



Cure For A Future

Shwachman-Diamond Syndrome Foundation

NEWSLETTER

Winter 2009

WHAT A YEAR!

In order to plan for SDSF's and the SDS community's future, I find myself reviewing this past year of 2008. What a year!! So many things happened within our SDS community this past year besides welcoming so many new families to our community!

It started out with a fundraising challenge that was brought to us by Joan Mowry (aided by Debbie Kadel) through the Parade Magazine. Many people participated and \$4,000 was raised for SDSF. In addition to this fundraising, our total fundraising efforts for 2008 were \$99,000.00. We added the SDS rubber bracelets to our bracelet fundraiser which has been a big hit. If you don't have one, go to the web site and order one now. We also created a fresh new look and feel for the web site. We now have an intern (as of today January 13th!!) helping us update the web site so that we can bring you current information more frequently. If you have a gathering of SDS families or something you want to share with the SDS community, send us your pictures and your stories. We will try to accommodate your requests.

We planned the 2nd Family Conference at Camp Sunshine this past summer that was fabulous!

There were many new and wonderful faces that joined us and we had 6 terrific doctors/scientists who traveled far and wide to come and educate us. Dr. Peter Durie,

Dr. Johanna Rommens, Dr. Akiko Shimamura, Dr. Richard Harris, Dr. Elizabeth Kerr and Lynda Ellis, RN were on hand to answer questions and give helpful presentations about SDS.

We added a new member to the Medical Advisory Board named Dr. Monica Bessler who will help us navigate and educate the transition from pediatric to adult care for SDS patients. She is an adult hematologist from St. Louis who has been studying bone marrow failure syndromes for a long time. We currently have 11 board members on our MSAB now!

A truly exciting event has happened and that is the creation and opening of the North American Shwachman-Diamond Syndrome Registry that is based out of Seattle and managed by another Medical Advisory Board member, Dr. Akiko Shimamura. This has come after so much work and planning by many wonderful doctors including Dr. Shimamura, Dr. Peter Durie, Dr. Johanna Rommens, Dr. Blanche Alter, Dr. Johnson Liu, Lynda Ellis, RN, Dr. Richard Harris, Dr. Frederick Goldman, Dr. Jeff Lipton, Dr. Adrianna Vlachos, Dr. David Dale, Dr. Steven Werlin, and with the majority of the funding by the Kolar family of given in honor of their SDS child, Dylan. SDSF participated in the funding as well.

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Cure For A Future

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Syndrome Foundation

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Our last event for the year was attending the American Society of Hematologists 50th Annual Conference. I have written more about the conference in this newsletter. Other things that have been worked on throughout the year are changes in the grant offerings to potential researchers and scientists as well as a new “Guide to Understanding SDS” booklet that is being created and compiled by members of the Medical Advisory Board of the Shwachman-Diamond Syndrome Unity – an international board of doctors and scientists who get together at the bi-annual SDS Scientific Congress. The next congress is planned for June 2009 in Amsterdam. Representatives from SDSF will be attending.

So that’s it!! A very busy year! Please feel free to contact us if you have questions about any of these events. As a volunteer board of directors, we do our best to get back to inquiries but I do realize that we fall down sometime. So just feel free to send the reminder that you need an answer/help/advice etc. We aim to serve!

LETTER WRITING CAMPAIGN TO RAISE FUNDS FOR SDS

I want to re-introduce the idea of a letter writing campaign as an easy way to ask friends and family for help in fundraising. I recently spoke with the executive director of Fanconi Anemia Research Fund who said that their 2008 letter writing campaign through their family and patient community brought in \$2.1 million dollars!!

So let’s get hopping and bring in our own funds to support the efforts of SDSF which in turn support you! Here below is a sample that you can copy and use or feel free to edit or even create your own letter entirely. My personal opinion is to keep things positive and informative and limited to one page. This has worked for me. I conducted a letter writing campaign that yielded \$35,000. I would use your own stationary and we can provide the envelopes for you. Better yet, if you do an email campaign, you won’t need any stationary or stamps!! Just make sure to follow up with the recipients to ensure that they received your email and that it didn’t go into their spam folder. If you are asking corporate donors, ask for some stationary from the SDSF Administrative Assistant, Kim McDowell, info@shwachman-diamond.org.

Here goes (and this will be available on the web site for future use):

Dear Family and Friends,

As you may know, our (family member, relation to you, and name) has Shwachman-Diamond Syndrome. This disease is diagnosed in patients with bone marrow dysfunction (anemia, neutropenia or pancytopenia, multiple infections, bone marrow failure and higher risks for MDS, AML or ALL leukemias), pancreatic insufficiency (children are unable to digest food without pancreatic enzymes), skeletal abnormalities (bone growth doesn’t match the age growth), and other lesser reported symptoms involving the lungs, heart, and liver.

We are writing to you to ask you to send in any amount of money that you can to help us help (name of child) through the efforts of Shwachman-Diamond Syndrome Foundation.

