



REIN IN SARCOMA

Increase awareness. Increase survivors.



2016 ANNUAL REPORT

making it all happen: you



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In 2017 Rein in Sarcoma welcomes five newly elected members to its Board of Directors



Ted Erickson, Tom McCarthy, Chelsey Olafson & Dr. Denis Clohisy

Debra Cossette currently serves on the PR Committee as the Webmaster and her husband is a sarcoma survivor. Recently retired from 3M, Deb is incredibly organized and committed to RIS' vision and goals. She will serve as Rein in Sarcoma's Vice-President.

Chelsey Olafson is a sarcoma survivor. She currently manages our Facebook page and serves on the Patient and Family Support and PR/Marketing Committees. Chelsey will also be chairing the 2017 Party in the Park.

Thomas McCarthy will serve as Rein in Sarcoma's Treasurer. He is an Accounting Policy and Research Consultant at Securian Financial Group.

Dr. Denis Clohisy is a Professor and Chairman of the Department of Orthopaedic Surgery at the University of Minnesota and a member of the University of Minnesota Cancer Center. Dr. Clohisy has been a longtime supporter of RIS.

Ted Erickson, is Vice Chair at Holiday Companies and will serve on the Development Committee. He is also a board member at PACER and the Minnesota Land Trust.

ADDITIONAL ORGANIZATIONAL LEADERSHIP

Development Committee Chairperson: Thomas Dougherty

Controller: Kevin Overholt

Legal Counsel: Anthony (Tony) Smith

Red Flags Educational Committee Cochairpersons:
Michelle Kolling & Sue Wyckoff

Marketing & Public Relations Committee Chairperson: Taylor Dale

Social Media Subcommittee Chairperson: Valeria Lopez

Website Subcommittee Chairperson: Surinder Bimbira

SAVE
the
DATE

2017 PARTY IN THE PARK
KICKOFF MEETING

MARCH 14, 7:00 PM

Summit Brewery Co.
910 Montreal Cir, St Paul, MN 55102

All attendees are welcome to one free beer or root beer.

Join us to celebrate another successful year of Rein in Sarcoma and plan for Party in the Park 2017 at **Summit Brewing Company**.

Optional tour of the facility will start at 6pm, and Signature's café food truck will be available to purchase from 5:30 to 7pm.

Meeting begins promptly at 7pm with a presentation from a U of MN Researcher and this year's Party in the Park Chairwoman Chelsey Olafson.

RSVP at: reininsarcoma.org/kick-off-rsvp



2016 was a year of exciting changes, growth, and meaningful interactions for everyone at Rein in Sarcoma. We would like to thank all patients, survivors, and those who have lost someone to sarcoma; as well as all of the medical personnel and community members who have contributed to our threefold cause of Education, Patient Support and Research. These are some of 2016 highlights.

Patient & Family Support

In January, about 70 sarcoma patients, their families, and those who had lost someone to sarcoma got together to spend an uplifting and informational afternoon at **Bachman's** in Minneapolis. Our annual **Winter Gathering** featured **Dr. Branden Moriarity** from the University of Minnesota and **Dr. Eva Galanis**, from Mayo Clinic, who talked about their cutting-edge research on Osteosarcoma and Viral Therapy to treat sarcoma, respectively. Sarcoma survivor **Scott Burton** delivered an awe-inspiring juggling and comedy show, and also talked about his sarcoma experience. It was an enlightening afternoon in which the audience got to share their personal journeys and connect with other members of the community.

Annual Winter Gathering



Dr. Branden Moriarity, UMN & Dr. Eva Galanis, Mayo Clinic

The **Patient and Family Support Committee** put together **tote bags** with useful items for sarcoma patients at the U of MN Masonic Cancer Center, Masonic Children's Hospital, Mayo Clinic and Children's Hospitals and Clinics of Minnesota. Through a survey we found out what items the patients wanted—a highly requested item was a soft, colorful pillow case. Many individuals, church groups and organizations donated fabric and help sew pillowcases and crochet blankets and hats to include in the tote bag. The Committee also collected socks, lip balm and gift cards for each bag. Our totes were an instant hit!



