



# REIN IN SARCOMA

Increase awareness. Increase survivors.

Total Donations for 2019

Individual Giving

Fall Fundraiser

Party in the Park

Corporate Sponsorships

Golf Tournament

Special Giving Campaigns

Grants and Foundations

# 2019

## ANNUAL REPORT

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

## 2020 Board of Directors

### **Blake Hastings**

*President*

### **Eric Lien**

*Vice President*

### **Mitch Atherton**

*Secretary, Chair, Finance Committee*

### **Tom McCarthy**

*Treasurer*

### **Linda Andean**

*Chair, Red Flags Educational Committee*

### **L. Chinsoo Cho, MD**

### **Denis Clohisy, MD**

### **Brendan Dillon**

### **Lisa Griebel**

### **Michelle Kolling**

### **David Largaespada, PhD**

### **Valeria Lopez Torres**

### **Scott Okuno, MD**

### **Linda Pomeroy**

### **Colin Ryan**

### **Bruce Seiber**

*Chair, Nominating Committee*

## **STAFF**

### **Janelle Calhoun**

*Executive Director*

### **Theresa Fetsch**

*Development Director*

### **Pending**

*Sarcoma Education and  
Communication Manager*

### **Connie Dow**

*Office Administrator*

## Board of Directors UPDATE

**Linda Andean** retired from the University of Minnesota after 30 years as a department administrator, mostly in the academic Health Center. In 1995, she was hired as the manager of the Cancer Protocol Review Committee as the Center was seeking the NCI Comprehensive Cancer Center designation.

Hearing about Rein in Sarcoma, she stopped by the 2019 Winter Gathering to find out more about the organization. In talking with members, she decided it would be an organization she would be interested in pursuing. The Education Committee was of particular interest and she has been volunteering with the committee and is now the chair.

**Brendan Dillon** is a Vice President of Global Inventory Management for Target Corporation and previously held various leadership positions at Target. Brendan is motivated to leverage his professional experience to help expand Rein in Sarcoma's impact for sarcoma cancer patients, after seeing his neighbor Blake Hastings and family deal with Blake's sarcoma cancer diagnosis and treatment.

**Michelle Kolling** is returning to serve on Rein in Sarcoma's board. After many years in the commercial real estate business, she recently completed training to be an end of life doula. Michelle, who lost her husband Brett Dale to sarcoma cancer in 2011, has volunteered not only as a RIS board member, but as the Red Flags Education Committee Co-Chair, and as a member of the original strategic planning committee. Most recently, Michelle has focused her RIS volunteer time on patient and family support.

## Additional Organizational Leadership 2020

### **Tom Boardman**

*Development Committee Chair*

### **Linda Andean**

*Red Flags Educational Committee Chair*

### **Kraig Kuusinen**

*Patient and Support Committee Chair*

### **Julie Rose**

*Talent Resource Committee Chair*

### **Anthony (Tony) Smith, JD**

*Legal Council*

### **Amy Hoban**

*2020 Chair Party in the Park*

### **Tom Boardman and Colin Ryan**

*Sarcoma Cancer Research Golf Classic Chairs*

### **Carey Hastings, Katie Lien, Mara Ryan**

*Fall Fundraiser Chairs*

## 2019 Active Named Funds

Named Funds are established by individuals and families to honor the lives of sarcoma patients, survivors and loved ones who have passed away. In 2019, Named Funds raised over \$71,000. Thank you to families and individuals who have supported our mission through Named Funds. We invite others to start a named fund to help advance our mission.

To learn more about establishing a Named Fund of your own or to honor a patient, survivor or loved one who has passed away, visit [reininsarcoma.org/namedfunds/](http://reininsarcoma.org/namedfunds/) or contact Theresa Fetsch at [development@reininsarcoma.org](mailto:development@reininsarcoma.org)

- Bob Anderson Fund
- Nicole Anderson Fund
- Julian Baultrippe Fund
- Richard Berqual Fund
- Annette Bonaventura Fund
- Hallie Anne Brown Fund
- Sara Christensen Fund
- Nick Convey Fund
- Brett Dale Fund
- Meghan Marie DeBruycker Fund
- John Philip Douglass Fund
- Perry Ford Fund
- Wade Hohol Fund
- Lora Holmquist Fund
- Alyssa Jeske Dobson Fund
- Judy Jones Fund
- Katelyn Jurek 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
- Beverly and Dean Osterman Fund
- Andrea Pomeroy Fund
- Anna Rogotzke Fund
- Beverly Ann Schuld Fund
- Eric Skogman/Mud Dog Sarcoma Ride Fund
- Lucy Swift Fund
- Judith B. Wolson Fund
- Thomas Worthley Fund
- Laura Zeccardi Fund