Shwachman-Diamond Syndrome Foundation was started in 1994 by a mother of an afflicted child and has grown to serve over 300 families and their afflicted ones as well as hundreds of medical professionals who ask for and receive information from it. It was the first SDS organization in the world and it spawned numerous other support groups due to its leadership and vision. With only 7% of our revenue

going to administrative costs, 93% of every dollar donated goes to the activities listed below.

Activities supported and funded by SDSF are sending New Family Packets comprising of pertinent information for new families to learn about SDS, advocating grants for and fund research, baskets to hospitalized patients, providing email/phone family support, publishing tri-annual newsletter, attending pertinent medical conferences, hosting and maintaining an international web site, and hosting a bi-annual family conference. The gene was found (December 2002) through the financial help of SDSF and this has given way to a better understanding of the disease and to diagnostic tests that have been developed to help with faster diagnosis.

Our family has benefited from many of these supports and activities and wants to continue to do so. Please help by going online to www.shwachman-diamond.org and donate through Paypal on the Donate page or send a check in to: SDSF, 127 Western Avenue, Sherborn, MA 01770. We will have your name published in the newsletter as having contributed in (name of patient) honor.

This is not a case of “what if” (name of patient) takes a downturn, but “what if” we help fund a cure!

Don't forget to fill out the Matching Gift fund paperwork from your employer to maximize your donation. Our number is 43-1709945 and our tax exempt number is 9588351.

Thank you for your consideration to donate. Please feel free to call or email me with any questions.

SDSF attended American Society of Hematology's 50th Annual Conference this past Dec 6-8th in San Fransisco

Held each year in December, the Society's annual meeting provides hematologists from around the world a forum for discussing critical issues in hematology. More than 21,000 clinicians, scientists, and others attended the four-day meeting, which consisted of a superb educational program and cutting-edge scientific sessions. The annual meeting featured oral and poster presentations that are chosen by peer-reviewers from abstracts submitted prior to the meeting and contain the latest and most exciting developments in scientific research. Plenary symposia and named lectures on specialized areas of hematology are also presented throughout the meeting program.

There was an entire session on bone marrow failure where Shwachman-Diamond Syndrome was talked about and highlighted often. There were also 7 different papers and posters that were presented during the conference. We are fortunate that there are so many doctors and scientists who are interested in SDS and by having a presence at this conference, we are showing our support of them as they are showing it for us.

During the annual meeting, attendees can also visit the state-of-the-art exposition, which features exhibits from pharmaceutical companies, medical suppliers, clinical diagnostic and research-based companies, publishers, and nonprofit organizations.

SDSF hosted a booth at the ASH conference this past December in order to raise awareness of SDS as well as make new contacts amongst hematologists. Some of the opportunities presented were:

- Interacting face-to-face with hematology professionals from all over the world to tell them our story of SDS
- Building visibility for our Foundation

- Expanding our prospect base for researchers and scientists to study SDS
- Conducting a survey concerning the knowledge of doctors/scientists who thought that SDS was only a pediatric disease and getting the word out about SDS in order to serve our growing adult population of patients

The next annual meeting will be December 5-8, 2009 in New Orleans, LA. We plan to be there with our booth in order to have continuity of awareness and to continue create more connections.

NORTH AMERICAN SDS REGISTRY

SDSF would like to encourage every patient with SDS to register in the North American Shwachman-Diamond Syndrome Registry. The more data that is available to doctors and researchers, the faster they can help with diagnosis, treatments and hopefully a cure!

Here are some answers to frequently asked questions that may help you decide if registration is right for you:

What is the North American SDS Registry (NASDSR)?

Since SDS is a rare disorder, our understanding of the medical complications and best treatments for SDS are limited. For this reason, the NASDSR was established to collect medical information and clinical samples on all individuals with SDS and who are SDS-like across the United States and Canada with the goal of improving diagnosis and treatment. The NASDSR is headquartered at the Fred Hutchinson Cancer Research Center in Seattle with collaborating

centers in Toronto and Cincinnati. The SDSR is a research organization dedicated to gathering and analyzing information about SDS and sharing any new knowledge with the SDS community and medical professionals. Scientific studies using collected blood and bone marrow cells will focus on elucidating the causes of SDS and its complications in order to develop better treatments.

How can you participate in the NASDSR?

Patients can enroll in the registry by contacting the Registry coordinator, Melissa Alvendia at 206-667-6965 (toll-free 1-866-792-5876).

After signed informed consent is obtained, the patient or parents (if the patient is a minor) will receive a brief questionnaire which will be updated annually. Additional information is obtained from medical records, laboratory and pathology reports. Clinical samples are obtained when blood, bone marrow or other tissues are being obtained for clinical care, so no extra procedures are involved.

In the near future, enrollment will also be available through additional centers including Toronto and Cincinnati.

How much will this Registry cost me?

There is no charge to you for your participation in this Registry.

For more information, please contact

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For additional information, please visit our website:
www.SDSRegistry.org

GLOBAL RARE DISEASE DAY SET FOR FEBRUARY 28, 2009

Shwachman-Diamond Syndrome Foundation will participate in a global Rare Disease Day on February 28, 2009. As a Rare Disease Day Partner, we will join hundreds of other patient organizations, government agencies, medical societies and companies in focusing attention on rare diseases on that day.

