

S.D.A. eNewsletter

Shwachman-Diamond America

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Shwachman-Diamond America remained busy throughout the summer with our usual mailings and activities. SDA printed another one thousand copies of Dr. Richard Harris' booklet Management of the Hematologic Abnormalities of Shwachman-Diamond Syndrome. We are very excited that we have been able to send out over 1,000 copies of his booklet to date!

Shwachman-Diamond America was pleased to be able to send two physicians, a graduate student and a bone marrow failure nurse to the 5th International Congress on Shwachman-Diamond Syndrome. The International Congress was a gathering of researchers and physicians from around the world. The information shared at this Congress is important in helping to further our understanding of Shwachman-Diamond Syndrome and finding a cure. It was exciting to learn about the new findings in Shwachman-Diamond Syndrome research!

Presently, Shwachman-Diamond America is working on getting Dr. Harris to speak at various symposiums and venues around the country. This is a very important education mission to help educate physicians on the many aspects of Shwachman-Diamond Syndrome.

In order to help fund these projects, Shwachman-Diamond America has several on-going fundraisers. We still have the Shwachman-Diamond Syndrome Friends and Family cookbooks which include family recipes from Dr. Shwachman's own family, we have bumper stickers and even have a jewelry fundraiser. Roaming Oyster Pearl Jewelry and much more will give 25% of all purchases to Shwachman-Diamond America. In order for SDA to get the credit for your purchase through Roaming Oyster, you must use the link on our website under the "Help SDA" link.

Finally, using Goodsearch is a free way to help Shwachman-Diamond America. Goodsearch is a search engine powered by Yahoo! Each search generates over one penny for Shwachman-Diamond America. To date, SDA has raised over \$550 from members who use Goodsearch. Please consider asking friends and family to use Goodsearch—the pennies really do add up! It is a way that we can all raise money for Shwachman-Diamond America without spending a dime of our own money! It is FREE!

The procedure

Not long ago, my son, Luke started to complain about stomach pain. He would sometimes stop in the middle of play, look at us with his pitiful face and say “my tummy hurt.” We were really at a loss as to what we should do. I had told our GI who, quite honestly, blew me off a little bit. One month later, his tummy was still hurting and I insisted that our GI do something about it. So many times I get sick and tired of medical professionals writing it off as “well, it is just part of SDS.” Show me where in the medical literature where it says that stomach pain is part of this disorder. I don't want my child just to live with it, nor do I want to put him through something unnecessary. After much discussion, we decided to do an endoscopy and colonoscopy.

These procedures involve running a tube with a camera down the throat and up the rectum to take pictures of the digestive tract. They look for any abnormalities or polyps and take very small biopsies. The child is under anesthesia during the procedure, so they have no idea what is going on and they have no memory of it.

The day before, we had to put Luke on an all liquid diet. He could only have clear fluids such as Kool-Aid, apple juice, clear sodas, clear broths, Jello, and all of the Popsicles that he could eat. They told us to make sure that nothing he ate contained red food dye since that could show up as blood during the procedures. When he woke up on prep day, we fed him a huge breakfast of pancakes, eggs, and sausage. He wasn't scheduled until 9 AM the next day, so we had until 9 that morning to feed him as much as possible before the liquid diet started. Once it did, we offered him something every hour to keep his stomach full of liquid so that he wouldn't feel so hungry. I also dropped his younger brother and sister off with their grandmother since we did not feel that it was fair for Luke to see the other children eating and they were too small to understand why they should not eat in front of their brother. We spend a good part of the day in distraction mode to take his mind off the fact that he was only consuming clear liquids. My husband took him to a movie in the theater, we rented a new movie, we played games and did whatever we could to keep him happy and distracted.

