

change misdiagnosis  
change culture  
change late diagnosis  
**change**  
change the sarcoma story  
change education  
change survival rates

# 2017 ANNUAL REPORT



**REIN IN  
SARCOMA**

Increase awareness. Increase survivors.

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

## 2018 BOARD OF DIRECTORS UPDATE

In 2018 Rein in Sarcoma welcomes four newly-elected members to its Board of Directors



**Blake Hastings** is Managing Director Minneapolis/St Paul at CBRE, a commercial real estate services and investment firm. After being diagnosed with sarcoma in 2017, Blake and his co-workers at CBRE actively supported RIS, raising funds with a marathon and a chili cook-off. We look forward to Blake’s enthusiasm and non-profit board experience as a member of the Development Committee and as Board Vice President.



**Valeria Lopez Torres** is a visual artist, designer and educator. She has been our talented go-to graphic designer since she joined the PR-Marketing Committee in 2015, recently becoming Committee Chair. In addition to the event posters, annual reports, invitations, and programs she has designed, her graphic design students redesigned our organizational brochure in 2017.



**Scott Okuno, MD** is Medical Director of the Oncology Department for Mayo Clinic Health System in northwest Wisconsin and Cancer Coordinating Committee chair for all of Mayo Clinic Health System. He has been supervising the RIS Sarcoma Scholars at Mayo Clinic since 2014, serves on our Medical Advisory Board, and is the key link between RIS and Mayo Clinic.



**Linda Pomeroy** has been a long time RIS volunteer active with the Party in the Park auction and garage sales. She and her husband, Rick, established the Andrea Pomeroy Named Fund in honor of their daughter who died from sarcoma. Linda sells Andrea’s Tea Blend to raise money for RIS, inspired by the tea room and gift shop she and her daughter co-owned.

## ADDITIONAL ORGANIZATIONAL LEADERSHIP

Tom Boardman  
Development Committee Chair

Sue Wyckoff  
Red Flags Educational Committee Chair

Kraig Kuusinen  
Patient and Family Support Committee Chair

Anthony (Tony) Smith  
Legal Counsel

Frank Miske III  
2018 Party in the Park Chair

Denis Clohisy, MD  
Brenda Weigel, MD  
Fall Fundraiser Co-Chairs

Tom Boardman  
Tom DiPasquale  
Mike Trucano  
Golf Tournament Co-Chairs

## BOARD OF DIRECTORS

Debra Cossette  
President

Blake Hastings  
Vice President

Chelsey Olafson  
Secretary

Thomas McCarthy  
Treasurer

Denis Clohisy, MD  
Co-Chair, Fall Fundraiser

Jeffrey Dobbs  
Chair, Finance Committee

Valeria Lopez Torres  
Chair, PR & Marketing Committee

Kevin O’Keefe

Scott Okuno, MD

Linda Pomeroy

Julie Rose  
Chair, Talent Resource Committee

Bruce Seiber

Larry Seymour, MD  
Chair, Research Committee

Allan Swartz

Elisabeth Will  
Chair, Nominating Committee

## STAFF

Janelle Calhoun  
Executive Director

Connie Dow  
Office Administrator



## PARTY IN THE PARK KICKOFF MEETING

MARCH 13, 2018, 6:30 PM

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

Join us for a fun all-hands meeting and help us plan the 18th edition of our signature event.

Attendees are welcome to enjoy one free beer or root beer.

Optional brewery tours starting at 6:00, food truck available at 5:30.

**RSVP: [reininsarcoma.org/kick-off-rsvp/](http://reininsarcoma.org/kick-off-rsvp/)**

## MARK YOUR CALENDARS:

### 18<sup>TH</sup> ANNUAL PARTY IN THE PARK



### 2018 GOLF TOURNAMENT



### FALL FUNDRAISER





## 2017 IN REVIEW:

# LEADERSHIP UPDATE

A major focus for us in 2017 was transitioning from a founder-led organization to one led by an Executive Director and new Board President.

Since then, RIS has been working to make it possible for Pete and Sue Wyckoff to step away from the day to-day operation and significantly reduce their time commitment going into 2018.

## A message from the Incoming President

My husband Terry—a five-year sarcoma survivor—and I found Rein in Sarcoma through the New Patient Starter Notebook, and soon after we got involved through attending, then volunteering at the events. After my retirement from 3M as a Lab Manager, I found that working on the website redesign, along with learning the ins and outs of Salesforce were great ways to get to know the organization and the people we serve.

