

NCAA May Force Schools To Test For Sickle Cell Trait

<http://www.npr.org/templates/story/story.php?storyId=121829370&ft=1&f=1003>

Fifteen athletes, most of them college football players, have died in the past decade from a condition that is benign in most circumstances. They were carrying the sickle cell trait.

Kourni Livingston, a 14-year-old girl who played basketball for DeSoto High School near Dallas, died running laps outdoors in August 2002. Then University of Missouri linebacker Aaron O'Neal died during a voluntary workout in 2005. Devaughn Darling died shortly after complaining of dizziness and chest pains during off-season conditioning exercises in February 2001 at Florida State University. Experts have found that under conditions such as extreme exertion, high altitudes and hot climate, sickle cell trait is associated with a potentially deadly blood disorder called "sickling."

In January, the National Collegiate Athletic Association is expected to decide whether it will be mandatory for colleges and universities to test athletes for sickle cell trait. But some experts are concerned that this could lead to athletes with the trait being singled out and excluded from sports.

400,000 in Ghana with Sickle Cell Disease

http://www.ghananewsagency.org/s_science/r_11087/ Jan 6, GNA - A survey conducted by the National Sickle Cell Control Programme, shows that more than 16,000 Ghanaian children born within the last three years have the sickle cell disease.

Dr Andrew Adjei Druye, National Focal Person, described the figure as worrying and blamed the situation on public ignorance about the genetic and sickle cell status. It is estimated that there are currently 400,000 Ghanaians living with the disease. Dr Druye who was speaking to the Ghana News Agency in Kumasi described the disease as deadly and counter-productive to socio-economic development.

Persistent destruction of the immune system, bones and internal organs hasten the death of patients. They also suffer chronic anaemia, and bodily pains. Dr Druye, who is also the Programmes Director of the Health Education Unit, Ghana Health Service (GHS), said since Ghana is ranked among countries with the highest population of sickle cell patients in Africa, the service is liaising with the United States Agency for International Development to establish Genetic Counselling and Testing centres across the nation.

The centres would be attached to government hospitals with the primary aim to test people for the disease, provide counselling, as well as treatment and management. He said the GHS would also train health workers especially doctors and nurses to build their capacity, knowledge and skills to give proper care and efficiently manage sickle cell

patients. He advised the youth who want to marry to go for sickle cell test to know their status to help them to give birth to healthy children.

New Resource for Virginia

Peninsula Association for Sickle Cell Anemia, Inc. (PASCA)

Street address is: 512 E. Mercury Blvd. Hampton, VA 23663

Our mailing address is: PO Box 8201

Hampton, VA 23666

Our new Executive Director is: Johnnie M. Tidwell Our new number is: 757-813-1021

Our [website address](http://http://www.orgsites.com/va/pasca/) is: <http://http://www.orgsites.com/va/pasca/>

Our email address is: sicklecellofthepeninsula@yahoo.com

NIH News

Message from Dr. Susan B. Shurin January 08, 2010

Dear Colleagues:

I want to provide an update on the NHLBI's participation in NIH-Wide Recovery Act Research Funding Opportunities (FOAs) as part of the American Recovery and Reinvestment Act (ARRA).

On Dec. 28, 2009, the NIH Office of the Director announced five additional Recovery Act FOAs. The NHLBI is participating in two, as listed below. The NHLBI is also participating in four of the NIH Basic Behavioral and Social Science Opportunity Network (OppNet) ARRA opportunities, which were announced this week.

Like all other Recovery Act RFAs, these are intended to stimulate the economy, create or retain jobs, and advance scientific progress over the next two years. To learn more about the NHLBI opportunities, we encourage you to visit the [NHLBI Recovery Act Funding and Policies page](#).

Comparative Effectiveness Research

Announcement Number	Title	Issuing Org	Release Date	Receipt Date(s)
RFA-OD-10-009	Recovery Act Limited Competition: Methodology Development in Comparative Effectiveness Research (RC4)	NIH	12/28/2009	02/26/2010

Research and Research Infrastructure

Announcement Number	Title	Issuing Org	Release Date	Receipt Date(s)
<u>RFA-OD-10-005</u>	Recovery Act Limited Competition: NIH Directors Opportunity for Research in Five Thematic Areas (RC4)	NIH	12/28/2009	03/15/2010

NIH Basic Behavioral and Social Science Opportunity Network (OppNet)

Announcement Number	Title	Issuing Org	Release Date	Receipt Date(s)
<u>RFA-OD-10-003</u>	Recovery Act Limited Competition: NIH Basic Behavioral and Social Science Opportunity Network (OppNet) Short-term Mentored Career Development Awards in the Basic Behavioral and Social Sciences for Mid-career and Senior Investigators (K18)	NIH	01/05/2010	02/18/2010
<u>NOT-OD-10-032</u>	NIH Announces the Availability of Recovery Act Funds for Competitive Revision	NIH	01/07/2010	03/02/2010

