

## INTRODUCING OUR NEW LOOK



# REIN IN SARCOMA

Increase awareness. Increase survivors.

In 2001, Karen Wyckoff envisioned an organization dedicated to providing support for sarcoma patients and encourage sarcoma research. Fifteen years—and numerous achievements after—Karen’s vision is alive as ever.

Today, we have a new look, a new website, and our very first Director of Development. We are proud to say that, in 2016, Rein in Sarcoma is stronger and better-looking than ever!

We set out to create an identity that reflects our origins, who we’ve grown to be, and who we want to become. The process of defining that vision started with some serious digging. We asked ourselves: What makes us truly special? Why do volunteers join this organization? Why do our members reach out to us?

After numerous work sessions, surveys and interviews, we determined the strongest part of our organization is our sense of community and our commitment to supporting those touched by sarcoma. That’s how our iconic carousel horse had a revamp.

This new logo speaks about a sincere desire to honor our roots and look into the future. The Cafesjian’s horse is a landmark and symbol of a ritual that every sarcoma survivor looks forward to year after year.

A tagline was also introduced to make a strong statement about the reason we’re here and what our ultimate goal is. The effort, dedication and commitment of everyone at Rein in Sarcoma is reflected in: “Increase awareness. Increase survivors”.

With this new identity, we are honoring the example set by Karen Wyckoff, and helping make this organization more solid and ready to embrace new times.

Although each sarcoma story is different and unique, every sarcoma patient and survivor, every friend, family member and volunteer is part of something bigger and stronger.

Together, we can vanish effects of a devastating disease under the promise of a brighter future. Above all, there’s hope, passion, and an earnest commitment to Karen’s cause; our cause.

We hope you enjoy our new look.

Sincerely yours,  
*Rein in Sarcoma Branding Committee.*

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LAURA GOSSETT  
Office Administrator

PAUL GIEL, JR.  
Director of Development

# A LOOKBACK: REIN IN SARCOMA IN 2015

Your generosity is making a big difference! 2015 was a very busy and productive year for us as we made significant progress across the three priorities of our mission: patient and family support, education and research. And in so doing, we carry on the vision of Karen Wyckoff, which has brought us all together for a “world without Sarcoma Cancers”.

## SUPPORT

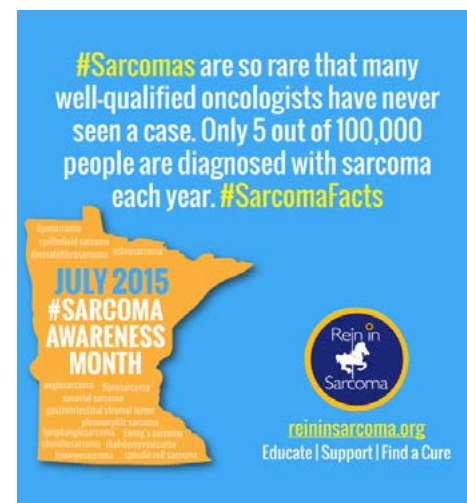
- In January, Rein in Sarcoma gathered patients, survivors, and those who lost someone to sarcoma at Bachman’s, where **Dr. Clohisy** from the U of M and **Dr. Okuno** from Mayo talked about the challenges doctors face treating sarcoma and how they manage the stress. Survivor **Kevin Lake** told his sarcoma journey through juggling.
- The 5th Edition of the **Sarcoma Patient Starter Notebook** was published in July. Over 200 copies were given to sarcoma patients around the country and hundreds of digital copies were downloaded from our website.
- In July, over 500 people attended the **Sarcoma Family Picnic**, held prior to the annual **Party in the Park**. This picnic offers an opportunity to socialize with doctors, researchers and other sarcoma survivors.
- Throughout the year, we pair new patients with survivor mentors. All our patient and family support services are available at no cost to all sarcoma patients, survivors and their loved ones.

## EDUCATION

- The **Sarcoma Red Flag Campaign**, under the leadership of the **Sarcoma Scholars** and the **Medical Advisory Board**, surveyed 1,500 Minnesotans at the **State Fair** regarding their knowledge of sarcoma. The campaign also surveyed doctors, care staff, and patients. The survey findings will be used to improve educational materials and programs, for both the public, and healthcare professionals.
- Our **Red Flags brochures** were distributed to the public and medical communities in multiple locations.
- In April, **Dr. Christian Ogilvie** made Rein in Sarcoma’s first presentation at **University of Minnesota Duluth Medical School**. We also had exhibits at both the spring refresher of the **MN Academy of Family Physicians** and the **Fall Nurse Practitioners Conference**. Several other educational activities were also held at both the University of Minnesota and Mayo Medical Schools.
- **Governor Dayton** declared July “**Sarcoma Awareness Month**”.

