Sickle Cell News for May 2016

**Sickle Cell in Focus Conference** June 2 & 3, 2016

Natcher Conference Center (Building 45)
National Institutes of Health
45 Center Drive
Bethesda, MD 20892

Sickle Cell in Focus (SCiF) is an annual two-day intensive and educational conference co-hosted by the National Heart, Lung and Blood Institutes (NHLBI) in Washington, DC and the South Thames Sickle Cell & Thalassaemia Network (STSTN) in London, UK. It highlights and discusses the emerging clinical complications and clinical management of sickle cell disease. The clinical and scientific research lectures are aimed at an audience of academics, trainee doctors, health professionals and interested others involved in the care of patients with the disease. It attracts local, national and international guest speakers and delegates.

*Watch online* (live on day of event) or *register to attend at NIH for free.*

Join the online conversation on Twitter:

- Use the Sickle Cell in Focus hashtag #SCDinFocus
- Follow [@nih_nhbl](https://twitter.com/nih_nhbl) for event information and updates

We look forward to your participation!

**Sickle Cell Artist, Hertz Nazaire, New Photo project** September 27th - October 1st 2016”

I want to ask friends and family who have lost someone to Sickle Cell Disease submit photos to be honored on art at this art show those who are still living and fighting may also submit photos so we can touch this world with images of real warriors
Please share this and send photos / images to

Hertz Nazaire
1042 Broad Street #407
Bridgeport, CT 06604

or digitally to nazaire@gmail.com please FWD email to family and Friends for the Sickle Cell Community so I can get the photos on time to me part of the art.
It is up to you to use our talents wisely, if I fail to do my part I fail those who I have already lost and those who continue to still fight Sickle Cell today.

I am a fighter and I do not plan to fail them

- Nazaire

**Funding for Sickle Cell Research** –

Dr. David Williams very much hopes the White House’s $755 million “cancer moonshot” finds cures, that Sean Parker’s $250 million “Dream Team” brings effective immune-system treatments to every kind of tumor, and that the $370 million raised by Hollywood-based Stand Up to Cancer fuels discoveries that make malignancies as treatable as headaches.

All Williams wants is $5 million — a rounding error to the billionaires making nine-figure donations to cancer research — to run a clinical trial that has a good chance of curing sickle cell disease.

There is no moonshot for sickle cell. There are no “ice bucket challenges.” When fundraisers at Boston Children’s Hospital and Dana-Farber Cancer Institute, where Williams is president of the Cancer and Blood Disorders Center, ask donors to support sickle cell research, benefactors say they prefer to fund efforts that promise to help the adorable little kids stricken with cancer. See more at [https://www.statnews.com/2016/05/19/sickle-cell-disease-cure/](https://www.statnews.com/2016/05/19/sickle-cell-disease-cure/)

**Sickle cell in the Medical Literature**


   **What motivates individuals with sickle cell disease to talk with others about their illness? Reasons for and against sickle cell disease disclosure.**

   Derlega VJ¹, Maduro RS², Janda LH², Chen IA³, Goodman BM 3rd³.

   **Abstract**

   This interview study documented how individuals with sickle cell disease make decisions about who to talk with concerning their illness based on psychological and interpersonal issues that are important to them. Reasons for sickle cell disease disclosure to specific persons were self-related (receiving support, venting feelings), other-related (educating others about sickle cell disease, forewarning others about sickle cell disease-related problems, someone asked for information about the disease), or situational (mostly focusing on another person being physically close or available to talk to). Reasons for sickle cell disease nondisclosure to specific persons
were self-related (fear of rejection, being stereotyped, maintaining privacy) or other-related (lack of support, not worrying someone).

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PMID: 27235142 [PubMed - as supplied by publisher]


Feasibility of Home-Based Computerized Working Memory Training With Children and Adolescents With Sickle Cell Disease.

Hardy SJ1, Hardy KK2,1, Schatz JC3, Thompson AL2,1, Meier ER2,1.

Abstract

BACKGROUND:

Children with sickle cell disease (SCD) are at increased risk for neurocognitive deficits, yet the literature describing interventions to ameliorate these problems and promote academic achievement is limited. We evaluated the feasibility and preliminary efficacy of a home-based computerized working memory (WM) training intervention (Cogmed) in children with SCD.