July culminated with our **Annual Party in the Park** and **Sarcoma Family Picnic** under the leadership of **Janelle Calhoun**, who served as this year's Chairperson. Over 500 members of the Sarcoma community attended our Picnic, which was generously sponsored by **D'Amico Catering**. We then marched up the hill to inaugurate the main event, where Sarcoma survivors rode the Cafesjian Carousel, participated at the silent auction and enjoyed **Kat Perkins'** fearless performance. **Walser Subaru** was this year's Presenting Sponsor. The event raised over **\$93,000**, with the generous support of **Mayo Clinic** and the **University of Minnesota Cancer Health**.



Tote bags by the Patient & Family Support Committee

Education

In April, we received a project proposal from **Rebecca Cummins** and her business class at **Augsburg College** to increase awareness about sarcoma cancers and raise funds for RIS. Rebecca was inspired by her friend **Nicole Anderson**, who was battling Leiomyosarcoma at the time. Unfortunately Nicole lost the battle against sarcoma in 2016, but her classmates continued with the project as a tribute to her memory. Their initiative brought in over **\$2,000**, thus establishing the **Nicole Anderson named fund**.

For the second year, **Minnesota Governor Mark Dayton** declared **July Sarcoma Awareness Month**. In celebration, we focused our efforts on spreading the word about sarcoma through our **social media** networks, where we reached over 1,500 individuals.



In March we held our first **Sarcoma Scholar Reunion**, where alumni were invited to talk about the different ways in which the Program has impacted their careers. This was an event to celebrate the many successes and positive outcomes of our scholars, many whom are already making a difference in the medical community, like **Brad Stish**—our very first Sarcoma Scholar—who is now a Radiation Oncologist at Mayo Clinic.

Stish mentioned: "My experience as the first Sarcoma Scholar was instrumental in cementing my decision to become a radiation oncologist and grew to appreciate the importance of a team based approach for the clinical management of sarcoma patients. I continue to be impressed with the efforts of subsequent Scholars and their goal to further education about sarcomas among the public and medical community". The group also exchanged perspectives about the future of sarcoma education inside and outside the medical circle.

SPOTLIGHT: Dr. Katie Dusenbery at the heart of Rein in Sarcoma



In the summer of 1997 Dr. Kathryn Dusenbery, Head of Radiation Oncology at the University of Minnesota, met Karen Wyckoff—a nineteen year old recently diagnosed with Synovial Sarcoma. So began a relationship that would, in many ways, continue for many years after. Katie led Karen's radiation therapy team and was there to show her support when Karen first founded our organization in July of 2001.

Shortly after, Dr. Dusenbery became a Charter Board member when the Karen Wyckoff Rein in Sarcoma Foundation officially became a non-profit organization in 2004.

In January 2017, after 14 years of service as a member of RIS' Board of Directors, Katie is stepping down—but her work and commitment to RIS continues.

Over the years, Katie served as Dean of the RIS unit at the University of Minnesota Mini Medical School, created and managed the RIS Sarcoma Scholar Program and, more recently, co-chaired our Fall Fundraiser in October 2016.

“It has been my privilege to be a part of the Rein in Sarcoma Foundation. Peter and Sue Wyckoff have taught me what a small group of committed individuals can accomplish.

SPOTLIGHT: Dr. Katie Dusenbery at the heart of Rein in Sarcoma (cont.)

In 2009 Dr. Dusenbery founded the Sarcoma Scholars Program for medical students at the University of Minnesota. She envisioned a program to provide scholarships for highly talented and motivated medical students who would conduct research to improve treatments for sarcoma cancers and educate the medical community about their symptoms.

Katie remembers: *"It had been so long since I had been a medical student myself, that I didn't know which was the best way connect with my class. At that time, there were no dedicated sarcoma lectures for medical students. I figured that getting students involved would be a good way to get our foot in the door."*

Since the Program's creation in 2009, we have had 28 scholars. In 2014 we expanded the program to include students at the Mayo Medical School, under the guidance of Dr. Scott Okuno.