Announcement Number	Title	Issuing Org	Release Date	Receipt Date(s)
	Applications (R01, R03, R15, R21, R21/R33, and R37) through the NIH Basic Behavioral and Social Science Opportunity Network (OppNet)			
<u>NOT-OD-10-033</u>	NIH Announces the Availability of Recovery Act Funds for Competitive Revision Applications (R01, R03, R15, R21, R21/R33, and R37) for HIV/AIDS-related Research through the NIH Basic Behavioral and Social Science Opportunity Network (OppNet)	NIH	01/07/2010	03/25/2010
<u>NOT-OD-10-034</u>	NIH Announces the Availability of Recovery Act Funds for Competitive Revision Applications for Small Business Innovation Research and Small Business Transfer	NIH	01/07/2010	03/25/2010

Announcement Number	Title	Issuing Org	Release Date	Receipt Date(s)
	Technology Research Grants (R43/R44 and R41/R42) through the NIH Basic Behavioral and Social Science Opportunity Network (OppNet)			

Best regards,
Susan B. Shurin, M.D.

New Organization

Dominique Friend has formed,"The Sickle International Family Coalition,"

The Mission for the coalition is :
 The mission of the Sickle International Family Coalition will be to connect families affected by Sickle Cell disease and Sickle Cell Trait worldwide to ensure a comprehensive approach and quality access to health care, programs and services.

For more info : please contact Dominique Friend @ 717.793.6294 or Email: Sickle1000@yahoo.com

Sickle cell trait (HbAS) is twice as prevalent among African Americans with end-stage renal disease (ESRD) than in the general African-American population, <http://www.renalandurologynews.com/sickle-cell-trait-highly-prevalent-in-black-esrd-patients/article/161438/>

The data emerged from a study that included 188 African-American patients receiving dialysis at four centers affiliated with the University of North Carolina (UNC) Kidney Center in Chapel Hill. All subjects underwent hemoglobin phenotyping for HbAS. The study also determined HbAS prevalence in the local population by studying 6,729 African-American newborns screened for hemoglobinopathies in three North Carolina counties served by the dialysis centers.

The researchers, led by Vimal K. Derebail, MD, of the UNC Kidney Center, found that 15% of the dialysis cohort had HbAS compared with 7.1% of the screened newborns,

according to report in the *Journal of the American Society of Nephrology* (2010; published online ahead of print). In addition, hemoglobin C trait (HbAC) occurred in 5% of the dialysis patients versus 2% in the general African-American population.). HbAC is a hemoglobin variant found in African Americans. If an individual with this variant has a child with somebody who has HbAS, a sickle cell disease (hemoglobin SC disease) can develop in the child.

“The high prevalence these hemoglobinopathies suggests that they may contribute to progression to ESRD by providing a background of renal injury,” the investigators wrote. “Our findings also raise questions as to how the presence of HbAS or HbAC may affect management of ESRD patients.”

Epidemiologic studies have linked HbAS with microalbuminuria and proteinuria, especially among men with diabetes, and shown that African Americans with autosomal dominant polycystic kidney disease and HbAS progress to end-stage renal disease more quickly than those without the trait.

New Edition of Hope and Destiny The New Hilton Guide to Sickle Cell Disease and Sickle Cell Trait for Patients and Parents is coming this Spring fro Hilton Publishing

The popular patient and parent guide book for sickle cell disease has been completely updated with the latest in treatment and preventive therapy. There are two new co-authors joining [Allan Platt PA-C](#), [Lewis Hsu, MD, PhD](#) and [James Eckman MD](#)

New and expanded chapters include:

- * Preventive therapy with hydroxyurea
- * Blood transfusions for complication prevention
- * Bone marrow transplants as cures for some and new hope for many more
- * Gene therapy - a new chapter by [Betty Pace, MD](#)
- * Nutrition - the foods and supplements that help prevent sickle cell complications
- * Pregnancy and issues surrounding reproduction, prenatal diagnosis, PGD and IVF, and cord blood banking.

New Pre sale offer from [Hilton Publishing](#): for the first 500 copies at a Pre Sale (Pre release) cost of 10.00 per book. As a Pre Sale it requires a 50% deposit to lock in the cost. The next 500 would be at 8.48 per copy and every order of 500 or more after that

would be at 50% off. They all would be plus delivery. To order the Book you can call Hilton Publishing at 866-455-1070.

