

Cheers to 20 Years! Rein in Sarcoma Milestones

July 2001 - Karen Wyckoff initiates the first Rein in Sarcoma Party in the Park event with over 250 friends and supporters. The event raised \$10,000 for cancer research

2004 – Rein in Sarcoma incorporates as a nonprofit organization

2005 - Sarcoma research funding begins under the Karen Wyckoff Research Fund

2007 - First RIS Patient Notebooks developed. First published (3rd edition) in 2010

2009 – Jan Maudlin RIS Scholars begins at the University of Minnesota, expanding to the Mayo Clinic in 2014

2011 – RIS's Medical Advisory Committee formed

2016 – RIS's first Patient Tote Bags given to sarcoma patients at the University of Minnesota. Later expanding to Children's MN Hospitals and the Mayo Clinic

On the cover: Miranda Mead Top: Laura Gossett

Middle: Regina Martinez and Omar Cespedes Bottom: Brenda and Mike Schurhamer

2016 - RIS received \$100,000 in honor of Hallie Anne Brown who passed away at 16 from osteosarcoma. RIS was able to increase sarcoma education and medical research through establishment of the Hallie Anne Brown **Educational Initiative**

2017 - RIS partnered with Dr. Randy Hurley of Health Partners on an early electronic diagnostic tool alerting medical professionals of potential soft tissue sarcomas. Clinical trials began in 2018 and continue to show promise

2017 — Transition from a Founder led to a Founder Legacy organization with a full volunteer Board of Directors, staff and committee structure

2019 – RIS funded \$195,000 in sarcoma grants: \$150,000 to the University of Minnesota, \$20,000 to the Children's MN Hospitals and \$25,000 to the Mayo Clinic

2020 – RIS celebrates 20 Years dedicated to sarcoma: patients, education and research

2020 - RIS reached over \$2 million dollars in sarcoma research funding resulting in over \$13.4 million in leveraged sarcoma research dollars at the University of Minnesota



Miranda Mead, Casey O'Brien and Conner O'Brien



Amelia Hames and Terrie Worthley



Blake Hastings President



Janelle Calhoun **Executive Director**

This past year was a challenging, yet rewarding year for Rein in Sarcoma. For obvious reasons, the COVID pandemic caused great anxiety early in 2020. Not only for our organization, but also for all cancer patients that have compromised immune systems.

Flashing back to March/April 2020, the Board of Directors and RIS Leadership came together numerous times to strategize, contingency plan, and best create a go forward plan in the COVID environment. I sit here today and believe we are blessed with the outcome from the remainder of 2020.

Not surprising, we did have a hit to our revenue, but not as originally COVID forecasted. No in-person events created hurdles, not only financially, but also for sarcoma education and patient support. The silver lining is that our organization was stressed to learn new ways to reach our community ... and we did in amazing fashion!

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. We were faced with many challenges and our team rose to the occasion. To all of our donors and sponsors, THANK YOU! Your support in 2020 was tremendous and we will continue to utilize your donations to increasing survivorship from the numerous types of sarcomas, educate healthcare providers, fund best in class research and support current sarcoma patients. Without your generosity, our organization would not have made the strides we did last year.

I say with confidence that we will see you all inperson at some point during 2021 and that will be a joyous day! I hope that you and your families continue to stay safe. Thanks again for being part of our community!

Karen Wyckoff's vision had stirred all of us these past twenty years, calling our skills to be used in community effort unfolding to national effect. She planted the seeds of research funding, education and patient support. Each of you has tended to their growth. You are the hearts of Rein in Sarcoma. You nurture the vision with our advocacy and energy. You bring family and friends together, growing the reach of our mission. You believe in what we can do, have done, and are doing together.

Some of the incredible milestones of our community include: held 20 Party in the Park style celebrations, educated 50 Jan Maudlin Sarcoma Scholars, published 7 editions of the Sarcoma Patient Starter Education notebook giving thousands of copies away through partner healthcare systems and online. (Someone from every state in the nation has received a sarcoma patient starter notebook.) Thousands of volunteer hours have been shared. Hundreds of committee meetings have been held. The RIS community funded 72 Sarcoma Research Grants, which leveraged over \$13.4 million in additional sarcoma research grant funds! Friendships and relationships grow through our shared vision.