Dr. Dusenbery is very impressed with the outcome of this program. All alumni and current Scholars have contributed to a better understanding of a rare and often misdiagnosed disease.

"The Sarcoma Scholars program has been more successful than I could ever have imagined. The energy and enthusiasm they bring to Rein in Sarcoma is wonderful."

Although Dr. Dusenbery is retiring from our Board, her legacy and impact in our community continues. She remains committed to supporting Rein in Sarcoma and will continue to manage the Sarcoma Scholar Program.

2016- 2017 Sarcoma Scholars

For the past 9 years, Rein in Sarcoma has been funding research through its Sarcoma Scholars Program at the University of Minnesota and Mayo Clinic. In June, Rein in Sarcoma selected five new Scholars from the U of MN and Mayo medical schools who will learn and conduct research about sarcoma during the 2016-17 term.

Our Scholars from the University of Minnesota—**Melissa White, Robert Gao** and **Aubrey Thyen**—are already busy planning lectures at the Twin Cities and Duluth Campus of the U of MN, in which they will gather physicians and patients together to tell their stories around treating and living with sarcoma. In addition, their research efforts have already begun to materialize; they recently submitted an article to be published on a medical journal, and are planning a Broomball tournament to raise awareness about sarcoma.



2016 Sarcoma Program Scholars

Left to right: Melissa White, Nazanin Yeganeh Kazemi, Robert Gao, Aubrey Thyen & Ashley Pacquin

Our Scholars from Mayo Clinic—**Ashley Paquin** and **Nazanin Yeganeh Kazemi**—are currently planning a series of education sessions for medical students that will focus on proton beam radiation therapy. They recently toured Mayo Clinic's Proton Beam facility and hope to put into action a lecture in early March of 2017.

While fulfilling their scholarship year, Sarcoma Scholars greatly contribute to the advancement of new and better treatments for sarcoma through research, while also becoming lifetime advocates for sarcoma awareness in their professional careers.

The Hallie Anne Brown Research & Education Initiative



Hallie Anne Brown, 1996–2013

In 2016, Rein in Sarcoma received a gift of **\$100,000** from the **Barbara Bradley Baekgaard Family Foundation** through **Todd and Kathy Brown**, in memory of **Hallie Ann Brown**. We are now utilizing this special gift to increase the level of education among members of the medical community, and to significantly increase and expand sarcoma cancer research.

The **Hallie Anne Brown Research and Educational Initiative** is now the cornerstone of major additional support from individuals, foundations, and corporation— all in Hallie's name—and with the hope that no more promising teenagers will face death due to sarcoma cancers.

Our Medical Advisory Board has identified an urgent need to educate medical personnel who come into initial contact with patients presenting symptoms suggesting sarcoma. This education initiative will address two issues in particular: **misdiagnosis or late diagnosis** and **improper initial treatment**. In 2015, Rein in Sarcoma began gathering data to determine

how to best address these problems. A study by the **Lund University**, in Sweden, has provided further guidance as it demonstrated how the implementation of simple diagnostic protocols have reduced mortality in sarcoma patients in Sweden. The protocols include MRI imaging for proper diagnosis and, when appropriate, referral to a sarcoma specialty center. In addition to reduced patient mortality, the protocols have provided financial cost savings to Sweden's health care system.

Rein in Sarcoma is now working with medical systems to provide accurate and understandable information that physicians and other medical personnel can use when first presented with a suspicious lump. This information will ensure that patients who meet established guidelines are referred to medical providers knowledgeable in the treatment of sarcoma—thus providing a seamless approach from diagnosis through treatment.

Dr. Randy Hurley, Rein in Sarcoma Medical Advisory Board member and head of Oncology at HealthPartners, is developing and piloting the educational program through **Regions Hospitals** and **HealthPartners**. Rein in Sarcoma will then collaborate with medical institutions in the upper Midwest to implement these protocols and educational programs. If this proves effective locally, it will serve as a model for national education.

The Hallie Anne Brown Initiative will enable us to refine protocols for best practices in sarcoma treatment, as well as fully develop and implement its educational outreach plan.