I am very excited to work with Janelle Calhoun, our Board, Committees, Event Leadership teams, and our many volunteers, to enact the updated Development Plan and Strategic Planning effort currently underway.

We will focus our efforts on the most promising areas for fundraising growth and impact for the Rein in Sarcoma mission. I look forward to getting to know more of you personally in 2018. Please contact me with any comments, suggestions or concerns.

—Debra Cossette, incoming RIS President



PETER WYCKOFF AND  
DEBRA COSSETTE

## A message from the Outgoing President

In 2001, our daughter Karen Wyckoff created Rein in Sarcoma— along with its mission, vision and signature event— Party in the Park, before she died from synovial sarcoma. For seventeen years, Sue and myself, along with Karen’s many friends have kept her vision alive and growing for the entire sarcoma community in Minnesota and across the country.

For the last fourteen years, I have held the roles of President and Executive Director. As in many nonprofit organizations, our Board has term limits and the time has now come for Sue and I to leave the Board—but not to the organization. Over the years, we have turned Rein in Sarcoma into one of the premier sarcoma advocacy organizations in the country. We now leave our roles in the capable hands of our new President, Debra Cossette, and our Executive Director, Janelle Calhoun, who has provided significant volunteer leadership throughout the entire life of Rein in Sarcoma.

In our new roles, Sue and I intend to continue to serve Rein in Sarcoma as long as we are needed, but with greater balance in our lives. My primary responsibilities will continue in helping raise the needed funds for the organization, especially through sponsorships and events, and Sue will continue to lead our Red Flags Committee.

For almost a year, we have partnered with other sarcoma organizations across the country to find common ground and be mutually supportive and collaborative; and I intend to further that vision. The Sarcoma Patient Advocacy Coalition (SPAC) has been crucial in connecting us with other sarcoma organizations to turn that vision into a reality.

We are entering a new and exciting phase in the growth and success of Rein in Sarcoma. Please join us in supporting the new leadership of our foundation.

—Peter Wyckoff, outgoing RIS President

## A message from the Executive Director

### A year of growth, transition, and hard work

Seventeen years ago, our signature event— Party in the Park—laid a foundation for using our community’s skills to improve sarcoma patient outcomes. Seeing and being a part of raising \$10,000 for sarcoma research mattered a great deal to me then and carries forward to now.

In 2017, Rein in Sarcoma has grown in community support, education, and fundraising. We significantly **increased our grants to \$170,000**, expanding beyond our core commitment to funding studies at the University of Minnesota, as well as **funding additional research projects with Children’s Hospitals and Clinics of Minnesota, Mayo Clinic and SARC**.

We have grown in **professional outreach**, delivering **educational presentations** at medical schools and medical clinic systems. Our **Sarcoma Scholar Program** for medical students at the University of Minnesota and Mayo Medical School continues to make a difference with current scholars and alumni who are expanding sarcoma education and creating ripple effects with colleagues, family and friends. The **Hallie Anne Brown Educational Initiative** is showing exciting progress towards developing new techniques to improve sarcoma diagnosis protocols among doctors.

We have grown our **patient support** this year by providing **over 300 Sarcoma Patient Starter Notebooks** to patients in the Midwest and throughout the US. We shared **care packages** for newly-diagnosed sarcoma patients to remind them they are not alone in a rare diagnosis. In the Fall, we began a new tradition for those who have lost a loved one to sarcoma, with our **Rein in Sarcoma Remembers** gathering to offer

support, fellowship and an opportunity to celebrate those lives. A successful **Party in the Park** brought the sarcoma community together at Como Park for the 17<sup>th</sup> year, with grounds renovations adding to a memorable summer evening.

In implementing the 2015 Development Plan over the past couple of years, we have transitioned from a volunteer-led to a professionally-led not-for-profit organization. With current **transitions in leadership**, we are taking time to carefully review our strengths and weaknesses in order to plan and carry out our mission for decades to come. We are working on an **updated development plan** and a **new strategic plan**. Additionally, we are now transforming donated office space in Fridley, MN into our new headquarters.

This year, after a thorough review process, Rein in Sarcoma again received **Charities Review Council “Meets Standards”** approval.



JANELLE CALHOUN,  
EXECUTIVE DIRECTOR



**Emeritus roles** for dedicated founders, **Sue and Pete Wyckoff**, are taking shape. Our leadership and committees work to communicate well and carry on the vision of Rein in Sarcoma with enthusiastic, multi-talented volunteers.

