Shwachman-Diamond
Syndrome Foundation
Support...Research...Cure

Visit our Website

Donate Online

Greetings!

Another summer is starting to transition into autumn and the kids are returning to school. We hope that everyone had a fun summer.

SDSF was proud to financially sponsor the Scientific Congress in Cincinnati. We were happy to see so many physicians and researchers share their findings and we're particularly happy that so many adult patients and parents could join us. If you weren't able to attend, we hope you were able to watch Dr. Rommens' presentation about the Congress. If not, you can watch it on YouTube. The link is shared below in the newsletter. One thing that the Congress made clear is that there is much more research needed on the various aspects of SDS. We are all aware of the blood and bone marrow issues, but it was made clear that more work is needed on GI, liver, neuropsych, and other problems which are affecting the quality of life of patients. SDSF is aware of this and will continue to pursue research to find curative therapy that will make patients' lives healthy and enjoyable. The health and happiness of SDSF patients is our priority.

Have a glorious autumn,

Joan Mowery
President
Shwachman-Diamond Syndrome Foundation

Camp Sunshine SDS Week Announced

2026

CAMP SUNSHINE

SHWACHMAN-DIAMOND WEEK

Casco, Maine

MORE INFO COMING SOON!

JULY 13-17, 2026

We Want to Share Your Story

We Would Love to Share Your SDS Journey and Patient Story! So Many Parents and Patients Share Similar Situations and it Would Be Helpful to Learn From One Another.
If You Would Like Us to Share Your Story in a Future Newsletter, Click the Button Below! We Cannot Wait to Hear From You!

Click to Email Us Your Story

Congress Update

The 11th International SDS Scientific Congress

June 5-8 2025, Cincinnati Ohio

On July 27th we had the pleasure of having Dr. Johanna Rommens, a renowned geneticist and molecular biologist, present an overview of the 11th International SDS Scientific Congress.
. . .

SDS Care Challenges

Dr. Rommens discussed challenges faced by families and individuals with SDS, including the need for lifelong care, age-appropriate education, and management of medication costs. She highlighted the importance of commitment to research and need for continued investigations into . . . hematological and non-hematological features of the syndrome. . . .

Ribosome Function in Shwachman-Diamond Syndrome

. . . a detailed overview of ribosome function and its relevance to SDS, explain[ed] how loss-of-function variants in genes like SBDS, EFL1 and DNAJC21 lead to ribosome maturation defects. . . .

Advancements in SDS Research Technologies

Dr. Rommens . . . highlighted newer approaches toward patient diagnoses, including broader use of genetic sequencing and the potential for newborn screening.

Clonal Hematopoiesis in Patients with SDS

. . . long-recognized chromosomal changes noted in blood and marrow cells of patients are now appreciated as a reflection of somatic evolution in blood stem cells. With the benefits of improved DNA sequencing, and ability to detect more subtle gene sequence alterations, the full extent of changing blood stem cells (i.e. clonal hematopoiesis) can be appreciated. . . . The first is EIF6, that when reduced, appears to provide a survival advantage to stem cells thus allowing better growth despite missing SBDS. The second, TP53, is typically responsible for multiple ‘guarding’ functions for cells but is known to be associated with cancer development and of concern when both gene copies become disrupted.

From Research Findings to Benefits for SDS

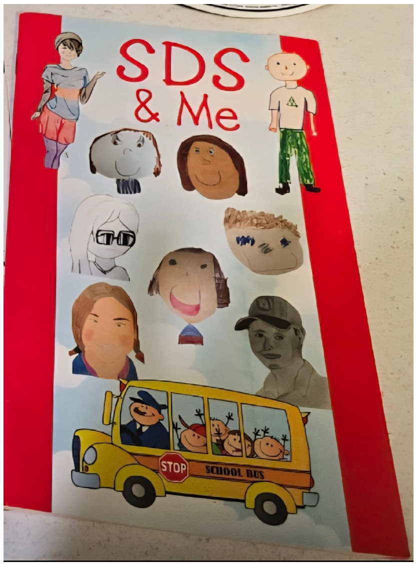
Dr. Rommens indicated enthusiasm for ongoing research, striving toward better understanding of the abilities of organs and cells with SDS, and how they maintain balance toward stresses. . . . She highlighted ongoing international studies and apparent potential for preemptive bone marrow transplantation, while acknowledging the complications associated with such procedures. Johanna also touched on the needs for further research . . .