PROCEDURE:

Youth with SCD between the age of 7 and 16 years completed an initial neuropsychological assessment; those with WM deficits were loaned an iPad on which they accessed Cogmed at home. Participants were instructed to work on Cogmed 5 days each week for 5 weeks (25 training sessions). We examined Cogmed usage characteristics and change on WM assessment scores following the intervention.

RESULTS:

Of the 21 participants (M age = 11.38, SD = 2.78; Mdn age = 10.00, interquartile range [IQR] = 5.00; 52% female) screened, 60% exhibited WM deficits (n = 12) and received the intervention and 50% (n = 6) completed Cogmed. The mean number of sessions completed was 15.83 (SD = 7.73; Mdn = 17.00, IQR = 16.00); females
were more likely to complete Cogmed, $\chi^2 (1) = 6.00, P = 0.01$. Participants who reported lower SCD-related pain impact completed more sessions ($r = 0.71, P = 0.01$). Children who completed Cogmed exhibited improvements in verbal WM, visuospatial short-term memory, and visuospatial WM.

**CONCLUSIONS:**

Initial findings suggest Cogmed is associated with WM improvement in youth with SCD; however, adherence was lower than expected. Home-based WM interventions may ameliorate SCD-related WM deficits but strategies are needed to address barriers to program completion.

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**Adherence to hydroxyurea medication by children with sickle cell disease (SCD) using an electronic device: a feasibility study.**

**Inoue S**$^1$, **Kodjebacheva G**$^2$, **Scherrer T**$^3$, **Rice G**$^4$, **Grigorian M**$^4$, **Blankenship J**$^2$, **Onwuzurike N**$^3$.

**Abstract**

Adherence to hydroxyurea (HU) is a significant modifying factor in sickle cell vaso-occlusive pain. We conducted a study using an electronic medication container-monitor-reminder device (GlowCap™) to track adherence and determine whether use of this device affected rates of HU adherence. Subjects were regular attendees to our clinic. They were given a 37-item questionnaire and were asked to use a GlowCap containing HU. When the device cap is opened, it makes a remote "medication taken" record. The device also provides usage reminder in the form of lights and alarm sounds if the cap opening is delayed. Nineteen subjects participated in the survey, and 17 in the intervention phase. Of the 17, 12 had reliable adherence data. Seventeen caregivers of patients and two patients completed the survey. Two
most common barriers to adherence identified were lack of reminders and absence of medicine home delivery. The intervention component of this study, which used both the electronic (GlowCap) method and medication possession ratio showed that the median adherence rate for the 12 patients evaluated was 85%. The GlowCap device accurately kept a record of adherence rates. This device may be an effective tool for increasing HU medication adherence.

PMID: 27225236 [PubMed - as supplied by publisher]


Presentations of sickle cell disease patients to hospital in Ghana: key findings from a preliminary study at Volta Regional Hospital.

Fisher AE¹, Oduro AK², Adzaku F³, Telfer P⁴.

PMID: 27221529 [PubMed - as supplied by publisher]


Psychometric Validation of the Insomnia Severity Index in Adults with Sickle Cell Disease.

Moscou-Jackson G¹, Allen J¹, Smith MT², Haywood C Jr³.
Abstract

BACKGROUND:

The Insomnia Severity Index (ISI) is an instrument to evaluate insomnia symptoms. The psychometric properties have not been established in adults (18 years of age or older) with sickle cell disease (SCD).

OBJECTIVE:

Evaluate the reliability and validity of the ISI among adults with SCD.

METHODS:

Analysis included psychometric evaluation with exploratory factor analysis.

RESULTS:

Our 263 participants had a mean age of 35.6 years and primarily were female (54.8%) with HbSS genotype (69.2%). Almost 41% were classified as clinical insomnia cases (ISI ≥14) using the traditional scoring approach. Two factors, Insomnia Symptoms and Insomnia Impact, emerged during factor analysis. Reliability of both factor-scales was good and each correlated with pain severity and depressive symptomatology (r = 0.38 to 0.66, p<.01).

CONCLUSION:

The ISI demonstrated construct validity and reliability for evaluating insomnia symptomatology among adults with SCD and can be used in research and clinical practice.

PMCID: PMC4874249 [Available on 2017-02-01]

PMID: 27217712 [PubMed]
Coping with Pain in the Face of Healthcare Injustice in Patients with Sickle Cell Disease.

Ezenwa MO¹, Yao Y², Molokie RE³, Wang ZJ⁴, Mandernach MW⁵, Suarez ML⁶, Wilkie DJ².

