



# *Shwachman-Diamond Syndrome Foundation*

## **NEWSLETTER**

**Spring 2008**

Dear SDS Community,

I am committed to doing whatever it takes to accomplish the goals and mission statements created by past and present board members. It is hard to believe that I am writing this editorial as the new President of the Board of Directors for SDSF. Debbie Kadel did such a great job in leading this Board and Foundation for the past four years and I will do my best to continue the progress. I have been involved with SDSF since 1997 when my family and I attended the first family conference. We then raised \$40,000 in 1998 to support Dr. Johanna Rommens to begin her gene finding journey and have since raised between \$40,000 - \$95,000 each year for research.

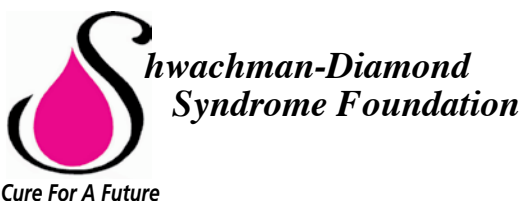
We have had another change within the board this year. We are sad to say that Kelly Bright has resigned her position of Secretary. We are thankful for all her dedication to SDSF over all these years and wish her the best. We are thrilled to announce that Matthew Palmer of Boston has decided to join our leadership team for this organization as Secretary. Welcome aboard!

We are in the process of a new website design which we hope you will find easier to navigate as well as host an abundance of information you need and want. We will keep you posted when it is up and running for you to check out.

The Kolar family sponsored a SDS registry/database meeting back in February which I had a chance to attend. It was a very informative and successful session with many doctors from around the country and Canada. More information inside this newsletter edition.

**I am looking forward to seeing many of you at our 2nd Camp Sunshine Family Conference in Maine, July 20-25, 2008.**

Best Wishes,  
Blair Van Brunt



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# WELCOME ABOARD MATTHEW PALMER

My name is Matthew Palmer and I have just joined the board as Secretary. I am the father of two children, Giorgio (5 yrs. old) and Beatrice (18 months) along with my wife, Elda, we live in Brookline, a town next to Boston, MA. My wife and I both work in the Harvard medical area -- I am a medical physicist and Elda is a research biologist.

Giorgio's diagnosis at 3 months of age, at Children's Hospital Boston, was an experience that we will never forget. Despite being at the center of one of the most concentrated areas of medical expertise in the country and at the very hospital where Drs. Shwachman and Diamond once practiced, we soon understood the isolation that comes from having to deal with such a rare disorder.

Early on, SDSF put us in touch with the broader SDS community and those contacts became valuable resources to us. We are now in touch with a number of affected families and we've taken part in two SDSF sponsored family conferences. In becoming a board member, I'll be taking a more active role in an organization that's been important for us and I hope to be able to support its continued service to the SDS community.

# AXCAN PHARMA PROGRAM UPDATE

Now that winter appears to finally be retreating, we hope that spring proves to be a happy and healthy time for you and your family. Many of you are probably familiar with Axcn Pharma and the services they provide, however you may not be aware of recent changes to their programs. We want to take this opportunity to pass along some updated program information that is available to SDS families.

The programs are summarized below with further information available from their website (<http://www.axcan.com>). Axcn now provides several different programs for individuals with Cystic Fibrosis or Shwachman-Diamond Syndrome.

## **Enzymes & Supplements:**

- CareFirst Program: free enzymes and supplements for children under the age of two.
- Comprehensive Care Program: free enzymes and supplements for individuals older than two years of age.

## **Assist Program:**

- Free medications available based on income and state assistance

## **RxCost Reduction Program:**

- Assists with copays for those individuals with insurance

Individuals may only be active in one program at a time and registration is required. With the new AXCAN Rx Complete Card, program changes can be made with just a simple phone call. An Axcn representative can be reached at 1-866-292-2679 for additional information.

