



REIN IN SARCOMA

Increase awareness. Increase survivors.

2018 ANNUAL REPORT

reininsarcoma.org

BOARD OF DIRECTORS

- Blake Hastings
President
- Lisa Griebel
Vice President
- Mitch Atherton
Secretary
Chair, Finance Committee
- Thomas McCarthy
Treasurer
- L. Chinsoo Cho, MD
- Denis Clohisy, MD
- Debra Cossette
- David Largaespada, PhD
- Eric Lien
- Valeria Lopez Torres
Chair, PR & Marketing Committee
- Scott Okuno, MD
- Linda Pomeroy
- Colin Ryan
- Bruce Seiber
- Larry Seymour, MD
Chair, Research Committee
- Allan Swartz
- Elisabeth Will
Chair, Nominating Committee

STAFF

- Janelle Calhoun
Executive Director
- Theresa Fetsch
Development Director
- Naomi Bowman
Health Programs Coordinator
- Connie Dow
Office Administrator

2019 BOARD OF DIRECTORS UPDATE

Lisa Griebel is self-employed as President of Crescendo Inc., a Minneapolis performance consulting firm committed to the growth and development of healthy organizations. She has over 35 years of experience in leadership and organization development. Lisa connected with Rein in Sarcoma in 2006, shortly after being diagnosed with Fibrosarcoma. Since then, she has played many roles within Rein in Sarcoma: Party in the Park Chair, RIS Transition Team Leader, Board Member and RIS Strategic Planning Committee member.

Dr. David Largaespada is a Professor in the Department of Pediatrics and the Department of Genetics, Cell Biology and Development at the University of Minnesota. He is the Associate Director for Basic Research in the Masonic Cancer Center at University of Minnesota, and currently holds the Hedberg Family/Children’s Cancer Research Fund Endowed Chair in Brain Tumor Research. Dr. Largaespada is an authority on mouse genetics, gene modification, cancer genes, and disease models. He has also been a Rein in Sarcoma Research Grant recipient.

Eric Lien is Senior Vice President and Regional Manager with Wells Fargo’s Payments, Virtual Solutions, and Innovation group. He lives with his wife and three daughters in Wayzata, MN. “Joining the Rein in Sarcoma Board provides the opportunity make a difference and leverage my professional experience to make a personal difference in lives of patients and their families, and hopefully preventing others from encountering this horrible disease.”

Colin Ryan is Senior Vice President for Colliers International’s Investment Services. Colin’s community involvement includes the University of St. Thomas Dougherty Family College Advisory Board, Children’s Hospital of MN Leadership Council, and Former Chair of Golf “FORE” Diabetes. Colin was motivated to join the Rein in Sarcoma Board after experiencing his brother-in-law, Blake Hastings’ sarcoma diagnosis, treatment, and the effect it had on their family. He is eager to leverage his business skills and experience to make a positive impact for sarcoma patients.

ADDITIONAL ORGANIZATIONAL LEADERSHIP

- Tom Boardman
Development Committee Chair
- Sue Wyckoff
Red Flags Educational Committee Chair
- Kraig Kuusinen
Patient and Family Support Committee Chair
- Julie Rose
Talent Resource Committee Chair
- Anthony (Tony) Smith
Legal Counsel
- Amy Hoban
Allison Mulcahy
2019 Party in the Park Co-Chairs
- Tom Boardman
Perry Ford
Golf Charity Co-Chairs

2018 NAMED FUNDS

Named Funds are established by individuals and families to honor the lives of sarcoma patients, survivors and loved ones who have passed. In 2018, Named Funds raised over \$85,000. Thank you to all the families and individuals who have supported our mission through Named Funds.