Thanks to the Initiative, the RIS Board has now approved **\$40,000 in additional sarcoma grants** in 2017 at Mayo Clinic and Children's Hospitals and Clinics of Minnesota. Combined, this will be **the largest annual amount of sarcoma research funded by Rein in Sarcoma**.

We are honored that the Brown family chose us as for this wonderful gift, and we are committed to using it strategically to create the greatest impact in the mission of creating *a world without sarcomas*.

2016 Sarcoma Research Grants

Rein in Sarcoma authorized a request for research grants from the University of Minnesota in the summer of 2016. We had five external experts review the eleven proposals received, and their recommendations were presented to the Board on January. In return, the RIS Board approved the following four proposals:



\$40,000
Engaging the immune system as a strategy for sarcoma therapy
Principal Researcher:
Antonella Borgatti, DVM, MS

STriKE is a novel drug designed for the killing of cancer cells with minimal damage to normal cells. The goals of this study are to better understand the role of the immune system in sarcoma therapy and to bring a newly discovered drug to Phase 1 clinical trial in humans. Results from this research could lead to promising data for further therapeutic evaluation.



\$35,000
Effects of beta-adrenergic receptor antagonists on sarcoma radiosensitivity
Principal Researcher:
Jessica Lawrence, DVM
DACVIM, DACVR

Radiation is routinely prescribed for the control and treatment of sarcomas, and while it kills some sarcoma cells, it can also enhance survival in others. This study will investigate the effectiveness of Propranolol—a readily available, well-tolerated and inexpensive B-blocker—to decrease tumor recurrence in sarcoma patients by NKFB inhibition.



\$25,000
Enhancement of the response of sarcoma to SBRT by targeting HIF-1a
Principal Researcher:
L. Chinsoo Cho, M.D.

Stereotactic Body Radiotherapy has shown to be effective to control sarcoma by exposing tumors to larger doses of radiation. However, the low-oxygen environment in the tumors after SBRT also activates HIF-1a, which leads to recurrence and metastases. The purpose of our study is to find the most effective drug to enhance the efficacy of SBRT by HIF-1a inhibition.



\$25,000
Defining the Immunologic Landscape of Spontaneous Canine Osteosarcoma
Principal Researcher:
Jaime F. Modiano, VMD, Ph.D.

Our previous research has shown that the presence of immune cells in tumors from Osteosarcoma patients is a predictor of delayed metastasis and improved survival. However, we don't know what permits immune cells to reside in tumors or how they delay metastatic progression. This study will allow us to develop new strategies for Osteosarcoma prevention and treatment.

2016 Financial Report

Strategic Plan

In February 2016, Rein in Sarcoma hired Paul Giel Jr. as the new **Development Director** to help meet the ever increasing needs of our mission. The RIS Board approved the use of some of the funds remaining from the Transition Campaign at the end of 2015 to offset the first year cost of engaging a development director.

New Named Funds, Gifts & Events

During 2016 financial and volunteer support for the ongoing educational programs, patient and family support, and sarcoma research grants totaled **\$510,000—an increase of \$223,000 over 2015**. Our Development Director worked with many of our donors to secure this increase through continued and new Named Fund gifts, and a special **\$100,000 gift from the Hallie Brown Fund**.

This enabled the Foundation to meet for the tenth year the terms of the **\$15,000 challenge grant** from the **Katherine B. Andersen Fund** of the Saint Paul Foundation.

We look forward to building on the partnerships we have established with the Katherine B. Andersen Fund, the Barbara Bradley Backgaard Family Foundation, the Hardenbergh Foundation, the Luther Foundation, Walser Subaru, and other individual campaign sponsors to secure financial support for our mission.

Our signature annual event **Party in the Park** raised over **\$93,000** (before expenses) to support the Rein in Sarcoma mission. In addition, our first fall fundraiser event held in

October **“Let’s Change the Story”**—coupled with several other donor-sponsored events—added a total of **\$130,000** this year.

Disbursements

Rein in Sarcoma tracks disbursements in three general categories: research and education, patient and family support, and general/administrative expenses.

