

# S.D.A. ♥ eNewsletter

Shwachman-Diamond America

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## Happy Thanksgiving and Merry Christmas!

It seems like the year 2010 has only just begun, yet here we are amid the holiday season once again. This has been a very exciting year for Shwachman-Diamond America. This year began with our support of the North American Shwachman-Diamond Syndrome registry and the registry website finally going live. We were able to attend the second Bone Marrow Failure Symposium in Bethesda, Maryland where we helped to get our medical Advisor, Dr. Richard Harris, in as a speaker. Dr. Harris also presented Pediatric Grand Rounds at Wake Forest University Baptist Medical Center this month. We are excited about being able to educate physicians on Shwachman-Diamond Syndrome.



Shwachman-Diamond America has also supported research projects through our Alex Turnquist Memorial Research Grant program. These research projects along with the education projects SDA funds, are the core of our mission. Research and education will eventually lead to a cure. SDA also purchased a brick at Camp Sunshine this year to help support SDS week at camp. Camp Sunshine is a special place for SDS families and SDA was glad to support the camp in this small way.

As we look into 2011, Shwachman-Diamond America has already approved funding for the sixth International Congress on Shwachman-Diamond Syndrome which will take place in New York City in June 2011.

As we reflect on the accomplishments of this past year, we also remember why it is we work so hard to help SDA with its mission. This past year, we have celebrated with the families whose children received successful bone marrow transplants and we have also grieved with those families who lost their precious children to Shwachman-Diamond Syndrome complications. The children and families serve as our inspiration and motivation.

As you gather around the Thanksgiving table this year, remember to give thanks for all of the doctors and researchers who work tirelessly to find better treatments and ultimately a cure for SDS. Please remember all the families who have lost their precious loved ones as you celebrate Thanksgiving and Christmas, too.

Happy Thanksgiving and Merry Christmas!

Pattie Curran



## Generous Off Roading Community Supports SDA

Dear Shwachman-Diamond America,

You have to love the off roading community. They are all like family. Many kids, moms, dads and friends going to the woods to ride their off road vehicles. Having been involved with two grandchildren having and dying from SDS, and a third that is a carrier, SDS is dear to my heart. I have spent much time raising money for SDS.

The off roading community has heard my please, sometimes with tears in my eyes. Most off roaders and off road parks in Alabama know my passion. They are always willing to help.

In August, Morris Mountain Off Road Park in Delta, Alabama held a race event called the Rock Rally. This event was a race of fours laps of about six miles each. The 100 degree day, really made it a tough race. The promoter, and friend, Jimmy Boykin, along with the park donated \$700.00 from the proceeds to Shwachman-Diamond America.

This past weekend, Clay County 4X4 Club from Florida held an event called South east Tough Truck Challenge. It was a three day event with multiple difficult trails being done. It was based on time, with penalties for hitting cones or going out of bounds. The winner was not decided until the last event on Sunday. It was pouring down rain. After I broke on Saturday, and fixing it between events, I was able to come away as the overall winner. I won \$1,000.00 plus some nice prizes. Jimmy, the same one that donate \$700.00 above, challenged me to match what he could raise from the other racers and friends that were at the awards ceremony. I accept the challenge. I was amazed when some took hundred dollar bills out. In about five minutes, we had \$620.00 laying on the stage. So with my match, that give Shwachman-Diamond America \$1, 940.00.

I posted on a local off road internet forum that these two evens had raised \$1, 940.00 for Shwachman-Diamond America. A couple of hours later, I saw the following post: "We will match Jimmy's and MMs \$700 from the benefit (motorcycle) ride we had in honor of my dad who passed away. He loved helping people and he loved kids. So we would be honored if you would accept our donation. Walt Williams Golden Deeds."

I bumped it by another \$160.00.

So when good things happen, sometimes they just snowball. That brings the total raised by the off roading community this time to \$2,800.00.

Sincerely for the kids,

John Galbreath Jr



## SDA Approves a Research Grant

Shwachman-Diamond America recently approved an \$8,000 Alex Turnquist Memorial Research Grant for a research project titled "Establishment of a Novel Model for Shwachman-Diamond Syndrome" by investigators Drs. Seth Corey and Sergei Revskoy. This research is an attempt to dissect the function of the SBDS protein using a zebrafish model, which is a key to understanding Shwachman-Diamond Syndrome and developing better treatments and ultimately a cure. Researchers hope to identify genetic risk factors that predispose patients to developing acute myeloid leukemia and develop strategies to prevent this complication of Shwachman-Diamond Syndrome.



Dr. Harris with Dr. Sabio at Grand Rounds

## SDA Approves Funding for Sixth International Congress

The Sixth International Congress on Shwachman-Diamond Syndrome will be held at The New York Academy of Sciences Conference Center in New York City June 28-30, 2011. Shwachman-Diamond America has approved a minimum of \$8,000 to help fund the Congress.