# **FAMILY CONFERENCE AT CAMP SUNSHINE JULY 20-25, 2008**

Come to the fabulous, free, family conference in July at Camp Sunshine in Casco, Maine. All you have to pay for is your travel to get there and there is even free transportation from the airport to the camp. We hope that every family will consider attending camp because of all the information and support for parents and kids alike. Every age group will be catered to by 70 volunteers and the fantastic staff is an integral part of making all families feel welcomed and a part of every activity and discussion group. The camp offers 24-hour onsite medical and psychosocial support with a hospital only 25 minutes away.

We have scheduled a “meet and greet” on Sunday night followed by a children’s entertainer and family bonfire. On Monday and Tuesday during the day, doctors from our Medical and Scientific Advisory Board as well as other doctors who work with SDS patients that SDSF has invited will present their latest research and information and hold open discussions for parents. Topics will include updates on new research, hematology 101, genetics and genetics counseling information, gastroenterology insights, transplant information and more.

While the parents are busy during those two days, the older kids will be busy with “camp”. Camp includes archery, swimming, mini golf, waterfront activities (canoeing, kayaking, and paddleboats), rock wall climbing, volleyball, arts and crafts, playing on the playground, computer time, and the challenge course. The toddlers and nursery age kids are lovingly taken care of by the volunteers in their own play spaces which provide for their every need.

At night there are special activities to reconnect families to each other after a long day as well as to other SDS families. There will be a masquerade

dance with a DJ, carnival night, talent show and a celebrations ceremony put on by the kids and their counselors. There will also be free time for the parents to participate in games organized for them or they can just relax in their individual suites that provide perfect accommodations for up to six.

All of the meals are taken together in the dining hall which will provide a much needed relief from cooking for five days. There will even be an adult only dinner served by candlelight with karaoke music for entertainment that will give parents a little respite and time to themselves.

Camp Sunshine thinks of it all. They have found a way to give families a vacation from cooking, cleaning, worrying about doctor’s appointments, etc. while really giving them time with their loved ones as well as new friends and doctors in a fun, supportive, loving, connecting environment. Please join us by downloading the application from [www.campsunshine.org](http://www.campsunshine.org), filling it out and sending back to camp or call them at (207)655-3800 to have an application sent to you.

SDSF looks forward to seeing you and your family in Maine. If you can’t make it, we will provide a summary of adventure and seminars in the next newsletter.

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## **CYTOGENETIC RESOURCES**

If you are looking for in-depth information on cytogenetic results, an excellent source is: <http://www.kumc.edu/gec/prof/cytogene.html>. This website is a compilation of links to images, educational resources, lectures, and support groups all focused on cytogenetics. Although not for those new to deciphering medical results, those that are ready for more detailed information should find it very useful.

# FAMILY SHARING PAGE

## TONY PARK'S STORY

My name is Susan and I am a mother of an SDS child. My son, Tony, was diagnosed when he was 2 years old and like most others this diagnosis came after many infections and wrong diagnosis. We were relieved to finally know what was wrong with our son but were distressed to find out all the possible complications of SDS. As it turned out in Tony's case the complications were minimal, that is until he reached puberty!

Just after his 15th birthday, he woke up one day and told me his knee was aching. I thought he slept on it wrong so I showed him some stretches to get the kink out and told him to just take it easy that day and try not to play football. By 3:00PM he was running a fever so high he was shaking and his knee was seized into place. I rushed him to the hospital where they ran cultures and blood work. I called his hematologist who didn't work out of that hospital and asked him to come take a look for us. When he got there, he ordered some extra blood tests which simply came back usual, low counts all around. They did an ultrasound and an MRI on his knee and couldn't find any reason for the pain Tony was feeling. The ER doctor as well as our hematologist felt that the pain might have been caused by an infection so they put him on a broad span antibiotic until they got the test results back from the cultures. The preliminary cultures at 24 hours showed no infection and after four days on the antibiotic, he was back to normal. His leg wasn't bothering him, his fever was normal and the 48 hour cultures showed no infection so the antibiotics were stopped and we were sent home.