Imagine the impact of faster sarcoma diagnosis nationally. We have started testing an electronic medical records best practice alert tool embedded in medical records (at HealthPartners). This tool will assist medical providers with sarcoma diagnosis, education and healthcare information.

Our history is as inspiring as our future. Our unifying vision to improve patient outcomes, increase awareness and increase survivors stirs within us all. We nurture this together, and keep growing energy from each other and looking up to the sun.

Cheers to 20 years, and here's to 20 more!

RIS hosts fundraising events throughout the year to raise awareness and resources for people with sarcoma cancer and to support sarcoma cancer research. 2020 brought with it the new paradigm of working through the Covid 19 pandemic. We adapted our events to online models, and held our RIS Golf Classic outdoors with careful social distancing. A Cause for Celebration!







Top: Legacy Wealth Sponsors: Michael Brocker, Ben Brocker, Mathew Brocker & Tom Boardman, Chair Development Committee

Middle: Sarah Jean Knox

Bottom: Blake Hastings and Miranda Mead

Sarcoma Cancer Research Golf Classic

We had an incredible day at Edinburgh, USA with 22 foursomes on September 15! Casey O'Brien, Golden Gopher Football player and osteosarcoma survivor, golfed with our teams to help raise \$40,000 for sarcoma research! The golfers competed in a scramble format on a picture perfect day. Players also tried to outbid each other for fine wines and fantastic foursomes in our silent auction. In all over \$40,000 was raised through this event. We are thankful for generous sponsors, especially the strong support of our Diamond sponsor, Legacy Wealth, of Woodbury, MN. Our thanks to Development Committee Chair, Tom Boardman for hosting a fantastic event, and all the golfers and volunteers who made it a great success!

Party in the Park Virtual Event

Thanks to our event sponsors, donors and thoughtful care of our leadership team, the 20th Anniversary Party in the Park was a memorable look back, and look forward to celebrate the mission of Rein in Sarcoma! Amy Hoban, our event chair, successfully led us through the shift from family picnic and in-person party to an online celebration of our past, present and future.

The virtual celebration shared stories about Karen Wyckoff, our founder, her passion to help others, the early years, and community building to improve outcomes through education, support and research. Featured videos included physician updates, patient histories and community reflections. It was a wonderful time to look back on the past and share in the vision for our future!

Fall Fundraiser Virtual Event

This year, 17-year Rein in Sarcoma volunteer and sarcoma survivor, Ruth Bachman was our MC. She guided us through our virtual celebration along with Board President, Blake Hastings (sarcoma survivor), and his wife, Carey. We also were inspired by sarcoma survivors, Jan Maudlin, Casey O'Brien and Miranda Mead. The 50th Jan Maudlin Sarcoma Scholar, David Supinski, shared the importance of the scholar program in raising sarcoma cancer awareness and education. Finally, celebrity singer, Kat Perkins, helped us celebrate with a special rendition of "Ring Them Bells."

Presenters, along with at home attendees, helped Rein in Sarcoma celebrate twenty years of working together to improve sarcoma patient outcomes! Rein in Sarcoma passed a major milestone — \$2 million in sarcoma cancer research funded over the past 20 years at Rochester Mayo Clinic, Children's Minnesota, and the University of Minnesota. During the celebration, RIS research grants were awarded to the Mayo Clinic and Children's Minnesota. The Red Flags Education Committee also announced its Excellence in Education Award which recognized the work of Dr. Scott Okuno, Mayo Clinic. We extend our gratitude to sponsors: Oppidan, Great Clips, PrimeX by Gresser, and APi. Your silent auction donations and purchases, and generous donations raised over \$121,000 in support of our sarcoma community and strengthened the impact of our mission. Our 20th celebration ended with one final toast — one final cheer... to twenty more!

Funding Change — Changing Lives



Cheers to 20 Years! A Cause for Celebration!

In celebrating Rein in Sarcoma's 20th year, RIS was incredibly fortunate to have a supportive and dedicated membership and donor community. There were many challenges facing nonprofits, businesses and families alike in 2020. As a nonprofit funded 100% by our supporters and donor network, RIS met these significant challenges. The dedication to our mission and the capacity to adapt and do whatever it takes helped us rise to the occasion to continue to not only maintain, but advance, the support our donors provide the sarcoma community.

