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Greetings!

Welcome to the new SDSF board. I have been on the board since 2019, as secretary and as of December, I moved up to president. I have worked with many of our families, gone to many ASH conferences, and sent out all the education materials to our families. As we enter this new phase with this new board, we will be working more closely with our Medical Board, we also will be working much closer with other SDS groups because our one and only goal is to get our families the help that they need, no matter where it comes from. We are all one united towards the same goal.

Please feel free to reach out to me, or any of our board members, if you need anything or have any concerns or questions. We would like to know what you want from our board that will help you the most.

Mary Balint
President
Shwachman-Diamond Syndrome Foundation

Website Update

Exciting News! Our New SDSF Website is Live!

We're thrilled to announce that the Shwachman-Diamond Syndrome Foundation (SDSF) has a brand new website! Our refreshed site is designed to be easier to navigate, full of helpful resources, and a place to celebrate our amazing SDS community.

We want the website to truly reflect you—our families, patients, and supporters! If you have photos of your SDS journey, family moments, we'd love to feature them on the site.

 We can really use "horizontal" pictures taken with your phone sideways, but any picture is great! Share your pictures with us: Please send your photos to info@shwachman-diamond.org and include a brief description (first names, location, or event, if you're comfortable). By sending your photo, you're helping us showcase the heart of the SDS community.

Visit the new site now: www.shwachman-diamond.org

Let's make this website a celebration of every SDS story!

Camp Sunshine SDS Week Details
July 13-17, 2026

Every two years, SDS families have the wonderful opportunity to attend Camp Sunshine in Casco, Maine. This special week is a fantastic chance to connect with other families, share your SDS journey, and build lasting friendships. Adult patients are welcome too and are included in engaging adult activities. While your children enjoy fun and engaging activities, you can meet medical experts, reconnect with old friends, and make new ones.

The Shwachman-Diamond Syndrome Foundation works closely with Camp Sunshine to customize this week for the SDS community. As part of the program, two full days of workshops are offered with leading SDS physicians, providing families and adult patients the opportunity to learn, ask questions, and engage directly with experts. SDSF organizes and fully covers the doctors' transportation and lodging so they can be onsite to lead these workshops.

In addition, SDSF makes a donation to Camp Sunshine to help support the families attending during SDS week and to ensure this special experience remains available to our community.

It's truly a FABULOUS experience for the whole family! SDSF encourages all SDS families to attend. The only cost to families is transportation to and from camp.

Important: Camp spots are first come, first served. To secure your place, you'll need to:

1. Register an account with Camp Sunshine.
2. Complete the Family Application packet, including physician forms signed by the patient's doctor.



Register For Camp!

Click the link below to register your family for Camp Sunshine's SDS Week.

If you have a family member that you would like to attend camp with you but they are not part of your immediate family, they can register as a volunteer. On their free time, they can also learn about SDS from our doctors.

[Click to Register](#)

Celebrating our Own Matthew Valiante

by Deana Valiante



Matthew recently began a Veterinary Technician Program at Camden Community College, a path that reflects his deep compassion for animals and hands-on care. . . . This past summer, while awaiting his most recent biopsy results, Matthew found comfort and purpose in an unexpected place — protecting one of nature’s most iconic and vulnerable species, the monarch butterfly. . . . Matthew’s story is a powerful reminder that even in the midst of rare disease challenges, hope, purpose, and impact can be found.

[Click to Read Matthew's 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](#)

ASH Update

The 67th ASH Annual Meeting & Exposition December 6-9, 2025, Orlando, Florida

SDSF was honored to be offered a last-minute nonprofit booth for the American Society of Hematology (ASH) Annual Meeting, held December 6–9, 2025. Embracing the opportunity, Mary Balint, newly appointed President of SDSF, and John Wall, Treasurer, attended on behalf of the Foundation. . . . Mary and John also held an in-depth meeting with Dr. Shimamura and Dr. Myers to discuss collaborative efforts between SDSF and the SDS Registry. . . . In addition, [they] met with Eszter Hars of the SDS Alliance for a productive discussion on ways our organizations can collaborate to better support the SDS community and work toward our shared goal of finding a cure.



[Click to Read More About ASH](#)

Rare Disease Day 2026 February 28th



As Rare Disease Day approaches, we are even more aware of how rare SDS is and that there is no cure. We are further saddened by the recent deaths in our SDS family. This has heightened anxiety and concern for many of our patients and families.

