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Greetings!

As I sit writing this, it is 9 degrees outside. I am literally counting the days to Spring. I'm sure many of you feel the same.

We are all excited about the SDS International Scientific Congress in June. Physicians and researchers from around the world will gather in Cincinnati to share their latest knowledge and findings about SDS. Although this is a scientific congress, adult patients and their caregivers are invited to attend. There is no registration fee for adult patients and a reduced fee for caregivers. I hope everyone, who is able, will take advantage of this opportunity. For more info or to register go to: <https://www.sdscongresscincinnati.com/>.

I'm happy to announce the newest member of our Board of Directors, Deana Valiente, has joined us as our Family Liaison. We look forward to working with Deana. She is a very experienced member of our SDSF family.

Rare Disease Day is coming up on February 28th. The perfect time to make a donation in honor of your SDS warrior. SDSF is providing funds for two research projects, the first in drug development and the second to hopefully find a way to avoid the need for annual bone marrow biopsies. Both projects are important to the future of all patients.

Stay warm and join me in counting down to the first day of spring.

SDS STRONG!

Joan Mowery
President
Shwachman-Diamond Syndrome Foundation

Camp Sunshine SDS Week Announced

2026



SHWACHMAN-DIAMOND WEEK
Casco, Maine

**MORE INFO COMING
SOON!**

JULY 13-17, 2026

Rare Disease Day 2025

February 28, 2025

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 unraveling 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 go to www.shwachman-diamond.org to make a donation.

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

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

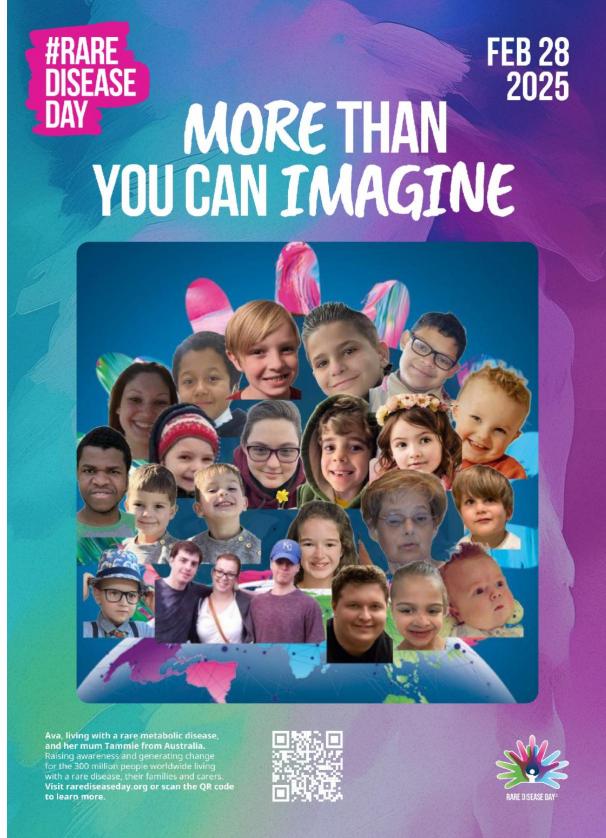
The theme for 2025, is the power of resilience and connection.

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
www.shwachman-diamond.org

And never forget. We are SDS Strong!!



#LIGHTUPFORRARE

Everyone can participate in the Global Chain of Lights and Share Your Colours!

In an effort of global solidarity, you are invited **to light or decorate your home** with the Rare Disease Day colours at **7 PM your local time on 28 February 2025**.

You can use garlands, social media filters, candles, disco lamps, colourful decorations... Let your creativity shine!

We suggest you take **a picture of yourself with the illuminations or decorations you chose** and **publish it on your social media** using our **"Global Chain of Light" filters** and **#rarediseaseday**.

We have prepared information and instructions for you in the attached document. Print it out or email it to friends!

Click to Visit the Rare Disease Day Website

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

Contact Us

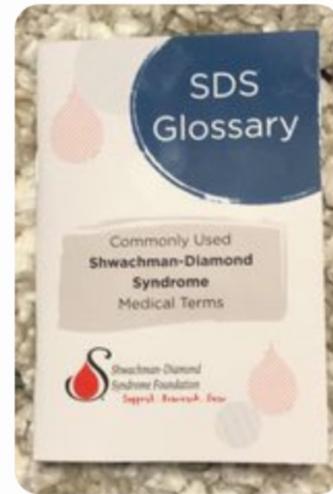
Did You Get Your Copy of the SDS Glossary?

