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Dear Pamela,

I hope everyone had a fun summer, but summer is coming to an end, and with that, everyone is getting ready for another school year. I hope the kids are as happy to be going back to school as the parents are to see them go.

We attended the World Rare Drug Congress last month. It is a meeting that brings together government officials, drug companies willing to work with rare diseases, data and consulting firms, and patient advocacy organizations. Attendees came from all over the world. We presented a poster about SDS and it was very well received. Many of the over 1000 attendees viewed our presentation, asked questions, and offered assistance in their areas of expertise. We will also be attending the NORD (National Organization of Rare Diseases) Summit in October where we also will be presenting information about SDS as well as learning more ways to help our patients. It is very important to make SDS known to as many organizations and people as possible, as we are an extremely small disease group, especially compared to other rare diseases who can have as many as 100,000 patients.

Additionally, we are proud to say that there are several SDS research projects ongoing in areas of gene and drug therapy as well as other areas. I realize that research is very slow moving, but I, for one, am happy that these researchers are taking their valuable time to devote to helping our patients.

Please keep all of our patients who are having health issues in your thoughts and prayers.

Wishing you a lovely fall.

SDS Strong,

Joan Mowery
President
Shwachman-Diamond Syndrome Foundation

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!

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.

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Support...Research...Cure

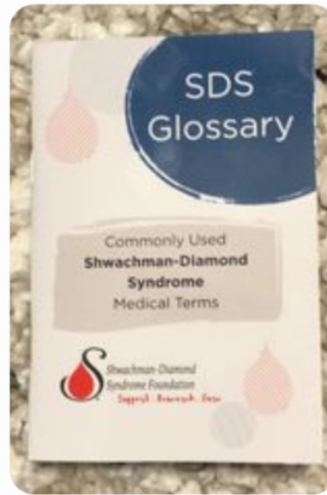
Send us an email when you go to transplant
so we can share hope
info@shwachman-diamond.org

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](#)

Celebrating Our Own

Awesome Addie is SDS Strong

by Amanda Jacobs



Addie's SDS journey started around the age of 9 months when she was correctly genetically diagnosed with SDS. For us, hearing her diagnosis was devastating but it also provided a lot of answers as to her medical struggles. Addie has struggled with nearly every facet of SDS from thoracic insufficiency, pi, malrotation, aplastic anemia, feeding tube dependency, and she is also autistic. With her small rib cage, we consulted with the top VEPTR physician in the country, who was also the founder of VEPTR, Dr. Campbell at CHOP. At a year and half Addie started her VEPTR journey and it has not been an easy road. After the first rod insertion she suffered severe respiratory failure and ended up needing a trach and was ventilator

dependent. She withstood a 5 month long grueling hospital stay where she ended up undergoing 5 major surgeries. She went into the hospital a happy bubbly talking 18 month old and left the hospital a bed ridden, non-verbal, extremely sick child that went home on a ventilator (with trach). It was a complete lifestyle change. I lost my job while I stayed bedside during the entire hospital stay and took another year off before I could return to work. Addie has nearly 24/7 in home nursing care, is seen between 2 hospitals by 10 different specialists between both.

Addie has gone from bed ridden, ventilator and trach dependent to a very active 7 year old that can run laps through the house, detached from being ventilated for over a year and decannulated from her trach which she had for over 5 years!! She has also attended kindergarten this past year,

which she attended twice a week in a classroom with other children with disabilities and thrived! Addie is now working with a communication device that is assisting her in finding her voice, even though it may be electronically. Even though her journey is not complete, she has already overcome so much from the code blues, a year and half of narcotic withdrawal, kicked the vent and trach to the curb, and now is blossoming into a beautiful young girl with a bright and hopeful future.

Although SDS does not define her, SDSF and SDS families have provided our family with a tremendous amount of support and advice along the way. It is an amazing community that we are very proud to be a part of!

Michelle Pluta

I'm Michelle Pluta. I am engaged and have four children. I am a social worker who works with individuals who have disabilities. I am deciding whether to go back to school to be a pharmacy technician.

I have SDS, Shwachman-Diamond Syndrome, and I was not diagnosed until I was age 22. My hematologist was very thorough with the tests and monitored my blood. I also have pancreatic insufficiency. It is hard for my body to digest fats but my pancreas is depleting. My biggest frustration in life is my recurring migraines.