Click to Read the Full Update on the Congress

Click to Watch the Congress Meeting

SDS & Me Books - My Great Experience

by Mary Balint



When Rylie was in the younger years at school, I would take the SDS and Me books to her class for her birthday and give each child a book and SDSF bracelet and read the book to the class. One year her older sister went to school and read to the class as well. Not only did it teach the kids and teachers about SDS, but they went home with the book and would share with their families, so it spread awareness and taught the kids why Rylie was different and why their coming to school sick would hurt her.

If you would like to get books for class or any other purpose please feel free to contact **mary@shwachman-diamond.org**.

Click to Request SDS & Me Books

We Support You!

Please let us know if your child is going to be transplanted. We would like to send them a gift to let them know we care.

Contact Us

Did You Get Your Copy of the SDS Glossary?

SDS Glossary

An in-depth glossary for families and patients with definitions of the most common Shwachman-Diamond Syndrome terminology

Thanks to a generous community grant this is a

Free Resource

However, donations to cover shipping costs are appreciated if possible.

Click to Request a Glossary

How to Communicate About SDS and Our Children's Needs?

by Christian Del Ré

September can be a time of anxiety in any home with the start of a new school-year. Kids are nervous, parents are nervous, and between battling to get back into school routines, we also have to worry about whether or not our child’s teacher knows what SDS is and what special needs have to be met each day . . .

Since Anthony was in Pre-K, we have scheduled an appointment with the school principal, and before the start of the year, she meets with the administrative team as well as Anthony’s teachers to give them the SDS 101 talk and to go over what special considerations Anthony needs while in school . . . .

I have attached some of the documents we use each year; feel free to adapt and edit them for your own family. Here is also a check-list of important things you may want to do before the start of the school-year . . . .

Click to Read More & See Check List

School Letter

SDSF Info Packet

Medication List Template

Registry Remarks

SDSR
Shwachman-Diamond
Syndrome Registry

LIVING WITH SDS

MAKE YOUR VOICES HEARD

The SDS Registry is inviting input from individuals with SDS as well as parents caring for children with SDS in order to better understand the patient and family experience of SDS. By hearing directly from patients and families, rather than an interpretation of a patient's condition by a medical provider, the SDS Registry aims to better understand the patient and family experience of SDS and its associated treatments. The goal is to improve medical care and to inform research priorities to align with areas of importance to patients and families.Knowledge gained from this study will improve partnerships between patients and medical providers for shared medical decisions that better align with patient and caregiver values and preferences.

This study is open to participants in the SDS Registry and their caregivers. The average time to complete the survey is 30 minutes.

An email from SDS Registry research assistant Elizabeth Korn with a link to the online survey for this study is being sent to all participants on the SDS Registry. The email will be sent via a secure link with the subject title "SDS Updates from Boston Children's Hospital". If you want to confirm that the email is a legitimate link from the SDS Registry, please call or email the SDS Registry at the email or phone number below.

Please reach out to the SDS Registry team if you have already joined the registry and have not received the link for the study. If you are not already in the SDS Registry and would like to participate, please contact the SDS Registry.

SDS Registry Email: SDSRegistry-dL@childrens.harvard.edu
SDS Registry Phone: 617-919-1574

SDSR
Shwachman-Diamond
Syndrome Registry

Research Advances from the SDS Registry

Just Published! SDS Registry Publication in the Journal of Pediatrics: Dr. Jane Koo led an SDS Registry study characterizing growth patterns in Shwachman-Diamond Syndrome. We studied growth after bone marrow transplant as well as the effects of growth hormone for patients with SDS. These results were shared at the 2025 SDS Scientific Congress. A short summary is presented below. To read a full version, click the link below.

Click to Read the Full Report from the Registry

In Memoriam

Although we fight daily to save the lives of SDS patients and search for a cure, we must acknowledge those for whom a cure did not come in time.

SDS Live

Our past SDSF Videos are available on line. Click the button below for our library.

Click for SDS Live Videos

Birthday Celebration!

Let SDSF help celebrate your birthday! Everyone loves getting mail, especially when things have been rough. Send an email to: info@shwachman-diamond.org

include your/your child's name, mailing address and birthdate.