## RESEARCH

- Rein in Sarcoma has now funded over **\$1.5 million** for **sarcoma cancer research** through the **University of Minnesota Masonic Cancer Center**. These seed grants have a multiplier effect, leveraging over **\$6 million** in **additional peer-reviewed grants** from private and public funders.
- During 2015 Rein in Sarcoma funded **four sarcoma research grants** for a total of **\$125,000**.



# 2015 FINANCIAL REPORT

## NEW NAMED FUNDS AND GIFTS

During 2015, financial and volunteer support for the ongoing educational programs, patient and family support, and sarcoma research grants totaled \$287,000 (an increase of \$17,000 over 2014) and countless numbers of volunteer hours. Helping to achieve this increase were new Named Fund gifts and a special gift secured by Mike Kellett from the 3rd and 4th Districts Nurses Associations to the Therese Daniel Memorial Fund. This level of financial support enabled the Foundation to meet for the ninth year the terms of the \$15,000 challenge grant from the Katherine B. Andersen Fund of the Saint Paul Foundation.

Kevin O’Keefe repeated as Chair of our signature Party in the Park event on the grounds of Como Park in July. The Party in the Park and other events provided over \$81,000 of financial support before expenses to support the mission of the Foundation.

## STRATEGIC PLAN

During 2015, members of the Rein in Sarcoma Board reviewed and updated our strategic plan. Building on the success of the initial phase of the strategic plan adopted in 2013 for the transitional campaign, the Board approved the recommendation of Access Philanthropy to engage a fundraising consultant to meet the ever increasing needs of our mission.

## TRANSITION CAMPAIGN

RIS has \$115,000 remaining from the transition campaign at the end of 2015 that will provide some of the funding required to attract a seasoned fundraising consultant, develop a case statement, and identify and solicit supporters

to achieve the goal. We look to build on the partnerships we have developed with the Katherine B. Andersen Fund of the Saint Paul Foundation, the Hardenbergh Foundation, and our other individual campaign supporters to provide the initial support to our new campaign.

## DISBURSMENTS

Rein in Sarcoma tracks disbursements in three general categories: research and education, patient and family support, and general/administrative expenses. In February, the Foundation gave \$137,000 in gifts to the University of Minnesota Foundation in support of sarcoma research and education. This reflects an increase of about \$35,000 from the support provided in 2014.

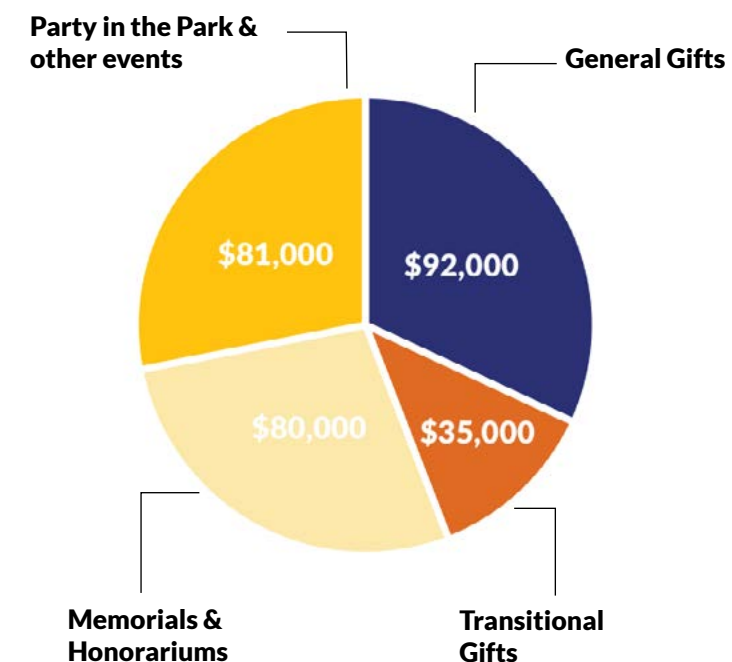
During 2015, the Foundation spent \$41,000 in cash and many volunteer hours on patient and family support, including our events and the Red Flags and Sarcoma Notebook programs.

Finally, the Foundation spent about \$29,000, or about 10% of total receipts, on general and administrative expenses; the bulk of which was for improvements to our volunteer database system and assistance received from Access Philanthropy. As of December 31 2015, our internal financial statements show receipts in excess of expenses of \$80,000, of which \$21,000 is from the receipt of transitional campaign gifts.

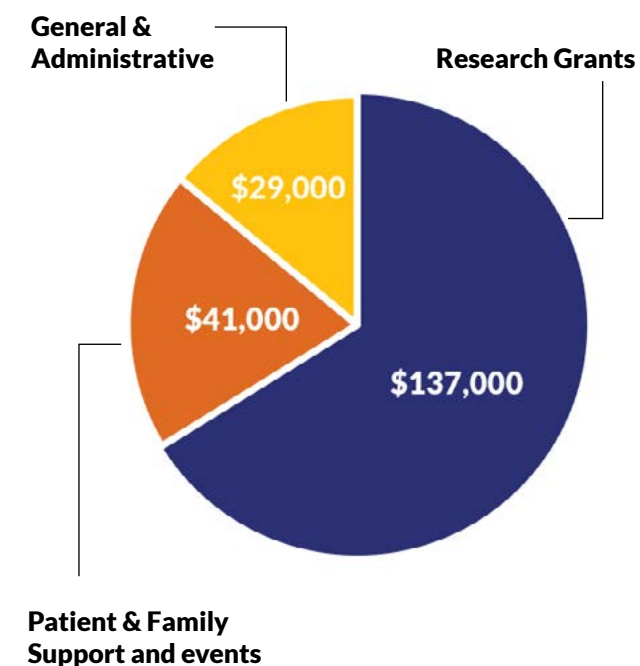
Thanks to the gifts from our supporters, the Foundation is in a good financial position at the end of 2015 with cash, temporary investments and endowment funds of \$468,000.

A complete financial report for 2015 and a copy of the 2015 Tax Report will be available when filed with the Internal Revenue Service in May.

## RECEIPTS



## EXPENSES





## SARCOMA SURVIVOR STORIES: SARINA MCNAMARA & CHELSEY OLAFSON

Every sarcoma story is unique. Some aspects of them are sad, others comical, but they all leave a lasting impression on the patients and their loved ones. This is true for sarcoma survivors Chelsey Olafson and Sarina McNamara, who were both in their 20's when diagnosed. It's safe to say neither one expected something like sarcoma to cross their path, but learned a lot about life and love along their journeys. Here are their powerful stories.

### SARINA MCNAMARA

In October of 2014 I noticed a large knot in my right thigh. I enjoyed running, so this wasn't all that abnormal, and I figured it would work itself out. A few weeks later I noticed it had gotten larger and was beginning to hurt more. By the end of November, the lump in my leg had swollen so much that I could no longer fit into my jeans.

A week and a half later I found myself sitting in the surgeon's office talking about my treatment options for Soft Tissue Sarcoma. He told me very little about what to expect; he did however give me an RIS Notebook. He told me I should probably wait a few days to read it, until after everything had had a chance to sink in, however, I read the whole thing that night. And I am glad I did.

The RIS notebook felt like my own private Google search on sarcoma. Only, it had already filtered out all of the garbage and only showed me the information I needed and without the scary (unreliable) statistics found online. I finally felt like someone (or something) was giving me the information I needed to prepare myself for the fight of my life.

About seven months later, I attended my first Party in the Park as a cancer survivor. I have continued to attend RIS events and have gotten a chance to share my story. I can't think of anything more empowering than standing in front of a group of people and saying that, at 23, I beat cancer. And I can't think of any response more delightful than hearing that my story has inspired someone else.

I let my suffering make me a more compassionate person. I let my fear of sarcoma give me passion and appreciation for each day I have. I fought cancer long and hard, and now I am OK admitting that some good came from it, but I will never say that it was easy or that cancer was itself a blessing.

Cancer was hard and painful, which is why I have chosen to stay involved with Rein in Sarcoma. I know how difficult going through treatment can be, and I want to help those going through it in any way that I can. Sarcoma shouldn't be as ugly as it is today and I firmly believe that Rein in Sarcoma is helping make sure that someday it isn't.



### CHELSEY OLAFSON

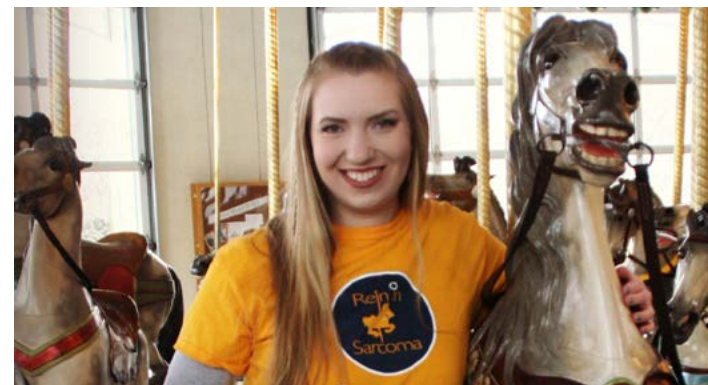
Before my diagnosis, I didn't have any symptoms besides a small, hard bump underneath my skin, about an inch away from my spine. When I first noticed it five years ago, a doctor told me it was a benign lipoma, or fatty tissue, and that it was nothing to worry about. So I didn't and forgot all about it. In 2014, I noticed it again and it was still small, but felt about twice the size.

It was the week before my husband and I celebrated our first year of marriage. It started off as a regular day, but now, January 6th 2015, is a day I will never forget. I was at work when my doctor called to tell me my tumor was malignant. I was 24 years old.

Upon being reviewed at another clinic, I learned I had sarcoma. About 60% of Soft Tissue Sarcomas begin in an arm or leg, but my tumor was in my back. I was glad this meant amputation was not an option, but worried because the tumor was very close to my organs. Finding out I had cancer was absolutely terrifying. What I read online was devastating and heartbreaking, I felt like my diagnosis was my death sentence. After seeing the 5-year survival rates, I thought I would never see my thirties.

I had 25 sessions of radiation at the Mayo Clinic, once a day, Monday through Friday. I stayed at the American Cancer Hope Lodge, which turned out to be a major blessing. I tried to make the experience as positive as possible; I went for walks and took photos, went to the art museum and to dog therapy. I made crafts. I made friends. I was lucky that in all the time that I was misdiagnosed, the cancer never spread. I am lucky that I have awesome doctors who truly believe my tumor will not return, and I believe them.

Today I'm part of a wonderful community of other cancer survivors. Having the support of Rein in Sarcoma is amazing. This experience has opened my eyes in a lot of ways. I now treasure life in a way I really didn't before. I'm more grateful, more passionate, and more loving. I try to make every moment count, because I know that it only takes a moment for everything to change.



## INTRODUCING OUR DEVELOPMENT DIRECTOR

Please join us in extending a warm welcome to Paul Giel, who will be joining Rein in Sarcoma as the Director of Development. Paul most recently served as a Development Officer at the Minneapolis Heart Institute Foundation.



*A message from Paul:*

I am honored, humbled and so very excited to be joining the Rein in Sarcoma family as your Director of Development.

Thirteen years ago I lost my best friend, Todd Hendrickson, to Leiomyosarcoma. I saw first-hand Todd's fight against this disease and the impact sarcoma had on his family and friends. I have a strong appreciation for the mission of Rein in Sarcoma, and have heard amazing stories of hope and your tireless efforts in support of the foundation, so I cannot wait to start working with you. We share a common goal and together we can change the story!

You may recognize the name, and yes, my dad was Paul Giel.

I stay busy outside of work as a single parent with four kids—Joe, Aly, Paul III and Francee. We live in the Lake Minnetonka area and have very active lives. I also enjoy sports, especially golf, biking, working out, and reading.

I look forward to meeting you all. Please do not hesitate to reach out—I promise not to bite!

## MAKING IT ALL HAPPEN: YOU



Hundreds of you made all of our work possible. Your generosity throughout the year allowed us to fully meet the challenge gift of the **Katherine B. Andersen Fund** and the **Give to the Max Day** challenges, and more than doubling the **Year-End Challenge**, raising over **\$40,000** in the last six weeks of the year. Thanks to all of you.

