

NEWSLETTER

Spring 2006

FAMILY CONFERENCE at CAMP SUNSHINE

Casco, Maine JULY 9 -14, 2006

www.campsunshine.org

MEET LEARN PLAY

***Download application now at web site above
limited space to 40 families***

***FREE
(except travel)***

**Shwachman-
Diamond
Syndrome
Foundation**

710 Brassie Drive
Grand Junction, CO 81506 U.S.A.
1-877-737-4685 (Toll Free)
Fax: 970-255-8293
E-mail: 4sskids@shwachman-diamond.org
Website: www.shwachman-diamond.org

FAMILY CONFERENCE at CAMP SUNSHINE, JULY 9-14, 2006

By now you have hopefully received a letter or e-postcard from us notifying you of the upcoming family conference to be held at Camp Sunshine in Casco, Maine from July 9-14, 2006. This will be quite a different experience from past conferences and we are excited to be able to offer this amenity.

The plan so far is to have a welcome reception, dinner and bonfire, on Sunday to introduce everyone to the camp organization as well as to each other and the visiting doctor specialists who are on our Medical and Scientific Advisory Board. On Monday and Tuesday, the doctors will offer seminars and discussions throughout the day with breaks for meals and to check in with your kids. Topics will include updates on new research, hematology 101, genetics and genetics counseling information, gastroenterology insights, transplant information and more. Meanwhile the kids will be having fun exploring the camp and the fun activities planned for them by the camp with the aid of the 75 volunteers they staff. There is also 24-hour onsite medical support as well as a hospital only 25 minutes away. On Wednesday, the fun activities will resume for the parents as well. There will be a camping overnight for any of the older kids that want to join in, as well as, a "parents night out" for dinner. All activities and meals are completely optional.

The Board of SDSF wants to provide an informational, safe, and fun environment for all attendees and Camp Sunshine fits this criteria. Come meet the doctors and ask them questions and come meet other families and ask them questions knowing Camp Sunshine is the perfect medical, emotional, and supportive safety net under it all.

Log onto the camp web site to download your application. Complete the application along with the paperwork completed by your child's hematologist and mail it in to the camp. Space is limited to 40 families, therefore this is a first come first serve

basis. We have been asked to let the camp know by April 1, 2006 our preliminary number of families coming. If you want to come and haven't sent in your paperwork, please e-mail us and we will forward the information on to the camp. If you do not have access to the internet, please go to your local library or call 1-877-737-4685 and we can mail you an application. If you have questions for the camp itself, please call 207-655-3800 to reach them directly. **Make sure you look at "What to bring to camp" section. The camp does not provide linens, you must bring your own. If you would like to receive linen service, please e-mail: 4sskids@shwachman-diamond.org and let us know. We will arrange this service and pay for it through the Foundation.**

We look forward to **MEETING** you, **LEARNING** with you, and **PLAYING** with you!!!

FEDERAL EMPLOYEES CAN DONATE TO SDSF AT WORK

SDSF has just received a generous donation from a family who lost a son to SDS. For a silent auction held as part of an event for the Combined Federal Campaign, Lynne and Michael McCay, donated an item which sold for \$750.00. Through their kindness, that money has been designated to go to the Shwachman-Diamond Syndrome Foundation via the CFC. **What is the CFC you ask?**

"The mission of the CFC is to promote and support philanthropy through a program that is employee focused, cost-efficient, and effective in providing all federal employees the opportunity to improve the quality of life for all.

As the world's largest and most successful annual workplace giving campaign, each year, more than 300 CFC campaigns throughout the country and internationally help to raise millions of dollars. Pledges made by Federal civilian, postal and military donors during the campaign season (September 1st to December 15th) support eligible non-profit organizations that provide health and human service

benefits throughout the world.

CFC Charities are organizations with status as tax-exempt charities as determined by the Internal Revenue Service under 501 (c) (3) of Title 26 of the United States Code that provide health and human services and that are determined to be eligible for participation in the CFC. Organizations may apply and be listed in the CFC brochure as either a local, national or an international unaffiliated organization or as a member of a local, national or international federation.

Charities that apply to receive funds through the CFC are required to submit to extensive review of their financial and governance practices prior to acceptance. This eligibility review has helped set standards for participation in giving initiatives that transcend the community.”

Thanks to families like the McCays, SDSF received over \$9,000 in 2005. Although this is an arduous process and application to go through each year, it is an invaluable resource for donations.

Thank you to all the families who donate through the CFC.

POLITICS AND OUR CHILDREN WITH GENETIC DISEASES

There is a bill in the House of Representatives right now that can prevent genetic information discrimination (losing your employment or insurance because of your genetic make-up). It is bill number HR 1227. It was introduced by a Republican (Judy Biggert - IL) and it passed the Senate unanimously. The President has said in writing (SAP, February 2005) and in a radio address that he will sign it when it comes before him. With the discovery of and use of more and more diagnostic, genetic testing, this is an issue that will affect our children as they grow up and enter the workforce. If you would like to learn more about this issue and find out how you can help, please log onto: www.geneticalliance.org.

E-MAIL YOUR FRIENDS TO EN- COURAGE MORE CFC DONATIONS

According to Robert Handloff, Ph.D., Manager of the Combined Federal Campaign at the Library of Congress, the main reason people don't contribute to the CFC is: "Nobody asked me."

So, how do we encourage federal employees to donate to CFC? Ask them!!! Here is an e-mail template that you can use to e-mail to 10 friends who can pass it on to 10 friends, etc. urging them to designate a charity on their CFC form next fall when the decisions are called for.

Dear Friend,

If you know someone who is a federal employee, please ask them to **designate #1329** on their CFC form to pledge their donations to Shwachman-Diamond Syndrome Foundation, the patient advocacy, research-granting support organization that my family is a part of due to our child's diagnosis of SDS, a rare bone marrow and pancreatic insufficiency disease. You will be helping not only our child but many children with SDS all over the country. Go to www.opm.gov/cfc to see how your federally employed friends can participate.

Please e-mail 10 friends and ask them to e-mail 10 friends and together we can support this effort. Somewhere amongst all the e-mail addresses, there will be a federal employee who will be willing to help.

Thank you for your kindness.

Just cut, paste and edit to your liking and hopefully we will see our yearly donations rise for 2006. In fact, we can send our non-federally employed friends e-mails reminding them to donate too. You just need 10 e-mail addresses. Thank you for all your support.

HAVE FUN FUNDRAISING!

Hi! My name is Julie and my husband, John, and I have done many fundraisers. We have raised money for important research for SDSF that benefits ALL families dealing with this disease. I have to say that my favorite fundraiser of all is working with local high schools! Almost all high schools every year pick a charity that they raise funds for, and I feel that this may not be known to many of us SDS families looking to pitch in with fundraising for SDS research. I have found that just by calling your local high schools, most will say that they DO raise money for charity. I always ask if I could give a small talk or presentation about SDS to the school or student council in the hopes that they will choose SDS as their charity to work for. In four years, I have had 4 high schools raise money for SDS!

Three years ago, Athens High School choose to sponsor Shwachman-Diamond Syndrome, these students raised over \$15,000. This year I went in and talked to the student council again, and they seemed to love to help needy charities, especially like ours where we do not get government funding. Showing them Patrick's picture and making it personal always helps the students to really connect with what SDS is all about. Next week is their "charity week" and their goal is to raise \$20,000 for SDS research this year!!

For me, it is the easiest way to fundriase. The students do all of the work planning and just keep me updated on how things are going. In the end, SDSF and all SDS families benefit from all their hard work. Thank you AThens High School!!!

Happy fundraising!
Julie Kroppe
jkroppe@wowway.com

SUPER BOWL FUNDRAISER

This year was our 8th annual Super Bowl fundraiser and as always it was an enjoyable event. We rent a hall and provide food and refreshments for everyone to watch the Big Game and play cards. We sell raffle tickets for a Big Screen TV and for a 50/50 cash prize as well as other prizes that are donated by businesses and individuals. This year we donated \$5,000 to benefit all the families and children of SDSF.

This fundraiser continues to be a success because of all the wonderful, caring people that help. My husband, Al, works very hard each year to pull this all together. My father in-law, Ed Jenuwine, still sells more raffle tickets than anyone, my sister, Peggy Lentz, gets all the prizes donated (that involves a lot of phone calling and letter writing), and Al's uncle, Norm Brideau, always donates the TV. Many other families and friends help sell and purchase raffle tickets. I am thankful to know such amazing people.

Sometimes I think that this is too much work, but then I look at my two beautiful daughters and wonder how could we not do this for them. If as their parents we won't fundraise, than who? So, we continue to fundraise until there is no need, until there is a CURE!

Jenny Jenuwine

***NEW FAMILY AND COMMUNITY
PAGE TO BE DEVELOPED ON THE
WEB SITE***

We will be developing a new page on the web site that will list any events that friends, families and communities are producing to raise money and/or awareness for Shwachman-Diamond Syndrome. Please send along any information you have about a fundraiser that you are putting together or have just completed in this year 2006. We will update the listings as appropriate.