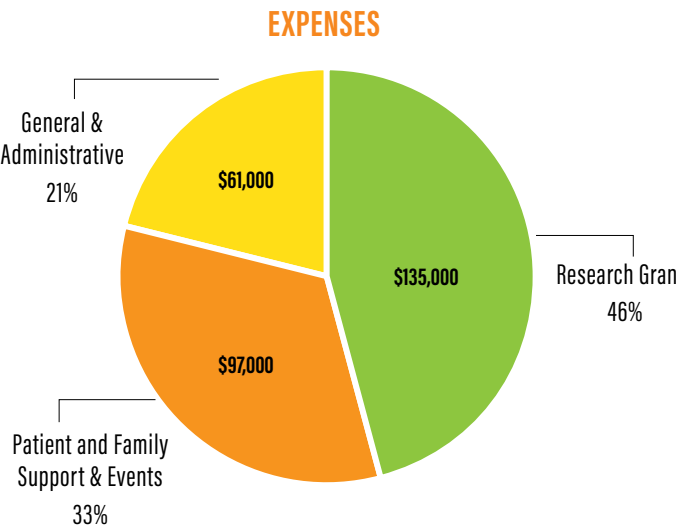
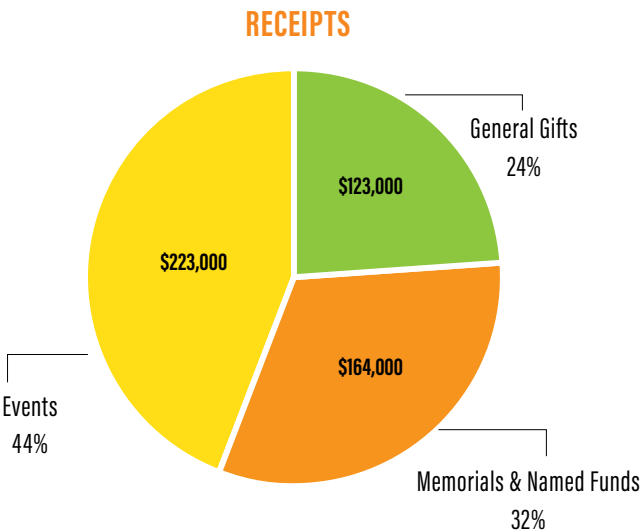
The Foundation made **\$135,000 in gifts to the University of Minnesota Foundation** in support of **sarcoma research and education**. This reflects about the same level of support provided in 2015.

During 2016, the Foundation spent **\$97,000 on patient and family support**, including our events and the Red Flags and Sarcoma Notebook programs.

Finally, the Foundation spent about **\$61,000 on general and administrative expenses**, including improvements to our volunteer database system and assistance received from our new development director and support staff.

On December 31 2016, our internal financial statements showed receipts in **excess of expenses of \$215,000**.

Thanks to the gifts from our supporters, Rein in Sarcoma is in a good financial position at the end of 2016 with **cash, temporary investments and endowment funds of \$683,000**. A complete financial report for 2016 and a copy of the 2016 Tax Report will be available when filed with the Internal Revenue Service in May.



Outreach

2016 was an extremely active year full of events to raise funds and to spread awareness about sarcomas. The community's active participation is a constant reminder of the great support network we have. These are just a few of the different ways in which members have supported Rein in Sarcoma.

Jeff Holmquist, manager of Walser Subaru invited Rein in Sarcoma to take part in their **Share the Love Campaign**. The campaign, which donates a percentage of the proceeds from every new car leased or sold during December, brought in a delightful surprise—we received a check for **\$41,000!** With this generous support, Walser Subaru became our 2016 Party in the Park presenting sponsor. A named fund was also established in memory of Jeff's wife, **Lora Holmquist**, who died from sarcoma in 2009.



Jeff Holmquist, manager of Walser Subaru & Peter Wyckoff

In February, and for the eight consecutive year, the **Mud Dog Riders** rode their snowmobiles in memory of **Eric Skogman**, who lost his life to liposarcoma. In 2016 they raised **\$6,000** and over the years, the Eric Skogman fund has raised \$42,000 for Rein in Sarcoma.