Gifts come in different forms – the gift of time as a volunteer or a financial gift to support Rein in Sarcoma programs and services. Opportunities for financial gifts encompass recurring donations, one-time donations, legacy or planned gifts, establishing a Named Fund honoring your sarcoma experience or loved one, or an outright gift of appreciated stocks. No matter how you give to Rein in Sarcoma, your gifts are greatly appreciated and touch the lives of thousands of people each year. Thank you so much!

Overall Financial Outlook

The impact of COVID-19 on Rein in Sarcoma's finances is unprecedented. The RIS Executive Team met and worked with the board mapping out a plan to reduce expenses. We were able to maintain grant funding, patient and family support and reinvest in Rein in Sarcoma's infrastructure, to continue to support the strategic plan to grow and expand the mission of RIS. We also were able to add a new fulltime position to support the EMR BPA, volunteers, education and communications.

Although COVID impacted our fundraising events, the impact was not as significant as anticipated. We successfully hosted a virtual Party in the Park and Fall Fundraiser and continued a live, COVIDsafe, golf event. Although the virtual events brought in less revenue; it was offset by lower hosting expenses. Our community came together to support the mission of Rein in Sarcoma and demonstrate the value of our work.

Contributions, Sponsorship and Grants

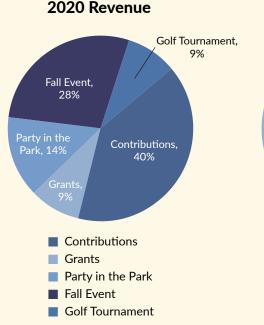
Corporate and general contributions combined with program revenue decreased from the previous year by \$131,000 during the year to \$446,000. The organization was able to fund \$150,000 in grants to the

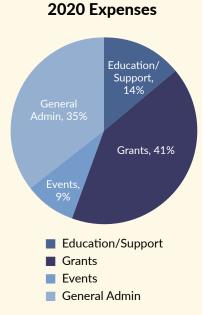
U of M again in 2020. This left 2020 with a negative cash position of \$43,000. The organization has adequate cash reserves to cover the short-term impact of the pandemic and all indications are that 2021 contributions will return to previous levels.

Expenses and Cash Position

Expenses decreased from the prior year largely due to lower costs associated with hosting virtual events. The organization remains adequate cash reserve levels of over \$500,000 and has started an investment program to invest excess funds into a professionally managed investment portfolio.

Revenue	2020	2019
Contributions	\$ 179,00	\$ 197,000
Grants	41,000	77,000
Events		
Party in the Park	63,000	92,000
Fall Event	122,000	170,000
Golf Tournament	41,000	41,000
	\$ 446,000	\$ 577,000
Grants	\$ 202,000	\$ 146,000
Expenses		
Education/Notebook	1,000	14,000
Office Expense	28,000	29,000
Events		
Party in the Park	13,000	26,000
Fall Event	23,000	35,000
Golf Tournament	10,000	13,000
Consulting	125,000	127,000
Payroll	88,000	94,000
	490,000	484,000
Net Revenue	\$ (44,000)	\$ 93,000





Thank you to 2019-2020 Jan Maudlin Sarcoma Scholars, updates on 2020-2021 scholars



Regina Martinez, Nicholas Reiners, Ryan Claxton, June Zolfaghari, Jake Kloeber

Scholar Impact

We thank the 2019-2020 Jan Maudlin Sarcoma Scholars for their work and dedication to advancing sarcoma education and awareness and improving sarcoma patient outcomes. We are proud of each of the program participants and thankful to their mentors, Dr. Katie Dusenbery (UMN) and Dr. Scott Okuno (Mayo Clinic).

A synopsis of their projects:

June Zolfaghari developed a slide presentation for the University of Minnesota Medical School Radiology-Sarcoma Curriculum. "Identifying Osteosarcomas on Radiographs" is a beneficial resource for students.

Regina Martinez completed a Spanish translation of the RIS organization and Red Flags brochures. Regina partnered with Valeria Lopez, RIS board member, to translate the RIS brochures into Spanish and modify portions to maximize cultural sensitivity and community engagement.

