



Christian DelRe &lt;christandelre@shwachman-diamond.org&gt;

## [TEST] Rachel SDSF Winter 2024 Newsletter - The Latest SDSF News For You

1 message

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Sun, Jan 28, 2024 at 11:23 PM


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Dear Rachel,

SDSF is extremely excited about funding the SDS Registry's new research project. This research has the potential to make the lives of SDS patients happier and less traumatic. We all hate the need for bone marrow biopsies but realize their necessity to look for mutations that may indicate a problem. The possibility that a blood test can provide the same information, about genetic mutations, as a bone marrow biopsy, is fantastic. The researchers will be using samples that they have in the Registry for this project.

Funding costs money. We ask each of you to make a gift to SDSF to fund this research.

**SDSF IS PROUD TO ANNOUNCE THAT WE ARE FUNDING A NEW EXCITING RESEARCH PROJECT THAT CAN BENEFIT ALL SDS PATIENTS.**

The purpose of this project is to improve Surveillance for leukemia risk in SDS.

The researchers are Akiko Shimamura, MD, Ph.D., Kasiani Myers, MD, Coleman Lindsley, MD, Ph.D., and Edie Weller, Ph.D.

SDS patients are at high risk for blood cancers including MDS and AML. Currently, survival is very low once blood cancers develop.

The SDS Registry's studies have shown that regular monitoring of the bone marrow, using specific tests including genetic sequencing for acquired genetic changes (mutation), can identify early signs of impending blood cancers. Identification of high-risk features allows for intervention with hematopoietic stem cell transplants to prevent the development of leukemia.

Annual surveillance of the bone marrow is painful and stressful, so patients are often

reluctant to do this.

The objective of this study is to explore whether **testing for genetic mutations in the blood is an effective screening strategy to identify patients most likely to benefit from a surveillance bone marrow exam.**

THIS STUDY WILL ADVANCE OUR UNDERSTANDING OF MINIMALLY INVASIVE RISK ASSESSMENT FOR PEOPLE WITH SDS.

Joan Mowery  
President  
Shwachman-Diamond Syndrome Foundation



Akiko Shimamura,  
MD, Ph.D.

Kasiani Myers, MD

Coleman Lindsley,  
MD, Ph.D.

Edie Weller, Ph.D.

[Click to Donate](#)

## Ride for Research

by John Wall

At Camp Sunshine this summer, several doctors from the Medical Advisory group presented some of their research to the parents and adults with SDS. They all noted that SDS has such a small population and getting initial funding to do research through NIH is difficult. One researcher at Boston Children's Hospital needs \$100,000 to get started, which was the impetus for doing this fundraiser. While at Camp Sunshine, my wife, Joyce, and I were thinking about how we could raise money for SDSF. Paul and I had been planning this ride all summer so I asked him if he would be willing to do this as a fundraiser; he enthusiastically said yes. . . .

As of this point we have raised \$10,400 for SDSF. . . . We are thinking about a ride across Vermont next year and will try to invite others for another *Excellent Adventure*.



Click to Read John's Ride for  
Research



### Registry Remarks



The SDS Registry team participated in the 65 th American Society of Hematology (ASH) Annual Meeting and Exposition in December 2023. We presented research from the SDSR and established collaborations with providers from around the world.

SDSR investigator Dr. Helen Reed, presented her work on Lymphoid Malignancy in Shwachman-Diamond Syndrome during the ASH Scientific Workshop on Germline Predisposition to Hematopoietic Malignancies and Bone Marrow Failure. The study from the SDSR found an increased risk of lymphoma among patients with SDS compared to the general population. The patients with SDS who had been diagnosed with lymphoma achieved remission after therapy but experienced increased toxicity with standard chemotherapy regimens. Subsequent AML was observed in one patient following treatment with lymphoma. This study expands our understanding of potential medical complications of SDS and informs treatment decisions.



SDSR investigators together with the French neutropenia registry brought together a

SDSR Co-Director, Dr. Kas Myers, was invited to discuss the long-term outcomes and complications in inherited bone marrow failure syndromes, including Shwachman-Diamond Syndrome. Education of medical providers is an important priority of the SDSR. Advances in medical care are made possible by the medical records and samples provided by SDSR participants.

group of SDS experts from around the world to develop an international collaborative project studying leukemia risk in SDS.