Abstract

To evaluate the pain coping strategies of patients with sickle cell disease (SCD) who experience healthcare injustice from either physicians or nurses during medical visits for pain management. It is unknown how patients' coping with pain relates to their experiences of healthcare injustice from physicians or nurses. This descriptive comparative study included adult outpatients with SCD who completed the PAINReportIT®, Healthcare Justice Questionnaire®, and Coping Strategies Questionnaire-SCD. Data were analyzed using independent t tests. Frequent coping strategies of patients who experienced healthcare justice from physicians were praying-hoping and from nurses were praying-hoping, calming self-statements, diverting attention, and increasing behavioral activity. In contrast, frequent coping strategies of patients who experienced healthcare injustice from physicians were catastrophizing and isolation and from nurses were isolation. Patients who experienced healthcare justice used different sets of pain coping strategies than those who experienced healthcare injustice during medical visits for pain management.

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Regular long-term red blood cell transfusions for managing chronic chest complications in sickle cell disease.

Estcourt LJ¹, Fortin PM, Hopewell S, Trivella M, Hambleton IR, Cho G.
Abstract

BACKGROUND:

Sickle cell disease is a genetic haemoglobin disorder, which can cause severe pain, significant end-organ damage, pulmonary complications, and premature death. Sickle cell disease is one of the most common severe monogenic disorders in the world, due to the inheritance of two abnormal haemoglobin (beta globin) genes. The two most common chronic chest complications due to sickle cell disease are pulmonary hypertension and chronic sickle lung disease. These complications can lead to morbidity (such as reduced exercise tolerance) and increased mortality. This is an update of a Cochrane review first published in 2011 and updated in 2014.

OBJECTIVES:

We wanted to determine whether trials involving people with sickle cell disease that compare regular long-term blood transfusion regimens with standard care, hydroxycarbamide (hydroxyurea) any other drug treatment show differences in the following: mortality associated with chronic chest complications; severity of established chronic chest complications; development and progression of chronic chest complications; serious adverse events.

SEARCH METHODS:

We searched the Cochrane Cystic Fibrosis and Genetic Disorders Group's Haemoglobinopathies Trials Register. Date of the last search: 25 April 2016. We also searched for randomised controlled trials in the Cochrane Central Register of Controlled Trials (CENTRAL) (The Cochrane Library, Issue 1, 26 January 2016), MEDLINE (from 1946), Embase (from 1974), CINAHL (from 1937), the Transfusion Evidence Library (from 1950), and ongoing trial databases to 26 January 2016.

SELECTION CRITERIA:

We included randomised controlled trials of people of any age with one of four common sickle cell disease genotypes, i.e. Hb SS, Sβ0, SC, or Sβ+ that compared regular red blood cell transfusion regimens (either simple or exchange transfusions) to hydroxycarbamide, any other drug treatment, or to standard care that were aimed at reducing the development or progression of chronic chest complications (chronic sickle lung and pulmonary hypertension).
DATA COLLECTION AND ANALYSIS:
We used the standard methodological procedures expected by Cochrane.

MAIN RESULTS:
No studies matching the selection criteria were found.

AUTHORS' CONCLUSIONS:
There is a need for randomised controlled trials looking at the role of long-term transfusion therapy in pulmonary hypertension and chronic sickle lung disease. Due to the chronic nature of the conditions, such trials should aim to use a combination of objective and subjective measures to assess participants repeatedly before and after the intervention.
PMID: 27198469 [PubMed - as supplied by publisher]

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Alloimmunisation rates of sickle cell disease patients in the United States differ from those in other geographical regions.

Zheng Y¹, Maitta RW¹.

Abstract

OBJECTIVES:
Comparison of the alloimmunisation rates of patients with sickle cell disease in the Unites States versus other countries.

BACKGROUND:
Sickle cell disease (SCD) patients treated with chronic transfusion therapy are at a high risk of red blood cell (RBC) alloimmunisation.
MATERIALS AND METHODS:

We reviewed published literature describing alloimmunisation rates of SCD patients. Average alloimmunisation rates and number of alloantibodies per transfused patient in the United States and other countries were evaluated.