The International Congress on Shwachman-Diamond Syndrome (SDS) has been held biannually since 2001 to promote the exchange of scientific and medical information between clinical and basic science investigators and clinical leaders involved in patient care. The Sixth International Congress on Shwachman-Diamond Syndrome in 2011 should be especially exciting given the recent identification of the Shwachman-Bodian-Diamond-Syndrome (SBDS) gene that is mutated in this syndrome and ongoing investigations into SBDS protein function. Since 2001, this meeting has continued to promote ongoing interest in SDS, stimulate new avenues of research and foster collaborations. The goal of the Congress is to present a selection of the most important advances in the understanding of the clinical features, current management and treatment of SDS and the molecular function of SBDS in hematopoiesis, leukemogenesis and organogenesis.



Dr. Sabio Introducing Dr. Harris at Grand Rounds.

## Pediatric Grand Rounds at Wake Forest University

Dr. Richard Harris Presented Pediatric Grand Rounds at Wake Forest University Baptist Medical Center on November 12, 2010.

The Pediatric Grand Rounds took place at Wake Forest University Baptist Medical Center in Winston-Salem, North Carolina. There were over 80 physicians and medical students in attendance. Dr. Harris presented "Hereditary Marrow Failure Syndromes - Diagnosis and Treatment Options" which included an in depth section on Shwachman-Diamond Syndrome.

Shwachman-Diamond America was a proud sponsor of these pediatric grand rounds. If you would like to set up grand rounds with Dr. Harris at your local hospital, please contact Shwachman-Diamond America for more information. Educating physicians is a key part of Shwachman-Diamond America's mission and SDA would be happy to work with your local hospital to have Dr. Harris present grand rounds.



## George Washington's Thanksgiving Proclamation

As just a bit of American History behind the observance of Thanksgiving, below you will find President George Washington's Thanksgiving Proclamation from October 3, 1789. This was the first national observance of a day of Thanksgiving. On October 3, 1863, President Abraham Lincoln gave a Thanksgiving Proclamation that fixed the day of national Thanksgiving to the last Thursday of November. It was no mere coincidence that Lincoln chose October 3, 1863 to issue his Thanksgiving Proclamation. Happy Thanksgiving to all!

### Thanksgiving Proclamation

[New York, 3 October 1789]

By the President of the United States of America, a Proclamation.

Whereas it is the duty of all Nations to acknowledge the providence of Almighty God, to obey his will, to be grateful for his benefits, and humbly to implore his protection and favor -- and whereas both Houses of Congress have by their joint Committee requested me to recommend to the People of the United States a day of public thanksgiving and prayer to be observed by acknowledging with grateful hearts the many signal favors of Almighty God especially by affording them an opportunity peaceably to establish a form of government for their safety and happiness.

Now therefore I do recommend and assign Thursday the 26th day of November next to be devoted by the People of these States to the service of that great and glorious Being, who is the beneficent Author of all the good that was, that is, or that will be-- That we may then all unite in rendering unto him our sincere and humble thanks--for his kind care and protection of the People of this Country previous to their becoming a Nation--for the signal and manifold mercies, and the favorable interpositions of his Providence which we experienced in the course and conclusion of the late war--for the great degree of tranquility, union, and plenty, which we have since enjoyed--for the peaceable and rational manner, in which we have been enabled to establish constitutions of government for our safety and happiness, and particularly the national One now lately instituted--for the civil and religious liberty with which we are blessed; and the means we have of acquiring and diffusing useful knowledge; and in general for all the great and various favors which he hath been pleased to confer upon us.

and also that we may then unite in most humbly offering our prayers and supplications to the great Lord and Ruler of Nations and beseech him to pardon our national and other transgressions-- to enable us all, whether in public or private stations, to perform our several and relative duties properly and punctually--to render our national government a blessing to all the people, by constantly being a Government of wise, just, and constitutional laws, discreetly and faithfully executed and obeyed--to protect and guide all Sovereigns and Nations (especially such as have shewn kindness unto us) and to bless them with good government, peace, and concord--To promote the knowledge and practice of true religion and virtue, and the encrease of science among them and us--and generally to grant unto all Mankind such a degree of temporal prosperity as he alone knows to be best.

Given under my hand at the City of New York the third day of October in the year of our Lord 1789.

Go: Washington





### **Shwachman-Diamond America's Mission:**

Fund and promote research in all aspects of Shwachman-Diamond Syndrome.

Disseminate current medical literature to families and physicians.

Facilitate the development of a medical management plan.

Promote parent education through a family support network.

Help Fund the Biennial International Congress on Shwachman-Diamond Syndrome

### **SDA Thanks the Off Roading Community!**



[www.shwachmandiamondamerica.org](http://www.shwachmandiamondamerica.org)



**S.D.A.**  
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