The hardest part was giving him the medication to cleanse out his colon. It was recommended that we give him magnesium citrate. We had heard from several people that it was pretty nasty medicine, so I called my doctor and they told us we could give him Miralax which is tasteless, gentler, and usually does the trick. Honestly, we probably started to late

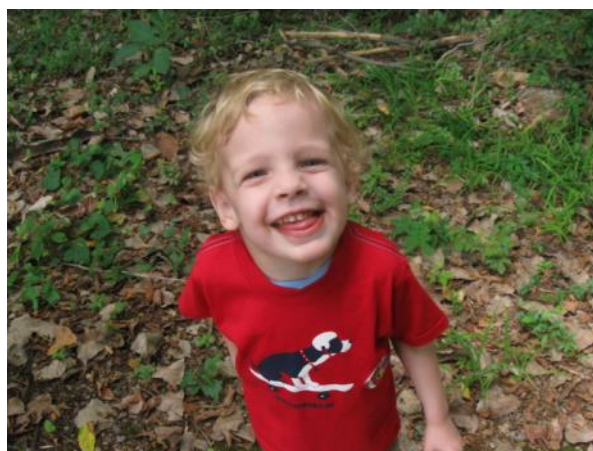
because I think Miralax takes longer to work than the other medicines, but we gave him several doses mixed into whatever drink he had requested over the course of 4 hours starting at 4:30 PM the night before the procedures. He drank it with little fuss, probably wondering why we were so insistent that he drink all of his Sprite. The hardest part were giving him the suppositories. It is near impossible to give a four year old who is all ready afraid of medications a suppository. He screamed “No Thank You, No Thank You” the entire time while we held him down and squeezed his little bottom together to keep it in. It worked fairly quickly. We had to do it again at 4 AM the morning of the procedure. We were honestly afraid that he was going to have a heart attack, but it was easier. Him being half asleep probably helped.

The day of, we arrived at the bright and early time of 6 AM. I swear some hospital staff are way too happy to be awake at that time of day. We checked in, and were called back. Luke got a special pair of pajamas and a stuffed gorilla to add to his collection of simian creatures (The kid has a thing for monkeys). He played around in a child sized car until it was time to go. When they came to get him, they let him “drive” his car back to the operating room. He didn't even miss us.

Recovery was hard for Luke. It always is. He took a long time to wake up and when he did you would have thought that we were the meanest creatures on earth for disturbing his rest. He cried and proclaimed that he did not want to go home. I'm really hoping that that was the drugs talking because who would want to stay at the place where all of the “pokies” happen? Eventually he came to his senses. They required him to eat or drink something before we left and they warned us not to let him climb our stairs by himself or leave him alone for long periods of time since the medications that they had given him could cause him to loose his balance easily. By the time dinner rolled around, we had our little boy back to normal.

The tests came back clear of any physical issues. We are still at a loss as to what is causing the stomach pain, but lately it has been better. We just hope and pray that we never have to put him through that again and that the stomach pain is gone for good.

By Honey Denson



Avoiding illness in the classroom

Finding ways to keep your child healthy at home is challenging enough, but as parents we know that we cannot possibly keep our children home all the time. While necessary trips to the hospital or doctors office can cause exposure to illnesses we try to avoid, finding ways to enrich our children's lives through play or school can be a daunting task. We can ask our friends and families to stay away when they are sick or have been exposed to certain contagions, but there is just no way to do that with every child in school.

When Katie was headed to transplant, she was too young for school, but that did not mean we were exempt from the dangers of infectious disease. We had three school aged children at home and throughout even the worst of Katie's condition my other children had to attend school.

We informed the school that we had an immune compromised child at home and were placed on an alert list. This was so that the school could notify us of any major illness or outbreaks that they became aware of. Illnesses such as chicken pox, Strep throat, the flu and viruses can wreak havoc on an immune compromised child. My children that attended school were taught about proper hand washing techniques, not to share food or drink with other children, and to avoid touching their mouth, nose etc. We showed the children how to use the bend in their arm to catch their coughs instead of their hands and explained the importance of not holding hands with others when it could be avoided.

While at school the kids used portable hand sanitizer to keep their hands germ free. We made sure that the classrooms had hand sanitizer in place for all of the children as well even when that meant purchasing it ourselves and sending it to the school. We also packed their lunches to prevent food borne illness.

When my children arrived home from school, they had to strip down to their undergarments and head for the shower or bath. The clothes were treated as contaminants and were bagged and sent to the laundry room for disinfecting. We had pump bottles of hospital grade antibacterial soap and hand sanitizer placed all throughout the house for added coverage.

Although nothing was 100% effective, taking extra steps to safeguard against infection did help tremendously. When one child becomes ill in a household, oftentimes it spreads through the home to everyone else. Fortunately, because of the precautions we were taking, the number of illnesses our healthy children did get was greatly reduced. At the first sign of any illness we quarantined the ill child, as well as Katie to reduce the exposure risk. We utilized

(Continued)

masks, gowns and gloves when necessary to take care of the children.