To learn more about establishing a Named Fund of your own or to honor a patient, survivor, or loved one who has passed, contact Theresa Fetsch at development@reininsarcoma.org or visit: reininsarcoma.org/NamedFunds/

- Nicole Anderson Fund

Julian Baultrippe Fund

Richard Berqual Fund

Annette Bonaventura Fund

Hallie Anne Brown Fund

William Clemens Fund

Nick Convey Fund

Brett Dale Fund

Meghan Marie DeBruycker Fund

Perry Ford Fund

Wade Hohol Fund

Lora Holmquist Fund

Alyssa Jeske Dobson Fund

Judy Jones Fund

Barbara Kimker Fund

Marge Krauter Fund

Jacob Martell Fund
- Jan Maudlin RIS Sarcoma Scholar Fund

Miranda Mead Fund

Jackie J. Middleton Fund

Heidi Minor Fund

Kevin O’Keefe Fund

Chelsey Olafson Fund

Beverly and Dean Osterman Fund

Andrea Pomeroy Fund

Anna Rogotzke Fund

Beverly Ann Schuld Fund

Eric Skogman/Mud Dog Sarcoma Ride Fund

Mark Wehner Fund

Judith B. Wolson Fund

Thomas Worthley Fund

Laura Zeccardi Fund

MARK YOUR CALENDARS

2019 PARTY IN THE PARK
Como Park, St. Paul

July 29



GOLF CHARITY EVENT
Edinburgh USA Golf Course, Brooklyn Park

August 20



2019 FALL FUNDRAISER
Metropolitan Ballroom, Minneapolis

October 10



MESSAGE FROM OUTGOING AND INCOMING BOARD PRESIDENTS

It has been my honor and privilege to serve as Rein in Sarcoma’s Board President during this year of transition. Crucial to this transition has been fostering continued commitment and participation of current Board members, donors and volunteers, while expanding our support base as well. As an organization we have taken important steps such as the development of a new three-year strategic plan, moving day to day operations from the Wyckoff’s home to our Fridley office, and with that, new processes and procedures. The hiring of part-time Health Programs Coordinator, Naomi Bowman and Development Director, Theresa Fetsch midway through 2018 was a critical step in expanding the capacity and impact of our mission going forward.

I especially thank Pete and Sue Wyckoff, Rein in Sarcoma co-founders, for their support, understanding, and patience during the transition. I will continue to serve as a board member and volunteer for Rein in Sarcoma, working to further the impact of our mission. I believe Rein in Sarcoma has come through this year of transition well positioned to grow with the passion and leadership Blake Hastings will bring as our new Board President.

Debra Cossette



Outgoing RIS
Board President
Debra Cossette

Incoming RIS
Board President
Blake Hastings



2019 is set to be an exciting year for Rein in Sarcoma. In 2018, we were able to successfully transition from a founder-led organization to one led by an Executive Director—Janelle Calhoun, and new Board President—Deb Cossette. I would again like to thank our founders, Pete and Sue Wyckoff, for their passion, vision and continued interest in the success of RIS. I would also like to thank Janelle and Deb for a successful 2018. To all my fellow board members, committee members, volunteers, and staff: thank you for your tireless work during 2018, your efforts were evident.

I found Rein in Sarcoma in 2017 during my own battle with Ewings Sarcoma. My first interaction with the organization was through the New Patient Starter Notebook, which was educational as I faced an unknown opponent. After receiving incredible support during my treatment I wanted to give back to those who gave me support. I sought out fellow RIS Board Member and my primary caregiver, Dr. Denis Clohisy. Denis highly recommended meeting Pete Wyckoff and the rest is history.

As the incoming Board President, I am excited about what the new year brings to our organization. We are coming off an excellent year, so the bar has been set extremely high to continue our growth. We will continue to focus our attention on research, education, and patient support. With a very talented staff at RIS coupled with an active Board of Directors, 2019 has a very positive outlook. I am excited to work with all of our Board Members, Staff and Volunteers and getting to know each of you personally in 2019. If you have any comments, suggestions, or concerns, please do not hesitate to reach out to me directly.

Blake Hastings



RIS Executive Director
Janelle Calhoun

The work and footprint of Rein in Sarcoma continues to transition and grow thanks to Committee Members, Board Members, volunteers, advocates, medical providers, researchers and donors.