RESULTS:

Twenty-four studies on alloimmunisation of SCD patients were found, 15 studies with 3,708 patients in the US and 10 studies with 2203 patients from other regions, including South America, the Caribbean, Middle East, Africa and Europe. The United States has a higher alloimmunisation rate (22.33 ± 0.13% versus 16.25 ± 0.35%, p < 0.0001) and a higher number of alloantibodies per transfused patient (0.45 ± 0.003 versus 0.20 ± 0.005, p < 0.0001) than other countries. Brazil with a higher proportion of multi-ethnic donors demonstrated a lower alloimmunisation rate compared to the United States (14.60 ± 0.40% versus 22.33 ± 0.13%, p < 0.0001) and fewer alloantibodies per transfused patient (0.20 ± 0.02 versus 0.45 ± 0.003, p < 0.0001) than the United States.

CONCLUSION:

SCD patients in the United States had a higher alloimmunisation rate, which could be reduced by a more ethnically diverse donor pool and a more conservative transfusion strategy in non-critical conditions.

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PMID: 27197689 [PubMed - as supplied by publisher]

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Hematopoietic stem cell transplantation for people with sickle cell disease.

Oringanje C¹, Nemecek E, Oniyangi O.

Abstract
**BACKGROUND:**

Sickle cell disease is a genetic disorder involving a defect in the red blood cells due to its sickled hemoglobin. The main therapeutic interventions include preventive and supportive measures. Hematopoietic stem cell transplantations are carried out with the aim of replacing the defective cells and their progenitors (hematopoietic (i.e. blood forming) stem cells) in order to correct the disorder. This is an update of a previously published review.

**OBJECTIVES:**

To determine whether stem cell transplantation can improve survival and prevent symptoms and complications associated with sickle cell disease. To examine the risks of stem cell transplantation against the potential long-term gain for people with sickle cell disease.

**SEARCH METHODS:**

We searched the Cochrane Cystic Fibrosis and Genetic Disorders Group Group’s Haemoglobinopathies Trials Register complied from electronic searches of the Cochrane Central Register of Controlled Trials (CENTRAL) (updated each new issue of The Cochrane Library) and quarterly searches of MEDLINE. Unpublished work was identified by searching the abstract books of major conference proceedings and we conducted a search of the website: [www.ClinicalTrials.gov](http://www.ClinicalTrials.gov). Date of the most recent search of the Group’s Haemoglobinopathies Trials Register: 06 October 2015.

**SELECTION CRITERIA:**

Randomized controlled and quasi-randomized studies that compared any method of stem cell transplantation with either each other or with any of the preventive or supportive interventions (e.g. periodic blood transfusion, use of hydroxyurea, antibiotics, pain relieverson, supplemental oxygen) in people with sickle cell disease irrespective of the type of sickle cell disease, gender and setting.

**DATA COLLECTION AND ANALYSIS:**

No relevant trials were identified.

**MAIN RESULTS:**
Ten trials were identified by the initial search and none for the update. None of these trials were suitable for inclusion in this review.

**AUTHORS’ CONCLUSIONS:**

Reports on the use of hematopoietic stem cell transplantation improving survival and preventing symptoms and complications associated with sickle cell disease are currently limited to observational and other less robust studies. No randomized controlled trial assessing the benefit or risk of hematopoietic stem cell transplantations was found. Thus, this systematic review identifies the need for a multicentre randomized controlled trial assessing the benefits and possible risks of hematopoietic stem cell transplantations comparing sickle status and severity of disease in people with sickle cell disease.

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**Similar articles**


**The global burden of pulmonary hypertension in sickle cell disease: a systematic review and meta-analysis.**

Musa BM¹, Galadanci NA², Coker M³, Bussell S⁴,⁵, Aliyu MH⁴,⁵,⁶.

**Abstract**

Elevated tricuspid regurgitant jet velocity (TRJV) is a surrogate measure of pulmonary hypertension (PH) in persons with sickle cell disease (SCD). We sought to estimate the burden of PH in people living with sickle cell disease based on TRJV. From 2000 to 2015, we searched electronic databases for eligible publications and included 29 studies (n = 5358 persons). We used random effects modeling to determine the pooled estimate of elevated TRJV. The overall pooled prevalence of elevated TRJV was 23.5 % (95 % CI 19.5-27.4) in persons with SCD. The pooled prevalence of elevated TRJV in children and adults with SCD was 20.7 % (95 % CI 15.7--25.6) and 24.4 % (95 % CI 18.4-30.4), respectively. TRJV is
prevalent among adults and children with SCD. Our finding support international recommendations that call for screening for PH in SCD patients.

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Safety and feasibility of red cell exchange for sickle cell disease across Canada.