When Katie went to transplant, we continued with the same protocol and tried to limit the exposures as often as possible. Through our diligence, all of our children stayed very healthy through a very difficult time. Now here we are 5 years later and although we have relaxed some, there are many things we still practice like proper hand-washing and steering clear of sick friends and family. I no longer keep masks, gloves and gowns outside my child's room and my children do not immediately strip down upon walking in the house, but they still wash up as soon as they enter the house.

We are still on the alert list at our children's schools, and at 5 years post transplant Katie is now in kindergarten doing very well. She even tells the other kids the proper way to cover their coughs and reminds everyone to wash their hands so they do not get sick! No matter which options you choose for your family, or for your child's education, there are many ways to prevent illness at all times, even when your child is healthy.

By Christina Wells



Out of the Darkness

Many of our readers are coming from the same place: Life with chronic illness. We can all relate to the ongoing debate in our minds, “Should we have done more?, Should we go to yet another specialist?, Is this next opinion the one that counts as ‘too many’?, Am I crazy for wanting answers?” We struggle with these ongoing thoughts and wonder if we will ever have what we deem to be a “normal life”. As I often say, none of us live in that elusive land called “Perfect”. Often times, we find that our world is tumbling out of control. Stress, hospitalizations, trying to balance school, work and play wreak havoc on our lives. You might have already been there. I have already been there before.....that dark recess of gloom. Thankfully, I’ve always managed to make my way out of the darkness and back into the light.

Climbing out of the dark place we sometimes find ourselves in can be very difficult. Once we get out of the dark pit, it can also be difficult not to backslide right into that same dark place we try so desperately to avoid. Life with chronic illness is a challenge. Not only do we have the challenges all other parents on the planet face, we also have to fit in extra medical appointments and procedures for our children. If your family is like mine, you are also performing various medical procedures at home on a daily basis. Lastly, let us not forget the insurance and billing stresses along with the stress of financial responsibility. It is enough to push anyone over the edge.



So, what can one do to keep from falling down the slippery slope into the darkness? I certainly do not have all of the answers, but I do have a few ideas that have made a difference in my own life. The one thing that has made the biggest difference in my life has been to pay attention to my own spiritual needs. Most of us do an okay job of taking care of our physical needs, but more often than not, tend to neglect our spiritual needs.

When my boys were a lot younger, we were living in San Antonio, Texas. Living there afforded me the opportunity I have not had in other places we have lived. I was able to go to

Out of the Darkness (continued)

a twenty-four hour Adoration chapel. It was perfect! I could go alone to pray once the kids were asleep. Sometimes, a close friend of mine would come with me. We would sit in the chapel from midnight until two in the morning. It was a place of serenity and calm. Something rarely achieved in a household with three toddlers bouncing around! In this place, I could pray and just listen to what God was trying to say to me. Another plus, as I often felt I missed what God was trying to tell me amid all of the “Mom I want, mom I need, mom I’ve got to have” of each day.



Once we moved, it became increasingly harder to find the quiet space I needed for prayer and meditation. Even now with older children, I still struggle with finding a quiet place to pray. One place that usually works for me is the bathroom. Dad can handle the kids and I lock myself in for an hour long bath! Soothes the tense muscles and gives my brain a rest..... even with the occasional knock on the door, “Mom, I need.....” as dad grabs them away. I use this time to read books on the lives of the saints, pray or just sit in silence. Reading about the lives of the saints is something I find particularly helpful as many saints struggled with the darkness. St. John of the Cross and his Dark Night of a Soul is something I have found particularly helpful. As you have probably noted, we are Catholic, but you can use these techniques to fit your own spirituality.

One way in which I take care of my physical and spiritual needs at the same time is by taking a long walk. Many years ago, my father-in-law gave me money for Christmas and I bought the one thing that I claim has saved my sanity a number of times over. I bought an iPod! Not only do I use it when we are sitting in waiting rooms and on long trips, I can also walk and listen to music, books on tape or short meditations. It has truly been a life saver for me. Walking relieves stress and helps build a physically strong body. Of course it is also nice to be alone and free for a short time.