The next morning he went to school and everything was fine. That evening at the dinner table he told me that he was feeling tired and he went to his room to lie down and play video games with his sister. That is when the projectile vomiting began and I called the hospital and they told me that because he wasn't running a fever and his cultures had been normal, I should chalk it up to a bug that he had most likely picked up at school. They told me that I could bring

him back if I wanted but that they would only keep him in a room and keep an eye on him. Tony told me he didn't want to go back to the hospital so I kept an eye on him at home. The next afternoon it wasn't getting any better so I called the hematologist who asked me to bring him right over. When we got there he checked Tony over and told me that he had made arrangements for his colleagues at the children's hospital, who were more familiar with these types of things, to take a look at him. They arranged for him to be admitted to the Q cluster, which I later found out is the Oncology ward. This is where I got scared. A few minutes later a team of about 8 doctors strolled into the room and introduced themselves. They explained that they were the diagnosis team for this ward and they all specialized in different fields. They would run some tests collaboratively until they narrowed down what the problem was and then they would make sure he was taken care of by the best physicians for the problem at hand. The tests began right away (blood work, x-rays, biopsies, you name it). After two days we were taken into a small meeting room and introduced to the resident family therapist. My heart sank, I knew that if they were bringing in the psychiatric team things weren't going to be easy. The team introduced us to the Oncology transplant doctor and his assistant, they explained that Tony had gone into complete bone marrow failure and had subsequently developed Osteomyelitis in his knee and had 50% chance that his leg would need to be amputated. At this point the psychiatric team started talking, I am not sure exactly what they were saying but I told them "NO" Tony is a fighter and he will beat this.

They started to get rid of the infection they would have to put him on a high dose of intravenous antibiotics for about 8 to 10 weeks. They further explained that a normal IV line is only good for 3 days so in order to accommodate that he would need a PICC line inserted in his arm and fed through the vein into the opening to the heart. He went into surgery that afternoon, they gave him some medication to put him under and this is when we found out he is allergic to the usual anesthetic

# CARING SUPPORT FOR THE CAREGIVER

to put children under. His heart stopped beating and they had to administer atropine to get his heart going again, needless to say, surgery was cancelled for that day. The next day they tried with a different anesthetic but the PICC line wouldn't cooperate, by the third attempt they were successful. After a couple of days I took a crash course on how to use and care for a PICC line and portable IV pump and then we were sent home with all the supplies needed. He was exempt from the end of the school year and his exams and spent the whole summer unable to participate in normal teenage activities.

In August the line was removed and we received bitter sweet news, the infection cleared up but he would have to go to transplant right away or other infections would start soon. A new surgery was performed and a broviac line (a permanent IV line that goes from the chest to the neck to the vein into the heart) was inserted. After a few days training on how to care for this new line we were sent home until the end of September but continued to have many appointments until his transplant. On October 4, 2005, Tony went into transplant with his sister Ashley being the donor. She was very brave! Since then Tony has gone back to school and is doing OK. Still, after two years, his transplanted marrow has not fully taken over. His XY Fish number, the number that tells what percent is Ashley's vs. Tony's marrow, continues to fluctuate and there is a good chance he will have to go through this process again. We are told it is quite common for the first attempt to fail and the second to be successful. Tony is being followed by the Toronto Sick Kids re-transplant team but will be moved to an adult hospital in May when he turns 18. We are apprehensive about leaving the children's hospital but I guess all good things must eventually come to an end.

The silver lining is that because Tony is an SDS child, the symptoms of the Osteomyelitis were evident very quickly which helped to save his limb. Without this infection, we may not have known that he had gone into bone marrow failure which may have led to an even bigger, perhaps irreparable infection. I know, not much of a silver lining....you have to really want to see it!!!!

Having a chronically ill child or family member with a progressive illness is a very stressful situation for everyone involved and finding ways to keep family and friends far and near updated can add to an already stressful situation. If you are finding it hard to keep those worried about you and your family up-to-date, you might want to consider checking out Caringbridge ([www.caringbridge.com](http://www.caringbridge.com)) or Carepages ([www.carepages.com](http://www.carepages.com)) websites. These sites and others like them offer free website space for those in need of support during an illness or long-term recovery.

