

#### Dear Friend of Swifty,

Welcome to our 2017–2018 Impact Report! This is our chance to say thank you to our donors for your generous support and to share how that support is helping children with brain cancer. We take a look back as we celebrate the work we have accomplished together, and a look forward to what is on the horizon.

Tissue continues to be the issue for Swifty. The truth is, without tissue to study, research cannot progress. However, as a researcher put it at a recent conference we attended, "tissue is not sexy." Inside we explain what he means.

Regarding our efforts to get more tissue in researchers' labs, this past year our program at the Children's Hospital of Philadelphia hit full stride; we started a new initiative at Lurie Children's in Chicago; and in 2018... **California here we come!** 

Speaking of California, read how our friend, Eric, helped Swifty raise \$125K for research hiking the Pacific Crest Trail. If that isn't cool enough, Swifty raised the money with three other foundations creating a collaborative new model for pediatric cancer fundraising... **"Four Pennies"**.

More collaboration efforts and our 2017 audit are presented in this report. This Impact Report, our Annual Appeal and thank you notes are the only U.S. mail you will receive from us. To follow Swifty more closely, please join us on social media or go to our website and sign up for our monthly e-newsletter.

Thank you for continuing to help us make my twin brother Michael's dream of ending pediatric brain cancer a reality!

**Bridget Gustafson** Co-Chair Junior Board



# Tissue is the Issue



Michael Gustafson sporting his sexy hat

#### **Tissue is Sexy?!**

While attending the International Symposium of Pediatric Neuro-Oncology we heard many researchers talk about the need for tissue to study, including Dr. Stefan Pfister of Heidelberg University Hospital. He said,



"tissue is not sexy but it is the most fundamental thing philanthropy can fund. Only through tissue can we understand the heterogeneity of tumors and start constructive research projects. Furthermore, it is impossible to get government funding for tissue donation and insurance won't cover it." But, as you know, Swifty does!!

Tissue is not sexy because the cure will be found in a clinical trial, the final step in the research process. Understandably, most funders want to fund the final step. But tissue is required in all the steps leading up to the trial. **No tissue, no trial**. Just as no one sees the foundation of your house, we all know without that foundation, there wouldn't be a home for your family to gather in.

Swifty is helping build the foundation for the clinical trials that will lead to the cure and perhaps **redefining what sexy is**. Michael, who chose to donate his tissue is pictured here in one of his favorite hats. He knew a little something about redefining sexy.

## A Tissue Navigator

Our 2017 Annual Appeal focused on raising money to fund a Tissue Navigator at Lurie Children's Hospital in Chicago. **You responded so generously**... thank you! We presented Lurie a check for the first installment of the \$300,000 grant at the end of 2017.

In May of 2018, **Kayleigh Eisenstein became the first pediatric Tissue Navigator in the country** and she has hit the ground running! She has formalized an autopsy donation protocol at Lurie modeled after the program Swifty started at the Children's Hospital of Philadelphia. Her primary role is to provide services to children and families that will increase the number of tissue donations at the time of diagnosis, recurrence and autopsy. Not only will she be working with the patients at Lurie, but she will also be coordinating tissue donations from smaller regional hospitals.

> Our first impression of Kayleigh is she has the **right combination** of compassion and enthusiasm that makes her perfect for this important work.



Lurie Tissue Navigator, Kayleigh Eisenstein, with board members David McHugh, Al & Patti Gustafson

MICHEAL'S MASTER PLAN: PROGRESS REPORT AND ANNUAL APPEAL

# Tissue is the Issue

### California Here We Come!

We began in Philadelphia, moved to Chicago, and now in order to create a coast to coast network of the best children's research institutions focused on increasing post mortem donations, we are looking to California, specifically to the lab of Dr. Michelle Monje at Stanford. We have been in conversation with Dr. Monje and hope to finalize plans for a Tissue Navigator at Stanford when we visit her lab in August. Stay Tuned!

When a life ends far too soon and science receives the precious gift of a child's tissue, we must guarantee the way the tissue is collected and processed ensures all possible opportunities for future research.

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### Our Big Hairy Audacious Goal

Swifty's ultimate vision is to develop 5 Integrated Regional Centers of Excellence for tissue collection and processing across the country. These regional centers

must be able to process whole brain and spine donations. The donation protocol will be standardized among the five centers. In addition to tissue, other bio-specimen and clinical data from the patient and parents will also be collected.

Then all the data that the gift generates will be collected and shared throughout the research community in order to assure the child's gift makes the greatest impact possible.



A lab processes a whole brain donation in the early morning hours. It's all hands on deck and time is of the essence to ensure the gift of tissue makes its greatest impact.

### Swifty on the Road

Swifty has been busy networking, advocating and leading the charge for post mortem tissue collection:

- Coalition Against Childhood Cancer Annual Summit Chicago, IL June 2017 Participant
- Kid's First Data Resource Center Launch Meetings Baltimore MD August 2017 Participant
- Post Mortem Tissue Donation Consensus Meeting Chicago, IL. Sept. 2017 Participant, Exhibitor
- ASPHO Conference Pittsburgh, PA April 2018 Conference Exhibitor
- Children's Brain Tumor Tissue Consortium Investigator Meeting Philadelphia, PA May 2018 – Conference Exhibitor and Facilitator
- International Symposium of Pediatric Neuro-Oncology Denver, CO June 2018 – Participant.

# **Together Toward Hope**

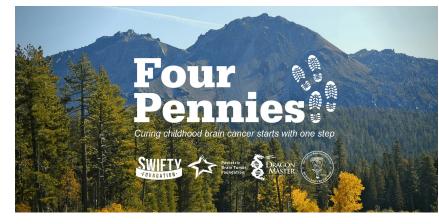
#### SWIFTY SPOTLIGHT: Junior Board Member, Kira Couch



Kira spent the summer of 2017 in DC advocating on "The Hill" for the **RACE for Children Act** and **this important pediatric cancer legislation has now been signed into law and more importantly funded!** Kira's commitment to making Michael's dream of a childhood cancer free world come true stems from their close friendship. For now, that means advocating and fundraising for the Swifty Foundation and in the future, Kira hopes to have a more direct impact as a pediatric oncologist. No matter where she's at in her life though, Kira will find a way to help kids with cancer.

#### **Four Pennies**

When Eric Montgomery told us he was going to take four months of his gap year before he starts medical school to hike 2659 miles on the Pacific Crest Trail and raise \$5200 for Swifty, we were inspired. His herculean effort inspired us to make



his hike bigger than Swifty! We recruited three other pediatric foundations and branded the hike Four Pennies ... to remind donors that the National Cancer Institute spends only 4 pennies of every federal dollar available for research on **children's** cancer research.

Working together, our four foundations aimed to raise four pennies for each of the 4.6 million steps Eric would take on his hike. Every dollar raised supports a collaborative research project targeting DIPG, a childhood brain cancer that is always fatal and has a median survival time of 9 months. At the time of this writing, Eric's hike has raised more than \$125,000!

Together Toward Hope!

Eric's hike has raised more than \$125,000.

## Together Toward Hope

#### PEER TO PEER FUNDRAISING: A Way for You to Lead

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Swifty has raised over \$400,000 from people just like you who said yes to hosting a peer to peer fundraiser. These fun, personal events add up! Not only do they raise money but they play a major part in spreading awareness. These events are simple, fun, quick and a great way to take the lead on building the momentum we need to find a cure! Anyone can do it. No one is too young, too old, or too far! You can find inspiration on our website and register there to host your own event.

### **Swifty Community Leaders**

Thank you to our Swifty Community Leaders who hosted a recent peer to peer fundraiser in 2017! Their creativity ranged from growing a beard to shaving a head, from trivia to triathlons, and from sharing a birthday to sinking a putt.