We are a vibrant community, which takes time to care for and grow. It is said that it takes a village to raise a child. Similarly, it takes a village to develop a successful organization. Come and be a part of the Rein in Sarcoma village to improve the precious lives in our community.

Join me and our Leadership team this year to build on the successes of our past, continue to increase awareness, and ultimately increase the number of sarcoma survivors.

—Janelle Calhoun, RIS Executive Director

Over the past seven years, Rein in Sarcoma has met all accountability standards outlined by Charities Review Council, which certifies the strength and reliability of non-profit organizations in Minnesota.



2017 IN REVIEW:

EDUCATION & RESEARCH

We believe that education paired with research can greatly diminish the number of lives lost to sarcoma. Our aim is to educate medical students, doctors, medical personnel, patients and the general public about sarcomas for better diagnosis rates, appropriate treatment, and to raise awareness and increase survivors.

Why are we so proud of our Sarcoma Scholars?

Our scholars at the UMN and Mayo Medical Schools exemplify the creative and intellectual energies that drive Rein in Sarcoma. Since the inception of the **Sarcoma Scholar Program** in 2009, we have had a total of 37 scholars, and our very first scholars continue to impart knowledge to other doctors, medical personnel and patients. **This year we welcome six new Sarcoma Scholars to the program.** Our Mayo Scholars—**Claire Cambron** and **Tessa St. Cyr**—are both from Phoenix, AZ, and were hardy enough to travel to Minnesota for medical school. They have been working on general oncology and sarcoma education and are planning a lecture on sarcoma at the Mayo Medical School in March. Our University of Minnesota Scholars are **Ying Gibbens**, **Andrew Hughes**, **Allison Martin**, and **Madison Weg**. Ying Gibbens comes to us with a Ph.D. in molecular

biology and genetics. Allison Martin graduated from the Naval Academy and has a brother currently battling Liposarcoma. Andrew Hughes is working toward better understanding of sarcoma after losing his father to Leiomyosarcoma. Madison Weg is from Worthington, MN and spent her first two years of medical school at the UMN, Duluth. Each of the six scholars is writing an article about different types of sarcomas to be included in our Patient Notebook and website, and are planning a sarcoma education lecture at UMN Duluth in February and at the UMN Twin Cities in March.

Why the Hallie Anne Brown Educational Initiative?

The Hallie Anne Brown Educational Initiative was initially funded by a major gift from the **Barbara Bradley Baekgaard Family Foundation** in memory of Hallie, who died from Osteosarcoma. As an important part of this initiative, we

assembled a multidisciplinary team of experts including **Dr. Christian Ogilvie** (orthopedic surgeon), **Brittany Matthews** (EPIC Specialist), **Jay Syverson** (Point of Care-President), **Robert Gao** and **Melissa White** (Sarcoma scholars on a research year), and representatives from the **Red Flags Committee** led by **Dr. Randy Hurley** to explore ways of using electronic medical records to improve timely and correct diagnosis rates. The team has engaged in **direct physician education** and currently exploring techniques such as Natural Language Processing and Best Practice Alerts to inform doctors of what to consider if they see certain red flags. Robert and Melissa are working on a research paper about diagnostic codes that most often lead to a sarcoma diagnosis. Additionally, the Red Flags Committee is piloting an **informational program for school nurses** that, if successful, could also be used for athletic trainers. The team is also working with former Sarcoma Scholar **Tori Bahr** on educational programs for medical residents.



LEFT TO RIGHT: CLAIRE CAMBRON, TESSA CYR, MADISON WEG, 2016 SCHOLAR ROBERT GAO, ANDREW HUGHES, ALLISON MARTIN AND YING GIBBENS.

Why is Research so important to RIS?

One of the biggest changes in 2017 was the funding of sarcoma research beyond the University of Minnesota. While our commitment to the UMN remains core to our mission—including \$125,000 in 2017 and new grants in 2018 totaling \$148,000—in 2017 we established the **RIS Research Task Force**, led by **Dr. Larry Seymour** and composed of faculty from **Children’s Hospitals and Clinic of Minnesota, Mayo Clinic and the UMN**. The Task Force set up a process that led to the **funding of \$45,000 in new sarcoma research**. These initiatives went to Mayo Clinic, Children’s Hospital and SARC. The SARC grant is support of a multi-institutional **Sarcoma SPORE grant proposal of over \$12 million** to bring significant new sarcoma therapies within the next five years. **Total research funding in 2017 topped \$170,000**, the largest amount RIS has ever been able to contribute to sarcoma research.

