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Dear Pamela,

We hope you had a wonderful Christmas and Holiday.

We attended the American Society of Hematology (ASH) Meeting in early December. The attendance of physicians and researchers, from all around the world, definitely rebounded following the pandemic, with over 25,000 attendees. Our SDSF booth, in the exhibit hall, attracted the attention of hundreds of attendees, who shared their experience caring for patients, asked questions, and accepted educational information we had available. We spoke to physicians from more than 20 countries. We were also pleased to be able to spend a some time with some of our own medical advisors. There were several presentations, both oral and poster, regarding SDS this year, including a very detailed report from the SDS Registry, reports from Dr. Cory's lab, another from Boston, and also a presentation from the Italian group.

The SDS Scientific Congress will be held on April 18th, following a delay of 3 years due to COVID. We expect to hear that significant progress has been made in our quest for a cure.

Last, but definitely not least, Camp Sunshine is back! SDSF is proud to be sponsoring this family event. We have all missed it. It is always a fun and informative week. Applications will be available on January 30th. As many of you know, this is always on a first come first served basis. So get those applications in as quickly as possible. We look forward to seeing you there.

Stay warm and well.

SDS Strong,

Joan Mowery  
President  
Shwachman-Diamond Syndrome Foundation

## Camp Sunshine Schedule Announced



### SDS Week - July 9-14, 2023

We are excited to announce that Camp Sunshine will be holding an in-person SDS Week! Applications, policies, and program information for SDS Week at Camp Sunshine will be announced on January 30th! Click the link below to access Camp Sunshine's Website!

[Click for Camp Sunshine's](#)

## COVID-19 Vaccine Information

We have had many questions about whether or not the COVID vaccine is safe for our SDS patients. We asked one of our medical advisors, Dr. Kasini Myers of Cincinnati Children's Hospital and this is her recommendation:

***"The SDS registry continues to support vaccination and we are not aware of any particular concerns with the vaccine or complications specific to SDS but of course recommend patients and families discuss any concerns with their primary doctor who knows them best."***

So you can feel safe getting the Covid vaccine for your child if they are over 12 and your primary doctor has no concerns. Stay safe out there, everyone!

## Rare Disease Day 2023

### February 28, 2023

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.

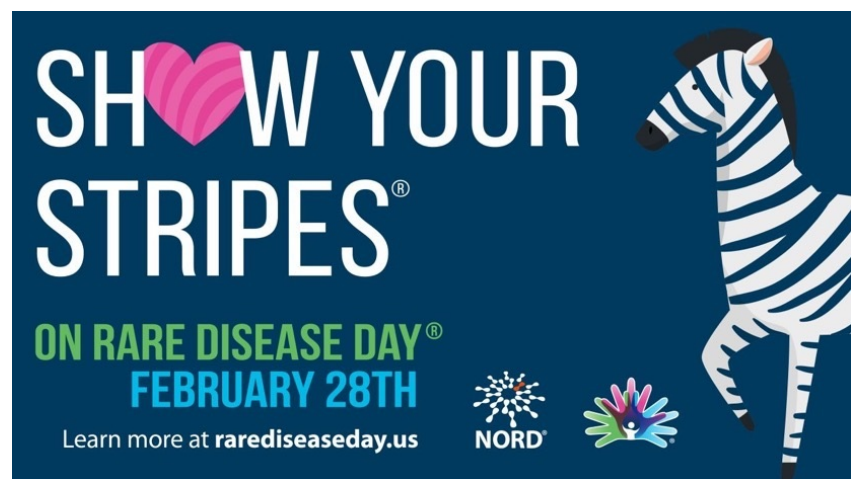
While this is a very valid concern, we must continue to fight and not focus on the negative. There are many researchers around the world trying to unraveling the mystery that is SDS. We want to assure you that there are several researchers, both in the U.S. and other countries, working very hard to develop 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](http://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 2023, is **Show your Stripes** and **Show your colors**.



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](http://www.shwachman-diamond.org)

And never forget. We are SDS Strong!!

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**

brave fearless bold & Strong  
[www.shwachman-diamond.org](http://www.shwachman-diamond.org)

SDS Strong

brave fearless bold & Strong  
[www.shwachman-diamond.org](http://www.shwachman-diamond.org)

Send us an email when you go to transplant  
*so we can share hope*  
[info@shwachman-diamond.org](mailto:info@shwachman-diamond.org)

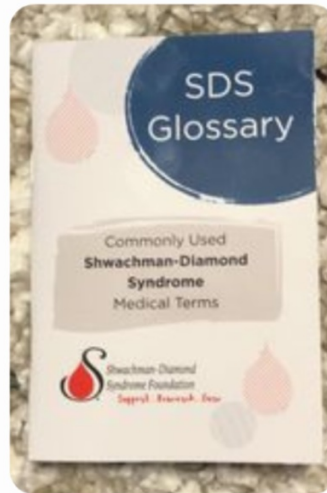
**Shwachman-Diamond Syndrome Foundation**  
Support...Research...Cure

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](#)

## 10th International SDS Congress



[Click to Visit Website](#)

## Registry Remarks



Happy New Year from the SDS Registry



We have concluded another wonderful year with the SDS Registry culminating in sharing some of our research with the greater medical community. Congratulations to Ashley Galvin, our former SDSR research coordinator and current medical student! Ashley was invited to present her SDS research at the American Society of Hematology conference this month.

Ashley and the SDSR team investigated outcomes of hematologic complications in SDS. We found that comprehensive marrow surveillance identified high-risk features that require close monitoring or transplant prior to progression to malignancy. Please visit the "Physicians and Researchers" tab of the SDS Registry website ([sdsregistry.org](https://sdsregistry.org)) to view the abstract.