They provide not just free space but also give you templates and tools to make creating your personal website easy and fun to do. They typically provide templates for a journal area (where a patient or caregiver can write a short message about what is happening), a picture gallery (where photos can be uploaded and shared), and an area for visitors to leave messages of support, concern and encouragement. The websites, although on the internet, can be made public or private (password protected) depending on how you like it.

Hope they are helpful to everyone!

# SPOTLIGHT ON RESEARCH

## **A STUDY INVESTIGATING HEMATOPOIETIC CELL TRANSPLANTATION USING A REDUCED INTENSITY CONDITIONING REGIMEN FOR THE TREATMENT OF PATIENTS WITH SHWACHMAN-DIAMOND SYNDROME**

Drs. Lauri Burroughs, Ann Woolfrey, and Rainer Storb of the Fred Hutchinson Cancer Research Center (FHCRC), in collaboration with Drs. Akiko Shimamura and Siobhan Keel, experts in the field of pediatric and adult bone marrow failure at the Children's Hospital and the University of Washington Medical Center, are investigating a new transplant approach for the treatment of patients with Shwachman-Diamond Syndrome (SDS). At the current time, successful cures for the hematopoietic complications of SDS have been attained only after hematopoietic cell transplantation (HCT). However the typical HCT procedure uses an intensive conditioning regimen (chemotherapy or radiation therapy), which may cause serious complications. Indeed, SDS patients seem to be more sensitive to the conditioning regimen and as a result more likely to suffer complications for the transplant procedure. To address this serious problem, the doctors at Fred Hutchinson Cancer Research Center have developed a new transplant procedure, based directly on the pioneering research of Dr. Storb and his colleagues. The new transplant procedure is termed a "mini-transplant" because much of the conditioning regimen is more gentle. The "mini-transplant" procedure has been used successfully for HCT from both HLA-matched and mismatched related and unrelated donors in the treatment of more than 12,000 patients with various malignant and nonmalignant blood disorders. The advent of the

"mini-transplant" procedure has improved the success rate of HCT for many patients who otherwise would be considered too sick, too old, or too risky to undertake a typical HCT conditioning regimen. The doctors at the FHCRC believe that the "mini-transplant" procedure has the potential to improve outcome for SDS patients as well.

The Seattle Cancer Care Alliance (SCCA) is a comprehensive medical center that unites the expertise of the FHCRC with two other internationally renowned institutions - the University of Washington Medical Center and the Children's Hospital & Regional Medical Center. Patients are offered state of the art multi-disciplinary medical care and are provided with excellence in nursing care, child life, pharmacy and psychosocial support which are all vital in the care of patients. The SCCA has a long history and commitment to advancing the field of bone marrow failure and HCT. No matter what treatment is given, every patient received specialized attention and support to help them and their families through a difficult time.

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## **DR. RICHARD HARRIS THE BONE MARROW FAILURE CLINIC AT CINCINNATI CHILDREN'S HOSPITAL**

Dr. Richard Harris, Director of the Bone Marrow Failure Clinic, has been at Cincinnati Children's Hospital since 1979. He started the bone marrow transplant program in 1980 and this program has developed into one of the premier and largest pediatric transplant programs in the United States. Dr. Harris now focuses his efforts on bone marrow failure syndromes, including idiopathic aplastic anemia, Fanconi anemia, Shwachman-Diamond Syndrome,

Diamond Blackfan anemia, dyskeratosis congenita, congenital amegakaryocytic thrombocytopenia, severe chronic neutropenia and other hereditary causes of bone marrow failure. The bone marrow failure clinic sees about 50 new patients a year and actively follows over 200 patients with various forms of bone marrow failure. Besides Dr. Harris, two other physicians actively see these patients: Dr. Stella Davies and Dr. Parinda Mehta. Dr. Davies is now the head of the transplant program and is internationally known for her expertise in bone marrow transplantation. She has a strong interest in marrow failure syndromes as well. Dr. Parinda Mehta trained at Cincinnati Children's and has taken a special interest in this group of patients as well.