While this is a very valid concern, we must continue to fight and not focus on the negative. There are many researchers around the world trying to unravel the mystery that is SDS. We want to assure you that there are several researchers, both in the U.S. and other countries, working very hard to develop curative therapies for our patients. SDSF is helping to

fund some of this research and we are prepared to fund yet another research project within the next few months.

All of us want a happy and healthy life for our patients. We need your help to continue funding this research. Please become part of the cure and help by contributing. Please click below to make a donation.

[Click to Donate](#)

This day, like no other, is our opportunity to focus attention on SDS.

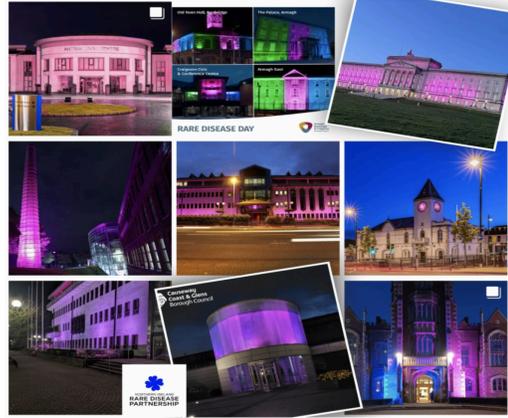
What are you going to do to bring attention to SDS?

SDS is one of 6000 diseases considered a rare disease, as it affects fewer than 200,000 people.

Ways You Can Bring Awareness to SDS:

- Tell your child's story
- Put the Rare Disease sign in your front window or Light up Your House in Rare Disease Day Colors
- Go to the Rare Disease Day Web site and download the Facebook picture for your own page
- Start a fundraiser and be part of the cure
- Ask your child's school to bring awareness to Rare Disease Day by having students color or give out ribbons, have a read-a-loud of our SDS Children's Book - *SDS & Me*
- Join SDSF to fund more research, as that is the path to a cure

AWARENESS STARTS WITH CONVERSATION



And never forget. We are SDS Strong!!

[Click to Visit Rare Disease Day Website](#)

[Click to Visit NORD's Rare Disease Day Page](#)

[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.

CARE PACKAGES
for families going through
TRANSPLANT

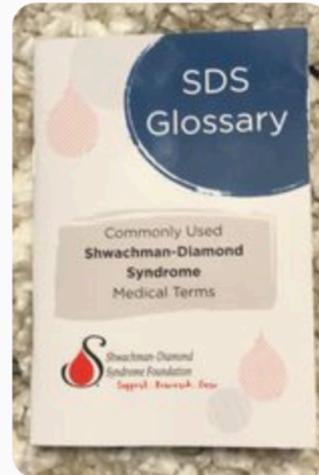
Send us an email when you go to transplant
so we can share hope
info@shwachman-diamond.org

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

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](#)

New Board Positions at SDSF

In December, we held an election after Joan Mowery stepped down from her role as President of SDSF. She has transitioned into role of Founder, where she will provide training and support to our board members and families. Below is the new slate of officers.



Joan Mowery
Founder



Mary Balint
President



Christian Del Ré
Vice President



Deana Valiante
Secretary



John Wall
Treasurer



Tom Dahlman
Family Liaison Chair



Shari St. Hilaire
Fundraising Chair



Bryan Sample
Legal Advisor

Registry Remarks



Updates from the SDS Registry



SDS Survey Deadline Extended to



January 23rd, 2026:

Thank you to all of our SDS Registry participants who participated in our survey study so far! If you have not yet filled out your survey, please submit by 1/23/2026. If you do not have the survey link or cannot open the link, please contact the SDS Registry at email: SDSRegistry-dl@childrens.harvard.edu / phone: 617-919-1574

Presented at the 2025 American Society of Hematology:

- **Determining the Lifetime Risk of Blood Complications in SDS:** The SDS Registry was joined by registries and investigators around the world to combine their data together and found that not only is leukemia risk unexpectedly high, but the risk of additional blood complications requiring transplant is also high. The leukemias in patients with SDS are extremely challenging to cure, so this study helps patients and medical providers assess potential benefits of earlier transplant.
- **Improving Surveillance to Prevent Leukemia:** This new SDS Registry study found that peripheral blood molecular tests were good at detecting the same mutations found in the bone marrow and provide critical data to support the use of minimally invasive blood tests for surveillance. The lab also found that blood tests can only go so far and identified key limitations to the use of blood molecular testing.
- **Gene Therapy Project:** Fixing the SBDS gene to treat SDS: Dr. Akiko Shimamura and Dr. Dan Bauer have collaborated to successfully conduct proof-of-concept experiments with the goal of developing a gene therapy clinical trial for SDS. Please see below for more details about the next steps for this project.



