The Shelly Glaspell Schiellerd Ewing's Sarcoma Fund</strong></td>
<td>Sandy Glaspell <a href="mailto:sandvg@carolina.rr.com">sandvg@carolina.rr.com</a> PO Box 1174 • Harrisburg, NC 28075 704.795.7010</td>
<td>Financial assistance for Ewing’s families</td>
</tr>
<tr>
<td><a href="http://www.ewingssarcomafund.com">www.ewingssarcomafund.com</a></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>The Terry Fox Foundation</strong></td>
<td>Darrell Fox Ex Director <a href="mailto:national@terryfoxrun.org">national@terryfoxrun.org</a> Canada (604) 701-0246</td>
<td>National Cancer Institute of Canada</td>
</tr>
</tbody>
</table>
Organizations with changes since distribution of the October 2013 publication:

- Curesearch see Children’s Oncology Group
- Dani’s Foundation
- Jareds Juggernaut to Cure Sarcomas (name change)
- Steel Lillies Foundation (added)

Added to Appendix: