

# S.D.A.

## Shwachman-Diamond America

### Bone Marrow Failure Disease Symposium 2010

On March 11-12, 2010, the Aplastic Anemia & MDS Foundation hosted the Bone Marrow Failure Disease Scientific Symposium in Bethesda, Maryland.

The symposium brought together physicians treating bone marrow failure diseases and laboratory researchers studying the immunology and cell biology of bone marrow failure. This was the second ever Bone Marrow Failure Symposium. The first was held in October of 2005.

Shwachman-Diamond America's medical advisor, Dr. Richard Harris, spoke at the symposium. His presentation was titled: The Characterization of the Pathophysiology of Aplastic Anemia: The Treatment of Inherited Marrow Failure Syndromes. He did a

great job and included information about diagnosis and treatment of Shwachman-Diamond Syndrome in his presentation.

Other presenters, such as Dr. Stella Davies, also gave presentations on the inherited bone marrow failure syndromes. We are very thankful for all of the work and research these physicians do throughout the year to help advance diagnosis and treatment of these rare diseases.

The AAMDS has a medical writer working on transcribing the presentations into lay terms. These will be available in two to three months from their organization. For more information on the Aplastic Anemia & MDS Foundation, please visit their website

at [www.aamds.org](http://www.aamds.org)

The AAMDS Foundation is also hosting a symposium for families and friends at the Mayo Clinic in Rochester, MN on May 8-9, 2010. This symposium is titled, "Living with a Blood Disease Symposium: a Comprehensive Workshop for Patients, their family and friends."

The blood disease symposium has a renowned group of speakers organized to provide specific breakout sessions on a variety of blood diseases. It also includes topics of exam room, overcoming fatigue, nutrition, advocacy and much more. Contact the AAMDS Foundation for more information and to register for this upcoming symposium.

### SDS Children Going Through Transplant



Brandon Fletcher received chemotherapy which was successful in getting his leukemia into remission. He began the chemotherapy in preparation for his

bone marrow transplant the second week of March and will receive his bone marrow transplant, new bone marrow stem cells, on March 17, 2010. I was recently able to visit Brandon at Children's Medical Center in DC. He is a delightful boy and was doing well at the time of my visit. Please continue to pray for Brandon to do well through transplant and engraftment of

his new stem cells!

Jasmine Binette received her BMT just a few days after Christmas 2009. She is still in the hospital battling GVHD. Please continue to pray for Jasmine.



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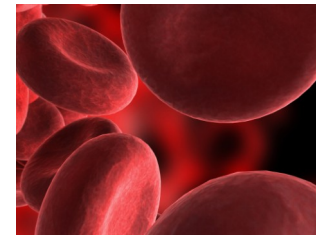
## HLA typing vs. Blood Type – What Does It All Mean?

By Richard E. Harris, MD  
– Blood and Marrow Transplant Program,  
Bone Marrow Failure Comprehensive Care Center Cincinnati Children’s Hospital Medical Center

There is some confusion out there among parents about the difference between these two relative to a bone marrow transplant. HLA typing is the blood test which is done to search for the best donor for a transplant. It helps determine the likelihood of a graft rejection or graft vs. host disease after transplant. Generally, the better the match by HLA typing, the lower the risk of these two complications. The blood type refers to the antigens on the surface of red cells which determine whether a patient is A, B, AB, or O and Rh Positive or Negative. The blood type really has nothing to do with the HLA type. Post-

transplant, the patient will switch his blood type (and HLA type) over to the blood type (and HLA type) of the donor. All the red blood cells will eventually become the same as the blood type of the donor and provided the donor marrow has fully engrafted, the HLA type will become all donor as well. Patients do not have to be matched with the donor as to blood type, though if there is a mismatch, we physicians must be sure the blood we transfuse into the patient is still ‘compatible’ with what is in the patient at the time of the transfusion. At times, the patient may have red blood cells from his own old marrow mixed with red cells produced by his new donor marrow as well as red cells received from prior transfusions. The average red cell lives about three months in the blood stream. Sometimes, patients may produce antibodies

to their old red cells, their new red cells or transfused cells, which may make management by the physician complicated. Sometimes patients may even require treatment with special drugs to manage these antibody problems.