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

11th International SDS Congress

June 5 - 8, 2025



Click to Visit
Website

Registry Remarks



SDS Highlights from the 66th ASH Annual Meeting

SDS Registry investigations have shown improvements in early transplant outcomes and provided a deeper understanding of MDS/AML risk in patients with SDS. This past December, the SDS Registry was invited to present two key research studies at the 2024 American Society of Hematology meeting in San Diego, highlighting this progress in SDS research. This important work would not have been possible without the involvement of SDS Registry participants and valuable collaborations with international partnerships.



“Outcomes of Hematopoietic Stem Cell Transplantation for High-Risk Marrow Features without Malignancy in Shwachman-Diamond Syndrome”

This study observed excellent and superior early outcomes in SDS patients transplanted for high-risk marrow features compared to patients transplanted for MDS or AML.

Updates to be presented at the 2025 SDS Congress

“Incidence of Myeloid Malignancy in Shwachman-Diamond Syndrome: An International Cohort Study”

This international collaboration created the largest cohort of SDS patients to date and identified a high lifetime risk of myeloid malignancy in the SDS population.

Updates to be presented at the 2025 SDS Congress

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 SDSF 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](#)

Help Us Find a Cure

SDSF Swag Shop

Visit Our SDSF Swag Shop

INTRODUCING
SDSF Swag Shop
FEATURING

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

[Visit the SDSF Swag Shop](#)

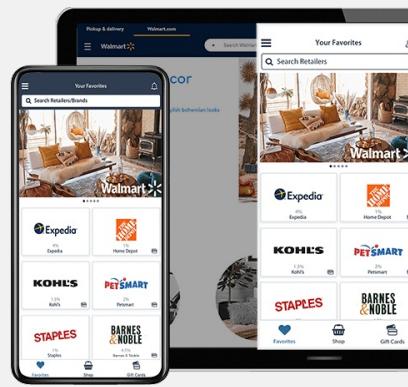
Raise Funds Just by Shopping

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



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

Scottsdale, AZ
Duluth, MN
Horseshoe Bend, ID
Tacoma, WA
Liverpool, UK
Toronto, Ontario
Clarksville, IN
Landau Rheinland-Pfalz
Bluefield, WV
Corona, CA
Calgary, Alberta

Thank You For Your Donations

Donations received between November 1, 2024 - February 25, 2025

John & Wilma Daniels
Lew Sumislaski
Kathleen Sumislaski
Melissa Bowman
Susan Utz
Terry Duvall
Yvonne Stewart
Lorraine Lagesse

PayPal Giving Fund
Fidelity Charitable Giving
Blackbaud Giving Fund
Give Lively Foundation
Bonfire
ThriventChoice

In Honor of Camden Kilcrease - Lisa and Steve Kilcrease

In Memory of Nico Hernandez - Felix Hernandez, Angela Hernandez

In Memory of Andrew Bull - Kimberly Gillespie, Julie Ragan

In Memory of Joseph Collins, Jr - Lewis Quin, Mario Scalora, Margaret Michelangelo, Ross & Bonante Families

In Honor of AJ Pitelli - Robert Pitelli

In Honor of Keller Wilson - Matthew Hull, Candace Owens, Vadim Yeliseyenko, Lisa Edick, Tonya Spires, Florence Owens,

Special Thank You to the dozens of Anonymous and Unnamed Donors

The Many Supporters Through Network for Good Fundraisers

Thank you for your monthly donation

Indro Hoffmann
Maria Hall
Keung King Man James
Jason Huttinger
Angela Greiss

Leah Hyles
Eylem Atilgan
Nicole Carp
Amie Ollis
Melissa Hingula
Dan Donohue

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 Marissa Avroch - Dianne Moschetta

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 - Jenny and Edna Arnold

[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!

[Shop The SDSF Store](#)

Shwachman-Diamond Syndrome Foundation

FOUNDER: Joan Mowery 1994

BOARD OF DIRECTORS

Joan Mowery, President
Christian Del Ré, Vice President
Mary Balint, Secretary
John Wall, Treasurer
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Tom Dahlman

Pamela Miller, Executive Director

Other Amazing Leaders

Joyce Wall - Anna Angel Basket Coordinator

ATTORNEY: Ann Bodewes Stephens, Herzog Crebs



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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](mailto:christiandelre@shwachmandiamond.org)

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Emails

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

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Shwachman Diamond Syndrome

Foundation

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