Our **July Party in the Park** may have been our largest ever. Under beautiful skies, 200+ volunteers, 1,500+ sarcoma survivors, loved ones and supporters picnicked (thanks to the sponsorship of **D'Amico Catering**), partied, responded to great entertainment on two stages, were moved by stories at the beautiful new setting for Sarcoma Corner, enjoyed a great Children's Arcade, bid on 400+ auction items, and of course *reined in sarcoma* on **Cafesjian's Carousel**. Our special thanks to Kevin O'Keefe for leading an amazing volunteer team, and to the **Mayo Clinic** and **M-Cancer Care** for their corporate sponsorship and support.

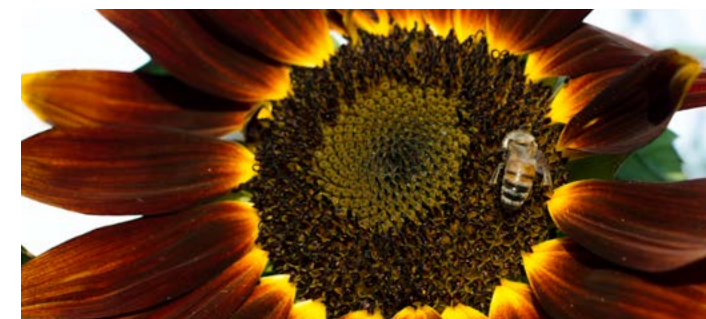
During the year, our grassroots fundraising efforts continued to multiply:

- The **Mud Dogs** had an amazing snowmobile ride raising over **\$4,000** in memory of **Erik Skogman**.
- The **Celebration of Life** held for **Mark Wehner** in Oseo, WI raised over **\$2,700**.
- The **Berqual Family** held the **Berqual Memorial Open Golf Tournament** and established a new Named Fund, raising almost **\$3,000**.
- For the fifth year the **Rogatzke Family** of Sanborn, MN held their annual **Kick Ball Memorial Tournament** and raised over **\$6,000** in memory of **Anna**.
- The fall "**Throw Down for Beans**" went national as **Theresa Baultrippe** organized over twenty "throw downs" of great cooking and friendship in different locations, raising almost **\$4,000**.

## SAVE THE DATE!

16th Annual  
**PARTY IN THE PARK**

**July 25th 2016**  
Como Park, St. Paul.





**SARCOMA RESEARCH GRANTS**

The future of Rein in Sarcoma is dependent on the gifts of financial support that we receive from the community. Thanks to all of you, we made significant progress in making sarcoma less of a mystery to patients, their families, and healthcare providers. We are extremely grateful for your partnership in making our vision a reality during 2015.

The Board of Directors approved a total of **\$122,500** to fund three new research projects.

In addition, **\$12,000** were approved for the 2016-2017 Sarcoma Scholars.

Our thanks to all of you whose generosity made these grants possible.

**\$50,000**

**The impact of Beta Adrenergic receptors**

**Principal Researcher:**  
Erin Dickerson, Ph.D.

The wide diversity of sarcoma subtypes creates diagnostic and treatment challenges. Dr. Dickerson and her team found a unifying feature among some sarcomas—the expression of beta adrenergic receptors, which indicate the importance of these receptors in signaling pathways for sarcoma cell viability and tumor progression. Their findings suggest that several sarcoma subtypes may be inhibited with beta blockers. This study advances the understanding of sarcoma progression and lays the foundation for improving the overall survival of sarcoma patients.

**\$23,000**

**A better process for predicting gist reoccurrence**

**Principal Researcher:**  
Amy Skubitz, Ph.D.

Dr. Amy Skubitz and her team are focused on identifying better ways to predict which therapy a patient should receive. Her group has used gene expression patterns from Soft Tissue Sarcomas to predict which sarcomas will metastasize. They anticipate being able to use gene sets to separate sarcoma samples into subsets with different probabilities of developing metastases. This technique may be useful in predicting which sarcoma patients would benefit from adjuvant chemotherapy and lay the groundwork for individualized treatments for sarcoma patients.

**\$49,450**

**Improving the survival rates of Osteosarcoma patients**

**Principal Researcher:**  
Subbaya Subramanian, Ph.D.

This study will provide new insights into the molecular mechanisms that drive poor outcomes for Osteosarcoma patients, and establish a mechanism by which Osteosarcoma cells repress the host immune response. Results will advance knowledge of how miRNAs regulate immune response and cancer progression. The project could also help develop future treatment and detection strategies, thereby improving the overall survival of Osteosarcoma patients.