## STAY TUNED FOR FURTHER DETAILS



### 20<sup>th</sup> Anniversary Party in the Park and Sarcoma Family Picnic

July 27

### Sarcoma Cancer Research Golf Classic

Edinburgh USA Golf Course,  
Brooklyn Park  
September 15



### Fall Fundraiser

Metropolitan Ballroom  
Golden Valley  
October 8

# Message from the President



RIS Ride 2019

Eric Lien, Vice President, Blake Hastings, President, Colin Ryan, Boardmember, Brendan Dillan, Boardmember, Tom Boardman, Chair Development

2019 was a record year for **Rein in Sarcoma**. We were able to end the year with a 30% increase in our top line revenues, which equated to substantially more dollars for research, education, and patient support. This growth came as a direct correlation to the investments we made in staff during 2018. 2020 is set up to be a similar year to 2019, more investments to continue to grow our reach and effectiveness. To highlight our investment, we are working to fill a fulltime position that will lead our Education and Communications initiative. As one of our sarcoma doctors told the board, educating the doctors, nurses, and caregivers on the signs and symptoms of sarcoma is the best focus to lead to increased survival outcomes. We are doubling down in this area!

I want to personally thank my fellow board members, committee members, volunteers, and staff: thank you for your tireless work and dedication to our organization. Your commitment is the reason we had a record year in 2019. To all of our donors and sponsors, **THANK YOU!** Your support in 2019 was tremendous and we will continue to utilize your donations to increasing survivorship from the numerous types of sarcomas. Without your generosity, our organization would not have made the strides we did last year.

I also want to thank Lisa Griebel, who is stepping down as Board Vice President. Your support and guidance during 2019 allowed us to reach great heights! Lisa will be staying on the board, but we will be adding Eric Lien as our new Board Vice President in 2020. Eric has big shoes to fill.

Thanks again to our community. We will continue to double down our efforts to educate the medical community, support sarcoma patients and families, and donate money to the most promising research.

Blake Hastings



Carey and Blake  
Fall Fundraiser



Together We Move Mountains  
Eric Lien, Vice President  
Blake Hastings, President

**In October the following research grants were announced:**

*Integrated Proteomic and Transcriptomic Profiling of Rhabdomyosarcoma Reveals Target Antigens for Immune-Based Therapies*

Principal Investigator:  
Patricio Gargollo, MD,  
Associate Professor in Urology, Mayo Clinic

Funding: \$25,000

*Expanding Opportunities for Early Detection of Sarcoma*

Co-Principal Investigators:  
Kris Ann Schultz, MD, Pediatric Oncologist;  
Megan Hilgers, MD, Pediatric Oncologist  
Children's Hospital and Clinics of Minnesota

Funding: \$20,000

**We are proud to announce the 2020 University of Minnesota Sarcoma research projects:**

*eBAT as a Modulator of the Myeloid Immune Checkpoint in Cancer*

Primary Investigator:  
Jaime Modiano, VMD, PhD  
Co-Investigator:  
Jong Kim, VMD, PhD

Funding: \$50,000

*Using Propranolol to Generate an Anti-Tumor Microenvironment*

Primary Investigator:  
Erin Dickerson, PhD  
Co-Investigator:  
Kaylee Schwertfeger, PhD

Funding: \$50,000

*Computationally Deciphering the Paths of Genomic Catastrophe in Osteosarcoma*

Primary Investigator:  
Ruping Sun, PhD  
Co-Investigator:  
Lauren Mills, PhD

Funding: \$50,000

To learn more about these research projects, visit our website: [reininsarcoma.org](http://reininsarcoma.org)

**Transition: Message from the Executive Director**

This past year embodies our hashtag #StrongerTogether. This was a year of transition. We worked to understand issues with communication. We became fully integrated with the use of online conferencing, video, audio, and livestream communication strategies. Event space was modified at Party in the Park and a new location for Fall Fundraiser have set us up to expand for our upcoming 20th anniversary year.