Children who come to Cincinnati Children's for evaluation can expect to be here for 2-3 days or more depending on their particular circumstances. The evaluation is comprehensive in that most patients are not only seen by Dr. Harris and/or others in the Bone Marrow Failure Clinic, but may be seen by an endocrinologist, gastroenterologist, cardiologist, dentist or other subspecialists such as a geneticist, pulmonologist, or urologist. The specialists who see these patients are hand picked for the specific expertise in their subspecialty relative to bone marrow failure patients. The goal of the visit is generally to completely evaluate all the organ systems which are indicated for the particular marrow failure under consideration. Some children come without a specific diagnosis, and in this situation the appropriate genetic and other testing is done in an attempt to arrive at a concrete diagnosis. However, it is clear that not all children will be able to leave with a specific diagnosis. It is hoped that eventually we will find genetic causes for most patients with hereditary bone marrow failure syndromes.

Some children with marrow failure syndromes require a bone marrow transplant to cure either the marrow failure itself or to treat the intercurrent development of myelodysplastic syndrome (MDS) or leukemia. Many marrow failure syndromes have a high risk for the development of abnormal cytogenetic clones, MDS or leukemia. The BMT program at Cincinnati Children's has been a leader in the development of relatively safe approaches to transplant for these

children. The Cincinnati BMT program is well known for its expertise in transplantation of children with Fanconi anemia. Now much emphasis is being placed on improving the outcomes of transplant for SDS. Children with SDS receive a preparative therapy which is fairly low in toxicity and results in excellent engraftment without significant graft vs. host disease. The first seven children with SDS treated with this preparative therapy are all alive and well. The preparative therapy includes fludarabine, Campath monoclonal antibody and melphalan - specifically avoiding total body irradiation and cyclophosphamide, two agents which children with SDS do not tolerate well. A journal article on this experience is in press in the medical journal *Bone Marrow Transplant*.

Dr. Harris will be at the SDS Family Meeting at Camp Sunshine in Maine this summer to present his results with transplant for SDS and will have time to meet with any families who wish to do so. Dr. Harris is also involved in the development of a North American SDS Registry and the progress on the development of this registry will also be reported at the Camp Sunshine meeting.

Referrals to the Bone Marrow Failure Program at Cincinnati Children's can be made by contacting one of the BMF coordinators at 513-636-3570 or by emailing Dr. Harris directly at [Richard.Harris@cchmc.org](mailto:Richard.Harris@cchmc.org). If patients self-refer, then Dr. Harris will need to contact the child's physicians to obtain medical information. He recommends parents discuss a potential referral with their child's local hematologist in advance to allow for a smooth referral process.

#### **Contact Information:**

**Dr. Richard Harris, MD:** Director Bone Marrow Failure Clinic, Professor, Division of Hematology/Oncology and Bone Marrow Transplantation, Cincinnati Children's Hospital, 3333 Burnet Avenue, ML 7015, Cincinnati, OH 45229, 513-636-3570 (BMF coordinator), 513-636-7951 (fax), [Richard.Harris@cchmc.org](mailto:Richard.Harris@cchmc.org)

# **SDS PATIENT REGISTRY/DATABASE UPDATE**

The need for establishing a registry/database about Shwachman-Diamond Syndrome patients has been known for a long time, decades in fact; but it has always been so hard to collect data from such a small group of scattered patients all over the world. To be able to collect a standard set of data such as gender, enzyme levels, CBCs and bone marrow biopsy results and to store all that data in one place would help promote more ideas for research for all aspects of the disease and for strategies towards symptom management, clinical and drug trials and potentially a cure. However, it is very expensive to establish this kind of database because it takes so much time to think through, organize and fund. There are so many questions that arise: what to include on the forms/consent forms that patients will be filling out, budget issues, legal matters of who owns the data, where the data will reside, who will do the data entry, whether the doctors who take the time to fill out the forms are reimbursed, should there be a phone number manned by a nurse who can answer questions for patients, will the data be able to be remotely input and accessed and if so how is security of the data to be maintained, will there be statisticians to understand the data, who will be on the advisory board for this endeavor, will there be money for a tissue bank, who will verify the data, how do you incorporate the issue of patients who do not have the SBDS gene yet have all the symptoms and the list goes on.