A MESSAGE FROM THE EXECUTIVE DIRECTOR

The impact of sarcoma education expanded through the work of our Red Flags Committee, reaching more people through medical conferences, professional presentations, and Sarcoma Scholar-led medical student seminars. Research grants increased, enabled by donations from Team Sarcoma Peloton and generous supporters of the Chainbreaker bike ride, Golf Tournament participants, Party in the Park sponsors and attendees, Named Fund support, Individual events, foundation grants, and our Fall Fundraiser. Sarcoma Patients and families were supported through community events (Winter Gathering, Sarcoma Family Picnic, RIS Remembers). Our Patient and Family Support Committee also led our peer-to-peer support program, delivered 80 handmade tote bags to new patients, and distributed over 250 patient education notebooks nationwide. Our community members and supporters generated over 3600 hours of volunteer time to advance our mission and ensure the work of Rein in Sarcoma is carried out with compassion and care.

Our team has grown with the additions of Naomi Bowman, RN, BSN, our Health Programs Coordinator, focused on advancing sarcoma education, and Theresa Fetsch, Director of Development, strengthening our relationships and ensuring funds to carry out the Rein in Sarcoma mission. Donated office space became fully operational and busy with committee meetings, volunteer activities, social gatherings, and daily operations. Give us a call, join us for an update with coffee, share your time working on a project, share your ideas and skills, open a door, and connect us where we can make a difference. Every community member provides a critical component of our work together. It takes all of us to fulfill our mission. Truly, all of our parts working together leads to better outcomes for sarcoma patients and families.