We feel that this will be a good way for our SDS community to share our experiences, ideas, and good news about events that we are working on to benefit all of us.

As an example, we will be doing our annual Barn Dance this coming September so the listing will look like this:

Event: Van Brunt 9th Annual Barn Dance - Gracie Fund

When: September 9, 2006

Where: Sherborn, MA

Description: To raise funds in honor of their daughter, Gracie, Blair and Brad Van Brunt have created an invitational party at their house that usually raises between \$35,000 - \$40,000 each year. They ask for a minimum donation of \$100.00 per person. Although this is a private function, please feel free to donate funds. Please make checks payable to: Shwachman-Diamond Syndrome Foundation - Gracie Fund, and mail to Blair Van Brunt, 127 Western Ave., Sherborn, MA 01770.

By listing the address and location of the event, local people accessing the web site who do not know the event organizers can perhaps contact that person for

more information and possibly send a donation.

We hope that you will like this new addition to the web site. Please send me your information about your event and we will add it to our new Friends and Community page.

Blair Van Brunt
blairvanbrunt@comcast.net

***LOGAN STONE'S BLOOD DRIVE
UPDATE***

On November 22, 2005, I hosted a blood drive through the American Red Cross for my Eagle Scout Project. As a person with SDS, it was important for me to do a project that would help people that needed blood. I had to find a place to host it, secure a list of people to come donate, call everybody, get my Scout Troop involved and organized, and make sure everything went smoothly. The Red Cross had established a goal of 30 pints of blood for that day and we actually got 38 pints of blood. There were 7 new donors who gave blood at the drive. The Red Cross coordinator was very excited about the way it turned out. I also educated my Troop about Shwachman-Diamond Syndrome. I really enjoyed doing my project and hope I was able to help others.

I have finished all my merit badges and done my project. I've also had my Scout Master Conference and Committee Board of Review. The last thing I have to do is to meet with the District Representative and hopefully I will be granted my Eagle Scout rank soon.

Thanks to everyone,
Logan Stone, age 16

**CARRIE MARTIN, SON OF 4 YEAR OLD LOGAN,
CREATES CD FOR SDSF FUNDRAISER**

Carrie Martin, from Bradenton, Florida, has written and recorded music that she compiled into a CD released in March, 2006. Carrie has generously decided to donate her proceeds from the sale of the CDs to SDSF. Here is an excerpt of her e-mail to the Foundation that shares her thoughts of her new musical adventure.

“ I am desperately wanting to contribute financially to the research, and ultimate cure, of SDS, but like so many other people, I don't particularly have the funds available to truly make a difference. However, I have come up with a concept in order to raise funds and awareness for SDS. When attending college, I majored in piano and minored in voice and have been musically active since the young age of 4. My father is an accomplished pianist and songwriter, as well as a musical instructor for a large university. He started teaching me piano at a very early age and thus instilled me with a great love for music.

Over the last few years, I have begun writing piano pieces, as well as some piano/vocal songs. I have already begun the recording process and am halfway to completing a 10-song album. I have been doing this recreationally and as of yet, have only been sharing with family and friends.

About six months ago, I had the idea of using my recording projects, and ultimately a completed CD, as a means of raising money for SDS research/cure, as well as overall awareness.”

We are so grateful to Carrie for her efforts and urge all of you to purchase her CD for your enjoyment and all of the SDS patients' benefits. Log on the web site, www.c-lurecords.com/CarieMartin for more details..

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E-MAIL SUPPORT GROUP

Would you enjoy e-mailing other Shwachman-Diamond families? Have you ever thought your child seems to have something you may not think is related to the syndrome? Why not sign up for our e-mail support group through Yahoo. It is a good way to stay in contact with other SDS families and also a great venue for asking questions you may have.

If you would like to subscribe to our support group, the link is: shwachmandiamond-subscribe@yahoo.com

If you would like to look at the guidelines for our e-mail support group, the link is: <http://groups.yahoo.com/group/shwachmandiamond/?yguid=79215263>

If you have any questions, please contact Julie Kroppe at jkroppe@wowway.com

WELCOME NEW FAMILIES

Each year many new families from all over the United States have children diagnosed with SDS. Some of these families may be in your area and we would like to welcome them into the Shwachman-Diamond Syndrome Foundation circle of support.