Ward R¹, Barth D², Couban S³, Naessens V⁴, Ritchie B⁵, Yenson P⁶, Kuo K⁷.

Abstract

We outline a case whereby RBCX was successfully provided over disparate geographical areas and time zones in Canada and overcame the logistical challenges of coordinating care across four different health care systems with the application of modern telecommunication technologies. We present this case as a model for other SCD providers and patients.

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Young Adult Perspectives on a Successful Transition from Pediatric to Adult Care in Sickle Cell Disease.

Sobota AE¹, Umeh E², Mack JW³.
Abstract

OBJECTIVE:

This qualitative study sought to learn from young adults with sickle cell disease (SCD) about their experience leaving pediatric care and perspective on what makes a successful transition.

METHODS:

Fifteen young adults with SCD who had left pediatric care within the previous five years participated in focus groups led by a trained moderator. Transcripts were analyzed using grounded theory.

RESULTS:

Four main themes emerged from the analysis: facilitators of transition (meeting the adult provider prior to transfer, knowing what to expect, gradually taking over disease self-management and starting the process early), barriers to transition (negative perceived attitude of adult staff, lack of SCD specific knowledge by both patients and staff, and competing priorities interfering with transition preparation), what young adults wished for in a transition program (opportunities to meet more staff prior to transfer, more information about the differences between pediatric and adult care, learning from a peer who has been through the process, more SCD teaching, and flexibility in transition preparation) and how they define a successful transition (gradually assuming responsibility for self-management of their SCD).

CONCLUSION:

Our findings present unique opportunities to learn from young adults with SCD about ways to improve current transition programs.

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PMID: 27175364 [PubMed]

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A Mismatch Between Patient Education Materials About Sickle Cell Disease and the Literacy Level of Their Intended Audience.

McClure E\textsuperscript{1}, Ng J\textsuperscript{2}, Vitzthum K\textsuperscript{2}, Rudd R\textsuperscript{2}.

Abstract

**INTRODUCTION:**

Despite the first goal of the 2010 National Action Plan to Improve Health Literacy, the literacy demands of much health information exceeds the reading skills of most US adults. The objective of this study was to assess the health literacy level of publicly available patient education materials for people with sickle cell disease (SCD).

**METHODS:**

We used 5 validated tools to evaluate 9 print and 4 online patient education materials: the simple measure of gobbledygook (SMOG) to assess reading grade level, the Peter Mosenthal and Irwin Kirsch readability formula (PMOSE/IKIRSCH) to assess structure and density, the Patient Education Materials Assessment Tool (PEMAT) to assess actionability (how well readers will know what to do after reading the material) and understandability, the Centers for Disease Control and Prevention's (CDC's) Clear Communication Index (Index) to obtain a comprehensive literacy demand score, and the Printed Cancer Education Materials for African Americans Cultural Sensitivity Assessment Tool.

**RESULTS:**

Materials' scores reflected high reading levels ranging from 8th grade to 12th grade, appropriate (low) structural demand, and low actionability relative to understandability. CDC suggests that an appropriate Index score should fall in or above the 90th percentile. The scores yielded by materials evaluated in this assessment ranged from the 44th to the 76th percentiles. Eight of the 13 materials scored within the acceptable range for cultural sensitivity.
CONCLUSION:

Reading levels of available patient education materials exceed the documented average literacy level of the US adult population. Health literacy demands should be a key consideration in the revision and development of patient education materials for people with SCD.

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Self-care is key in sickle-cell disease.

Blakemore S.

Abstract

A NATIONWIDE survey of people living with sickle cell disease (SCD) in England has revealed that information provision and lack of public awareness of the condition are some of the biggest issues affecting their experiences and the care they receive.

PMID: 27165379 [PubMed - in process]

Similar articles


Family Engagement in Pediatric Sickle Cell Disease Visits.
Abstract

Adults with sickle cell disease (SCD) report problems in relationship building and information exchange during clinic visits. To explore the origin of these communication challenges, we compare communication in pediatric SCD, diabetes, and asthma visits. We collected visit videos and parent surveys from 78 children ages 9-16 years with SCD, asthma, or diabetes. Coders assessed child, parent, and physician utterances reflecting relationship building, information giving, and information gathering. Associations of engagement with type of chronic disease visit were performed with negative binomial regression. Compared to SCD visits, children in diabetes visits spoke 53% more relationship-building utterances (p < .05) and physicians in asthma visits spoke 48% fewer relationship building utterances to the child (p < .01). In diabetes visits, physicians gave almost twice as much information to children and gave 48% less information to parents (both p < .01) compared to SCD visits. Compared to SCD visits, physicians spoke fewer information-gathering utterances to parents in diabetes and asthma visits (85% and 72% respectively, both p < .001). SCD visits reflect less engagement of the children and greater physician effort to gather information from parents. These differences highlight opportunities to enhance engagement as a mechanism for ultimately improving SCD care.