I live in Indiana. My number one goal in my life is to own a one level ranch style home with a little bit of land to put a RV on as well.

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 . . .



For the past six years my wife has 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

SDS Live



Thank you everyone for helping make SDSF Live such a success.

Our upcoming scheduled shows include:

- August 28, 2022 at 7:30 pm EST - Hematology 101 - Dr. Blanch Alter
- September 18, 2022 at 7:30 pm EST - GI Issues - Dr. Amit Grover

We welcome any suggestions for future shows.

Please send any ideas to

SDSFLive@shwachman-diamond.org



Click for SDS Live Videos

Registry Remarks



Updates from the North American SDS Registry (SDSR), August 2022

SDS Registry investigators are collaborating with gene therapy experts to fix the SBDS gene as a new treatment for SDS.

To achieve this goal, we are collecting blood cells from adults aged 18-45 with SDS caused by mutations in the SBDS gene and the adult family members of SDS patients. These blood samples are used in the laboratory to develop effective gene therapy strategies for SDS.

The future goal is to develop gene therapy for SDS. Compensation is provided.

If you are interested in learning more, please contact the SDS Registry at SDSRegistry-dl@childrens.harvard.edu or Dr. Daniel Bauer at bauer@bloodgroup.tch.harvard.edu.

Save the Date - Virtual Shwachman-Diamond Syndrome Registry (SDSR) Family Day

by Cancer And Blood Diseases Institute at Cincinnati Children's

Date and time

Saturday, September 17, 2022
1:00 PM – 5:00 PM EDT

Location

Online event



Please join us virtually and learn about the SDS registry.

SDSR Family Day is an opportunity for patients, families and loved ones to hear updates about SDS. This virtual conference will discuss topics important to both pediatric and adult patients with SDS and their families. Attendees may participate in group discussions with SDS experts on such topics as hematology, surveillance to maintain health, bone marrow transplant, genetics, gastrointestinal issues and nutrition, bone health, and others. SDS Registry investigators will share knowledge gleaned from the SDS Registry and discuss ongoing research to improve the health of people with SDS.

Agenda - Coming soon!

[Click to Register for SDSR Virtual Family Day](#)

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.



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



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 or if you order from Amazon Smile, please set Shwachman-Diamond Syndrome Foundation as your charitable organization. Every little bit helps us fund research so help find a cure for SDS!

Welcome New SDS Families

Collins, MO
New York
Richmond, British Columbia, Canada
Molendinar, Queensland, Australia
San Bernadino, CA
Lancaster, PA
Cheshire, England
Walla Walla, WA
Pittsford, NY
Island of Mauritius
New Egypt, NJ
Philadelphia, PA
Ireland
Port Lexusstad, NC
Beverly Hills, New South Wales, Australia
Nowata, OK
Lincolnton, NC
Sinaloa, Mexico
Williamsport, PA
Asheville, NC
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Arezzo, Italy
Arizona
Miami, FL
Lancaster, PA
Allentown, PA
Breda, IA
Mokena, IA
Sydney, Australia

Landvetter, Sweden
France
Karachi, Pakistan

Thank You For Your Donations

Donations received between April 27, 2022 - August 15, 2022

Stephen Johnson
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Tag Sale Chick
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Amanda Swift
Dava Grammer
John Daniels

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In Memory of John Olivo - Linda and Paul Isben

In Honor of Maggie Collins - Jeffery Clark School

In Honor of Matt Valiante - Deana Valiante, Judith Bushelow

In Memory of Craig Smith - Robert Smith

In Memory of Donabelle Liska - Vicki Walker, Carol Aldridge, Terri Snyder, Mary Jane Bowen, Heather Marshal and Family, Dona Tharp, Deb Howard, Frank Ornelas

In Memory of Jacob Reitenhauer - Julie Blood, Ken and Christine McAllister, Rhea Berger, Linda Larkin

In Honor of Jess Bodron, Camden Kilcrease, Sophie Pilgrim - Tim and Joni Bodron, PrecisionIBC

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 Facebook Fundraisers

Thank you for your monthly donation

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

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

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

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