- Caitlin Holzer & Kira Couch's Shaving for Hope
- Chris & Laura Gilmartin's Gilvinia Concert
- David Hartstein's Crazy Beard
- Facebook: Donate your birthday to Swifty events
- Heaven on Seven Lundi Gras Event
- Inversion Jazz Trio
- Indiana University Pub Crawl
- Kacie Morris's Dance-a-thon
- Kennedy Junior High School Coin Wars
- Kennedy Junior High School Cookout

- Kennedy Junior High School No Shave November
- Lou Malnati's Swifty Pizza Night
- Naperville Central High School Senior Class Gift
- Naperville Central and Naperville North High Schools Girls Golf Tournament
- Naperville Central and Naperville North High Schools Mikey Match Play
- Naperville North High School Council for Exceptional Children Variety Show
- Naperville North High School NHS & DECA Yard Sale

Swifty has raised over \$400,000 from people just like you who said yes to hosting a peer to peer fundraiser.

- Naperville North High School Hockey Club Fundraiser
- Naperville North High School Kate's NHS Naperville Marathon Donation
- Northwestern University Delts Trivia Night
- Prairie Elementary School's Coin Wars
- Tammy Linder's Work Like a Dog Event
- Tribute/Memorial Gifts

#### SWIFTY SPOTLIGHT: Community Leader, Kacie Morris

Kacie is a lovely 8th grader who has a passion for dance and for service. She decided to host a dance-a-thon for Swifty to raise money for children with cancer. She and her family worked their tails off locating a venue, decorating, finding dancers to participate, getting donations, the list goes on and on. The event was a great success and raised \$3500! Now Kacie is asking for donations to Swifty at her bat mitzvah and her family is hosting a garage sale and giving the proceeds to.... you guessed it, Swifty! Wow, right? 2017

# **Swifty By The Numbers**

#### **Statement of Financial Position**

December 31, 2017

#### ASSETS

Cash & Equivalents	\$ 143,302
Investments	\$ 1,335,981
TOTAL ASSETS	\$ 1,479,283

#### LIABILITIES & NET ASSETS

#### Liabilities

Grants Due	\$ 150,000
Accrued Expenses	\$ 2,400
TOTAL LIABILITIES	\$ 152,400
Net Assets	
Unrestricted	\$ 943,900
Board Restricted (Admin Expenses)	\$ 382,983*
Total Net Assets	\$ 1,326,883
TOTAL LIABILITIES & NET ASSETS	\$ 1,479,283

The founders of the Foundation made a contribution to the Organization in 2013 to be restricted for use on paying any and all administration expenses. As part of the Foundation's annual review of designated assets, the Board has restricted \$382,983 as of December, 2017. Administrative costs of \$43,473 were paid and released during the year ended 2017.

\*\* In 2017, Swifty received contributions of \$245,344 and issued \$510,000 in grant awards.

#### Statement of Activities

For year ended December 31, 2017

#### **REVENUES & OTHER SUPPORT**

Contributions Program Service Revenue Unrealized Gain Realized Gain Dividends & Interest	\$ \$ \$ \$	245,344 1,401 149,463 34,988 27,738
TOTAL PUBLIC SUPPORT & REVENUE	\$	458,934
EXPENSES		
Program:		
Grants	\$	510,000
Advocacy	\$	21,964
Website	\$	8,488
Equipment & Misc.	\$	3,592
Administrative	\$	43,473*
Fundraising	\$	1,292
TOTAL EXPENSES	\$	589,797
Change in net assets Net assets, beginning of year Net assets, end of year	\$ 1	(130,863) 1,457,746 1,326,883

\* To receive a copy of Swifty Foundation's 2017 independent audit report conducted by Desmond & Ahern Ltd., please contact info@swiftyfoundation.org