**ACTIVE TRIBUTE AND MEMORIAL FUNDS**

Rein in Sarcoma is able to sustain, grow and succeed because of the active involvement of twenty Named Tribute and Memorial Funds. These funds have been created by families and groups to honor the lives of specific sarcoma patients.

While we are grateful and appreciate gifts of any size, we hope you will consider establishing a Named Fund.

**We thank the families that have established the following funds, which raised over \$92,000 for Rein in Sarcoma's mission:**

- Julian Baultrippe Fund
- Hallie Anne Brown Fund
- Richard Berqual Fund
- William Clemens Fund
- Brett Dale Fund
- Jerome Detviler Fund
- Alyssa Jeske Dobson Fund
- Meghan Marie DeBruycker Fund
- Pulse-The Christian Garcia Fund
- Wade Hohol Fund
- Carlie Jansen Fund
- Katelyn Jurek Fund
- Barbara Kimker Fund
- Kevin O'Keefe Fund
- Jacob Martell Fund
- Jackie J. Middleton Fund
- Beverly Sue Osterman Fund
- Andrea Pomeroy Fund
- Anna Rogotzke Fund
- Beverly Ann Schuld Fund
- Mark Wehner Fund
- Laura Zeccardi Fund
- Jan Maudlin RIS Sarcoma Scholar Fund
- Eric Skogman/ Mud Dog Sarcoma Ride Fund

**2015-2016 SARCOMA SCHOLARS**

As Sarcoma Scholars, these five medical students will lead the charge in educating the public and medical professionals about sarcoma. This is a critical component of the RIS mission, as sarcomas are often misdiagnosed or very late diagnosed, leading to an increased mortality rate among patients.

**MAYO MEDICAL SCHOOL**



Maggie Cupit

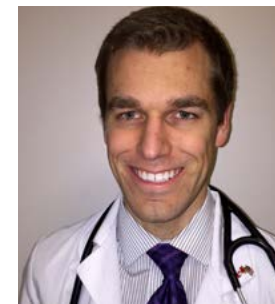


Jason Maroun

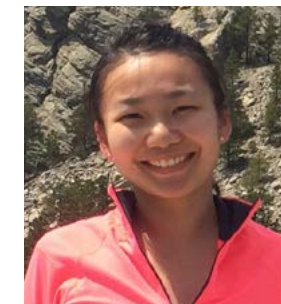
Maggie Cupit and Jason Maroun are analyzing current literature, case reports and compiling data using patients' words as indicators of symptoms, which will better prepare primary care physicians diagnosing sarcoma. They are also turning some of the more interesting case studies into educational material for medical student training.

Maggie Cupit is also a five-year sarcoma survivor who plans to use her personal experience to benefit her future patients.

**UNIVERSITY OF MINNESOTA MEDICAL SCHOOL**



Brendan Coutu



Susan Sun



Katie Thibert

Brendan Coutu, Susan Sun and Katie Thibert are planning presentations for medical students at the Twin Cities and Duluth campuses, which will include a talk by Dr. Ogilvie, as well as the testimony of sarcoma patients who will share their sarcoma stories.

Susan Sun is compiling a list of regional residential training programs in family medicine, internal medicine and pediatrics where sarcoma education and training programs could be incorporated.

They are also planning a reunion of former Sarcoma Scholars to exchange experiences and identify innovative ways to spread knowledge of sarcoma.



# REIN IN SARCOMA

## 2015 ANNUAL REPORT

### 2016 PARTY IN THE PARK KICKOFF MEETING

**March 14th, 2016**

**6:30 pm** Social time

**7:00 pm** Meeting

**U of MN Department of Orthopedic Surgery**  
2512 7th Street, Minneapolis, MN (West Bank)

Across the street from Children's Masonic Hospital.  
*Parking in the lot adjacent to the building is free.*

If you want to be part of a fun team committed to creating the best Party in the Park ever, join us for our kickoff planning meeting!

We need volunteers in the following areas: registration, games, displays, entertainment, concessions, raffle, silent auction, logistics, set up and take down.

**For more details visit: [www.reininsarcoma.org](http://www.reininsarcoma.org)**



## REIN IN SARCOMA

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