Richard Berqual Memorial Golf Tournament

The fifth annual **Richard Berqual Memorial Golf tournament** held in Blaine, MN raised over **\$3,500**, attracting over 150 players. Another golf event, this time the first annual **Jake Martell Gold Tournament**, was organized by the Martell Family at **Oak Glen Golf Club** in Stillwater, raising over **\$1,000** in Jake's memory.

In September we held our **Annual Garage Sale**, raising over **\$5,000** for the foundation. This was a great opportunity to recycle a lot of items and educate families and individuals about Sarcoma cancers.

For the sixth consecutive year, the **Rogotzke Family** and all of the town of Sanborn, MN turned out for the **Anna Rogotzke Kickball Tournament** raising over \$6,000 in memory of their daughter.



Fall Fundraiser "Let's Change the Story"

In October we hosted our first Annual **Fall Fundraiser "Let's Change the Story"**, which was a great success. We'd like to thank **Dr. Kathryn Dusenbery** and **Mike Trucano** for their work as Chairs of the Event, as well as **Ruth Bachman** who acted with humor and skill as our Master of Ceremonies for the event, which raised almost **\$122,000**.

The **Julian Baultrippe Fund** held their annual **Throw Down for Beanz** fundraiser as friends and family of Julian saluted his memory with great food and great times, raising over **\$4,000** for the organization.

Friends and family of **Mark Wehner** in Osseo, WI, came together on **Giving Tuesday** to celebrate life and raise funds in his name.

In November we gathered at the St. Thomas swimming pool to cheer on swimmers organized by sarcoma patient **Kevin Franklin's** family to raise money for sarcoma research. **Kevin O'Keefe** proved to be the best Cattle Bell Ringer in support of the swimmers!

On **Give to the Max Day**, we were able to raise over **\$20,000** and we also had a very good **End of the Year Giving Campaign**, which brought in an additional \$40,000 to support our mission. Thanks to all of you who gave on Rein in Sarcoma's behalf.



"Sunflowers & Support" painting gathering

The Patient & Family Support Committee organized the **"Sunflowers and Support"** gathering held at **Gilda's Club**, where children and adults of all ages created art while connecting with other individuals affected by sarcoma. The adult painting was led by **Allie DeCamillis** and the children's painting was led by **Chelsey Olafson** and **Erin Leckie**.

ACTIVE TRIBUTE AND MEMORIAL FUNDS

Rein in Sarcoma is in part sustained by the annual contributions of twenty seven Named Tribute and Memorial Funds. These funds have been established by sarcoma survivors and the families and friends of those who've lost the battle against sarcoma, and are very important to our work. To learn more about establishing a Named Fund of your own or to honor the life of a sarcoma patient, visit reininsarcoma.org/NamedFunds

We thank the families and individuals who have established the following Named Funds, which raised over \$88,000 for Rein in Sarcoma's mission in 2016:

- | | | | |
|--------------------------|----------------------------|--------------------------------|---------------------------|
| • Nicole Anderson Fund | • Meghan DeBruycker Fund | • Jacob Martell Fund | • Anna Rogatzke Fund |
| • Julian Baultrippe Fund | • Perry Ford Fund | • Jan Maudlin Fund | • Beverly Ann Schuld Fund |
| • Richard Berqual Fund | • Wade Hohol Fund | • Miranda Mead Fund | • Jordan Sighting Fund |
| • Hallie Ann Brown Fund | • Lorna Holmquist Fund | • Jackie Middleton Fund | • Eric Skogman Fund |
| • William Clemens Fund | • Alyssa Jeske Dobson Fund | • Kevin O'Keefe Fund | • Mark Wehner Fund |
| • Brett Dale Fund | • Katelyn Jurek Fund | • Beverly & Dean Osterman Fund | • Laura Zeccardi Fund |
| • Therese Daniel Fund | • Barbara Kimker Fund | • Andrea Pomeroy Fund | |



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