Janelle Calhoun



(left) Naomi Bowman,
RIS Health Programs
Coordinator at the 2018 PIP

2018 IN REVIEW: EDUCATION & RESEARCH

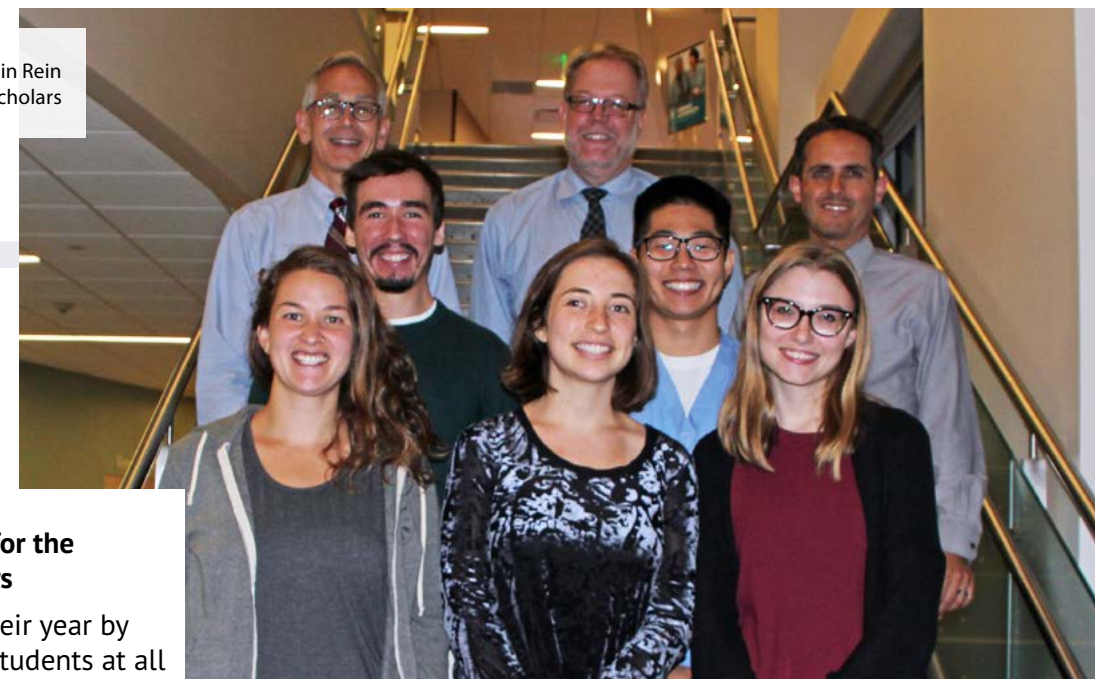
Health Programs Coordinator

In June 2018 we welcomed Naomi Bowman, Health Programs Coordinator. Drawing on a wide variety of health care experiences, Naomi works with the Red Flags Committee to expand our educational programs to increase awareness and save lives through early diagnosis. Thank you to the Red Flags Committee, the Talent and Resource Committee and Janelle Calhoun for their support of the hiring process.

Implementation of EMR Pilot Project

Continuing the legacy of the Hallie Anne Brown Initiative, the Electronic Medical Record/Best Practice Alert quality improvement project made steady progress and was piloted in HealthPartners Arden Hills Clinic in Q4 of 2018. The ultimate goal is to develop a program within the EPIC EMR system that will alert physicians for earlier diagnosis of soft tissue sarcomas. We appreciate the time and expertise of those involved and especially project taskforce chair and recipient of the 2018 Rein in Sarcoma Excellence in Education Award, Dr. Randy Hurley, Oncology Director at HealthPartners and Regions Hospital.

2018-19 Maudlin Rein
in Sarcoma Scholars



2018: A Year of Important Work for the Maudlin Rein in Sarcoma Scholars

Our 2017-18 scholars finished their year by organizing lectures for medical students at all three medical schools in Minnesota, writing papers on various type of sarcomas (see our website), and organizing a program for first-year pathology students that included a compelling talk by sarcoma survivor, Sarina Morrison.

We welcomed five new 2018-19 scholars. Our Mayo scholars are Mylan Blomquist and Taylor Weiskettel. They jumped into raising awareness by bringing in a lecturer from the University of Michigan to speak on Ewings Sarcoma. They also organized a “selective week” for first-year students interested in an oncology career and are planning a spring lecture for Mayo medical students.

The three University of Minnesota scholars are Colleen Bell, Alexander Kuehne, and Kyle Lau. They are planning the 2019 lectures for students at the Twin Cities and Duluth campuses. The five scholars are working together to survey all former scholars (where they are and what they’re doing) and to plan a reunion for this spring.

Many thanks to our former scholars who continue to make contributions. Robert Gao and Mel Albersheim (2016-17 Scholars) along with Andy Hughes (2017-18 Scholar) reviewed medical records of hundreds of sarcoma cases for codes, phrases and terms documented by doctors when they first identified symptoms that turned out to be a sarcoma. The EMR Task Force will evaluate how to use the data for earlier diagnosis of sarcoma. We appreciate the generosity of Jan and Tim Maudlin for their ongoing support of our Sarcoma Scholar program through the Maudlin Rein in Sarcoma Scholar Named Fund.

Expanding Professional Education

A key education strategy of the Red Flags team is to increase awareness with health care professionals who may be the first to notice a potential sarcoma. Thank you to Marlee Brice, volunteer and retired RN, who developed curriculum and, with sarcoma survivors and other volunteers, presented the educational program *Understanding Pediatric Sarcomas* to Osseo School District Nurses. The program evaluations were very positive and confirmed our commitment to exhibit and reach out to the 170 nurses attending the School Nurse Organization of Minnesota annual conference in November. Attendees expressed interest in providing more information about sarcoma to their nurses and families.

7th Edition of Rein in Sarcoma Patient Starter Notebook

To ensure we provide the most current information for sarcoma patients and their loved ones, the Rein in Sarcoma Medical Advisory Board, former scholars and several volunteers updated the Rein in Sarcoma Patient Starter Notebook. We are grateful to Elisabeth Will, RIS Board member and Red Flags Committee member, who once again served as the editor. Based on user feedback, the updates include more information on specific types of sarcomas and contact information on various sarcoma organizations from across the country. The 7th Edition was printed in January 2019.