## Rare Disease Day Fundraiser 2024



**ALONE WE ARE RARE, TOGETHER WE ARE STRONG**

LUZZE COLE ISAIAH GRILLA AWESOME JAZZ GUELIANA MADON LAVONNE [TAY] [JANE] CAME SMITH OLIVIA MERRILL EPORINE [JANE] NATALIE LIVENGOOD ANTHONY BRIDWAY III AJL BARTZIG CORBYN BARTZIG MICHELLE HOWERY EJ JORDAO PEYTON WEBER CLYTON WALKER ALEXIS KA JANI EMMA THOMAS KAYLA SUPPERNA NORA SUPPERNA JOYCE FITZ LUCAS SOLOMON FLETCHER EMMA GROSSMISCH LIANA BIRNMAN MIL WOLFE VALERIE WOLFE ASHLYN WOLFE WESTON CARTER CHELSE MOLINARD SOPHIE SAVKAS JUDIE BOWMAN SUPER TAYLOR JUNIPER-ANN BOWMAN RYLIE LABER TERRY FINK LIANA BIRNMAN MAX FRYLES ELVIS FUENTES DAVID FUENTES EMMA SILVA MONICA KAYDEN E LEAH GILES PETER GOVALS DELAN THOMPSON	MATTHEW J. TRAMMELL MOS GORGIANO BETTY DELGADO WYATT LEBN MORGAN LEBN LAVYNE SCHENGLER NOAH ISAAH VALENTINE SIMMONA JOCE KELLER WILSON ZOE TUGGLES HEATHER PENNINGER GEORGE JONES ELIJAH MARTINDALE LINDY REUTLINGER JIM REUTLINGER SARAH REUTLINGER FRELJA RAMMOUSEN LINDS RAMMOUSEN JOSHUA JONES GOVANNI INFERRERA ANTHONY DEL RE WILLOW KLINEFELTER KYLEE PRAGER MAGGIE ROY RABUL DODHI ANDREW LILLYWHITE LINDSEY LILLYWHITE WADE W BYRON GROSS KEIGAN BRICE NATHAN PILALA DIANA PALAIA CAMDEN KELCEASE WHITNER WISE MIKEL DJAK JACOB RUTENBERGER SALERNA ROSE JOYCE PULSIC JOHN SAMPLE FLECH VAN WERDEN CAGE YATES LINDSEY YATES BRITTANY LAURE LUCK DUNSON NICOLAS SINGLETON	TAYLOR KRAIGER MAGAN MILLER JONATHAN MILLER SCOTT MILLER FORAN HORN ARIANNA HORN SARIE HORN REID PONS ANGELA THOMPSON AJ PETTELLI MONI MIA JAYDEN SCHWENSKI CHRISTA MORGES HEALING FRENCHY ALEXIA KEAN DELWAR DEVIN WEAVER HELEN CORTEX RAJEE TRACKER CARTER CARY CHASE JASMINE PAGE ALEXIS BLANCHARD BECKER DANIELMAN SARAH HASKAN JACOB COX GRACE COX SAMUEL COX JENNIFER L. HOWER EMERIE GRANT-BUTLER JORDYN ZALAC COLLIN BROWN FRISLEY ROSE NOAH SWARTZ GRACE VAN BRUNT JAKE WALDEN JESSICA BROWN LEAH SUTHERLAND JOSLEY SHAW PHOENIX JANVYS STELLA SWITZ LUCAS SWITZ SRAMUS SILVANE MELISSA KAITLYN BRISHT SAMPSON	ARJAH DEVANNEY MELANIE DEVANNEY AJ PYZC JESSY LN KINLEY ELIASH WILLIAMS MATTHEW VALLANTE LIWA FELICITY LIDAN DANIEL CLAYBORN KUSTY CLAYBORN STEVEN CLAYBORN BRANDON FLETCHER ROMAN SHEH JENNIS ST. HELAINE GRACE DEAN ELIJAH KEELY DREW KENDRIS KYLE KENDRIS HAYZE KENDRIS ZANE CHERNEY LOLA JANE TOFT MYLO BOWMAN BRYE RIDD DAVIDSON BISHOP JACQUELYN POANCI ARJANNA TOLLE HUNTER LANTZ RYAN KIYU DANNY MEDINA KYWSLEE LION DAN THOMPSON BRYAN POKHATA LUCKA HECKOVA LENKA HECKOVA SARA RICHTAROK SMILEY JINOWINE FELISY JINOWINE GAUTHER LACRESSE DIELAN HILBERN JANIN SPATE TRIAN KANKEI LAURA VERSTOFFEN POPPY HAWKIN KANE TAKATA	NOAH SARGENT JAYDEN KNIBBLE TYLER KNIBBLE BRIAN PEREZ MICHAEL WILLIAM BELLING DAVID ARTZ GRACE ARTZ FONA ARTZ JACOB S TON HENDRICK KALI ANDERSON RYAN QUINN BECKEL ANNABELLE GRAE BRAXTON CUMINGS MARISSA AVROCH STELLA LUCAS RYLIE MARK SCHROEDER MICHELLE PUGLIARIS DORGAN BRANDIE CRAPMAN ASHLEE LASER JACKERY BUSH ALEXIS BODENSCHEZ GABRIEL GARCIA BRYN HENDER IBRISS EKAROVA ZACKERY BUSH ALEXIS BODENSCHEZ KAVAN BROWN CHERYN STUMP LEAH GROSS BRIAN J CARTER REE ASHLEY ESTES JAXON CLARK GRACEY N BUSHES MALACH BUSHES ISACH ZINSER MATTHEW ZINSER CHARLOTTE JAYNE HOLLANDS DAVID SMITH FRANK FRANK LUCAS JACOB FOX FRANK PETER BENCZENLITZER ALEXANDER TANNER SPIEL
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 **Shwachman-Diamond Syndrome Foundation**  
Support. Research. Cure.