Click to Send an Email to SDSF with Your Birthday

Rare Disease Fundraisers

Keller's Cookies

by Stacy Spires

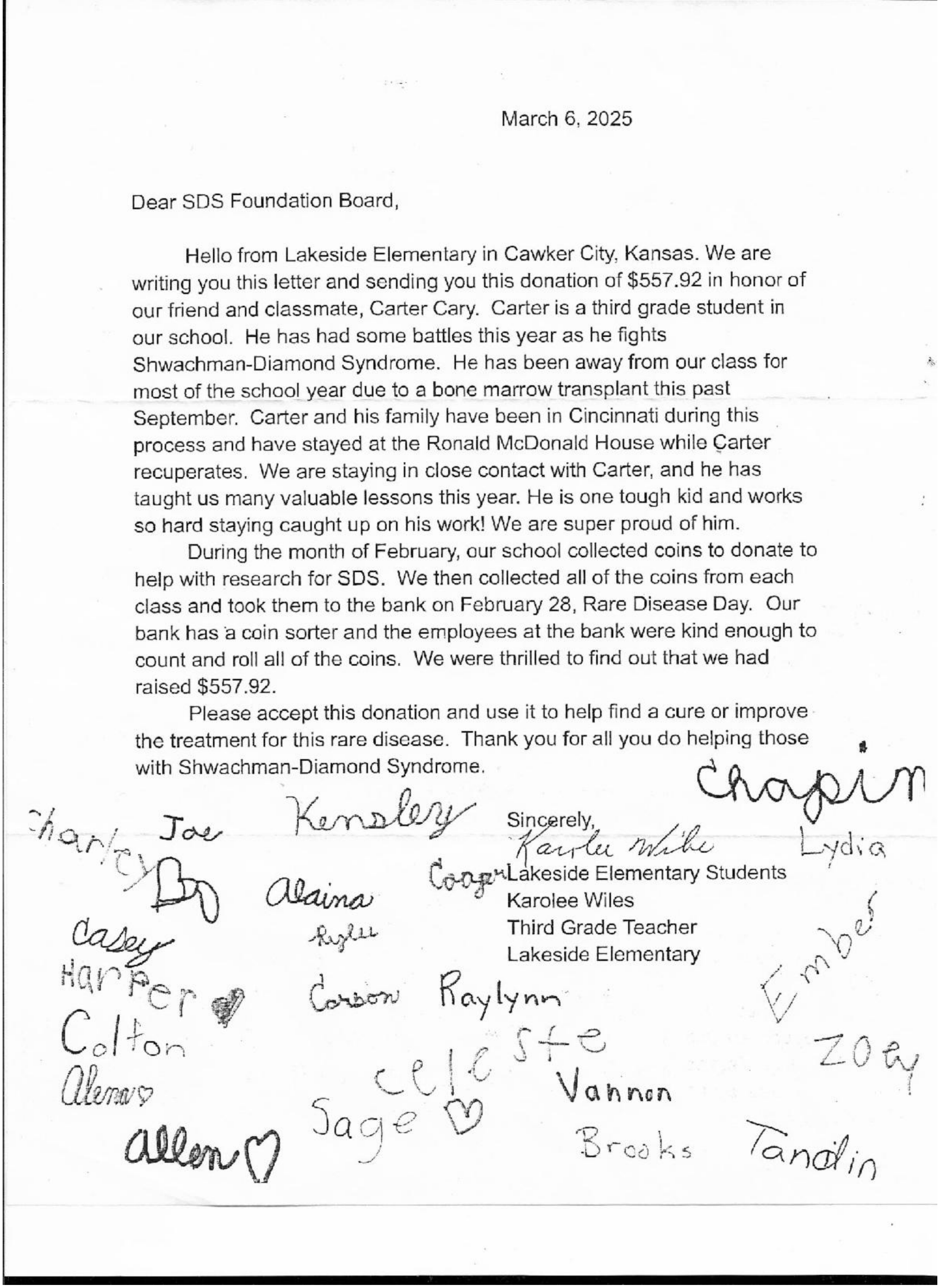
Keller Wilson is a Shwachman-Diamond hero! His family has created Keller's Cookies 6 years ago. Each year we raise money for the SDS foundation in February with a huge variety of baked treats. Hundreds of cookies, cupcakes, brownies, cinnamon rolls and now sourdough bread are baked and sold with 100% of the sales going to the SDS foundation. We do bake intermittently for others with the understanding that they donate to SDS such as graduation and wedding cupcakes just a few times a year. Many of our relatives and friends donate above the suggested price for the items. We so appreciate all of the generosity of everyone involved.