Our Education, Patient and Family Support and Communication and Marketing committees worked together, giving out more patient education notebooks through our MN partner medical systems, online requests, and added patient education support with Duke Oncology. Education tools were updated and shared via online and event work. Participation at meetings and events increased with video conferencing and live streaming tripling online social media interactions.

Thanks to dedicated volunteers, team work and collaboration, we raised more money at each of our fundraisers setting our community up to hire a new fulltime staff member supporting strategic plan vision for growth. Our board of directors is fully behind strategy to advance sarcoma education and use of technology to improve early detection of sarcoma. Committee members, board leadership and community enable our forward momentum. We have all worked hard, and it shows.

Janelle Calhoun

**John L. Seymour MD** has served on our Board of Directors and chairs the Sarcoma Research Taskforce Committee. Under Dr. Seymour's guidance, the committee has met by phone to work on funding the most promising sarcoma research, and manage grants. In 2017 RIS research funding expanded to Mayo Clinic in Rochester, MN and Children's Minnesota. This started a new tradition, a request bringing researchers together to report on grant findings.

On Saturday, April 27 at the Center for Cancer and Cardiovascular Research at the University of Minnesota the first annual **Sarcoma Research Symposium** was held. Researchers from 2017 grants presented findings together. Doctoral students attended adding to lively conversation supporting our mission of sarcoma education and work to improve outcomes for more patients and families.

## Red Flags Education Committee 2019

Jan Maudlin Sarcoma Scholars – 10th Anniversary Year

We thank three Maudlin Scholars: Colleen Bell, Alexander Kuehne and Kyle Lau for their work and time advancing sarcoma education at the University of Minnesota in collaboration with Mayo Maudlin Sarcoma Scholars Taylor Weiskettel and Mylan Blomquist. Having surveyed over forty alumni on program impact, positive results were shared at a beautifully prepared scholar reunion and program celebration. The tenth year celebration was held on March 16 at Camp Sacajawea Retreat Center Lodge and hosted by co-founders Pete and Sue Wyckoff. The event honored sarcoma education support of Jan and Tim Maudlin through the Jan Maudlin Rein in Sarcoma Scholar Named Fund as well as program physician mentors Dr. Katie Dusenbery, Dr. Scott Okuno, Dr. Randy Hurley, and Dr. Christian Ogilvie. The strong dedication to sarcoma education from all these supporters leads to improved patient outcomes for many years to come.



**We welcome five new Maudlin Scholars, accepted for 2019-20:**

Jake Kloeber and M. Ryan Claxton, at Mayo Clinic Minnesota, Regina Martinez, Nicholas Reiners, June Zolfaghari at the University of Minnesota. They attended Sarcoma Boot Camp in the fall with Dr. Katie Dusenbery, Dr. Randy Hurley, Dr. Scott Okuno, and Dr. Christian Ogilvie. Students gave glowing reports on Boot Camp and are eager to work on projects advancing sarcoma education.



Sarcoma Scholar Boot Camp

**Tenth Anniversary Year  
for Jan Maudlin  
Sarcoma Scholars Program**



Dr. Katie Dusenbery and Jan Maudlin

**2019 Winner of the Rein in Sarcoma  
Excellence in Education Award, Dr. Christian Ogilvie.**

Dr. Ogilvie's passion around education and improved speed of accurate diagnosis for patient care has touched the lives of medical students, physicians, physical therapists and athletic trainers across the state of Minnesota. Active on the Rein in Sarcoma Medical Advisory Board, he continues to provide training to many sarcoma scholars and quickly offers his time for educational talks. Congratulations and thank you, Dr. Ogilvie.

Physician  
Diagnostic Card and  
Sarcoma Education Brochure:

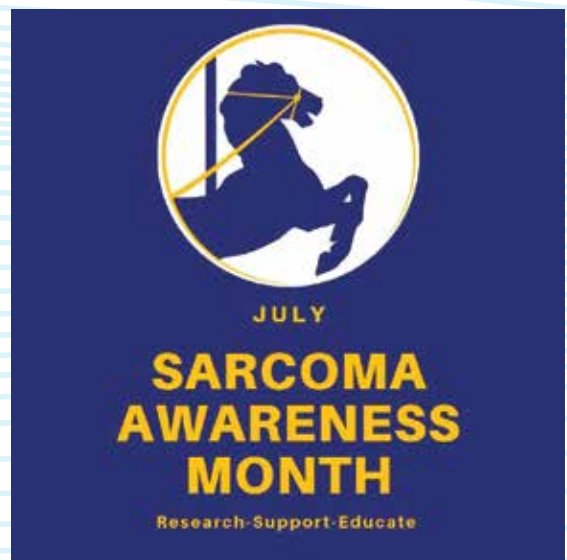
The Medical Advisory Committee worked in conjunction with the committee to update and refresh these tools. Sarcoma UK shared permission to use the golf ball as a visual aid in a campaign called "On the Ball" to help primary care providers visualize the size of a mass to support faster, accurate evaluation and diagnosis.