Summary of Swifty 2017 Grant **Making** 

# Lurie Children's Hospital Chicago Tissue Navigator

II \$25,000 I



John Hopkins Medulloblastoma Project

University of Denver Medulloblastoma Project

Lurie Children's Hospital of

Children's Hospital of Philadelphia Post Mortem

# **Total 2017 Grant Making**

Alison & Pete Abe Carolyn Abshire Chad Adelhardt Jennifer Adelhardt Natalie Agliato Steve Albrecht Susan Altmann Nick Altmann Pam & Ron Amato lan Anderson Lynn Ann & Paul Andrees Kathleen Angelos Albert Araneta lesus Arcilla K.L. & J.W. Arends Shari Arends Linda & Michael Arneth Nandini Asar Sheila Ashby Nancy & Doug Azzaro Barry Baldwin Camille Balla Eleanor Barbino **Bob Bartolone** Ruth & Christopher Barton Marie Batty Jean Bax Cathy & Jeff Bayer Dawn & Robert Bebej Johnna Belkiewitz Michelle Bella Amy Benak Chris Bennett Heather & Rajesh Bhatia Jennifer & Christopher Bianucci Nancy & John Bjerga Mindy Blatt Laura & Tom Bloodgood Kris & Dan Blouin Cindy & John Blumberg Heidi & Pete Boelke Olga & Jim Bond Christina & Walter Borst Leigh Ann & Brett Boscarino Rebekah Bradley Kathy Bradley Cindy & Brian Bradtke Katharine & Thomas Brandt Cathy & Dave Braner Emily Brennan Marylou & Fred Bricketto Kristin & Robert Bridaman Gail Brooks Ann & Donald Brotherly-Lamb Kelly & Keith Brown Lee & Steve Bruebach Beth Brus Gregory Bryon Karen & William Budicin Patty & Kyle Buikema Susan Bullock Gloria & Ed Burjek Crystal & Douglas Busch Jodi & Brett Cagan Kathy & Dan Cahilll Patrice & Kevin Campbell Bradee Campbell Cathy & James Caneff Laura & Lawrence Can Julie & Tony Carballo Kelly Carlstrom Stacy & Pete Carroll Lori & Brian Carroll Pete Carroll Stacy & Pete Carroll Pamela & Frank Cerchio Julie & Todd Chesnut Lene & Lars Christiansen Keri Churchill Maryann & Thomas Ciccarelli Susan & Richard Cisek Barbara & John Claussen

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Shelly & Joe Clayton Karen Colahan Skyler Cole Elizabeth Condon Linda & John Conway Chris Corhett Caroline Cordes Kristin & Bill Cordes Lauryn & Jeff Couch Judy Graf Kathy Couch Rachel Cowan Bill Creed Cheri & Jim Crockett Joy Greene Allvson Crockett Barh Crockett Sister Elizabeth Crottv Susan & Ed Crotty Ann & Joe Cunningham Jackie & Craig Cunningham Emily Cutcliffe Barb & Rich Czaplewski Kellie Dame Dianne Dame Denise Hall Kathy & Charles Damianides Rosa Lea Danielson Tara Degl'Innocenti Joel Dejager Jenna DeVov Kate Devries Ana Rosa & Rafael Diaz Char & Bob Dillon Robert DiRienzo Christine DiRienzo Jack DiRienzo Ducere LLC Claire & David Dunnett Deb & Paul Duvair Elizabeth Dye Meg Heger Carol & Rick Eckstein Madi Eichten Pat Henke Olivia Fiken Christina Elo Jennifer & Michael Ellberg David Hoad Daniel Enterlin Kerrie Erickson Kelly Erickson Kimberly & Dwayne Eriksen Chad Esslinger Kim Holzer Marcy & Tom Estvander Nancy & Dick Euler Jennifer Evanko Marlene Evans Scott Fahringer Paula & Marshall Felbien Vicente Ferro Kimberly & Sean Flaherty Meghan Flannery Sarah Fleming Mary Pat & John Fontana Barb Foss Daniel Fost Liz & Bob Fox Tom Hurley Dorothy & Jim Fox Josh Inglis Vicki & Gary Friedman Erin Fults Sue Jacobi Magaly Galarraga Carol & James Galen Sheila & Terry Gallagher Mike Galway Tracey Gamboa Joseph Garcia . Alexandra Gargano Cheri & Frank Gentile Margie Gibson Sarah Gibson Bettie & Jim Gilmartin Michael Gilmartin Brian Gilmartin Laura & Chris Gilmartin Julia Katz Geneva Goble Tia Goebel Sona & Nisarga Gohel