This will be the Second Annual Rare Disease Day. The first was observed in Europe last year and was organized by EURORDIS, the European Rare Disease Organization, and the national alliances of rare disease patient organizations in each country. This year, EURORDIS invited NORD, the National Organization for Rare Disorders, to organize a similar observance in the United States. Activities are also being planned in some other countries. The ultimate goal is to have a global Rare Disease Day on the last day of February each year. The theme is that rare diseases are a public health issue, affecting millions of people around the world. The hope is that Rare Disease Day will increase awareness of rare diseases, the special challenges encountered by those affected, and the need for research to develop safe, effective treatments or cures.

As a Rare Disease Day Partner, our organization has agreed to help publicize and promote Rare Disease Day. In addition, all Partners and their members have been invited to write to their state governors to request that Feb. 28, 2009, be designated Rare Disease Day in the state. (A sample letter and resolution are posted on the NORD Rare Disease Day web page.)

Watch our website, or the following sites, for more information on these and other activities:

U.S. Rare Disease Day page on the NORD website, http://www.rarediseases.org/rare_disease_day/rare_disease_day_info

Global Rare Disease Day website: <http://www.rarediseaseday.org>

Coping with SDS: Transitioning into Adulthood

by Corky DeBoer

Several years ago, I wrote a series of articles on Coping with SDS. That was when two of our children who have SDS were much younger. As a chaplain by profession, much of my training and work has been focused on helping others cope with their illness or other life transitions by drawing on both internal as well as external sources of support. As a father, I have been on this ongoing journey, navigating uncharted territory as our children continue to grow and mature. Today Troy is 19 and Kelsey turned 17 this past fall. Those with SDS, like those with many other diseases or chronic conditions, are living longer today than 15 years ago, due to a variety of factors, which include medical advances and better antibiotics. As there are more children with SDS transitioning into adulthood, there are more questions and other dynamics that families deal with. Some of these are typical dynamics that families face when children are transitioning into adulthood, while others are quite unique. In this next series of articles, I will be highlighting some of these dynamics.

Today, I'd like to make a few comments on our perception, as parents, of our children as they transition into adulthood. Part of our role as parents is to provide guidance and direction to our children so that they can eventually function as independently as possible. In many cases, this means with little or no parental control. Sure, a son or daughter in their twenties or thirties may turn to us for guidance or direction, but generally, there is a period of time, when for the sake of their own identity and development, our children intentionally do not initiate asking for such advice, even if down deep inside they may deeply desire it. That seems to be a normal part of growing into an adult.

Now add to this typically stressful transition a few other factors. One of these is that the chronic condition of our child has demanded a lot of attention and energy from us over the years. On account of this, often an unusually strong physical and/or emotional bond has developed over the years. I'm not saying

that this bond is always a positive, lovey-dovey sort of feeling—but I am saying that whenever time, energy, and attention is given to a son or daughter who has a chronic, and at times life-threatening illness like SDS, inevitably the “emotional umbilical cord” is stronger than in the typical parent-child relationship. As a result, the tenuous process of gaining independence can be more complicated. the “emotional umbilical cord” is stronger than in the typical parent-child relationship. As a result, the tenuous process of gaining independence can be more complicated.

Another factor is that for many of us, our children’s size keeps us from realizing that they are growing into adulthood. When Troy was 16, I remember asking our pharmacist what a child’s dosage of a certain medicine would be. The pharmacist reminded me that at age 16, Troy was no longer considered a child, but an adult. My question came more from the fact that I was concerned that the Troy’s smaller stature and weight may have an impact on the dosage. While this was a legitimate concern, it was a rude awakening for me, for I realized that I had never thought of Troy in term of approaching adulthood, let alone being an adult. This reality struck home again, when the dental bill from Troy went from child rates to adult rates. While I know that chronological age does not always correlate to emotional and or cognitive development, our children in their late teens are legally considered adults.

Some questions to think about:

- “How do you view your teenage children?”
- “What are the biggest barriers, or do you think will be the biggest barriers, for you to view your son’s/daughter’s approaching adulthood, let alone being an adult?”
- “What has been most painful for you as your son/daughter is approaching or going through this transition into adulthood?”; “Most painful for your son/daughter?”
- “Who / what has been the most helpful or supportive person / resource for you as your son/daughter is approaching or going through this transition into adulthood?”; “Most helpful or supportive for your son/daughter?”

I hope my thoughts, reflections, and questions will be a springboard for discussions in your homes as well as within the broader SDS community.