Keller is 10 years old. His last two years have been especially difficult as his ADHD, depression, and lack of physical growth have made school very difficult. He has always excelled at puzzles and drawing, he an expert on frogs and lizards, and loves exploring the outdoors.

All of the progress in the research and treatment for SDS patients are so appreciated and we plan to continue our baking to help.

Lakeside Elementary School Supports Carter Cary

Thank you to Lakeside Elementary School in Cawker City, Kansas for helping raise money to find a cure for their classmate Carter Cary for this past Rare Disease Day!



March 6, 2025

Dear SDS Foundation Board,

Hello from Lakeside Elementary in Cawker City, Kansas. We are writing you this letter and sending you this donation of $557.92 in honor of our friend and classmate, Carter Cary. Carter is a third grade student in our school. He has had some battles this year as he fights Shwachman-Diamond Syndrome. He has been away from our class for most of the school year due to a bone marrow transplant this past September. Carter and his family have been in Cincinnati during this process and have stayed at the Ronald McDonald House while Carter recuperates. We are staying in close contact with Carter, and he has taught us many valuable lessons this year. He is one tough kid and works so hard staying caught up on his work! We are super proud of him.

During the month of February, our school collected coins to donate to help with research for SDS. We then collected all of the coins from each class and took them to the bank on February 28, Rare Disease Day. Our bank has a coin sorter and the employees at the bank were kind enough to count and roll all of the coins. We were thrilled to find out that we had raised $557.92.

Please accept this donation and use it to help find a cure or improve the treatment for this rare disease. Thank you for all you do helping those with Shwachman-Diamond Syndrome.

Sincerely,
Karlee Wiles
Lakeside Elementary Students
Karolee Wiles
Third Grade Teacher
Lakeside Elementary

Chapin
Charley
Joe
Kensley
Lydia
Bo
Alaina
Cooper
Casey
Rylee
Harper
Carson
Raylynn
Ember
Colton
Celeste
Zoey
Alena
Vannon
Sage
Allen
Brooks
Tandin

Ride for Research II: 150 Miles for Shwachman-Diamond Syndrome

by John Wall

This September 9th – 11th, I, John Wall (Treasurer of the Shwachman-Diamond Syndrome Foundation), along with my good friend Paul Konish, and my brother Kevin, will be riding 150 miles along the Great Allegheny Passage from Pittsburgh, PA to Cumberland, MD.

We’re riding to raise $20,000 for the Shwachman-Diamond Syndrome Foundation (SDSF)—a cause that hits very close to home. Two of my sons have been diagnosed with Shwachman-Diamond Syndrome (SDS) . . . .

I recently attended the 11th International Congress on SDS in Cincinnati, where leading researchers and physicians emphasized the urgent need for more research and better treatments. Yet because SDS is so rare, federal funding is extremely limited—especially now, with major cuts in research funding.

That’s why we’re riding again. Two years ago, with your help, we raised $10,000.

This year, our goal is $20,000—and we know we can get there with your support.

Your donation will go directly to SDSF . . .[and] fund promising studies underway at Boston Children’s Hospital and other vital research initiatives working toward a cure. . . .

Ride for Research II:
150 Miles for Shwachman-Diamond Syndrome

September 9–11, 2025

From Pittsburgh, PA ➡ Cumberland, MD

This September, I, John Wall (Treasurer of the Shwachman-Diamond Syndrome Foundation), along with Paul Konish and my brother Kevin, will ride 150 miles along the Great Allegheny Passage to raise $20,000 for research and family support. This is an unsupported ride, all travel and lodging expenses are paid for by the individual riders.

Why we ride:
Two of my sons live with Shwachman-Diamond Syndrome (SDS), a rare genetic bone marrow failure disorder affecting 1 in 100,000 births. SDS can cause:

- Failure to thrive
- Recurrent infections
- Learning disabilities
- Increased risk of leukemia and MDS
- Currently there is no cure for SDS

Without more research, survival rates remain dangerously low for those who develop leukemia or MDS.

Your impact:
Two years ago, riding across Vermont, we raised $10,000.
This year, with your help, we can reach $20,000.
95% of donations go directly to SDS research and family support.