There was also a fantastic poster presentation by Dr. Mike Peters, PhD, who is a postdoctoral fellow in Dr. Dan Bauer's lab! Mike shared his exciting progress developing an animal model of SDS in collaboration with the SDS Registry!

We hope to see you all in 2023!

## In Memoriam

### Elijah Thompson

#### The Last Text Message

by Brian Thompson

I wrote the following to share at Elijah's celebration of life. When Joan asked me if I would be willing to share something about Elijah for the SDS newsletter, I quickly agreed. I was very surprised to learn how difficult that would prove to be. My intention was to write about how much of an inspiration Elijah was. I find that hard to do, without being able to write all about how he lived his life and with being able to go in to a hundred little stories.



Elijah was 24 when we found out about SDS. He went into the hospital for what seemed like the most minor of issues. Hindsight would show that he did show signs of SDS since birth but they were all easily enough explained away by doctors. For 24 years, he was a pretty healthy guy. This past year, as the Drs searched for answers, I think one of the last pieces of the puzzle came to them when we made an off hand joke about the size of his bowel movements. Quickly after that, we got the SDS diagnosis. As I write this it still seems like such a whirlwind. One day, Elijah is a young married man, with two kids and is just starting to put a life together for his little family. The next, he is being told he has MDS.....then AML.....then SDS.

I know that many of you reading this might not have been blessed with 24 great years. Some of you have been dealing with this since early childhood or birth even. I have read Facebook posts and have talked with other going through this. While my

sincerest hope is that I can offer a little inspiration with Elijah's story, I am afraid that I am inadequate for that. I don't think I am qualified to give encouragement to people who have to navigate this while still sending their precious kids to school. Or to people that silently wonder if you will be blessed with grandchildren. Some of you are even worrying about insurance coverage and travel expenses as you seek treatment. I struggle with how I can offer any inspiration to you. If I can tell you one more thing about Elijah, it would be this: at Cincinnati's Children's Hospital, Elijah became very well known for having a great attitude and always saying "thank you, so much" to anyone that came into his room. It didn't matter if it was a doctor, nurse, or house keeping (just a little secret, he may or may not have complained about physical therapy's timing once or twice). A young man, going through what he was dealing with and he was always concerned for others. He would be concerned for you as well. I know Elijah would want me to tell you to keep hanging in. He would want me to tell you to reach out when you need help or a break. He would want me to tell you that you are not alone; tell you make the most of your Gift. He would want me to tell you to keep fighting because in four short words..."Someone needs you here"

[Click to Read Elijah's Eulogy](#)

## 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](mailto: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



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](#)

### SDS Awareness Ribbons

The long awaited SDS Awareness Ribbons are

Alone we are rare, together we are



**Shwachman-Diamond  
Syndrome  
Awareness Ribbons**

Two layered  
awareness  
ribbon attached  
with a gold pin

\$5 ea  
3 for \$12  
Domestic shipping included



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

Belmont, MI  
Willowick, OH  
Freehold, NJ  
Hawthorn Woods, IL  
Boston, MA  
Mentor, OH  
Berea, OH  
Bremichen, Germany  
Oakville, Ontario

## Thank You For Your Donations

### Donations received between August 16, 2022 - January 27, 2022

John & Wilma Daniels  
Susan Davis  
Lissa Caltrider  
Marsha Misenhimer  
Randall Keyes  
Patricia Walker  
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Benevity  
Blackbaud Giving Fund  
Give Lively Foundation  
Richmond Rotary Club  
Community Fund of the Ozarks



**In Honor of Matt Valiante** - Deana Valiante, Judith Bushelow

**In Memory of Rose Canonico** - Jennifer Avroch, Mark Betz, Frank Canonico

**In Honor of Camden Kilcrease** - Lisa and Steve Kilcrease, Kathy Hymel

**In Honor of Meagan Miller** - Janet Jenkins, Chris Huntington, John Miller

**In Memory of Nico Hernandez** - Priscilla Hernandez, Angie Hernandez

**In Honor of Felicity, Maria, Linc, Charles, Corrina, Miara** - Holly Knight

**In Memory of Michael Billings** - Linda Azzarello

**In Honor of Collin Brown** - Pamela Chapman

**In Honor of Anthony DeRe** - Laura Birro

**In Honor of Keller Wilson** - Florence Owens, Stacey Spires, Joey Spires

**In Honor of Kelsey and Emily Jenuwine** - Diana Murphy

**In Honor of Jax Clark** - Tera Clark, Barbara Branscombe

**In Memory of Betty Hayden** - Claire Fin, Henrietta Strouse

**In Honor of Troy and Kelsey** - Cornelius DeBoer. Jacob DeBoer

**Special Thank You to the dozens of Anonymous and Unnamed Donors**

**Thank you to all those who did Birthday Facebook Fundraisers**

**The Many Supporters Through Various Other Fundraisers**

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**Thank you for your monthly donation**

Indro Hoffmann

Maria Hall

Keung King Man James

Jason Huttinger

Angela Greiss

Ali Elmi

Tag Sale Chick

Eylem Atilgan

**In Memory of Michele Mowery** - Joan & Greg Mowery

**In Honor of Camden Kilcrease** - Lisa Kilcrease

**In Honor of Jonathan and Joseph Wall** - Joyce Wall

**In Honor of Jake Walden** - Julie Walden

**In Honor of Wade Wachter** - Jennifer Wachter

**In Honor of Marissa Avroch** - Dianne Moschetta, Rose Cannonico

**In Honor of Scott, Meagan, & Jonathan Miller** - Pamela Miller, Ann Reed Macke

**In Honor of Riley Laber** - Mary Balint

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

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