Here are some of the topics I hope to cover in future articles, though not necessarily in this order:

Medical Care – Transitioning to Adult Practitioners

Insurance Coverage

Decision Making

Independence

For Those with Physical, Emotional, and/or Cognitive Disabilities

- Special Needs Trusts

FAMILY SHARING PAGE



IN HONOR AND MEMORY OF HEATHER PENDERGAST

Heather was born on February 25th 1977; I remember that day as if it were yesterday. It was in the wee hours of the morning. Penny and I had been planning on a natural childbirth delivery for Heather after taking natural childbirth classes; so we were timing the contractions in those early hours when the time between contractions markedly decreased. We quickly got in our 1968 yellow Cadillac and off to Mid Island hospital. Just a few minutes out Penny's water broke and things started happening really fast. Penny could feel the head pushing. When we arrived at the hospital everything became a blur. The nurses had to deliver Heather as I went to the admitting office. While I was in admitting the nurse called to say congratulations, you are the proud father of a little girl. Heather was 3lbs and 11oz. And full term. There were problems brewing already. Very loose and smelly stools and loss of weight. The doctors told us it was "Failure to Thrive."

Heather stayed at Mid Island hospital just less than two weeks and was transferred by ambulance in an incubator to the Nassau County Medical Center Neonatal

unit. During her many weeks there Heather was put through countless medical tests, including sweat tests. At first the doctors thought she had Cystic Fibrosis. However, every sweat test came back normal. They tried different baby formulas to try to get her weight up to 5lbs so we could take her home. It was a struggle but after many weeks Heather came home weighing just over 5lbs. During this time at home we made many trips to the pediatrician's office. She did gain some weight but it was very slow. There were many problems which I can no longer remember before we ended up back at Nassau County Medical Center, this time in the pediatric unit. This is where a Dr. Collip first mentioned Shwachman-Diamond Syndrome as a possibility; and this is when we first discovered enzymes for digestion. This is also the place when things got really bad. There was one formula that Heather could not tolerate and would vomit violently if it was given to her. Even though they were told about this, while we were not there she was given this formula and she vomited and aspirated into her lungs. She quickly got double pneumonia and was in the pediatric intensive care unit. So many things went wrong here. She even got an Ecoli infection in her blood. Doctors told us she had a 50/50 chance to survive. So on June 29th 1977 we had Heather baptized in the ICU and just prayed.

It was truly a miracle that Heather survived. We then had her transferred by ambulance to Long Island Jewish Medical Center. Here she was put in the neonatal unit under the care of Dr. Philip Lipsitz. Dr. Lipsitz ordered many medical tests for Heather including sweat tests. As usual, the sweat tests were normal and based on all the other results Dr. Lipsitz confirmed a diagnosis given by Dr. Collip at NCMC of Shwachman-Diamond Syndrome. She was put on enzymes as well as a special formula and after several weeks was sent home. We finally saw some improvement. From this point on things improved slowly but not without many trips to the doctor and some further stays in the hospital. Heather came down with bronchitis often and at least one bout with pneumonia. Heather did not let

any of this slow her down. She tried to do everything and be like her older brother. She was very tiny but with a huge spirit.

In the interest of saving space for the SDS newsletter I will try to be briefer and condense now. From about age five up to 18 years or so we had to deal with ear infections, dental problems, skin infections, and as always any cold went quickly to bronchitis. Heather had learning problems and spent her entire school career in the special education program in our school district. She graduated at age 21 with her special Ed diploma. Heather excelled in everything she did in school but at her level of ability. She so much wanted to be "Normal" like all the other students. She always gave 110% in everything she did. After high school she wanted to get a job like her brother.

Heather had chronic ear infections and was a patient of an ear, nose and throat specialist for nearly ten years. At one point she had to have tubes placed in both ears. This eventually cleared up one ear but she needed surgery to pretty much rebuild the inner ear on her right side. Another unexpected serious problem that came up was kidney stones. This was very challenging because of Heather's low platelet counts. She first had the ultrasound technique and finally needed a surgical procedure but both required a platelet count of at least 100,000. So for both procedures a platelet transfusion was needed and given by Dr. Lipton at Schneider Children's Hospital. Heather's platelet counts usually hovered around the 40,000- 50,000 range. Fortunately both platelet transfusions worked very well for both procedures at this time.

Heather did get her much wanted job at a pizza restaurant where her brother Jason worked. She loved working there along with her brother until the business closed. Then through the efforts of her mom, she was hired part time at a local Burger King. She worked part time there for nearly eight years until that dreadful day when Dr. Lipton said "I have bad news, it is Cancer"

I have had to consolidate and leave a good deal of information on Heather's life out to this point because there is just too much to tell. I could really write a book. Briefly, in the summer of 2006 Heather spent two weeks in Schneider Children's Hospital with a cellulitis infection on her leg from a cat bite. This

was a very difficult infection to fight but the doctors were successful. Infections were always a problem with Heather.

In early September of 2007 Heather complained of an itchy insect bite on her right breast. It looked like a mosquito bite at first. After a few days Heather said it's not going away and is very itchy. We looked and thought probably another infection and called our local intern immediately. Dr. Fogel examined it and detected a lump and ordered some tests. The tests showed a mass in the breast. It was off to Schneider's and Dr. Lipton who admitted Heather immediately. This was the beginning of a truly horrible and life changing year and also a year that we felt so much love and goodness from so many people. It would take several pages to tell the whole story of this year. I will simply say that Heather battled heroically to try and beat this horror but because of her bone marrow problems from SDS she could not have Chemo. And because of her platelet counts and the fact that transfusions of platelets no longer worked surgery was impossible. Our only weapon was radiation which worked for a time and gave some hope. Then in July 2008 she began having pain in her leg. Soon we discovered that the cancer had spread to her spine. The 7 weeks of radiation had seriously affected her bone marrow and all her counts were very bad. Nothing could be done. We arranged to bring her home and home hospice was arranged. We were determined for her to pass at home and to not be alone. On October 30, 2008, my wife, my son and I were with Heather when she passed peacefully and with no pain.

