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Special points of interest:

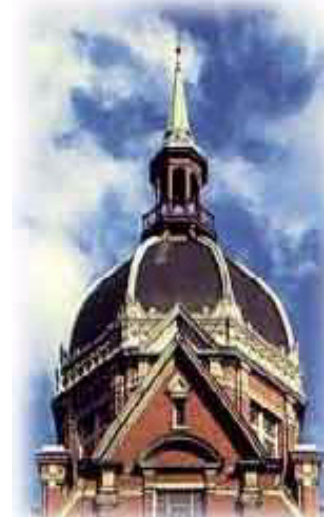
- Sickle Cell disease is an inherited disorder.
- It affects 1 out of every 475 African Americans.
- About 1,000 babies are born with SCD per year.
- Hydroxyurea is the first drug approved to treat SCD in adults.

NEWS FROM DR. SAMUEL CHARACHE, M.D.

I think it's really terrific to be asked to write something for this Newsletter...partly because I'm so glad there is a Newsletter, but mostly because it shows that there finally is a formal program at Hopkins centered on Sickle Cell Disease. For years, people would ask me about "the Hopkins program", and I'd have to tell them there was no such program. Now, Dr. Sophie Lanzkron is the Director of Hopkins Sickle Cell Center and Yvette Roane is her Physician Assistant. Many things seem to go sour, as I get older, but this is one thing that's gotten a lot sweeter.

So, what have I been doing? I have traveled, which I enjoy greatly. Usually I go alone, since my wife is still working at the Hospital. She comes along every now and then when I travel. I just got back from Vietnam, which was nothing like what I expected. The Vietnamese were friendly and helpful, the countryside (especially in the North) was beautiful, and sad to say (for my middle) the food was delicious. Next planned trip is to the Dordogne, in France, to look at prehistoric cave paintings and medieval castles. And eat French rather than Oriental food.

You may wonder, what do I see as "new and interesting" in the treatment of sickle cell disease? I think Hydroxyurea treatment has stood the test of time...it helps, but it isn't a cure. It has to be used (and taken) carefully, and it can't undo damage that has already been occurred. Chronic transfusions therapy helps in the short run, but its dangers make physicians and patients think hard about using it for long-term treatment. Bone marrow transplantation, still a hazardous treatment, can cure patients if a donor can be found...which isn't often the case. Hopkins will soon test one of the various experimental treatments.



SICKLE CELL MAINTENANCE

Follow-up care for sickle cell patients is imperative to avoid serious complications. Immunizations for pneumococcal infections, hepatitis, and the flu are among our preventive maintenance plan. Many sickle cell patients are susceptible to infections such as pneumococcal pneumonia or sepsis. Therefore, pneumococcal vaccine should be given every 5 years to prevent infections. We recommend our patients visit the ophthalmologist yearly to avoid retinal hemorrhage. Proliferative retinopathy is a common problem in sickle cell disease. It is more common in people with Hb SC. People may experience sudden vision loss due to a vitreous hemorrhage (bleeding in the eye). If you experience any changes in your vision, consult your ophthalmologist immediately.



RESEARCH ADVANCES IN SCD

The FDA approved Hydroxyurea in 1998 for the treatment of Sickle Cell Disease (SCD) in adults. This is the first time a drug gained approval specifically for use in individuals with SCD. It has been shown to decrease the number of crisis, decrease the frequency of Acute Chest Syndrome, and decrease the number of patients requiring transfusions. Hydroxyurea is offered to patients who have 3 or more sickle cell crisis per year. Patients starting on Hydroxyurea must return to clinic every two weeks to closely monitor laboratory values. Ask your hematologist if Hydroxyurea is right for you.

"I think hydroxyurea treatment has stood the test of time...it helps, but it is not a cure."

EMERGENCY ROOM VISITS

The Sickle Cell Team at Johns Hopkins Hospital is working in collaboration with the Emergency Department to decrease the amount of time sickle cell patients wait in the ED. We are implementing a plan to have every sickle cell patient triaged within 15 minutes and sent to the Emergency Acute Care Unit (EACU) for immediate care. Thank you for your patience in the past. It is a work in progress and we welcome your feedback.

Sickle Cell is a hematological disease
Affecting mostly African Americans across the border
A recessive condition attacking red blood cells
Sickle Cell Anemia- an inherited blood disorder.

Hemoglobin carries oxygen throughout the body
Under low oxygen, sickle hemoglobin becomes stiff
Red blood cells often clump together
Resulting in blockage of vessels and painful crisis.

Anemia is a reduction of hemoglobin in the blood
Or a decrease in the amount of red blood cells
The spleen enlarges leading to sequestration crisis
Cells get trapped in the spleen and then it swells.

Organ and tissue damage are complications
Hospital admissions are a sickler's worst fear
Treatments may include chronic transfusions
Penicillin, Erythropoietin, and Hydroxyurea.

Dehydration should be avoided at all cost
Eye exam visits scheduled yearly
Genetic counseling is provided for education
Hopkins Sickle Cell Center loves you dearly.

By Yvette Roane, PA-C

NEW PA PROGRAM COORDINATOR/EDITOR

We would like to introduce Yvette Roane, our new Physician Assistant Program Coordinator. Yvette graduated cum laude from Howard University PA program with a Bachelor of Science. She has worked in Internal Medicine for the past two years. She was born in Baltimore City, and attended high school at Baltimore Polytechnic Institute. Her desire to give back to the community led her to Johns Hopkins. Writing poetry is one of her hobbies. She has written the poem above for your enjoyment. Yvette will see you in clinic, examine you in the hospital, refill your prescriptions, and visit those on chronic transfusions. If you have questions, call Yvette at (410) 502-6997.



We are on the web!
sicklecellcenter.org

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*SOPHIE LANZKRON, M.D.
DIRECTOR OF SICKLE
CELL CENTER AT JOHNS
HOPKINS*

Adult Hematology Clinic Days:

Tuesday and Friday mornings

Upcoming topics next edition:

Depression in SCD, Transition Clinic,

Benefits of Breastfeeding

Upcoming Support Groups

Outpatient Ctr.

April 3rd

May 1st

June 5th

July 3rd

August 7th

September 4th

October 2nd

WHY SHOULD YOU ATTEND OUR SUPPORT GROUP?

Since May, 2002 a group of adults, ages 18 & up have been meeting once a month in the Johns Hopkins Outpatient Center to discuss what living with sickle cell disease is like. For some individuals it is the first time they have met another adult also living with this illness and for others it has been an opportunity to learn from and share with one another. The issues discussed have included pain management strategies, living with a chronic illness, and relationships with family/friends.

In addition we have had speakers come and present on various topics including the latest in medical research and dental concerns. A nutritionist will be the presenter at the upcoming June group meeting.

Some of you may say, "I don't feel comfortable in groups" or "I don't want to sit in a meeting with people who are crying b/c of having this illness." I think I can speak for those who have attended, while the focus is serious at times, there is also plenty of laughter and humor that is shared and useful information exchanged!!

Hope to see you at our April Meeting; Thursday, April 3rd, in the Johns Hopkins Outpatient Center, from 6:30 – 8:00 PM. Look for flyers in your mail!!

By Anita Mentzer, MSW