## Expanding Professional Education:

Dr. Ogilvie spoke at the Minnesota Athletic Trainers Conference April 13, RIS volunteers at the education display table. RIS attended the Rare Disease Day Conference and staffed a sarcoma information table on March 1. Volunteers staffed an education table at the 2019 Mayo Clinic Internal Medicine Board Review held June 3-7. Sue and Pete Wyckoff conducted a meeting with Mayo sarcoma medical providers thanking them for their participation in sarcoma education and patient support and reintroduced them to the notebook, education resources, and patient tote bag program. Marlene and Dave Dolney worked with the Physician Assistants program at Bethel, coordinating a sarcoma education program presented by Dr. Ogilvie, May 21. RIS attended the Fall School Nurse Conference on November 1, premiering The committee produced: "Sarcoma - A Rare and Deadly Cancer - A Discussion between Dr. Emily Greengard, Pediatric Oncologist and Sarina Morrison, Patient" along with the new Red Flag Brochure and Doctors' Cards. Thank you to Taylor Dale for Graphic Design and Michelle Kolling for the written content. RIS volunteers staffed a table at UMOEN: Upper Midwest Oncology Education Network, November 15. Our continued thanks and appreciation for the work of all Red Flags committee members, and conference subcommittee: Phyllis Balto, Marilee Bryce, Dick DeBlick, Marlene and Dave Dolney.



Researcher Symposium



### "Sarcoma: A Rare and Deadly Cancer":

This twenty-four minute video was produced thanks to Dr. Emily Greengard, Pediatric Hematologist/Oncologist at Masonic Children's Hospital, and her patient, Sarina Morrison, longtime volunteer. Featuring signs, symptoms, treatment, short, mid and long term patient impact, it is a powerful education tool for all looking to learn more about sarcoma. Links are found on the RIS YouTube channel [youtube.com/user/ReinInSarcoma/videos](https://www.youtube.com/user/ReinInSarcoma/videos) or website.

### EMR Pilot Project:

The Hallie Anne Brown Educational Initiative, lead by Dr. Randy Hurley of HealthPartners, is testing a Best Practice Alert (BPA), popup in EPIC, an electronic medical records system. The BPA is both an educational and diagnostic tool. It triggers when signs and symptoms consistent with a sarcoma diagnosis are documented in e-records. Maudlin Sarcoma Scholars, Andy Hughes and Mel White Albersheim reviewed records, identifying initial references to sarcoma symptoms to support medical code data. Brittany E. Mathews, EPIC expert, worked on popup design, testing and implementation. Best Practice Alerts will be evaluated after clinics pilot the program for a three-month test period.

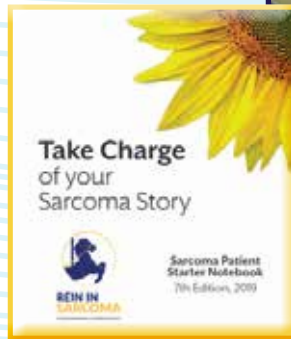
Dr. Hurley and EMR team are exploring software design strategy, possibly Natural Language Processing (NLP), as an alternate IT strategy to faster, accurately diagnose sarcoma. We are deeply thankful for the time, hours and care shared on the EMR project!

## 2019 Annual Report - Patient and Family Support

Under the leadership of chair, Kraig Kuusinen, the Patient and Family Support Committee plans and executes patient and family support events including RIS Gatherings. Events are held two to three times a year as well as the Sarcoma Family Picnic, in conjunction with the Party in the Park. Committee members assembled and distributed 58 Tote Bags of Hope to partner hospitals. Assigned members distribute the educational Sarcoma Patient Starter Notebook to partner hospitals as well as mail notebooks requested through the website.

206 Sarcoma Patient Notebooks were delivered to local hospitals and mailed to 27 states nationwide to patients requesting online. In addition, 64 Notebooks were downloaded directly from our website.