New Sickle Cell and Stroke Education Booklet from the UK

Sickle Cell & Young Stroke Survivors (SCYSS) Has produced a booklet in PDF format for downloading and printing

[Click here for the PDF download](#) Sickle Cell and Stroke from founder and CEO Carol Nwosu

www.scyss.org General e-mail: Info@scyss.org

Articles in the Medical Literature

[.Pain, coping and health care utilization in younger and older adults with sickle cell disease.](#)

Sanders KA, Labott SM, Molokie R, Shelby SR, Desimone JJ Health Psychol. 2010 Jan;15(1):131-7

[Acute human parvovirus B19 infection and nephrotic syndrome in patients with sickle cell disease.](#)

Quek L, Sharpe C, Dutt N, Height S, Allman M, Awogbade M, Rees DC, Zuckerman M, Thein SL.Br J Haematol. 2010 Jan 7

[High Prevalence of Sickle Cell Trait in African Americans with ESRD.](#)

Derebail VK, Nachman PH, Key NS, Ansele H, Falk RJ, Kshirsagar AV.J Am Soc Nephrol. 2010 Jan 7.

[The HDAC inhibitors trichostatin A and suberoylanilide hydroxamic acid exhibit multiple modalities of benefit for the vascular pathobiology of sickle transgenic mice.](#)

Hebbel RP, Vercellotti GM, Pace BS, Solovey AN, Kollander R, Abanonu CF, Nguyen J, Vineyard JV, Belcher JD, Abdulla F, Osifuye S, Eaton JW, Kelm RJ Jr, Slungaard A.

Blood. 2010 Jan 6

[Delayed Hemolytic Transfusion Reaction in Sickle Cell Disease.](#)

Scheunemann LP, Ataga KI. Am J Med Sci. 2009 Dec 31.

[Inpatient use of laxatives during opioid administration in children with sickle cell disease.](#)

O'Brien SH, Fan L, Kelleher KJ. *Pediatr Blood Cancer*. 2010 Jan 4.

[Respiratory symptoms and acute painful episodes in sickle cell disease.](#)

Jacob E, Sockrider MM, Dinu M, Acosta M, Mueller BU. *J Pediatr Oncol Nurs*. 2010 Jan-Feb;27(1):33-9.

[Placenta growth factor in sickle cell disease: association with hemolysis and inflammation.](#)

Brittain JE, Hulkower B, Jones SK, Strayhorn D, De Castro L, Telen MJ, Orringer EP, Hinderliter A, Ataga KI.

Blood. 2009 Dec 29.

[Genetic modifiers of the severity of sickle cell anemia identified through a genome-wide association study.](#)

Sebastiani P, Solovieff N, Hartley SW, Milton JN, Riva A, Dworkis DA, Melista E, Klings ES, Garrett ME, Telen MJ, Ashley-Koch A, Baldwin CT, Steinberg MH.

Am J Hematol. 2010 Jan;85(1):29-35.

[Cardiopulmonary complications leading to premature deaths in adult patients with sickle cell disease.](#)

Fitzhugh CD, Lauder N, Jonassaint JC, Telen MJ, Zhao X, Wright EC, Gilliam FR, De Castro LM.

Am J Hematol. 2010 Jan;85(1):36-40. PMID: 20029950

[Open heart surgery in patients with sickle cell hemoglobinopathy.](#)

Yousafzai SM, Ugurlucan M, Al Radhwan OA, Al Otaibi AL, Canver CC. *Circulation*. 2010 Jan 5;121(1):14-9.

[Relationships between Somatic Growth and Cognitive Functioning in Young Children with Sickle Cell Disease.](#)

Puffer ES, Schatz JC, Roberts CW. *J Pediatr Psychol*. 2009 Dec 21.

Ask the Experts

Question - Should my child with Sickle cell disease travel by airplane?

Answer -

Air travel does not cause problems for everybody with sickle cell disease. The major problem is a decrease in oxygen in the cabin air. The aircraft is only pressurized to about 7,000 feet, which is low enough to get some people with sickle cell in trouble. The other problem is related to dehydration because the humidity in the aircraft is very low and you may be too busy keeping on schedule to drink.

There are some steps you can take to prevent problems:

- 1) Increase the amount you drink before and during the flight. plan to drink a pint of water an hour during the flight. You may wish to carry on the water you will need. You may need to purchase some in the airport after clearing the security inspection. Make sure you know the security regulations on when you can & cannot carry liquids.
- 2) Ask the airline for an aisle seat so that going to the bathroom is easier.
- 3) If you have had trouble flying, we would recommend supplemental oxygen at 2 liters/minute or 120 liters/hour. Most airlines are willing to provide this but require two weeks notice and a doctor's letter that establishes the need for oxygen and specifies the rate of flow. Takeoff and landing are not the critical times. The period of concern is when the plane is at greater than 10,000 feet because that is when the cabin pressure is reduced and supplementary oxygen will be needed by the person with sickle cell.
- 4) When traveling, make sure you have a supply of all of the medicines you will need during your trip. You also should have a letter from your doctor that summarizes your disease complications and your most recent laboratory results, so that, if illness occurs, the treating doctors will know average values.
- 5) Discuss your destination with your doctor & plan where you would go for sickle cell care if a problem arises.
- 6) Be sure all vaccinations are up to date.
- 7) Traveling to areas above 6,000 feet in elevation may cause sickle complications. Check with your doctor before going.