Out of the Darkness (continued)

During a particularly stressful period recently, I was so riddled with anxiety that I started searching for natural ways to help relieve the physical pains it was causing. I came across this amazing tool kit by Dr. Andrew Weil, a Harvard trained physician who is also an expert in integrative medicine. What I love about this tool kit is that he is very open and honest. He says in the workbook, "You don't have to give up—or take on—any religious beliefs in order to meditate. While many forms of meditation come from religious traditions (Eastern and Western), you can apply the basic principles and techniques regardless of your belief system." As he states in his book: "Meditation is simply directed concentration and involves focusing on an object: the breath, a repeated word or phrase (known as a mantra), or a mental image." I have integrated his techniques that have been proven to alleviate stress and the effects of stress into my own Catholic belief system. For my Mantras, I pick quotes from saints or a passage from scripture. My mental images are usually scenes from the life of Christ taken from the mysteries of the rosary. Obviously, concentrating on breathing to lower anxiety and your heart rate it just that....concentrating on your breathing. I share this in hopes that some of you who have been afraid to try meditation and breath concentration to alleviate stress might give it a whirl once you realize you can make it fit your own belief system. Dr. Weil's kit takes it one step at a time, beginning with breath work. I was amazed with the results! Just learning to inhale and exhale properly while paying attention to my breaths, I was able to lower my heart rate, relax and reduce the effects of stress on my body.



Sometimes, the darkness is unavoidable. Something that has helped me from hitting the bottom as I free fall much like Alice in the dark rabbit hole, is having a support group of close friends. Friends who are dealing with the same chronic illnesses and know the intricacies of daily life with Shwachman-Diamond Syndrome and medical issues. Talking to others about my anxieties and fears and receiving feedback is a valuable asset. It helps me to know that I am not alone in my thoughts and feelings, that what I am feeling is normal. It lets me know that I am coping and that it is okay to fall – everyone does it. These friends have been there to pick me up when I fall, and I have hopefully been there for them in return. If you do not have access to a local support group, you may want to consider joining an on-line support group.

Out of the Darkness (continued)

I also find writing to be a creative outlet that helps me to get back on track and out of the darkness. While I am not very good about keeping a journal, it does help me from time to time. I may only have a few entries a year, but it is my journal, so who cares? I also write articles for a few on-line sources. The feedback from readers has really been encouraging and helpful. Other outlets might include keeping a blog, on-line journal or a family website. Do not underestimate the power of sharing your journey with others. It can be something positive and powerful!



The last bit of advice I can offer is to just let it go. I do not mean to let the darkness overcome you completely, but for a brief moment, allow yourself into the darkness and feel what you need to feel. I truly believe that denying oneself to feel these normal emotions of fear, sadness, and grief, one is never able to heal and move on. Allow yourself to cry, scream or just be sad. If you can't find a secluded place to let it go, consider taking a drive. Turn up the music and just cry. Our support group recently discussed this very topic and we realized that many of us were able to let go while we were driving. It was a time and place that we were alone and did not have to worry about family members being upset by our display of emotion. Of course, when driving, one must pay attention to driving and may need to pull over if the "session" becomes too overwhelming. I have found myself sitting in the car in our church parking lot many times! It is a safe place to sit alone in the car and it works for me!

We may not always be able to escape the darkness in our lives, but we can minimize the effects it has on our lives along with our physical and spiritual well-being. The next time you find yourself slipping into a place you do not want to be, try focusing on your spiritual needs along with the other strategies listed here and you might be pleasantly surprised to find the darkness disappears quickly.



By Pattie Curran



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**Shwachman-Diamond America (SDA) is a
501(c)(3) non-profit organization dedicated
to raising money for Shwachman-Diamond
Syndrome research and education.**

SDS Congress in Amsterdam

Traveling to Amsterdam was truly an amazing experience. It was overwhelming to be in a room filled with brilliant physicians, scientists and professionals just as passionate about SDS as I am. It gave me a lot of hope to know that the research is going on; these professionals want more information, just as we do as parents, and they are working diligently to provide that data.

Presentations lasted two days and topics included everything from genetics to bone marrow transformations, and from growth to the neuropsychological aspects. Each presentation was just as interesting and informative as the last. I also had many opportunities to speak one on one with many of the presenters. And no matter what the topic was all were approachable and willing to answer my questions.

The next International Congress will be held in the New York area. I highly recommend attending it for those that find it feasible. It provides an opportunity to learn from a group of tremendously intelligent people and an opportunity to connect with others who have a personal interest in SDS.