Nicholas Reiners worked on Electronic Medical Records
Best Practice Alert (EMR BPA) development and live
implementation with testing in five primary care clinics. The
ultimate goal is more timely, accurate diagnosis of sarcoma
tumors, resulting in improved outcomes for patients. The
hope is to add this tool to other EPIC medical records users
in Minnesota, expanding regionally, then nationally.

At Mayo Clinic Alix School of Medicine, scholars **Jake Kloeber** and **Ryan Claxton** worked to provide opportunities to expose Mayo medical students to sarcoma-centered education. Together, they coordinated several opportunities

for students to interact with and learn from sarcoma cancer physicians. They organized a week long experience for first year medical students to observe physicians in different oncology related fields. As part of this, students spent their week learning from several medical, radiation, and surgical oncologists who work in sarcoma care at Mayo Clinic. Another project brought a bone and soft tissue pathologist to speak to medical students about pathology and the role it plays in sarcoma diagnosis and treatment. These educational opportunities help to raise awareness of sarcoma cancers with medical students and potentially inspire students to incorporate sarcoma care into their future practice.

We are also pleased to introduce the five new 2020-2021 Jan Maudlin Sarcoma Scholars. Thanks to the generosity of Jan and Tim Maudlin, they become part of a larger group of 50 total awardees since the program's inception in 2009-2010! University of Minnesota: Guy Guenthner, Kristine Nachbor, and David Supinski. Mayo Clinic Alix School of Medicine: Siven Chinniah and Xander Schmidt.

RIS Education Activities: Minnesota Medicine Magazine Article — Elsa Keeler, MD and Nikki Miller

Rein in Sarcoma reached over 10,000 medical professionals to promote sarcoma awareness through our feature article "Sarcoma: A rare and deadly cancer Not just another lump, bump or bruise" in Minnesota Medicine, the journal of the Minnesota Medical Association (MMA).

Dr. Elsa Keeler, a pediatrician with HealthPartners, and volunteer freelance writer, Nikki L. Miller, wrote the article to speak directly to MMA members about the rare cancer and facilitate early detection by primary care doctors. "Partnering with the MMA was not only a way to raise awareness about rare cancers, but it also provided practical information for primary care doctors across our state to act on potential 'red flags' of sarcoma," said Dr. Keeler.

The article included signs of sarcoma, the proper protocol for handling potential sarcomas, and emerging treatment options and advances in technology were outlined. Patient stories are featured throughout the article to illustrate common sarcoma cancer scenarios that physicians may face.

The article also introduced Rein in Sarcoma and the resources we offer to the medical community, such as the Jan Maudlin Sarcoma Scholars program, annual research symposium, and research funding at the University of Minnesota, Mayo Clinic, and Children's Minnesota.

Many thanks to Linda Picone, editor of Minnesota Medicine, and the Minnesota Medical Association for their partnership and interest in promoting sarcoma awareness among their membership.

EMR — Poster abstract

Nicholas Reiners, a 2019-20 Jan Maudlin Sarcoma Scholar and UMN medical student, presented the results of a pilot study on the impact of a soft tissue sarcoma (STS) Best Practice Alert (BPA) at the CTOS 2020 Virtual Annual Meeting, November 18-21.

This work began in 2017 as part of the Rein in Sarcoma Hallie Anne Brown education initiative in conjunction with HealthPartners/Regions Hospital, under the direction of Dr. Randy Hurley, hematologist/oncologist at Regions Hospital and Medical Director of HealthPartners' Cancer Care Program. In addition to Nicholas, Robert Gao, Melissa Albersheim and Andy Hughes, also former sarcoma scholars, and Brandon Diessner, UMN graduate student, contributed to the project.

Objectives of the Pilot Study:

- Retrospectively review STS cases in HealthPartners (HP) system
- Develop an EMR BPA to prompt primary care clinicians to consider MRI evaluation of a STM based on specific criteria
- Assess primary care clinician acceptance of the BPA and measure the effect of the BPA on improving primary care clinician confidence in evaluating STMs
- Measure the impact of the BPA on patient care

Conclusion:

This pilot study linked a BPA to specific ICD9-10 codes associated with STM to prompt MRI evaluation for large or enlarging, deep, or painful masses. Seventeen MRIs were completed and three malignant or potentially malignant diagnoses were identified. Clinicians found the BPA to be a useful clinical decision-making support tool, and it improved their confidence levels when evaluating STMs. A larger healthcare system-wide project is planned.