We have much faith and truly believe she is finally Better Now!

We are so grateful to Dr. Lipton and all the wonderful staff at Schneider Children's Hospital as well as the wonderful people from home hospice who cared for and loved Heather. Heather was a special and remarkable person who touched and inspired so many lives. She is a SDS angel in Heaven for certain.

It has been difficult telling Heather's story in just a few pages because so much happened during her life and I had to leave much out. But I hope it's enough for everyone to get some idea of what her life has been with SDS.

THE PENDERGAST FAMILY, Massapequa, NY

Maura's Family Story

My name is Maura, and my husband Dan and I are parents to two children, Aisling (7) and Ruari (3 1/2), we are also expecting a baby girl in January. I must admit, I was more than a little surprised when Donna asked me to share our family story, as I feel our situation is rather atypical in the SDS world. But after attending Camp Sunshine this summer, and meeting many other families who find themselves, for one reason or another, in the "atypical" boat, I suppose it only makes sense for the larger SDS community to learn more about one another, even those of us who may one day end up with a diagnosis of a "sister syndrome."

Aisling's diagnosis story began shortly before her brother was born. She had been breastfed for an extended period of time, but she had to stop during my pregnancy with Ruari, as I had little milk for her. Shortly after she stopped nursing, she experienced a string of illnesses, including a second bout of chicken pox. She'd always been fairly healthy, although less healthy than most exclusively breastfed babies, but during this time period, it seemed we were constantly at the doctor's office. During one of these visits, I mentioned how she'd been experiencing excruciating leg pains, and our doctor decided to run some bloodwork, to see if a reason could be discovered. In the meantime, Aisling began having blood in her stool, so we were referred (and seen within a day) by a gastroenterologist in San Francisco. Aisling was anemic, but it was unclear why the bleeds began. The GI ordered more bloodwork, and this time, a complete CBC was run, which was when her neutropenia was discovered. I remember the feeling from that office visit, and commented to my husband when we were in the elevator afterwards, that I didn't know much about problems with white blood cells, other than leukemia, and I was worried, as it was clear from our GI's reaction that he didn't know what was going on, but that he clearly was concerned, and was trying not to show it. I began to research everything I could about anemia, neutropenia, leg pains and GI bleeds. The GI continued to follow us closely, and the day before Aisling's 4th birthday she had her first bone marrow biopsy, endoscopy and colonoscopy.

For the next year and a half, the doctors were puzzled by her symptoms. They couldn't reconcile her intermittently severe ANC's with her fairly decent health, so they kind of ignored the neutropenia for a while. Then, one ANC came back 1740, so our pediatrician declared her neutropenia "resolved." I pushed to have more frequent counts done, to look for a cycle, and while it wasn't smooth, she did have counts that ranged from severe to mild, frequently cycling up and down over the six weeks of testing.

By this time, I'd connected with some other families of kids with neutropenia and SDS, and began asking for more testing. Aisling had always had what I called "swampy" diapers, so I asked to have fecal fat and serum enzyme testing done. Both came back abnormal, but our hospital didn't flag the results as abnormal (one due to having the adult reference range, and the other didn't even have a lower limit for amylase).

I knew I needed more information. I attended a Neutropenia Conference, and was pointed in the right direction by the SCNIR. I heard from another mom of a child with clinical features of SDS, and heard about a wonderful hematologist who "was interested in following the kids without the mutations." I wrote to Dr. Harris in Cincinnati, and was amazed to hear back, that day, despite the fact that he was on vacation. After sharing some of Aisling's history with him, he thought it could indeed be helpful for her to have a full evaluation at CCHMC. I approached our local doctors about having Aisling seen by Dr. Harris, and amazingly, the visit was authorized. I say amazingly because we are with a large HMO, which I'm told rarely approves out of network referrals. I'd made a strong case that Aisling appeared to meet the criteria for a rare, life-threatening condition, but that she required evaluation and consultation with an expert in order to diagnose and follow her properly. In December 2006, our family traveled to Cincinnati, and after a comprehensive evaluation, Aisling was diagnosed SDS-like. We have since learned she has one SBDS mutation, and one CF mutation, but no one knows how this combination might interact (if at all) to contribute to her clinical presentation.

Aisling remains very healthy, which the doctors ascribe at least in part to her extended breastfeeding, and for this we are very thankful. She has been having some difficulty in school with learning to read and with attention, but the information shared by Dr. Kerr at Camp this summer helped our local school specialists to sort out her issues, and to figure out how best to support her learning. Our son Ruari has been diagnosed with Pancreatic Insufficiency, but his counts remain fairly normal, and we are hopeful his PI may resolve soon.