Donna & Jeff Golden Jonathan Goldford Bruce Goldford Lindsay Gonterman Trevor Gonterman Sr. Madelyn Gould Mary Kay & Charles Graber Mary Jo Graf Gina Graham Lynne & Rich Greene Suzanne & Michael Greene Sandy & Mike Greao Samuel Gruen Karen & Tim Guerra Rohit Gunta Khushbu Gunta Bridget Gustafson lan Gustafson Patti & Al Gustafson Jeanette & Mark Hacker Lisa & David Hamman Sharlene & Troy Hammond Elisha Hancock Susan Handis Laurie Hargrove Amanda & Larry Hartley Marcy & Marc Hartstein Kimberly Hartstein Ann Hartstein Ashlee & David Hartstein Cindy & Bill Hassett Theresa & Mike Hawley Mary Jo & Steve Hazard Colette & John Hazard Mary Henderson Kandice Henning Crisann & George Hillier Suzanne & Michael Hogarty Mr. & Mrs. Holder Lvnette Hollis , Betty & Bill Holmes Ina & Eric Holzer Marie Holzer David Holzer Matt Holzer Jean & Nick Hoyle Kathy & Chris Hubbard Robin & Robert Hudetz Kenneth Hughes Roger Hughes Cate Humbert Amanda Humphreville Tara & Gary Hunt Lisa & Mark Hurley Gail & Stephen Iovinelli Joanne & Carl Jakubowski Carol & Alireza Jalali Reth & Tom Janus Yvonne & Kurt Janvrin Sandra & Adrian Jaworski Robyn & Craig Johnson Norman Jones Sally Jones Audrey Jurek Paula Jurlow Dhananiav Kaimal Terry & Ray Karos Mary Kaskie Monica Keane Patricia & Vincent Keenan Karen & Chuck Keenley

Ellis Kelling Terry & John Kerr KJHS Julie & Tad Knight Beth Knobbe Karen & Charles Koch Karen & Richard Korbas Kelly Koscuiszka Alice Kraepel Gail & James Krema Julie & Larry Krema Gay & Harold Krueger Elizabeth & Derek Kruk Darlene Krull Mary Kay & Paul Ladone Dolores Lano-Gonzalez Melissa & William Langley Ellen Lee Sharon & Jim Lentino Josephine Lentino Peggy & Scott Leyden Janet & Frank Ligas Karen & Steve Lindahl Tammy Linder Steve Lindo Patti Littell LOuori & Charles Loehmann Jill Lohrfink Julie & Wally Lomax Jodi & Jeff Long Allyson Lough Robert Lubic Melissa & Daniel Lund Megan & Scott Mabrev Malissa Magiera John Maher Karyn & Dennis Manganello Jill & Brian Martin Ally & Brett Mastio Janell & Francisco Matas Jeannie Matula Rachel Mawi Bev & Frank Maver Natalie Mayer Renee & Dean McAllister Gwen & Brian McCallion Kim & Kevin McCarter Peggy McCarthy Laura & John McDonnell Mary & Dave McGowan Thomas McGrath David McHugh Janelle & David McHugh David McKeague Amy & Jerry McKeown Patti & Joe McKeska Ginny McLean Susan & Marc McLean Berette McNaught Peggy McNicholas Alex McQueary Carmen McSpadden Ashley Meyer Mary & Ken Miles Bob Millard Daniel Miller Al Mitchell Deb & Richard Mitchler Megan Mondek Nancy & Steven Mores Ben Morgridge Jody & Randy Morris Vickie Moser Virginia Mulholland Melissa & Christopher Mulvaney Denise Munro Maggie Murphy Andy & Jim Myles Rvan Nail Kathleen & Dominic Nakis Karen & August Naso

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HANK

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#### Swifty Thanks Our 2017 Schreiber A Greg Scriba U Semeria

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Pediatric Brain Cancer



Impact Report 2017–2018



3916 Sarazen Court Woodridge, IL 60517



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