And, especially since you live in the Northeast US, you can also consider ground-based travel alternatives like Amtrak train or long-distance bus. These are much more pleasant options today than 5-10 yrs ago.

Sincerely,

-Lewis Hsu, MD, PhD
Pediatric Hematologist

Featured Web Links

January

Sickle Cell & Young Stroke Survivors (SCYSS) is a charity that supports children and young people affected by Sickle Cell Disease and Stroke. <http://www.scyss.org/>

Conferences and Activities of Interest to the Sickle Cell Community

February 14 - 19, 2010 Hollywood , FL **4th Annual Sickle Cell Disease Research and Educational Symposium & Grant Writing Institute and Annual National Sickle Cell Disease Scientific Meeting PROGRESS AND PROMISE: SICKLE CELL DISEASE AT 100 YEARS** The Westin Diplomat Resort & Spa, Hollywood , Florida 3555 South Ocean Drive, Hollywood , FL 33019 Web <http://floridasickle.org/>

April 14 - 16, 2010 Leicester, UK Sickle Cell: The Next 100 Years International Conference on Social Research for Sickle Cell and Thalassaemia De Montfort University, Leicester, United Kingdom **Keynote Speaker:** Professor Kwaku Ohene-Frempong

Sickle Cell: The Next 100 Years will mark the 100th year anniversary since James Herrick published his first observations on ‘peculiar elongated cells’, what is now known as Sickle Cell Disease. This unique and highly distinctive 3 day conference will bring together a selection of papers offering delegates the chance to explore the social research being carried out around the world, now and for the next 100 years. This conference invites papers on the social aspects of Sickle Cell and Thalassaemia from academics and practitioners in the disciplines of: social medicine, public health, genetic counselling, nursing, social work, sociology, social policy, politics, health services research, social history, anthropology, cultural psychology, human geography, and law and ethics.

The best papers will be published in the international journal *Ethnicity & Health* <http://www.tandf.co.uk/journals/carfax/13557858.html> to be edited by Karl Atkin, Hannah Bradby, Seeromanie Harding and Simon Dyson.

2nd World Sickle Cell Day, June 19, 2010 - Multi city world wide

July 15 - 18 Kiawah Island Resort near Charleston, South Carolina - 10th Annual Using Transcranial Doppler, MRI/MRA and Transfusion to Prevent Stroke in Sickle Cell Disease. This activity has been approved for AMA PRA credit. For more information, contact: Office of Continuing Medical Education Medical University of South Carolina, Charleston, SC 29425 Phone: 843-876-1925 • Email: maxwells@musc.edu

July 20-23, 2010 Accra, Ghana within the *First Global Congress on Sickle Cell Disease*, July 20-23, 2010, co-sponsored by the Sickle Cell Center at Children's Hospital of Philadelphia and The Sickle Cell Foundation of Ghana.

22 - 27 November 2010— Raipur (Chhattisgarh) India - Sickle Cell Disease International Organization in collaboration with Centre for Genetic Diseases & Molecular Biology Department of Biochemistry, Pt. J.N.M. Medical College , Raipur (C.G.) INDIA are organizing the Fourth International Congress 2010 Sickle Cell Disease International Organization

1. Simple models of survey/ screening. 2. Methods of counseling for :a. General population b. Youth & marriageable age group (premarital counseling) c. Post marriage counseling for carriers and sufferers including antenatal checkup, family planning, MTP, adoption of child. d. Counseling for sufferers of the disease. e. Counseling for the parents of sickle cell disease affected children. 3. Models of treatment plan at primary, secondary and tertiary level including plan for sickle cell clinics at village level, district level and super specialty clinic at medical college level. 4. Scope of research in developing countries. 5. Advocacy for financial support, scope of a network and linking the various NGOs working in the field of sickle cell disease. **KEY DATES 22nd November 2010** - Preconference briefing: to be attended by NGOs, Doctors and Technicians working in the field of sickle cell anemia. **23rd -24th November 2010-** Scientific Sessions. **25th November 2010-** General/Executive body meeting of the congress & draft presentation of the proceedings. **26th November 2010-** Sight Seeing. **27th November 2010-** Valedictory Function; Conclusion note, approval of proceedings. **FIRST ANNOUNCEMENT & CALL FOR PAPERS**
<http://4sccongress.co.in>

If you would like to obtain this monthly e-mail newsletter about the latest sickle cell news or read past archives go to: <http://listserv.emory.edu/archives/sicklecell.html>