The process of answering these questions started in February 2006 in Verona, Italy where Dr. Peter Durie began to champion this cause and found funding from the company Altus Biologics Inc. to host a meeting in Italy and recruited 18 doctors from eight different countries to attend. Since then there have been seven more meetings held in Toronto, Washington, D.C., and Maine which have been funded in full or in part by SDSF. The latest meeting was held in Long Island, NY on February 3rd & 4th, 2008, funded and hosted by the Kolar family who have a young boy with SDS. Forms have been created that ask many questions

about a patient and their history, a collaboration has been worked out with the Severe Chronic Neutropenia Registry to use their existing framework and grants are being written to garner funding from the National Institutes of Health as well as from the Kolar family and SDSF.

Progress is being made. This is a very exciting step forward to help the patients of SDS both here in the United States and worldwide. We will keep you posted!!!

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## **NEWSLETTER ADDITION:**

### **CONGRATULATIONS ARE IN ORDER!!**

We would like to start a new feature in our newsletters highlighting the accomplishments within our SDS Community. These can include anything from a piano or ballet recital, sports victory, acceptance to college, and the announcement of a successful event sponsored by those to help support SDS (bone marrow or blood drive). These events do not need to be done by only those affected with SDS.

Help us make this an outstanding part of our newsletter by getting the word out and sending your highlights to:

Donna Garfield, Newsletter Editor [dkgarfield@garfieldhome.net](mailto:dkgarfield@garfieldhome.net)



## JOIN OUR “CLUB” FOR ADULT SDS PATIENTS

SDSF is becoming increasingly aware that many of our children are reaching or soon will be reaching an age when they are no longer able or wish to be seen within the pediatric medical community. Older patients also have additional and/or different social and other concerns from children with SDS. For this reason, we are starting a “club” for older and adult patients. Some of the areas we will be approaching are establishing referrals within the adult medical community of physicians who have knowledge and/or experience in treating adult SDS and other BMF patients. In addition, the club plans to set up a referral file to direct adult patients to those who can assist them in obtaining health and life insurance as well as their medications.

We would like input from both the patients themselves and/or their parents with any information or suggestions you might have about what else can be done. Please send your thought and ideas to SDSF by either calling 1-877-737-4685 or emailing us at [4sskids@shwachman-diamond.org](mailto:4sskids@shwachman-diamond.org).

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### SDSF DREAM BRACELETS FUNDRAISER

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](http://www.shwachman-diamond.org). Sorry no COD's or credit cards. Please allow 2-3 weeks for delivery. Make your check payable to SDSF and mail to 127 Western Avenue, Sherborn, MA 01770.

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  
810-395-2358  
[jengrsls2@banyanol.com](mailto:jengrsls2@banyanol.com)

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## BRACELET PURCHASES (December 1, 2007 - April 30, 2008)

Sarah Dolby  
Glen & Cathy Watson

**In Honor of Kaitlyn Bright**  
Noson & Michele Fontenot  
Lori Ess

**In Honor of Jaxon Knoble**  
Sindy Knoble

**In Honor of Brendan Murphy**  
Nancy Cunard

**In Honor of Matthew Valiante**  
Deana Valiante

# AMERICA'S GIVING CHALLENGE

We wish to extend our heartfelt thanks to everyone who contributed to SDSF for the America's Giving Challenge. A special thanks to all of you who encouraged friends and family to also donate. Together we raised over \$3,000.00 for SDSF. Because of your generosity, we were also awarded an additional \$1,000.00 from Parade Magazine and the Case Foundation, the Challenge sponsors, for having a high number of unique donors to our cause. TOGETHER WE CAN DO ANYTHING!