For me, the hardest part of this journey really has been the lack of definitive knowledge about the diagnosis and the future. With my daughter's presentation so atypical and mild, it has been hard to really believe she truly could have a bone marrow failure syndrome.

SPOTLIGHT ON RESEARCH

RESEARCH SUPPORTED BY SDSF THIS PAST YEAR 2008

I have often thought her neutropenia was benign and resolving, only to then find yet another low count. I have to do a mental dance to remind myself that abnormal chemotaxis, hypocellularity, and increased P53 levels don't suggest a benign condition. Nor does dropping off the growth charts yet again.

I don't know what the future will hold. I suspect those of us without the common mutations will end up having some sort of sister-syndrome discovered and named in time, and for us, the future is even less known than for those with genetic confirmation. But none of us know what the future holds, even for our healthy children. We all must just come together to learn all we can about this syndrome, support the wonderful research being conducted by the amazing doctors in our field, and continue to hope and pray for health, internal peace of mind, and ultimately a cure.

SDSF supported two grants in 2008. One was a grant submitted by Dr. Nikolaus S. Trede, MD, PhD, Assistant Professor of Pediatrics, Investigator, The Huntsman Cancer Institute, University of Utah, 2000 Circle of Hope, Salt Lake City, UT and the other by Dr. Akiko Shimamura, MD, PhD, Associate Professor of Pediatrics, Division of Hematology/Oncology, University of Washington, Seattle, WA.

Dr. Trede has proposed research to discover or “reveal a gene and/or pathway leading to SDS-like birth defects”. This elucidation of the molecular defect underlying the SDS patients without mutations in SBDS will yield new insights into the origin of diseases with a combination of SDS-like phenotypic characteristics. This research will hopefully be useful for both prenatal (SDS) diagnosis and, ultimately, the identification of new therapeutic strategies for existing patients with SDS-like phenotypes.”

Dr. Shimamura has helped to create (with a team of SDS dedicated doctors) a North American Shwachman-Diamond Syndrome Registry (a database of patient symptoms, ages, genetics, blood counts, as well as, tissue and blood) in order to help improve diagnosis and research. “The long term goals of the Registry are to elucidate the natural history of SDS, to define the diagnostic criteria for SDS, and to develop better treatments for SDS. To achieve these objectives, the Registry has the following specific aims: (1) Develop data forms and data collection systems to comprehensively and longitudinally collect clinical information on SDS patients; (2) Actively recruit SDS patients

STUDIES ON THE MOLECULAR MECHANISMS OF BONE MARROW FAILURE

Bone marrow failure (BMF) syndromes such as aplastic anemia or myelodysplastic syndrome (MDS) may develop by a number of different mechanisms. We believe a genetic predisposition to aplastic anemia and MDS is much more common than currently appreciated, and a significant proportion of individuals thought to have “idiopathic” aplastic anemia or myelodysplasia may have a genetic alteration as the underlying or predisposing cause.

Drs. Monica Bessler, Philip Mason, and David Wilson at Washington University in St. Louis, have begun a new study to identify alterations in genes that may predispose a person to the development of bone marrow failure and how these alterations cause disease. We are collaborating with researchers at several other institutions throughout the United States.

Our study seeks to identify genes, their mutations, and their role in the development of bone marrow failure and the genes contributing to leukemic transformation. By understanding the genetic contribution, we hope to gain a better understanding of the course of the disease and ultimately factors that predict leukemic transformation and response to treatment.

Our study is open to all children and adults who have or had aplastic anemia (inherited or acquired), paroxysmal nocturnal hemoglobinuria (PNH), or MDS.

Advancing our knowledge of how these conditions develop is only possible because of the participation of individuals with bone marrow failure. The study is still seeking volunteers, and anyone wishing to participate may contact the study coordinator for more information.

Our study uses a comprehensive approach to the evaluation of participants, which is necessary to truly understand the genetic contribution to the develop-

from a broad range of ages and diversity of racial and ethnic backgrounds; (3) Develop a repository of blood and bone marrow samples from patients with SDS to facilitate genetic, molecular, and cellular studies; and (4) Develop educational materials on the diagnosis, medical management and treatment of SDS for patients, families and physicians. The overriding goal of these efforts is to improve the diagnosis and care of patients with Shwachman-Diamond Syndrome. A nurse coordinator will be appointed to field phone call inquiries from patients and physicians.”

The Board of Directors is very excited about both of these projects and looks forward to getting updates of the studies as they progress.

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 thoughts and ideas to SDSF by either calling 1-877-737-4685 or emailing us at info@shwachman-diamond.org.

ment of disease. Individuals who wish to participate will be asked to:

- * Sign a consent form indicating your desire to participate,
- * Complete a written medical and family history questionnaire,
- * Submit a sample of blood (we can provide kits so a physician can draw your blood), and
- * Undergo a physical examination (for families in the St. Louis area only).