Why our Sarcoma Research Grants?

This year we are proud to fund cutting-edge research with great potential to make a significant impact, as well as research based on work previously funded by RIS, which has led to important advancements in sarcoma treatments in the past few years. After feedback from six outside experts and UMN Faculty recommendation, the following grants were approved by the RIS Board of Directors in January 2018:

PREDICTING RELAPSE AND RESPONSE TO CHEMOTHERAPY IN SARCOMA

Amy Skubitz, Ph.D. | \$49,000

Predicting recurrence of a sarcoma tumor after removal is critical in patient survival, however, current methods to predict recurrence are not accurate. In previous studies, we developed gene signatures that appear to distinguish differences in the probability of metastases in sarcoma patients. This study plans to generate gene expression data using sarcoma tumors from a new group of patients with soft tissue sarcomas who are at high risk of recurrence. The results of this study will serve to substantiate the potential of gene expression patterns to predict recurrence in sarcomas and rapidly move this technology to the clinic.

RETROSPECTIVE AND PROSPECTIVE COMPARISON OF PROGNOSTIC TRANSCRIPTIONAL BIOMARKERS IN OSTEOSARCOMA USING NANOSTRING RNA PROFILING

Aaron Sarver, Ph.D. | \$49,000

The goal of this project is to carry out NanoString sequencing in order to validate the prognostic potential of transcript levels to determine patient outcome in Osteosarcoma, determine which marker or combination of marker is best performing, and explore how to bring transcript level prognostic associations into the osteosarcoma clinical environment. The study will use recent molecular discoveries into the

biology of osteosarcoma to leverage this powerful new sequencing technology in order to examine actual OS patient samples collected from the clinic.

REPROGRAMMING CHOLESTEROL METABOLISM IN SARCOMAS USING ADRENERGIC RECEPTOR ANTAGONISTS

Erin B. Dickerson, Ph.D. | \$25,000

Recently published reports showing a 100% response rate of angiosarcoma patients to Propranolol are encouraging, however, tumor progression eventually recurs in all patients, underscoring the need to gain a better understanding of the impact of Propranolol on these tumors. We recently discovered that angiosarcomas and hemangiosarcomas rely on extracellular cholesterol and oxysterols for cell viability and tumor growth. We will test the hypothesis that Propranolol prevents oxysterols from activating LXRs, limiting tumor cell viability and enhancing sensitivity to chemotherapy.

IDENTIFICATION OF NOVEL DRIVERS OF EWING SARCOMA THROUGH ENGINEERED TRANSFORMATION OF CELLS WITH DIFFERING LEVELS OF AFRICAN ADMIXTURE

Beau Weber, Ph.D. | \$25,000

Ewing sarcoma (ES) occurs nearly exclusively among individuals with substantial European ancestry, displaying wide disparity in incidence compared with people of African or Asian ancestry. We hypothesize that disparity in occurrence is linked to differing lengths of specific repeated genome sequences in each population. We will use cutting-edge induced pluripotent stem cell-based tumor modeling and genetic engineering to test our hypothesis. The results of this study will provide crucial insight into the role that genomic context plays in susceptibility to ES, and will drive future research by identifying new, actionable drug targets for validation and therapeutic targeting.



2017 IN REVIEW:

OUTREACH

We support sarcoma patients and survivors in a variety of ways. Our events provide opportunities to meet other people whose lives have been touched by sarcoma. Our in-person and on-line support groups are another great way to connect, find information, and be part of a larger sarcoma community. While unable to erase the devastating effects of sarcoma, building relationships can lighten the load as empathy is shared.



RIDERS OF THE TEAM  
SARCOMA PELOTON AT  
THE CHAINBREAKER

Creating Community  
and Providing  
Support

2017 Annual Winter  
Gathering

The Winter Gathering brought about a gamut of emotions as over 100 people laughed, cried, shared their stories, and inspired others to lead happier and more fulfilling lives. **Ruth Bachman** moderated our survivors’ panel and comedian **Tim Gabrielson** performed live magic tricks and invited audience members to join him on stage. 2017 Party in the Park Chairperson **Chelsey Olafson** encouraged all attendees to get involved in our signature event. Thank you to everyone at **Bachman’s Corporate Garden Center** for helping us make our Winter Gathering a huge success!