**Post-transplant, the patient will switch his blood type (and HLA type) over to the blood type (and HLA type) of the donor.**

## SDA Cares and Cards for Kids

Children in the hospital going through treatment love to get mail! Over the years, I have tried to make it a habit of sending cards to our SDS friends spending time in the hospital or going through procedures.

If you would like to send one of our SDS children (or adults) going through a hospitalization or procedure a card, please

contact Shwachman-Diamond America for a list of addresses.

If your child is going through a hospitalization and would like to receive cards from other Shwachman-Diamond families, please contact SDA to have your child added to the list of addresses. SDA will not give out addresses without permission and addresses will never be

published on any website or in any materials.

SDA Cares is a care package program for SDS children in the hospital. Please contact SDA for more information.

## Nathan Canter

Nathan Canter, 30, passed away Sunday morning January 10, 2010. Nathan was the son of Phyllis and Terry Canter.

Nathan was a wonderful, warm and caring person who brought joy to everyone he met. He worked at Food Lion until he was hospitalized in October 2009.

After Nathan's passing, Shwachman-Diamond America received the following letter in the mail.

## 1979–2010

1-16-10

I shall miss Nathan. He became my friend as I shopped weekly for my groceries. He always had a smile, was always friendly. We would talk for a short time for he was always busy and he never complained. Even when he was moved from produce to the freezer section or other areas.—

I know God welcomed him with loving arms. I shall never forget my dear friend, Nathan—

-Mary Tysinger

Our prayers are with Nathan's family.



## Alison Taylor

Alison Taylor, 48, passed away on March 3, 2010. Alison touched many lives during her stay here on earth. She joined our email support group in 2003, just after she was diagnosed with Shwachman-Diamond Syndrome. Through the sharing of her experiences, she gave many parents insight and hope.

In 2004, Alison wrote an article titled, "Experiences of an Adult Patients with Shwachman-Diamond Syndrome." She distributed this article to our support group and once again, through her sharing, she was able to help many SDS parents.

Alison loved taking her nieces and nephews on camping and

hiking trips. The stories of her adventures always made her SDS friends smile.

Alison will be missed. Our hearts and prayers go out to her family and Robert, her loving husband.

**"I know God welcomed him with loving arms. I shall never forget my dear friend, Nathan."**

## SDS Children's Book

The Shwachman-Diamond Syndrome UK group is putting together a children's SDS book. The SDS UK group has received funding and has also received a copyright from the Roald Dahl Foundation for this effort.

The group would like for the content to be from the children themselves. Perhaps a drawing illustrating how they see their

illness (Shwachman-Diamond Syndrome) and/or how they feel about their illness. These drawings may be accompanied by a few lines from the parents detailing how their child feels and copes with Shwachman-Diamond Syndrome.

If you are interested in having your child being a part of this book, or would like more detailed

information about this book project, please contact SDS UK at the following email address:

[mail@sdsuk.org](mailto:mail@sdsuk.org)

## IEP App for iPod

Nurvee has developed an application called "IEP Checklist" which is available as a free download for your iPod Touch or iPhone. The IEP Checklist application is sponsored by The Parent Educational Advocacy Training Center (PEATC) [www.peatc.org](http://www.peatc.org)

IEP Checklist is a tool for parents and teachers to use as they develop an IEP for a child. Not every item on the checklist is required by special education regulations.

The IEP checklist is a simple application that includes sections for notes on IEP team members, notifications, current performance, annual goals, services, supports and aids along with sections for student placement and State and District assessment.

This application is free of charge. To download, simply visit the App Store on your iPod Touch or iPhone and search "IEP Checklist".

Shwachman-Diamond  
America

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## SDA Benefit Concert

On May 23, 2010, Shwachman-Diamond America will be hosting a benefit concert at St. Mary's Music Academy in High Point, NC.

The concert will begin at 2:00 pm. No tickets required, but donations are accepted.

Sean Curran will be playing the three piano pieces he played at the North Carolina Music Teachers Association District Competition this month. Sean received a superior rating and moves up to the North Carolina State competition later this month. Many students from St. Mary's Music

Academy will also be performing.

We welcome musicians of all types to come out and perform at our benefit concert.

Please contact Shwachman-Diamond America if you would like to donate your time and talent to this wonderful event. The hall has a grand piano, all other instruments must be brought by the musician. Vocalists also welcome to perform.



**Sean Curran with his piano teacher after the recent District competition.**