Individuals are not responsible for any costs associated with the study. The confidentiality of all study related materials will be maintained in accordance with State and Federal laws. To learn more about the study please visit our website at <http://bmf.im.wustl.edu/>, or contact the study coordinator:

Jennifer Ivanovich, M.S.
Study Coordinator
Washington University School of Medicine
Box 8100, 660 S. Euclid Ave.
St. Louis, Missouri 63110, USA
314-454-5076
jen@ccadmin.wustl.edu

Monica Bessler, M.D., Ph.D., Co-Director
Division of Hematology
Washington University School of Medicine;
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St. Louis, MO 63110, USA
314-362-8807
Mbessler@im.wustl.edu

David Wilson, M.D., Ph.D. Co-Director
Division of Pediatric Hematology/Oncology
Washington University School of Medicine;
Box 8208; 660 S. Euclid Ave.,
St. Louis, MO 63110, USA
Wilson_D@kids.wustl.edu

RESEARCH STUDY NEEDS YOUR PARTICIPATION

Dr. Akiko Shimamura, MD, PhD., Associate Professor of Pediatrics at the University of Washington in Seattle, is investigating the molecular functions of the SBDS protein. The goal of her research is to understand the causes of bone marrow failure and leukemia in Shwachman-Diamond Syndrome and to develop new therapies. Samples of blood and bone marrow from patients with Shwachman-Diamond Syndrome are critical for these studies. These samples may be collected when they are being drawn for clinical care. Dr. Shimamura or Dr. Trisha Wong would be happy to discuss the study further with anyone interested in sending a sample. Dr. Shimamura's e-mail is, shima2@u.washington.edu.

ONGOING RESEARCH NEEDS YOUR CONTINUED SUPPORT

SBDS Protein Expression in Peripheral Blood Leukocytes

Shwachman-Diamond Syndrome (SDS) is a rare genetic condition which causes a number of problems in different body organs, particularly the bone marrow (blood producing cells), pancreas (digestive gland) and bones. These problems may vary considerably from person to person, which sometimes makes it difficult for doctors to diagnose SDS. The mutated gene which causes SDS has recently been identified. To have SDS, one has to have a copy of the mutated gene on each chromosome. So far, three common mutations as well as about 50 rare mutations have been identified. Approximately 60% of SDS patients carry common mutations on both chromosomes. Others carry a common mutation on one chromosome and a rare mutation on the second chromosome. However, in about 5-15% of people with clinical findings of SDS, mutations cannot be found, even after extensive laboratory testing.

Each gene in our body acts as a code for making a unique protein. Each protein has a definite function. When a gene is defective, it either produces no protein, very little protein or produces a protein that doesn't work properly. We have now developed a way of measuring the normal SDS protein in blood cells from people without SDS. In addition, we have shown in a small number of people with SDS, that the level of this protein is absent or greatly reduced. These preliminary results suggest the possibility that we may be able to use this test to diagnose SDS. We also think that the amount of protein in blood cells might help to explain why some people with SDS have worse or different problems from other people.

To do a more extensive study of the SDS protein in blood cells, doctors at the Hospital for Sick Children, in Toronto and the Children's Hospital in Boston are seeking volunteers to join this research project.

We are seeking the following individuals to join our research study:

- People with SDS who carry the uncommon (rare) mutation on at least one allele.
- Parents of people with SDS who carry the rare mutation and/or an adult sibling who is a known carrier of the rare mutation.
- People with a confirmed clinical diagnosis of SDS but no SBDS mutation have been identified.
- People who are suspected to have SDS in whom testing remains inconclusive. This might include people who have: (a) a problem in the bone marrow but no known problem in the pancreas, or; (b) a problem in the pancreas and/or skeleton but no evidence of a bone marrow problem.

Individuals who wish to participate will be asked to:

- Sign a consent form indicating willingness to participate,
- Complete a brief written medical questionnaire,
- Submit a blood sample (we will provide a kit for your lab or physician)

Individuals will not be responsible for any costs associated with the study. The confidentiality of all study related materials will be maintained and no information that discloses the identity of the subject will be released or published without consent unless required by law. The results of the tests described above will be used for research purposes only.

To learn more about the study or to see if you are eligible, please contact the study coordinator:

Wan Ip at 416-813-6183 or wanip@sickkids.ca

Etiologic Investigation of Cancer Susceptibility in Inherited Bone Marrow Failure Syndromes (IBMFS)

The National Cancer Institute Institutional Review Board has given its approval to open a study entitled "Etiologic Investigation of Cancer Susceptibility in Inherited Bone Marrow Failure Syndromes." The principal investigator responsible for this study is Blanche P. Alter, MD, MPH. This study is open to patients with SDS, along with their immediate families. Individuals with one of the inherited bone marrow failure syndromes, and their parents, brothers, sisters, and children, are all invited to participate. Those who come to the NIH Clinical (CC) will belong to the "CC Cohort," and those who do not will belong to the "Field Cohort." Individuals who choose to participate in the NCI IBMFS [Alter, Blanche (NCI)] Cohort Study will be asked to complete a family history questionnaire and an individual information questionnaire. Physical examinations and samples of blood, bone marrow (from those affected with the disorder), and other tissues may be requested for research studies.