2017 ANNUAL WINTER  
GATHERING AT BACHMAN’S  
CORPORATE GARDEN

7th Annual Anna  
Rogotzke Memorial  
Kickball Tournament

After Anna Rogotzke died of Rhabdomyosarcoma in 2010, her parents, **Jim and Becky Rogotzke**, came up with the Kickball Tournament as their way “to honor Anna’s memory and raise money to find cures that can really make a difference for children like Anna.” Their family immediately offered leadership. The **Sanborn community** quickly embraced the tournament which has now become an eagerly anticipated event. **The event raised over \$6000.** Join us for our 8th edition on **Saturday, July 21 2018** as we run, kick, laugh, and have fun to honor and remember the life of Anna.

17th Annual Sarcoma  
Patient Picnic

Over 400 patients, survivors, loved ones, and those who have lost a loved one to sarcoma attended the 2017 Sarcoma Family Picnic. Attendees socialized with doctors and researchers from the **University of Minnesota, Mayo Clinic, and Children’s Hospitals and Clinics of Minnesota.** New connections were made among a community joined together by a personal connection to sarcoma.



PARTICIPANTS AT  
THE 2017 RIS GOLF  
TOURNAMENT

As the picnic closed, the **Dirty Shorts Brass Band** led the crowd New Orleans-style up the hill to the Party in the Park.

17th Annual Party in the Park

An incredible team of volunteers worked over six months to create a spectacular evening together, **raising over \$83,000.** We thank our key corporate sponsors **Walser-Subaru, University of Minnesota Cancer Care, Mayo Clinic, Building Arts, Minnesota Oncology, Ergodyne, Restoration Professionals** and **D’Amico Catering.** Over 1,000 attendees enjoyed the music of **Erin Schwab**

and the **Jay Fuch’s Band**, rode the **Cafesjian Carousel**, participated in the silent auction, and listened as keynote speakers **Ken and Julieann Selden**, shared their journeys as sarcoma survivor and caregiver, respectively. We thank all who sponsored, volunteered, donated to the silent auction, attended, and raised awareness together. Join us again this year on **Monday, July 23 2018.**

Chainbreaker: Team  
Sarcoma Peloton

Thanks to the generosity of the community, 18 riders from the **Team Sarcoma Peloton** raised over **\$24,000** for sarcoma cancer research at the **University of Minnesota.** Many riders finished the 25-mile ride and a few rode a whole lot more! We had a wonderful time making a real difference by funding sarcoma research in collaboration with Chainbreaker and the UMN.

Golf Tournament

Thank you to all who joined us at the **Deer Run Golf Club** for a wonderful day of golf and fellowship in support of our mission! We had 22 teams participate in our first RIS annual Golf Tournament and together we **raised over \$28,000.**



INAUGURAL SURVIVOR  
RIDE AT THE 2017  
PARTY IN THE PARK





KEYNOTE SPEAKER  
MIRANDA MEAD AT THE  
2017 FALL FUNDRAISER

## 2017 IN REVIEW:

# NAMED FUNDS

In 2017 RIS Named Funds raised over \$123,000. We thank the families and individuals who have established funds to support our mission and to inspire others to join in their efforts.

To learn more about establishing a Named Fund of your own, or to honor the life of a sarcoma patient, visit:

[reininsarcoma.org/NamedFunds/](http://reininsarcoma.org/NamedFunds/)

- |                                |  |
|--------------------------------|--|
| • Nicole Anderson Fund         | • Jacob Martell Fund                     |
| • Julian Baultrippe Fund       | • Jan Maudlin RIS Sarcoma Scholar Fund   |
| • Richard Berqual Fund         | • Miranda Mead Fund                      |
| • Hallie Anne Brown Fund       | • Jackie J. Middleton Fund               |
| • William Clemens Fund         | • Heidi Minor Fund                       |
| • Nick Convey Fund             | • Kevin O’Keefe Fund                     |
| • Brett Dale Fund              | • Beverly and Dean Osterman Fund         |
| • Meghan Marie DeBruycker Fund | • Andrea Pomeroy Fund                    |
| • Perry Ford Fund              | • Anna Rogotzke Fund                     |
| • Wade Hohol Fund              | • Beverly Ann Schuld Fund                |
| • Lora Homquist Fund           | • Eric Skogman/Mud Dog Sarcoma Ride Fund |
| • Alyssa Jeske Dobson          | • Mark Wehner Fund                       |
| • Judy Jones Fund              | • Judith B Wolson Fund                   |
| • Barbara Kimker Fund          | • Laura Zeccardi Fund                    |
| • Marge Krauter Fund           |  |