Call for volunteers to advance gene therapy research



The SDS Registry researchers have successfully conducted proof-of-concept experiments considered a first step in developing a cure for individuals with Shwachman-Diamond Syndrome. This project will work to try and fix the most common disease-causing mutation in the SBDS gene which causes SDS.

See video link here to hear Dr. Shimamura and Dr. Bauer discuss gene therapy for SDS:
[Gene Therapy Video](#)

The next step for this project is to test whether gene therapy works in cells from patients with SDS. If you are interested in providing blood samples to advance gene therapy research, please contact our study team at SDSRegistry@childrens.harvard.edu

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.



SDSF Live



Below are the links to our most recent SDSF Live Events:

Dr. Reilly: Adult Phenotypes of SDS and TP53 [Click to View](#)

Dr. Grover: GI and Digestive Issues in SDS [Click to View](#)

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

[Click for SDS Live Videos](#)

Birthday Celebration!



[Click to Send an Email to SDSF with Your Birthday](#)

Help Us Find a Cure

MAD Challenge

We want to thank every member of our community who participated, shared, donated, and showed support in our **Make A Difference (MAD) Holiday Challenge**. Your small acts truly made a big impact.

Throughout the challenge, we highlighted the strength of SDS warriors and the realities families face—including those currently preparing for or recovering from transplant. These stories remind us why our work matters and why continued research is essential so that one day transplant is no longer the outcome.

Together, our MAD Holiday Challenge raised **\$1,400** to support SDS families, research, and resources.

As we look ahead, SDSF remains committed to funding research, supporting families, and strengthening our community. The momentum from the MAD Challenge fuels what comes next—and we are grateful to have you alongside us.

Together, we will continue to make a difference.

♥ **Small acts. Big impact.**

FINAL WEEK
OF THE MAD CHALLENGE –
♥ FROM THE HEART ♥

More **research** today means fewer transplants tomorrow.
So someday, families never have to reach this stage at all.

Our SDS Warriors need us now, and we need you.

♥ SMALL ACTS. BIG IMPACT ♥

#MADChallenge #SDSF #HopeForSDS

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

by John Wall

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

We would like to thank all of you for your generous donations and support of our efforts on behalf of The Shwachman-Diamond Syndrome Foundation. To this point we have raised over \$15,000 dollars, with more still coming in.



[Click to Read About John's Ride](#)

SDSF Swag Shop



Visit Our 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](#)

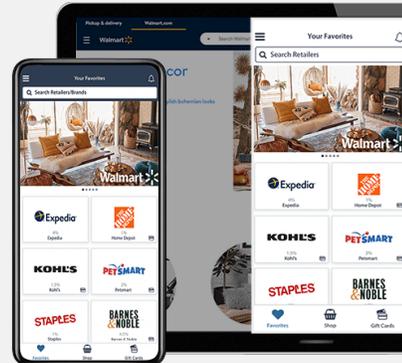
Raise Funds Just by Shopping

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](#)

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

Ontario, Canada
Toronto, Canada
France
Manchester, New Hampshire
Garner, North Carolina
Lenior, North Carolina
Winston, North Carolina
Norway
San Antonio, Texas
St. Albans, UK
Ukraine

Thank You For Your Donations

Donations received between July 26, 2025 - December 31, 2025

Janine Ali	Laura Birro
John & Wilma Daniels	Lois DeBoer
Cornelius DeBoer	William Decell
Terry Duvall	Deborah Evans
Richmond Rotary Charitable Foundation	Marsha Misenhimer Gifting Fund
Megan Hallman	Ronald Jones
Caralame Knickmeyer	Lakeside Elementary School
Vince & Sherri Mitznerf	Lorraine Lagesse
Lewis Quinn	BJ Larson
Yvonne Stewart	Florence Owens
Carol Walker	Heather Savakis
Renaissance Walker	Lewis Sumislaski
	Sherissa Wood

In Memory of Betty Wachter for Wade Wachter - Charlotte & Eddie Wachter, Earl & Diane Weber