Lou James  
Atherton Ryan  
Kristin Khalifa  
Kristi Slimak  
Albert Larson  
Geraldine Cole  
Harold Sample  
Francine Galko  
Marilyn Grabowski  
Kathy Young  
Steven Lebowksi  
Lawrence Panych  
Joan Poupard  
Brandon Woudstra  
Deana Valiante  
John Rod II  
Theresa Henle  
Michael Grizenko  
Sue Furry  
Elda Arrigoni  
Robert Budi  
Tere Hayward  
Charles Guttman  
Walter Beebe-Center  
Carol Lee  
Christiane Weyer  
David Andrews  
Karen Woudstra  
Richard Johnson  
Jim Quintana  
Annette King  
Joshua Thompson  
Daniel & Bonnie Westermann  
Joyce Wall  
Bryan Sample  
Jonathan Locker

## **In Honor of Brittany Kadel**

Donna Garfield  
Jodee Cronk  
Cindy Haerle  
Cherlyn Crawford  
Kimberly Latta  
Gwen Eller  
Joan Mulleady  
Debbie Kadel  
Lucy Martinez  
Linda Tucson  
Jill Cordova  
Kerry Turner  
Kerry Kadel Phillips  
JoDeen Relph  
Martha James  
Robert Schirer

## **In Honor of Michele Ellebracht Mowery**

Sharon Goodman  
Barbara Hagelstein  
Gregory Mowery  
Colleen Appel  
Joyce Serra  
Aimee Mowery  
Jenelle Leighton  
Mr. & Mrs. James Dwyer, Jr.  
Bill Olwig

**In Honor of Patrick Kroppe**

Julie Kroppe  
Michael Carpenter  
Pamela Carpenter  
Jennifer Shea  
Elizabeth Mayne  
John Kroppe  
Patricia Kroppe  
Patricia Serafini

**In Honor of Erin Johnson**

Joan Johnson  
Lois Hellberg  
Madalaine Thornsberry  
Patricia Kerl  
Eric

**In Honor of Collin Brown**

Debbie Brown  
Mike Brown  
Judy Salter  
Sharon Smith  
Pat Murdock  
Pamela Chapman

**In Honor of Dylan Kolar**

Jennifer Kolar  
Samantha Schildknecht  
Patricia Egan  
Carol Kolar

**In Honor of Troy & Kelsey DeBoer**

Cornelius DeBoer

**In Honor of Gavin Miller**

Amber Sanchez  
Jon Strohbehn

**In Honor of Logan Stone**

Susan Utz

**In Honor of Amanda Lamb**

Sharon Lamb

**In Honor of Ryan Miller**

Nancy Miller

**In Honor of Emily & Kelsey Jenuwine**

Jeanette Jenuwine

**In Honor of Chris Garfield**

Stefanie Holloway

**In Honor of Giorgio Palmer**

Sally Guy  
Matthew Palmer  
Rita Salzer

**In Honor of Gracie Van Brunt**

Blair Van Brunt  
Anne MacKenzie

**In Honor of Sophia & Ava Salzer**

Louise Palmer

**In Honor of Davison Bishop**

Joni Dean  
Jill Eaton  
Phillip Bishop  
Cheryl Henkenius

**In Honor of Logan Martin**

Karen Martin

**In Honor of Andrew Bull**

Doris Bull

**In Honor of Aisling Donahue**

Maura Ryan-Donahue

## 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 this support group, the link is: [shwachmandiamond-subscribe@yahoo.com](mailto: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](mailto:jkroppe@wowway.com)

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## WELCOME NEW FAMILIES

Each month 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.

Alexandria, VA  
Timberlake, NC  
Washington, DC  
Rock Hill, SC  
Webberville, MI  
Merced, CA  
Eaton, OH  
Indian Head, MD  
Elk Grove, CA  
Oak Park, IL

## 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 [psbishop1@yahoo.com](mailto:psbishop1@yahoo.com) or call me at (515)252-7445. 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!