There is still time to get your Rare Disease Day T-Shirt and to help support our patients and family members. All proceeds from this fundraiser will go directly to the Shwachman-Diamond Syndrome Foundation and will be used to fund medical research to improve treatment for our patients.

Don't forget to wear your shirt on February 29th - Rare Disease Day and tag us on Facebook and Instagram!

[Click to Get Your Rare Disease Day Shirt](#)

## Caroling for a Cure by Christian Del Ré



This past December, the Parent-Teacher Association at my wife's school, P.S. 36, in Staten Island, New York, held a Christmas Caroling event. For the second year in a row, the PTA raised donations from the participants and donated it to a worthy cause, and this year they selected SDSF, in honor of our son, Anthony, who graduated from the school last year. This was a fun event where parents and kids walked the neighborhood ringing doorbells and surprising homeowners; it was like a scene from a Hallmark Christmas movie! We ended at a non-profit, Lou's Helping Hand Foundation, who held a sale of handmade items, and snacks for the carolers, with all proceeds going directly to SDSF. In total, this few hour event helped raised \$1,350.00. We are grateful to the PTA of P.S. 36 and Lou's Helping Hand Foundation for thinking of Anthony and SDSF!

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## SDSF Live



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

[Click for SDSF Live Videos](#)

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## 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](#)

## 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.



## Help Us Find a Cure



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

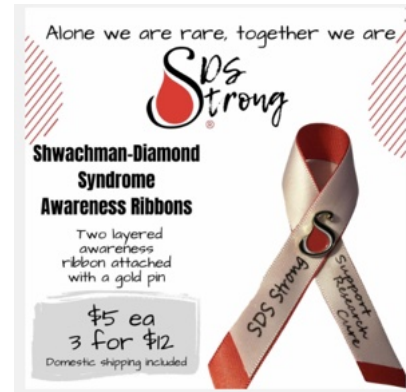
### Get Your Ribbons for Rare Disease Day!

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!

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## 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.

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## Welcome New SDS Families

Germany  
St Louis, MO  
Guatemala  
Jamestown, TN  
Consuma, Italy  
Estonia  
Portugal  
Serbia

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## Thank You For Your Donations

**Donations received between August 16, 2023 - January 24, 2024**

Linda Morgan  
Michael Smith  
Joy Sokolowski  
Nicole Carp  
Lew Sumislaski  
Marsha Misenhimer  
Scott Skibinski

PayPal Giving Fund  
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Pledgeling Foundation  
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Network for Good

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

**In Memory of Michael Billings** - Terry Billings

**In Memory of Nicholas Hernandez** - Feliz Hernandez

**In Honor of Anthony Del Re** - Christian & Gina Del Re, PS 36 PTA, Laura Birro

**In Honor of Booker Dahlman** - Lucian Farrar, April Stobbe, Joan Mowery

**In Memory of Kelsey Jenuwine** - Alan Jenuwine

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**In Honor of Sara Richtarik - Kelly Richtarik**

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**In Memory of Sarah - Mary McVeigh**

**In Memory of Craig Smith - Robert Smith**

**In Honor of Keller Wilson - Stacey Spires, Vernon Snider, Melissa Wright**

**In Honor of Saavin Aidhu - Preet Gill-Sidhu**

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**In Honor of Logan Stone - Matthew Stone, Susan Utz**

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

**In Honor of Betty Delgado - Dale Rohr**

**In Memory of Wayne Bull - Joan Mowery, Gerald King, Julie Ragan, Janice Delgado, Lyndel Bull, Vay Jensen, Judy Wilkinson**

**John's Ride for Research - Stephanie Conklin,**

**In Honor of Ruben Alvarez, Jr - Jill Thiffault**

**John's Ride for Research**

Denise & Phil McNutty    Jennifer Wilcox    Melanie Wixted  
 Tracy Pang    Tricia Cunningham    Scott French  
 Marilyn Scarano    Watkins family    Marianne Rutter  
 Helen Bryant    Kate Prendergast    Debbie & Tim Regan  
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Sharona Zaret in Memory of Michele  
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Lisa Troy in Honor of Jonathan and Joe  
Thuy Nguyen in Honor of Shay  
Matt Stone in Honor of Logan  
Lynette & Allan George in Honor of Quinn  
Al Jenuwine in Memory of Kelsey  
Jen Avroch in Honor of Marissa  
Stacey Spires in Honor of Keller  
Cornelius DeBoer in Honor of Troy and Kelsey  
Silvia Koch-Brown in Honor of Paul Konish

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

**The Many Supporters Through Various Other Fundraisers**

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**Thank you for your monthly donation**

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Keung King Man James  
Jason Huttinger  
Angela Greiss  
Tag Sale Chick  
Eylem Atilgan  
Cara Gallagher  
Indro Hoffman  
Judie Durie  
Tommie Weaver

**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 Marissa Avroch - Dianne Moschetta**  
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**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**

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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@shwachman-diamond.org).

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