In honor of Betty Delgado – Molly Traweek, Carol Meehan, The Armbrusters

In honor of Anthony Del Re - Nicole Buono

In honor of Andrew Lillywhite - Savannah Lillywhite

In honor of Booker Dahlman - Thomas Dahlman

In honor of Camden Kilcrease - Steve Kilcrease

In honor of Henley Johnson - John & Sheryl Homan

In honor of Jessica Bodron - Timothy & Joni Bodron

In honor of Keller Wilson - Stacy Spires

In honor of Kenzo Lambert - Marie-Jose and Paul Moal

In honor of Matthew Valiante - Betty Applegate, Nicole Bartels, Kristen Cecire, John Rod II, Carolyn Hassan, Mary Matyi

In memory of Gary Byrne - Carolyn Quackenbush, Fredrick Tanner

In memory of Joseph Collins - Henry Cieplinski, Rebecca Patterson

In honor and Memory - Diana Murphy

Ride for Research II: Sean Flynn, Jolyn Sloan, Gary Rawls, Kristin Calnan, Jean & Rich Serino, Kevin and Janice Roden, Judy Doucette, Deidra Rooney, Timothy Roden, Colleen DeBiase, Patrick, Jessica, Lauren & Jern Wall-Lee-Leshnowar, Brian Roden, Debby Regan, Kathleen Ferlito, Karen Holmes, Kathy McKay, Laura Kelly, Marie Bourgeois, Karen Konish, Jack Sheehan, Pamela Miller, Marianne Stamm, Steven Greiner, Kevin Shea, Mark Dendler, Stephen Marania, Rick and Cindy Jones, David Halverson, Steven Rotkoff, David Loving, Deana Valiante, Joyce Wall, Robert Bernard, Tom & Bonnie Burrell, Brian Concannon, Madeleine Bombeld, Terry Duvall, John and Vicki Morrison, Marty Younts, David Lemcoe, Hank and Debbie Loudon, Marylee Watkins, Coleen ODonnell, Bill & Judy Veno, Joe Wall, Nola Taylor, Noreene, Duggan, Thomas/Dennis Benthien/Sweeney, Eugene Helbig, William Konish, Jack Housenger, Sandy Morford, Gary Smith, Chris Schnell, Joseph Dudek, Burt King, David Patrick, Deborah Santoro, Sharon McGraw, Eileen & Fred Giannico, Christopher Rozycki, Julie Roden, Stephanie Conklin, Clark and Janice Houck, Shane and Ann Marie Frazier, Sherry Burris, Andrea O'Brien, Joan Mowery, Jonathan Wall, April Stobbe, Monica Konish, Lisa Welch, Erin Bauer, Thomas Dahlman, Becca Smoot, Jim & Michelle Hodge, Helen Bryant, Hanna Williams, Jill Fuller, Melissa Wall, Rick and Cindy Jones, Jed & Lisa Burger, Benjamin Heilmann, Jennifer Poirier, Bill and Mary Ellen Schumann, Sherry Simpson, Kenneth Rozas, Dan and Marty Webb, Dan and Marty Webb, Matt Wall, Jennifer Wilcox, Michael Byers, James Konish, Darlene Pelc, Stephanie Conklin, Daniel Field, Ali Melmi, Barbara Wall, Christian & Gina Del Re, Kevin & Janice Roffi, Sieglinde Aigner-Crooks, Linda Fortunato, Rich and Jill Klein, Jerry Warren, Richard Thomas, Pam and Larry Broderick-Hennessy, Dale MacCausland, Jeff Doucette, David Doucette, Greg Doucette, David Lindsay, Mary R Faherty, Jim (Eagle Trail Dancer) Ward, Steve Stuck, Sheila Roberts, Marjie Curtis, Alice Delaney, Dave Drake, Daniel Field, Patricia & Paul Kelsch, Dick & Jennifer Person, Tim & Linette Thompson, Joseph & Janet Strongwater, Elaine Strongwater

Special Thank You to the dozens of Anonymous and Unnamed Donors

Thank you for your monthly donation

Maria Hall
Melissa Hingula
Indro Hoffman
Jason Hutteringer
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
In Memory of Moe Giordano - Lauren Giordano
In Honor of Jonathan and Joseph Wall - Joyce Wall
In Honor of Jake Walden - Julie Walden
In Honor of Ryker Griess - Angela Griess
In Honor of Noah Swiatko - Diane Swiatko
In Honor of Berkley Ollis - Amie Ollis
In Honor of Marissa Avroch - Dianne Moschetta
In Honor of Scott, Meagan, & Jonathan Miller - 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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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!

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