### F.Y.I.

Axcan Scandipharm, the makers of Ultrase enzymes, ADEK vitamins, Scandishakes and many other products has included Shwachman-Diamond Syndrome in their patient support program. SDS patients who use their products may qualify for free and/or discounted products and information. Please note that Axcan Scandipharm patient support program has changed. Patients are no longer required to mail in receipts and forms in order to receive program benefits. The new card, AXCAN Rx COMPLETE card, will allow you to receive your program benefits more efficiently. To take advantage of this exciting new program card or to ask questions about it, please call the AXCAN Rx COMPLETE Program line toll-free, at 1-866-AXCAN-RX (1-866-292-2679), Monday-Friday, between 8:00 a.m. and 8:00 p.m., EST.

# Thank You to our Donors

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## Established Shwachman-Diamond Groups

### **Shwachman-Diamond Syndrome Support - Australia**

Contact: Joan Buchanan  
61 03 5427 0645  
email: [buchanan.joan@gmail.com](mailto:buchanan.joan@gmail.com)  
<http://www.shwachman-diamond.org>

### **Shwachman-Diamond Support-UK**

Contact: Sharon Clusker  
Tel: 024-76345199 Fax:: 024-76345199  
email: [sharwk60@btinternet.com](mailto:sharwk60@btinternet.com)  
<http://www.shwachman-diamondsupport.org>

### **Italy Association for Shwachman Syndrome**

Contact: Aurelio Lococo  
email: [aiss@shwachman.it](mailto:aiss@shwachman.it)  
<http://www.shwachman.it>

### **Shwachman-Diamond Syndrome Canada**

Contact: Heather Norton  
email: [sdscanada@sympatico.ca](mailto:sdscanada@sympatico.ca)  
<http://www.shwachman.org>

### **Shwachman Syndrome - Netherlands**

email: [koster.e@hccnet.nl](mailto: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 [opcrccdb@aol.com](mailto:opcrccdb@aol.com)

#### **Jenny Jenuwine - MI:**

(810)395-2358 or [jengrls2@banyanol.com](mailto:jengrls2@banyanol.com)

#### **Kelly Bright -TX: (409)738-2925**

#### **Donna Garfield -VA**

(703) 731-7889 or [dkgarfield@garfieldhome.net](mailto:dkgarfield@garfieldhome.net)

#### **Michelle Noble - CA:**

(760)947-4283 or [MNoble2day@aol.com](mailto:MNoble2day@aol.com)

#### **Cyndi Smith - SC:**

(803) 781-7100 or [Chs5099@aol.com](mailto:Chs5099@aol.com)

### OTHER COUNTRIES

#### **Sharon Clusker - England:**

[Sharwk60@btinternet.com](mailto:Sharwk60@btinternet.com)

#### **Lee-Anne Hayes - Australia**

61 02 49608428 or [hathor@bigpond.net.au](mailto:hathor@bigpond.net.au)

#### **Reinald Baumhauer - Germany**

Fax: 049-89-41902871 or  
[r.baumhauer@mnet-mail.de](mailto:r.baumhauer@mnet-mail.de)

#### **Aurelio Lococo - Italy**

Tel. e Fax: +049 8736130 or [aiss@shwachman.it](mailto: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 to our address or e-mail them to: [4sskids@shwachman-diamond.org](mailto: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 consider receiving this newsletter by e-mail to save our foundation money that we can put towards research and save trees to help our planet.

Please send all snail and e-mail address changes right away. If the newsletter is sent by US mail, the post office will not forward it due to "bulk rate" postage being used.

Either call us at **1-877-737-4685** or e-mail us at [4sskids@shwachman-diamond.org](mailto:4sskids@shwachman-diamond.org) with your changes.

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## WE NEED YOUR HELP PLEASE!!!!

Please send you tax deductible gift to: **Shwachman-Diamond Syndrome Foundation**  
127 Western Avenue, Sherborn, MA 01770 U.S.A.

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**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.



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