Youngstown, OH

Rotterdam, NY

Longview, TX

Thomaston, MA

Cranston, RI

West Harrison, IN

Edgerton, WI

REQUEST A BASKET FOR YOUR CHILD OR FAMILY MEMBER IF THEY ARE IN THE HOSPITAL

The Angel Anna Baskets are filled with gifts tailored specifically to each sick child's age and needs, and are sent out to the hospital or the child's home, upon learning of a lengthy hospitalization. Balloon bouquets are also sent out to those children who are temporarily in the hospital or who are going through a particularly rough time medically. It is our way to let these families and children know that we care and are thinking of them during their difficult time. I believe it is a wonderful addition to the family support that SDSF gives to each of our SDS families!

If you would like to request an Angel Anna Basket sent to a sick and/or hospitalized SDS child, or if you would like to make a tax deductible donation to our Angel Anna Basket Project (material or monetary donation), please call SDSF at the toll free number 1-877-737-4685 or contact me personally online at jkroppe@wowway.com or call me at (248) 619-9316. **I will be glad to answer any questions and I appreciate any and all input. Thank you to the many families who have contributed to this project! With love, Julie Kroppe**

F.Y.I.

Axcan Scandipharm, the makers of Ultrase enzymes, ADEKs vitamins, Scandishakes and many other products has included Shwachman-Diamond Syndrome in their CareFirst for CF Program, Comprehensive Care Program and RX Cost Reduction Program. SDS patients who use their products qualify for free and/or discounted products and information. For more information go to their website at www.axcanscandipharm.com and click on Products and Services or call 866-AXCANRX for enrollment information

Thank You to our Donors

(donations December 1, 2005 - March 10, 2006)

Leann & John Briggs
Amber Sanchez
Dr. Steven & Judith Werlin
Ali & Avishan Elmi
Mr. & Mrs. Donald McNew
Russell & Maria Long
Violet & Thomas Bishcoff
Berville Lioness Club
Allstate Giving Campaign
Southeastern Michigan Area CFC
Fort Polk CFC
United Way of Rome, CFC
United Way of Delaware
United Way of Southeastern Connecticut
Kern Inyo Mono County CFC
CFC of Louisville, KY
United Way of Metropolitan Atlanta, Inc CFC
CFC Fall 2004, Ft. Leonard Wood, MO
Global Impact CFC of Natl. Capital Area
United Way of Midlands
United Way of Miami-Dade, Inc.
CFC of Eastern Wisconsin

Gracie Fund

Superbowl Fundraiser 2006

Chuck Bowers
Norm & Mary Brideau

In Honor of Adian Wilson

Kelley, Casey & Moyer

In Honor of Jesse Simpson

Lisa A. Block, MD

In Honor of Kelsey & Emily Jenuwine

Diana & David Murphy

In Honor of the Wall Family

Sharon McBride
John & Joyce Wall

In honor of Kelly Bright

Noson & Michele Fontenot

In Honor of Jennifer Mower

Carol Hershey
Jennifer Ellis

In Honor of Amanda Lamb

Barker High School Staff
Jeff Pyskaty
Gail & Terence Upton
Molly Burns

In Honor of Katie Ruick

June Ruick

In Honor of Patrick Kroppe

John & Julie Kroppe
Merrill & Winifred Pussell
Danijela Stojcevska

In Honor of Dylan Kolar

Robert & Kristine Kolar

In Honor of Joan & Michele Mowery

The Rotary Club of Rockville

In Honor of Melissa Henle

Patrick & Marie Cillo

In Honor of Fallon Veicht

John & Jeanette Brooks

In Memory of Richard Gullet

Ben H. Franken Construction Co., Inc.

Angel Anna Baskets

Jeffrey & Lisa DeGrieck

DREAM BRACELETS

I am making Swarovski Crystal bracelets with Sterling Silver beads with SDSF charms as a fundraiser for SDSF. I have several colors to choose from and can customize for size. I have added a Premier Bracelet style along with the Standard Bracelet style. The Premier includes different shaped Swarovski Crystals, in clear only, with the colored stones. The shapes are cubes, cones, disc, and larger stones. They really add to the bracelet. Colors available are clear, black, dark blue, sapphire, light blue, pink, light amethyst, amethyst, tanzanite (lavender), light red, ruby, garnet, peridot (light green), emerald, white pearl, black pearl, pink pearl and birthstone colors. Include the size you wish. The Standard bracelet is still \$30.00 and the Premier is \$33.00. There is still a \$3.00 shipping charge per order to the same address, additional addresses will be an extra shipping charge. You can order your bracelet in honor of your child and a special card will be sent. It will also appear in the newsletter. An order form can be found on the web site for your convenience, www.shwachman-diamond.org.

Sorry no COD's or credit cards. Please allow 2-3 weeks for delivery. Make your check payable to Jenny Jenuwine. All proceeds go to SDSF.