2018 IN REVIEW: OUTREACH & IMPACT

EDUCATION

RIS Video: An organizational video debuted at the October Fall Fundraiser, which highlights the three-pronged mission of Rein in Sarcoma. In one week, the video was watched nearly 500 times on Facebook, increasing awareness about sarcoma and the work of our organization.

Leiomyosarcoma Symposium: This symposium, co-sponsored with the National Leiomyosarcoma Foundation and Mayo Clinic, was attended by 80 people and covered various aspects of Leiomyosarcoma and soft tissue sarcomas. It is planned again for 2020.

School Nurse presentations: Nearly 50 attendees from the Osseo ISD Nurses heard an RIS presentation on sarcoma symptoms and what to watch for as children's first line medical providers. RIS also was present at the School Nurse Organization of Minnesota 2018 Annual Conference.

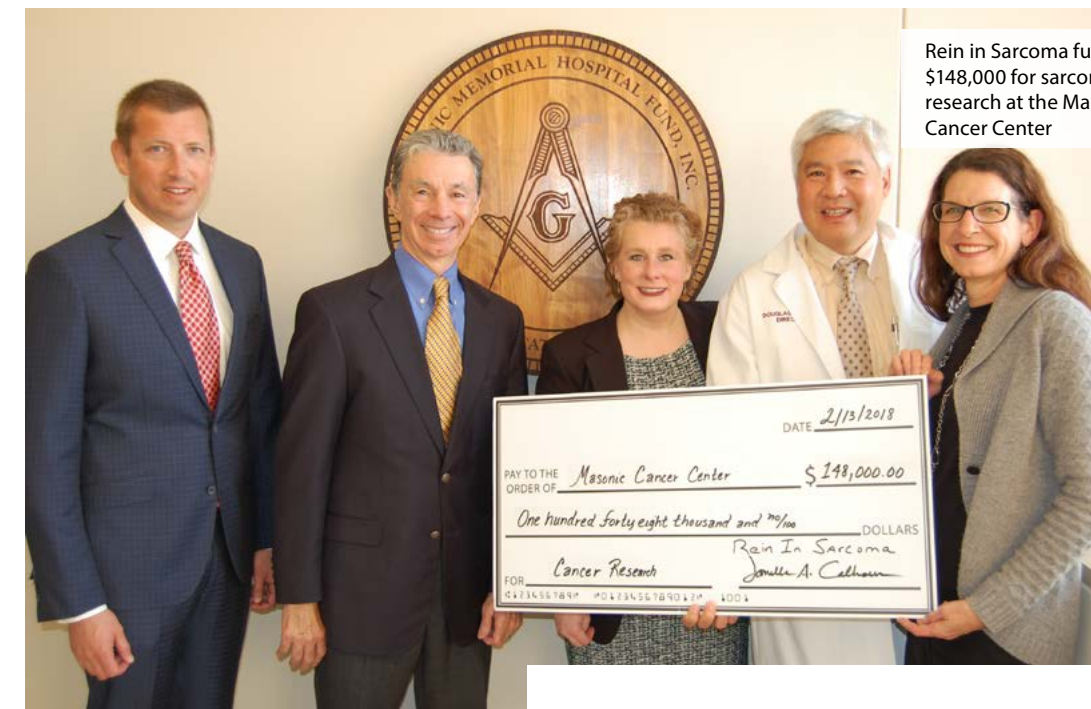
Maudlin Sarcoma Scholar Program: This program supports five Rein in Sarcoma Scholars each school year, including 40 scholar alumni since the program's inception in 2009. Sarcoma Scholars advocate for sarcoma awareness and impact the medical school programs and clinic systems in which they work.