The committee also works to support and oversee volunteer mentors program.



Survivor with Corsage  
Party in the Park



Blake and family  
at Party in the Park Picnic



Talk and Together Time

Luminaries





### Sarcoma Patient and Family Picnic:

Sponsored by M Health, 416 patients, survivors and family members shared a picnic dinner and support for one another, and then joined community members for the 19th Annual Party in the Park.

Rein in Sarcoma Remembers: Third annual event to support families grieving the death of a loved one to sarcoma was held at the Carl W. Kroening Interpretive Center in Minneapolis. Christy Moe Marek, an End of Life Doula, shared her story, grief support strategies and guided the group in meditation, followed by a naturalist-led walk along the Mississippi River.



**Winter Gathering:** 66 patients, survivors and community members braved the cold Minnesota winter day to come together at Bachman's Heritage Room in Minneapolis to share and learn about sarcoma and support each other. Entertainment was provided by Elvis Francois, MD, the "Singing Surgeon" from the Mayo Clinic in Rochester. Jacalyn See, MS, RDN, LD (Mayo) shared the importance of nutrition for cancer survivors; Kris Ann Schulz, MD (Children's) shared her research on the international Pleuropulmonary Blastoma (PPB) registry; and Beau Webber, PhD (U of M) shared his research on Ewing's Sarcoma.



## 2019 IN REVIEW: FINANCIAL REPORT

### Strategic Plan

2019 was a strong year in terms of contributions and program development which had a positive impact on advancing education and providing patient and family support. During 2019, the organization continued to benefit from having dedicated office space in Fridley, MN for staff, volunteers and the community. Under the leadership of a full-time Executive Director, the organization re-evaluated its management structure and expertise and determined the need to expand the part-time Education Program Coordinator position to full-time. Program expansion and partnerships will continue to pay dividends in the future.

### Events

Events were well supported during the year. Party in the Park corporate sponsorship increased year over year. Both the Fall Fundraiser and Golf Tournament increased net contributions. Significant event increases were Fall Fundraiser live auction which more than doubled and Fund a Need increased 25%.

The third Annual Golf Tournament at Edinburgh USA Golf Course surpassed the success of the second. Team Sarcoma organized its own bike ride raising over \$18,000 in contributions keeping the momentum going from the previous year's Chainbreaker ride fundraising \$89,000 in 2018 for 2019 sarcoma research awards.

### Contributions, Sponsorship and Grants

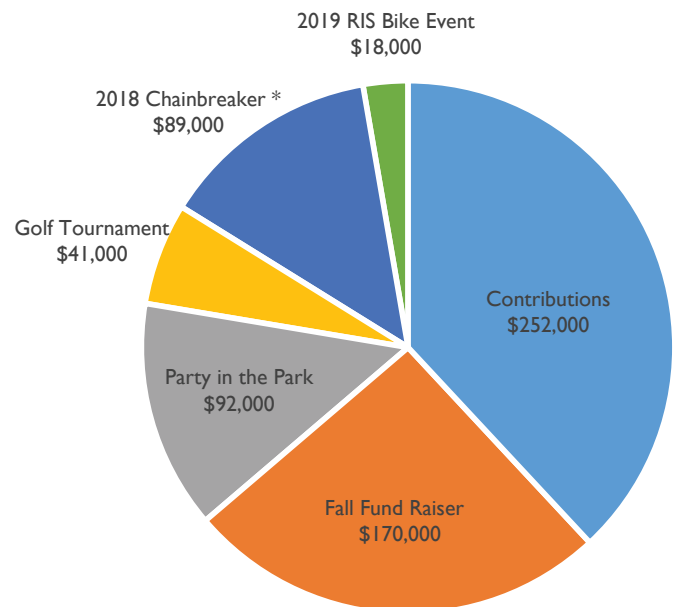
Corporate and general contributions combined with program revenue increased cash received by over \$145,000 during the year to \$575,000. While Foundation grants remained flat, nearly every category of contribution and event revenues increased during 2019. Specifically, sponsorship increased across all three fundraising events.

The higher level of contributions allowed for increased investment in grant and other programs while keeping RIS in a net positive cash position of approximately \$100,000 for FY 2019.