The bracelets are beautiful and make great gifts. What a great way to support all SDS children. Thank you for your support in our dream to find a cure. Any questions, please contact me directly.

Jenny Jenuwine
15028 Hough, Allenton, MI 48002
810-395-2358
jengrsl2@netzero.net

BRACELET PURCHASES (December 1, 2005 - March 10, 2006)

In Honor of Partick Kroppe
Julie Kroppe

In Honor of Gavin Miller

Barbara Hughes
Amber Sanchez

In Honor of Dylan Kolar

Ginine Lucarello
Carol Kolar
Linda Osborne

In Honor of Ryan Miller

Nancy Miller

In Honor of Teresa Buchanan

Joan Mowery

In Honor of Michele Ellebracht Mowery

Joan Mowery
Sharon Goodman

In Honor of Christian James Allen "C.J."

Dell Allen
Debbie Lovelace
Holly Higgs
Heather Higgs
Brooke Higgs

In Memory of Jason Matthew Bennette

Ginny Bennette
Brad Bennette
Pat Gordon

Established Shwachman-Diamond Groups

Shwachman-Diamond Syndrome Support - Australia

Contact: Joan Buchanan
61 03 5427 0645
email: buchananfam@bigpond.com.au
<http://www.shwachman-diamond.org>

Shwachman-Diamond Support-UK

Contact: Sharon Clusker
Tel: 024-76345199 Fax:: 024-76345199
email: enquiries@shwachman-diamondsupport.org
<http://www.shwachman-diamondsupport.org>

Italy Association for Shwachman Syndrome

Contact: Aurelio Lococo
email: aiss@shwachman.it
<http://www.shwachman.it>

Shwachman-Diamond Syndrome Canada

Contact: Karen Campbell
email: sdscanada@sympatico.ca
<http://www.shwachman.org>

Shwachman Syndrome - Netherlands

email: koster.e@hccnet.nl
<http://www.shwachman.nl/>

REGIONAL PARENT CONTACTS

In a effort to help increase family support, these parents have volunteered to help with questions and concerns:

IN THE USA

Corky DeBoer - IL: (708)532-4954 or oprcrddb@aol.com

Jenny Jenuwine - MI: (810)395-2358 or jengrls2@netzero.net

Kelly Bright -TX: (409)738-2925

Michelle Noble - CA: (760)947-4283 or MNoble2day@aol.com

Cyndi Smith - SC: (803) 781-7100 or Chs5099@aol.com

OTHER COUNTRIES

Sharon Clusker - England:
Sharwk60@aol.com

Lee-Anne Hayes - Australia
61 02 49608428 or hathor@bigpond.net.au

Reinald Baumhauer - Germany
Fax: 049-89-41902871 or
r.baumhauer@mnet-mail.de

Aurelio Lococo - Italy
Tel. e Fax: +049 8736130 or
aiss@shwachman.it

NEWSLETTER IDEAS

Do you have ideas for our newsletter? Do you have a question you would like to ask a doctor? Want to share your story?

Please send your stories and/or questions to SDSF at the address or e-mail them to:

4sskids@shwachman-diamond.org

We appreciate ALL input! We will print stories and answers in future newsletters.

Thank you.

CHANGE OF ADDRESS OR E-MAIL

Please forward your change of address or e-mail to continue receiving your newsletters.

If your newsletter is sent by regular mail, the post office will not forward it to you due to "Bulk Rate" postage being used.

Either call us at **1-877-737-4685** or e-mail us at **4sskids@shwachman-diamond.org** with your changes.

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Coordinator

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Mailing Directory
Peggy Lentz

Attorney
Ann Bodewas Stephens

WE NEED YOUR HELP PLEASE!!!!

Please send you tax deductible gift to: **Shwachman-Diamond Syndrome Foundation**
710 Brassie Drive
Grand Junction, CO 81506 U.S.A.

NAME: _____

BILLING ADDRESS: _____

CITY _____ STATE: _____ ZIP: _____

TELEPHONE: _____

In Honor or Memory of: _____

The children and adults you are helping THANK YOU for caring.
Your generosity in giving is greatly appreciated.

Shwachman-Diamond Syndrome Foundation is a tax exempt organization as described under the Internal Revenue Code, Section 501 (c)(3). Our Tax ID number is 43-1709945.

710 Brassie Drive
Grand Junction, CO 81506
1-877-737-4685

ADDRESS SERVICE REQUESTED

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Disclaimer: The views expressed in this newsletter do not necessarily represent the views of the Board of Directors, Professional Advisory Board or members of the organization. We do not promote or recommend any particular treatment, etc. The relevance of any medical information in this newsletter should be discussed with your physician.