Medical students learn about sarcoma cancers during Sarcoma Days at Mayo



Sarcoma Survivor at the 2018 Patient and Family Picnic



Rein in Sarcoma funded \$148,000 for sarcoma research at the Masonic Cancer Center

FUNDING RESEARCH

Rein in Sarcoma continues its commitment to fund sarcoma research, with **grants totaling over \$190,000** in 2018 to the University of Minnesota, Mayo Clinic and Children's Hospitals and Clinics of Minnesota. The RIS Research Task Force, led by Dr. Larry Seymour and composed of faculty from Children's Hospitals and Clinics of Minnesota, Mayo Clinic and the University of Minnesota, works with each institutions' request for proposal and external evaluation process to determine the most promising research projects for recommendation to the RIS Board.

We are proud to announce **\$150,000 in new grants approved in January 2019** by the Rein in Sarcoma Board. This grant will fund the following three exciting University of Minnesota projects:

MYOG Promoter-Controlled Oncolytic Adenovirus to Treat PAX3-FOXO1-Positive Rhabdomyosarcoma

Masato Yamamoto, MD, PhD | \$50,000

SHH signaling genetic alterations: A relevant and targetable trait in peripheral nerve sheath sarcomas

David Largaespada, PhD | \$50,000

Registry-based analysis of risk and survival for young-onset sarcomas Primary Investigator

Logan Spector, PhD | \$50,000

To learn more about these research projects, visit our website: reininsarcoma.org

PATIENT AND FAMILY SUPPORT

Winter Gathering: 105 patients and community members came together at Bachman's Heritage Room in Minneapolis for support and education. Attendees learned about cutting-edge advances with Dr. Mark Truty's surgery and immunotherapy work at the Mayo Clinic, and Dr. Jamie Modiano's canine sarcoma research innovation at the School of Veterinary Medicine.

Sarcoma Patient and Family Picnic: sponsored by University of Minnesota Health, 419 patients and community members shared time and a picnic dinner together, finding and giving support to each other.

Rein in Sarcoma Remembers: We held the second annual memorial event to support families who grieve the death of a loved one.

Over **250 patient notebooks** were delivered to local hospitals as well as mailed nationwide with a personal note of support from a dedicated Rein in Sarcoma volunteer. The peer-to-peer mentoring program engaged fifteen patients.

FUNDRAISING EVENTS

Chainbreaker: This year we almost doubled our riders and tripled our donations. Team Sarcoma's 31 riders raised nearly \$85,000, enabling Rein in Sarcoma's largest research grant at the University of Minnesota! This brought our total sarcoma research dollars awarded to over \$2 million since 2001.

Golf Tournament: 83 golfers and 11 sponsors enjoyed the historic Keller Golf Course. In addition to golfing, attendees bid on great golf packages, made donations, and purchased 240 yards of string and mulligans for a competitive edge; all in the name of raising funds and awareness of sarcoma cancers.

Fall Fundraiser: The third annual event brought 227 people together to raise \$130,000. The evening included live and silent auctions, fun games, announcements of new research grants, awarding of the RIS Excellence in Education Award to Dr. Randy Hurley, and inspiration from the Blake Hastings family who shared their sarcoma journey.

Subaru Share the Love Event: Rein in Sarcoma was a designated Share the Love charity once again, giving us the opportunity to raise sarcoma awareness with Walser Burnsville Subaru customers and benefiting from the Share the Love charity donation potential with each auto purchased.



Theresa Fetsch,
RIS Development Director

Team Sarcoma Peloton
riders at the 2018
Chainbreaker



2018 RIS Golf
Tournament attendees

2018 IN REVIEW: FINANCIAL REPORT

Strategic Plan

Various changes have come into effect during the year that have impacted Rein in Sarcoma's operations and finances. During 2018, the organization has benefitted from having dedicated office space in Fridley, MN from which to manage operations. Under the guidance of a full-time Executive Director, the organization has continued to build its management team and expertise through consultants, volunteers and third-party service providers. New programs and partnerships have been initiated that will pay dividends in the future. Although events generated contributions consistent with prior years, the need to build a management team and rely less on the time contributed by Pete and Sue Wyckoff to manage operations is noticeable in the net use of cash for the year. This impact was anticipated as RIS makes this transition and appropriate operating reserves are maintained to ensure RIS' ability to make grants and fund other operations are not impacted.