Click the link or scan the code to sponsor or donate:

Ride for Research II

Contact: john.@shwachman-diamond.org
Shwachman-Diamond Syndrome Foundation 501(c)(3) Nonprofit | Federal ID# 43-1709945
www.shwachman-diamond.org

Click to Read More

Click to Donate to John's Ride

SDSF Swag Shop

Click the button below to access the SDSF Swag Shop. We have a wide variety of SDSF merchandise to choose from.

Visit the SDSF Swag Shop

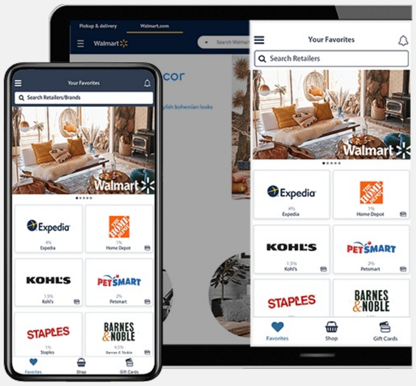
Raise Funds Just by Shopping

We know you are passionate about finding a cure for Shwachman-Diamond Syndrome. We are asking for your help in raising funds to help our cause and the best part is it is free for you to use. We are partnering with the ShopRaise app, which gives a portion back to us whenever you do your normal shopping online at over 1,000 stores like Macy's, Home Depot, and Walmart.

Please help us support and promote our program by doing these 3 simple things:

- Click the link below to get the ShopRaise app
- Use tools in the mobile app to share it with family and friends
- Shop online using the app to support and help us reach our fundraising goals

Click the link below to get started.



Click to Sign Up for ShopRaise

SDS Awareness Ribbons

Alone we are rare, together we are SDS Strong®

Shwachman-Diamond Syndrome Awareness Ribbons

Two layered awareness ribbon attached with a gold pin

$5 ea
3 for $12
Domestic shipping included

The long awaited SDS Awareness Ribbons are custom made double layer ribbons to bring awareness to SDS. Each ribbon will arrive assembled with a gold pin attaching them.

Ribbons are $5 per ribbon, or 3 ribbons for $12. Domestic shipping is included.

There is only a limited quantity of these - act fast!

These are great to spread awareness! Fill out the form below to place your order.

Click to Order SDS Awareness Ribbons

Online Fundraisers

We know that this is a challenging time for so many. We are asking that if you set up an online fundraiser for a birthday or special event, please set Shwachman-Diamond Syndrome Foundation as your charitable organization. Every little bit helps us fund research to help find a cure for SDS!

Welcome New SDS Families

Calgary, Alberta
San Jose, California
Ontario, Canada
Toronto, Canada
Carbondale, Colorado
Colorado Springs, Colorado
China
Lenoir, North Carolina
Pakistan
Poland
Hope, Rhode Island
Milton, West Virginia

Thank You For Your Donations

Donations received between March 1, 2025 - July 25, 2025

BJ Larson
Renaissance - Team Lizzie
Lewis Sumislaski
Lorraine Lagesse
Megan Hallman
Heather Savakis
Ronald Jones
Michelle Aimino
Kathleen Suickiel
TEP Holdings
Denise Heal
John Barrett
Tonya Spires
Gail Walker
Caralame Knickmeyer
Brandon Leitnaker
PayPal Giving Fund

In Memory of Betty Wachter for Wade Wacther - Luella Frank, Allen Wachter, Arlyn & Leta Sprecher, Carene Schilling, Robyn Roy, James & Vicki Frank, Early & Diane Weber, Nancy & Clint Collier

In Memory of Andrew Bull - Doris Bull

In Memory of Vincent Deiters - Kristen & Mike Deiters, Mary Falcetti, Joann Sind

In Memory of Whitner Wise - Judy Joyner, Richard Craig, and Kelly Hubbard

In Memory of Nicholas Hernandez - Angela & Felix Hernandez

In Memory of Michael Billings – Terri Billings and Pamela Pauline

In Memory of Joseph Collins, Jr and in Honor of Maggie Collins- Ross & Bonante Families, Alison Griffin, Aniko Gorman, Bernard Collins, Beverly Matozzo, Carmine Verrecchia, Catherine Berger, Colleen Taylor, Crazy Summer Productions, Cynthia Tafaro, Dawn Collins, Elise Morgan, Ellen Hannan, Geraldine McCloskey, Henry Cieplinski, Jean Anne Cieplinski-Robertson, Joanne Ley, Kathleen Shannon, Kathy Varady, Lewis Quin, Luke French, Lynne McCabe, Margaret Michelangelo, Mario Scalora, Matthew Creamer, Maureen DeNinno, Megan Hallman, Melissa Agresti, Rachel Wilkins, Teresa Fisher, Thomas Burnham, Tracey Daniels