## FY 2019

	FY 2019	FY 2018
<b>Contributions</b>	\$ 252,000	\$ 186,000
<b>Programs:</b>		
<b>Fall Fund Raiser</b>	170,000	129,000
<b>Party in the Park</b>	92,000	80,000
<b>Golf Tournament</b>	41,000	27,000
<b>2018 Chainbreaker *</b>	89,000	85,000
<b>2019 RIS Bike Event</b>	18,000	
<b>Total</b>	\$ 662,000	507,000

\* Presented net of grants on certain financial reports.  
RIS made contribution in 2019 and follows cash basis accounting.



## 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 \$150,000 (including \$9,000 in scholarships), along with other grants of \$25,000 to Mayo Clinic (including \$3,000 scholarship) and \$20,000 to Children's Minnesota.

Patient and Family Support was provided through Patient starter notebook mailings, patient tote bags, peer to peer mentors and several support events.

The number of educational awareness programs for medical professionals increased in 2019. The Hallie Anne Brown Education Initiative progressed with additional research, education and expanded the pilot Best Practice Alert (BPA) project.

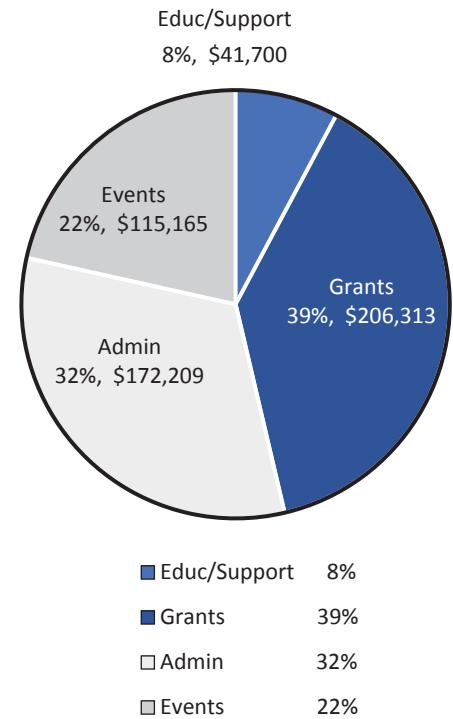
General and administrative expenses increased due to additional consultant costs; including a full year salary costs for a dedicated Development Director and a part-time Health Programs Coordinator for half the year.

## Cash Position

The organization has a net positive cash position of over \$600,000. There is sufficient reserve to fund operations for one year. Given the high level of cash holdings, conservative short-term investments are being explored. In turn, this will earn a nominal investment return.

\*A complete financial report for 2019 and a copy of the 2019 Tax Report can be made available for review upon request.

## Expenses



RIS MCC Funding Research Impact

## Subaru Share the Love Event

Rein in Sarcoma was designated a hometown charity for Subaru's Share the Love event once again for the Walser Burnsville location. In 2019, RIS was designated a charity at a second location, the new Walser Subaru in St. Paul. RIS is so grateful to have the support of two metro locations to raise sarcoma awareness with Subaru customers and potential donations from each auto purchased during the annual event in November and December.



## RIS Bike Ride

Team Sarcoma organized an all-volunteer trail ride in lieu of Chainbreaker taking 2019 off. Nearly 20 cyclists started in Wayzata riding the Dakota Rail Trail 25 miles and raised over \$18,000 for sarcoma research.

## Rochester Fundraiser

The first fundraiser in Rochester was hosted by Little Thistle Brewery. Doctors, researchers, volunteers and community members enjoyed music by members of the band Six Mile Grove and raised over \$4,000.

# 2019

# ANNUAL REPORT

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

## Sarcoma Cancer Research Golf Classic

This year's tournament moved to the Edinburgh USA Golf Course in Brooklyn Park. One hundred golfers and over a dozen sponsors enjoyed the beautiful course, only one of two courses in Minnesota designed by world-renowned architect Robert Trent Jones II. In addition to golfing, attendees bid on golf packages in a silent auction, made donations and purchased over 300 yards of string for a fun competitive edge; all in the name of raising funds and awareness for sarcoma cancers.

## Fall Fundraiser

The Fall Fundraiser moved to the Metropolitan Ballroom in Golden Valley. The fourth annual event brought over 250 guests together to raise nearly \$180,000. The evening included live and silent auctions, new research grant announcements, awarded the RIS Excellence in Education Award to Dr. Christian Ogilvie and inspiration from keynote speaker, Casey O'Brien, Gopher football player and 4-time sarcoma cancer survivor.



Casey O'Brien speaking at Fall Fundraiser



2019 Fall Fundraiser Leadership