Events

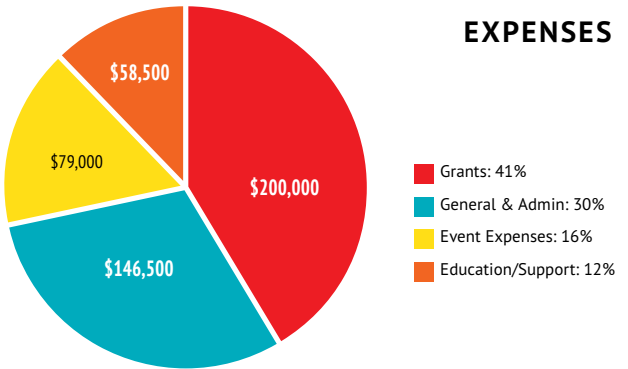
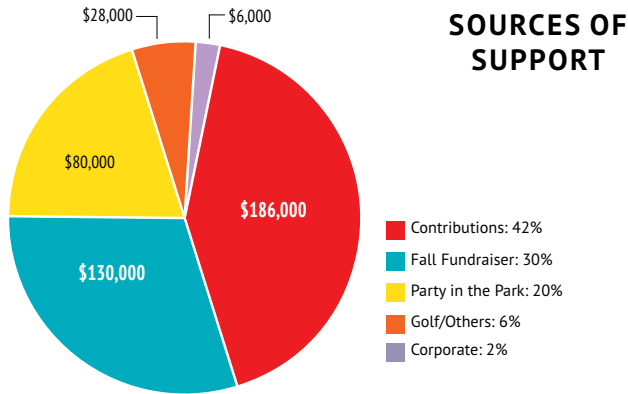
Consistent with 2017, events were well supported during the year. Both the Fall Fundraiser and Golf Tournament increased net contributions. Contributions net of expenses generated from events were approximately \$175,000, an increase of over \$5,000 from the prior year. The second Annual Golf Tournament at Keller Golf Course surpassed the success of the first. The Team Sarcoma Peloton in partnership with the University of Minnesota Masonic Cancer Center Chainbreaker ride also continued its success with the team generating nearly \$85,000 in contributions.

Contributions, Sponsorship and Grants

Although certain corporate and other foundation sponsorships decreased during the year, individual contributions remained strong. Grants and general contribution provided close to \$190,000 during the year. With the addition of a Development Director in the second half of 2018, contributions are anticipated to grow in 2019.

Disbursements

The use of funds by the organization outside of event costs is categorized as research grants, patient support, education, and general and administrative.



Rein in Sarcoma provided research grants to the University of Minnesota of \$147,000 (including \$9,000 in scholarships), along with other grants of \$5,000 to SARC, \$33,000 to Mayo Clinic (including \$3000 scholarship), and \$15,000 Children's Hospitals and Clinics. Patient and family support was provided through notebook mailings, patient tote bags, and several support events. The number of educational awareness programs for medical professionals increased in 2018, and the Hallie Anne Brown Educational Initiative progressed with additional research, education and a pilot 'Best Practice Alert' project. General and administrative expenses increased in 2018 due to the restructuring of RIS' management and additional consultant costs; including a full year of salary costs for an Executive Director and the addition at mid-year of a part-time Health Programs Coordinator and a dedicated Development Director.

Cash Position

The organization has a net positive cash position of over \$700,000. There is sufficient reserve to fund operations for over one year. Given the high level of cash holdings, conservative short-term investments have been initiated to earn a nominal investment return.

*A complete financial report for 2018 and a copy of the 2018 Tax Report can be made available for review.



REIN IN SARCOMA

Karen Wyckoff Rein in Sarcoma Foundation
7401 Central Ave NE, Suite A
Fridley, MN 55432

Nonprofit Org.
U.S. Postage
PAID
Twin Cities, MN
Permit #3749



REIN IN SARCOMA

Increase awareness. Increase survivors.

2018 ANNUAL REPORT

reininsarcoma.org