July: Sarcoma Awareness Month

Rein in Sarcoma launched the "31 Sarcoma Facts" social media campaign to raise awareness and educate the public and the medical profession about sarcoma cancers.



New Education and Communications Manager

Katy Engelby joined Rein in Sarcoma as Education and Communications Manager in late 2020. She works primarily with the Red Flags Education Committee to continue to expand awareness of sarcoma cancers among medical professionals, patients, and the public. She also supports the Public Relations and Marketing Committee to promote and share RIS information through all forms of communication, including continuing to build social media brand. Katy's career spans over 20 years in nonprofit management, dedicated to program and project management focusing on patient and healthcare professional education and support services. She has extensive experience working with volunteers and is in awe of the support and time people generously give.

Research \$2 million funded

Research Funding

Rein in Sarcoma proudly awarded \$150,000 research grants approved to the University of Minnesota Masonic Cancer Center. RIS also awarded \$40,000 in new sarcoma research grants to Children's Minnesota and the Mayo Clinic. This brings the cumulative research funding by Rein in Sarcoma to \$2 million since the organization's founding in 2001.



Blake Hastings, Dr. Douglas Yee, Dr. Larry Seymour, Dr. Brenda Weigel, Tom Boardman, Janelle Calhoun, Theresa Fetsch

University of Minnesota Masonic Cancer Center



eBAT as a Modulator of the Myeloid Immune Checkpoint in Cancer Jaime Modiano, VMD, PhD — Principle Investigator, Jong Kim, VMD, PhD — Co-Investigator | \$50,000



Using Propranolol to Generate an
Anti-Tumor Microenvironment
Erin Dickerson, PhD — Principle
Investigator, Kaylee Schwertfeger, PhD —
Co-Investigator | \$50,000



Computationally Deciphering the Paths of Genomic Catastrophe in Osteosarcoma Ruping Sun, PhD — Principle Investigator, Lauren Mills, PhD — Co-Investigator | \$50.000

Children's Minnesota



DICER1-related Genitourinary Sarcomas Kris Ann P. Schultz, MD — Principal Investigator | **\$15,000**

Mayo Clinic



Targeting the Immune Checkpoint B7-H3 for the Treatment of Rhabdomyosarcoma
Dr. Fabrice Lucien-Matteoni, PhD —
Principal Investigator, Dr. Haidong Dong,
MD, PhD and Dr. Akilesh Pandey, PhD,
Professor — Co-Investigators: | \$25,000

SAVE THE DATE:

2021 Research Symposium October 22, 2021

Research Symposium

Rein in Sarcoma and the University of Minnesota Masonic Cancer Center sponsored a virtual research symposium, "Minnesota Sarcoma Research Virtual Conference 2020: Progress and Promise," which featured presentations from leaders in sarcoma research in Minnesota. It was a day filled with science, innovation, and information sharing. Presentations were recorded and put on the Rein in Sarcoma YouTube channel. www.YouTube.com/ReininSarcoma

Winter Gathering — Mindfulness

More than 60 patients, survivors, and family members attended the January 26, 2020 Winter Gathering at Bachman's Floral, Gift, and Garden Center in Minneapolis. In addition, the live-stream video of the event on Facebook reached over 2000 people.



Sarcoma survivors

Highlights of the event include mindfulness exercises from the University of Minnesota's Bakken Center for Spirituality and Healing; 17-year-old guest speaker and sarcoma fundraiser, Grace Sugg; and dedicated time for patients to share experiences and advice in a group setting. At this Winter Gathering we increased the amount of time dedicated to patient sharing, and several patients and survivors spoke of their experiences. They discussed the importance of advocating for oneself and persevering, and shared feelings of devastation upon learning of a diagnosis or weariness from the unrelenting demands of treatment. They asked questions and offered advice, and talked about the hidden blessings that sometimes grow out of life crises. The Winter Gathering brought us together to treat our bodies with relaxation and mindfulness, congratulate a young leader who is supporting sarcoma awareness and research, and offer support, advice, and encouragement to one another. Thank you to our volunteers who made the event possible and to everyone who attended or live streamed the event!