In Honor of Carol Kolar's 80th Birthday – Eileen Brenner

In Honor of Isabela Quinones' 1st birthday – Kristen Miggans

In Honor of Jude Bowman – Melissa Bowman, Jane Bowman and Linda Jennings

In Honor of Johnse St. Hillaire – Donna Morgan

In Honor of Marissa Avroch - Michael Carpiniello

In Honor of Betty Delgado – Molly Traweek

In Honor of Anthony Del Re - Florence Roca

In Honor of Jessica Bodron - Timothy & Joni Bodron

In Honor of Henley Johnson - John & Sheryl Homan

In Honor of Carter Cary - Karolee Wiles's Third Grade Class & Lakeside Elementary School

In Honor of Ronin Porrata - Park Ridge Rotary Foundation, Inc.

In Honor of Andrew Lillywhite - Savannah Lillywhite

In Support of Tom's Run - Amy Best, April Stobbe, Bethany Pendergrass, Bryan Beard, Cami Stinson, Catherine Hughes, Christian & Gina Del Re, Cindy Bartley, Connor Hammer, Courtney Smithson, Dana Langley, David Spires, Deana Valiante, Gerhard Laule, Gregory Grant, Jane Lodes, Jeff Stewart, Kacie Cassaday, Katherine Vance, Kimberly Hanigar, Laurel Schlueder, Little Pleasures Foods, Lucian Farrar, Matthew Brannon, Nancy Barrett, Pamela Dotson, Pamela Miller, Phillip Chapman, Randy Kamm, Richard Davis, Saundra Tenison, Savannah Lillywhite, Shirley Williams, Suhaila Nease, Suzanne Shepherd, Sylwia Hair, Zoe Davis

Special Thank You to the dozens of Anonymous and Unnamed Donors

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Thank you for your monthly donation

Maria Hall
Melissa Hingula
Indro Hoffman
Jason Huttinger
Keung King Man James
Eylem Atilgan
Nicole Carp
Frank and Jane Seaman

In Memory of Michele Mowery - Joan & Greg Mowery
In Honor of Camden Kilcrease - Lisa Kilcrease
In Honor of Matthew Valiante - Deana Valiante
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In Honor of Jonathan and Joseph Wall - Joyce Wall
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In Honor of Scott, Meagan, & Jonathan Miller - Susan Butsch, Ann Reed Macke
In Honor of Riley Laber - Mary Balint, Cara Gallagher
In Honor of Anthony Del Re - Christian & Gina Del Re
In Honor of Roman and Alex Fetzer - Arnold & Jennie Edna

Donate Today

Ongoing Fundraisers

SDSF would like to encourage everyone to raise funds to support research and the Foundation. We have had families raise money through letter writing campaigns, school dances, corporate matching gifts through their employers, golf tournaments, physical competition events, Super Bowl parties and more.

Click for Ongoing Fundraisers

Shop The SDSF Online Store

Did You Get Your SDSF Car Magnet Yet? Don't Have a Car - Put it On Your Fridge or File Cabinet. Spread Awareness - Start a Conversation. Click the Link Below to Get Yours and See What Other SDSF Merchandise We Have! All Proceeds Support Finding a Cure for SDS!

Click to Order a Magnet

Shwachman-Diamond Syndrome Foundation

FOUNDER: Joan Mowery 1994

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Joyce Wall - Anna Angel Basket Coordinator

ATTORNEY: Ann Bodewes Stephens, Herzog Crebs

Share This Email

Have an article, update, or fundraising activity you would like to share in a future newsletter? Email your story to: **christiandelre@shwachman-diamond.org**.

We would love to hear from you and share your stories!

Sign Up For Emails

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Shwachman Diamond Syndrome Foundation
888-825-7373
info@shwachman-diamond.org
www.shwachman-diamond.org

Contact Us