## 2017 IN REVIEW:

# FINANCIAL REPORT

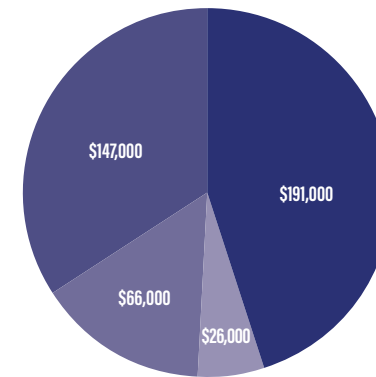
## STRATEGIC PLAN

Rein in Sarcoma has made a number of **strategic decisions** during 2017. The organization hired its first **Executive Director**, Janelle Calhoun, effective July 1, 2017. Janelle has contributed to the organization in a variety of capacities since its inception; now she will continue to contribute on a full-time basis to bring a new level of organization and growth to the entity. RIS also saw the departure of Paul Giel, Jr. as the Development Director. Paul’s efforts in growing the financial support and establishing a Golf Tournament and Fall Fundraiser are appreciated. In addition, we have been generously gifted the **use of office space in Fridley, MN** for the day to day work of our growing team.

## EVENTS

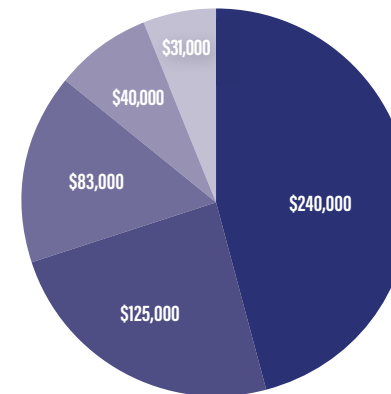
The organization continued to have excellent support at its recurring events. **Party in the Park contributed over \$60,000** (net of expenses) to the organization and the **Fall Fundraiser increased its revenue by over 10% to \$125,000**. The combined events netted over **\$150,000** for the organization. Both events provided a chance for sarcoma patients, survivors, medical professionals and others to come together and have a good time supporting the cause.

We also added two new events which are anticipated to become annual fun events for RIS support. The first annual **RIS Golf Event** took place on August 25 at Deer Run Golf Club. The more cardio-inclined supporters participated in the



2017 EXPENSES

- Grants: 45%
- General & Admin: 34%
- Event Expense: 15%
- Education/Support: 6%



2017 SUPPORT & REVENUE

- Contributions/Grants: 46%
- Fall Fundraiser: 24%
- Party in the Park: 16%
- Corporate: 8%
- Golf/Merchandise: 6%

**Chainbreaker** held earlier in August. All 18 participants of the Team Sarcoma Peloton **raised over \$24,000** for sarcoma cancer research and education at the University of Minnesota.

## CONTRIBUTIONS, CORPORATE SPONSORSHIP AND GRANTS

Support through **Named Funds** gifts continued to grow with the following funds added during 2017: **Heidi Minor, Nick Convey, Marge Krauter, Judith B. Wolson and Miranda Mead**.

Corporate sponsorship predominately came through generous contributions from **Walser Subaru**. In addition to contributions, Walser Subaru sponsored Rein in Sarcoma through their **‘Share the Love’** campaign running from November 11, 2016 to January 2, 2018. The campaign allows car buyers to contribute \$250 to a charity partner.

## 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 University of MN of \$125,000** along with other grants totaling **\$45,000 to SARC, Mayo, Children’s Hospitals and Clinics and others**. Patient support through notebook mailings, education and other programs also continued. General and administrative expenses increased in 2017 due to the addition of an Executive Director and other support staff costs.

## CASH POSITION

The organization has a net positive cash position of over \$750,000. There is sufficient reserve to fund operations for the next two years. A complete financial report for 2017 and a copy of the 2017 Tax Report will be available for review.



# REIN IN SARCOMA

Karen Wyckoff Rein in Sarcoma Foundation

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# REIN IN SARCOMA

Increase awareness. Increase survivors.

## 2017 ANNUAL REPORT

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