Inherited bone marrow failure syndromes (IBMFS) are rare disorders in which there is usually some form of aplastic anemia (failure of the bone marrow to produce blood), associated with a family history of the same disorder. Some of these conditions have typical changes in physical appearance or in laboratory findings which suggest a specific diagnosis. There are several well-described syndromes, which can be recognized by health care experts. There are also patients who are harder to classify, but who appear to belong in this category. Patients with these syndromes have a very high risk of development of cancer [Alter, Blanche (NCI)] (leukemia or solid tumors). At the moment we cannot predict which specific patient with an IBMFS is going to develop cancer. The NCI IBMFS [Alter, Blanche (NCI)] Cohort Study will enroll North American families in which at least one member has or had an IBMFS. The web page "marrowfailure.cancer.gov" describes the study and provides contact information. By telephone, please call 1-800-518-8474 and ask for the Referral nurse or you may also contact SDSF for more information.

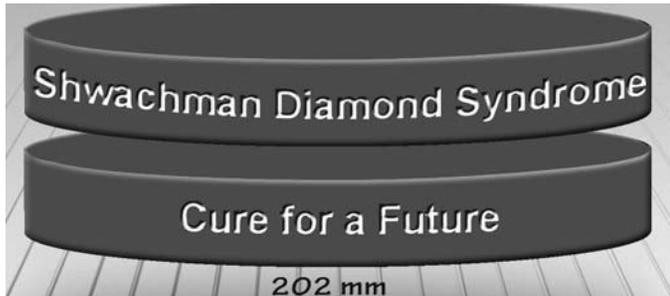
University of Texas Medical Branch- Galveston, Texas

Dr. Tarek Elghetany, Division of Hematopathology at the University of Texas Medical Branch in Galveston, Texas is studying the bone marrow and blood of patients with Shwachman-Diamond Syndrome for early signs of myelodysplastic syndrome and leukemia. If you or your child have a bone marrow study performed, Dr. Elghetany can perform several research studies on the samples. Dr. Elghetany will also receive some bone marrow samples from Dr. Blanche Alter.

Dr. Alter is the principal investigator for the Etiologic Investigation of Cancer Susceptibility in Inherited Bone Marrow Failure Syndromes (IBMFS) that is taking place at the National Cancer Institute. The specific aims of these studies are to study similarities and differences between SDS bone marrow, other bone marrow failure disorders, and RA bone marrows; to characterize all SDS patients with regard to presence or absence of AA or MDS; to classify SDS patients with MDS and to study MDS features in SDS; to also identify early markers of clonal evolution and to correlate MDS grade or early clonal markers with the development of acute leukemia; and to evaluate different MDS scoring systems regarding their predictive value for survival and development of acute leukemia in SDS patients. Dr. Elghetany will study patients with SDS and follow them up for several years. Their bone marrows will be studied for a variety of markers and will be compared with 40 patients with other inherited bone marrow diseases, 20 patients with refractory anemia (RA), 10 patients with acquired aplastic anemia (AA), and 10 with normal bone marrows.

These long-term goals require several years of follow up. This study will address and clarify the significance of the diagnosis of MDS in SDS. Dr. Elghetany's studies are not intended to take the place of the usual studies done by your doctor(s). For more information on how to participate and/or to obtain the needed forms, please contact Dr. Elghetany at 409-747-2468, e-mail melgheta@utmb.edu. Dr. Elghetany's research is an ongoing study and he is still accepting bone marrow samples.

RUBBER BRACELETS FOR FUNDRAISING AND COMMUNITY AWARENESS



If you would like to help increase awareness of Shwachman-Diamond Syndrome in your community and at the same time assist in raising funds for medical research and family support, order some of our new Shwachman-Diamond red rubber bracelets! You can buy them in sets of 10 for \$25.00. Just contact us at info@shwachman-diamond.org to order them and they will be mailed to your home. They are great to use as conversation starters to help family, friends, and medical professionals in your area understand about SDS and its impact on families. In addition to that, they are cool!!!!!!!!!!!! You can give them to your friends and family or re-sell them to others.

THANKS ALL!!!

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. 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
jengrsl2@banyanol.com

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@yahoogroups.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.

Gibsonton, FL
Alto, MI
Atlanta, GA
Oak Park, IL
Evansville, IN
Castle Rock, CO
Sacramento, CA
Arlington, TX
Ottawa, IL
Lyman, WY
Bellevue, WA
Arden, NC
Bladensburg, MD
Moore, OK

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 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
<http://www.shwachman-diamond.org>

Shwachman-Diamond Support-UK

Contact: Sharon Clusker
Tel: 024-76345199 Fax:: 024-76345199
email: sharwk60@btinternet.com
<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: Heather Norton
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 opcrcddb@aol.com

Jenny Jenuwine - MI: (810) 395-2358 or jengrls2@banyanol.com

Kelly Bright -TX: (409) 738-2925

Donna Garfield -VA (703) 731-7889 or dkgarfield@verizon.net

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@btinternet.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 to our address or e-mail them to: info@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 info@shwachman-diamond.org with your changes.

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127 Western Avenue, Sherborn, MA 01770 U.S.A.

Credit Card donations can be made through our website - www.shwachman-diamond.org

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

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