Sarcoma Remembers

The Patient & Family Support Committee hosted the 4th annual Rein In Sarcoma Remembers event on September 27, 2020. At this year's event, Nina Guertin expertly guided us as we create a contemplative watercolor. In addition to being an artist with over 20 years' experience, Nina is an End of Life Doula, a Certified Interfaith Spiritual Director, Grief Support Specialist and Ritualist/Celebrant at Tending the Spirit. Nina has seen the transformation and healing in those with whom she works through listening deeply to story and working contemplatively with them in the mediums of clay and watercolor. This year, participants created a piece of Contemplative Watercolor that honors their experience of losing a loved one to sarcoma. The results were quite magical. Creating a painting is not the goal; rather, the goal is surrendering yourself to being one with the precise moment you place color onto the paper, losing track of everything except the moment's action.

Tote Bags

The Patient and Family Support Committee continued to distribute "tote bags of hope" to newly diagnosed or relapsed patients. Tote bags were given to hospital nurses to give to these patients to demonstrate that they are not alone in their battle with sarcoma. Each bag may be a little different as we have received many donations for the bags. Included in the bag are a handmade blanket, shawl, colorful pillow case, adult or children's coloring book, tooth brush and tooth paste, lip balm, socks, and a gift card, etc. Also included is a list of RIS patient support activities and how to contact us.



Laurie Convey



2020 Named Funds

RIS Named Funds honor the entire sarcoma community of survivors, patients and loved ones who have been diagnosed with a sarcoma cancer.

RIS Named Funds help sustain and support our mission to educate the public and medical community about sarcomas, support sarcoma patients and their loved ones, and fund research directed toward developing treatments and finding a cure for sarcoma cancers. In 2020, Named Funds raised over \$150,000.

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



Active Named Funds

- Julian Baultrippe Fund
- Richard Bergual Fund
- Annette Bonaventura Fund
- Hallie Anne Brown Fund
- Sara A. Christensen Fund
- Nick Convey Fund
- Brett Dale Fund
- Meghan Marie DeBruycker Fund
- Kara Dolnev Fund
- John Philip Douglass Fund
- Lisa Griebel Fund
- Blake Hastings Fund
- Wade Hohol Fund
- Lora Holmquist Fund
- Alyssa Jeske Dobson Fund
- Judy Jones Fund

- Katelyn Jurek Fund
- Barbara Kimker Fund
- Jacob Martell Fund
- Jan Maudlin RIS Sarcoma Scholar Fund
- Miranda Mead Fund
- Jackie J. Middleton 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
- Kathleen Marie (Klein) Strum Fund
- Lucy Swift Fund
- Thomas Worthley Fund

Mark Your Calendars:

Fifth Annual RIS Golf Classic — June 8, 2021

21st Annual Party in the Park — July 24, 2021

Initial Sarcoma Ninja Obstacle Course Fundraiser — August 15, 2021

RIS Fall Fundraiser Event — October 7, 2021

Board of Directors List

Officers:

Blake Hasting – President

Eric Lien – Vice President; Research Chair

Mitch Atherton – Secretary; Finance Chair

Tom McCarthy – Treasurer

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Linda Andrean – Red Flags Committee Chair

John Charlson, MD

Denis Clohisy, MD

Brendan Dillon

Lisa Griebel

Aaron Halbe

Michelle Kolling

David Largaespada, PhD

Valeria Lopez Torres – Website Manager

Conner O'Brien

Scott Okuno, MD

Colin Ryan

Bruce Seiber

Stephanie Terezakis, MD

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Janelle Calhoun – Executive Director

Katy Engelby – Sarcoma Education and

Communications Manager

Melissa Davies – Development Director

Connie Dow – Office Administrator

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Anthony (Tony) Smith – Legal Counsel

Kraig Kuusinen — Patient and Family Support

Committee Chair

Tom Boardman – Development Committee Chair

Julie Rose – Talent and Resource Committee Chair











Dr. Keith Skubitz and Dr. Amy Skubitz



7401 Central Ave. NE, Ste. A Fridley, MN 55432-3571



Our 2020 Impact

Your donations at work



Patient starter notebooks distributed/downloaded



Tote bags distributed



Sponsorship dollars



Sarcoma scholars became a part of 50 awardees since 2009



Awarded in new sarcoma research grants