PMID: 27159356 [PubMed - as supplied by publisher]

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Accuracy of Point-of-Care Lung Ultrasonography for Diagnosis of Acute Chest Syndrome in Pediatric Patients with Sickle Cell Disease and Fever.

Daswani DD¹, Shah VP², Avner JR¹, Manwani DG³, Kurian J⁴, Rabiner JE¹.
Abstract

OBJECTIVES:

To determine the test performance characteristics for point-of-care lung ultrasonography (LUS) performed by pediatric emergency medicine (PEM) physicians compared with radiographic diagnosis of acute chest syndrome (ACS) in patients with sickle cell disease (SCD) and fever.

METHODS:

This was a prospective study of patients up to 21 years with SCD and fever requiring chest X-ray (CXR) evaluation of ACS. Before obtaining CXR, a blinded PEM physician performed LUS using a standardized scanning protocol. Positive LUS for ACS was defined as lung consolidation. All patients received CXR and follow-up. The gold standard for ACS was consolidation on CXR as determined by a blinded radiologist. LUS clips were reviewed by a blinded expert PEM sonologist.

RESULTS:

One hundred and sixteen febrile events from 91 patients with a median age of 5.7 years were enrolled by 15 PEM sonologists. CXR was positive for ACS in 15 (13%) patients, and LUS was positive for ACS in 19 (16%) patients. Positive LUS had a sensitivity of 87% (95% confidence interval [CI]: 62 to 96%), specificity of 94% (95% CI: 88 to 97%), positive likelihood ratio of 14.6 (95% CI: 6.5 to 32.5), and negative likelihood ratio of 0.14 (95% CI: 0.04 to 0.52) for ACS. The interobserver agreement (κ) was 0.77. There were 2 missed cases of ACS on LUS.

CONCLUSIONS:

LUS may be sensitive and specific for diagnosis of ACS in pediatric patients with SCD and fever. LUS may reduce the need for routine CXR and associated ionizing radiation exposure in this population. This article is protected by copyright. All rights reserved.

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Sickle Cell Conferences and Events

Event: Sickle Cell in Focus (SCiF) 2016, National Institutes of Health, Bethesda, Maryland, USA
Date: Thursday 2nd – Friday 3rd June 2016
Venue: Natcher Conference Centre, National Institutes of Health, Bethesda, MD 20894 USA

The 10th Sickle Cell in Focus conference returns to the USA in June 2016. Sickle Cell in Focus is an internationally renowned educational update for sickle cell disease. It attracts a wide audience of clinicians, academics and other healthcare professionals involved in the disease from around the world.

Website: [http://www.ststn.co.uk/scif/sicf2016/](http://www.ststn.co.uk/scif/sicf2016/)
To book: Free registration will be opening soon. If you would like to be kept up-to-date, please join the STSTN mailing list by sending an email to: [info@ststn.co.uk](mailto:info@ststn.co.uk)
Contact details: [info@ststn.co.uk](mailto:info@ststn.co.uk) / [@STSTNetwork](https://twitter.com/STSTNetwork) / [www.ststn.co.uk](http://www.ststn.co.uk)

Sickle Cell Education Conference in Orlando, FL June 18th hosted by Kids Conquering Sickle Cell Disease Foundation.

Theme of the 2nd Annual Conference: The Future is Now! Empowering the Generation of Today. Our conference will include the subjects that focus on the care of children, adolescents and adults. We understand the need to address the care of the transitional stage of adolescents to adult care so our topics will also fulfill a need to further educate this population.

Registration Check In & Refreshments are available at 8:30 Am. Conference Begins at 9 AM
Join Medical Experts & Our panel guest of young adult warriors excited to share updated info and experiences.

www.kidsconqueringscd.org

The California Rare Disease Surveillance Program invites you to attend a webinar to hear representatives from four companies talk about their sickle cell disease (SCD) treatments under development, clinical trials, and the FDA approval process on **Tuesday, June 14, 2016, from 10-11:30 am PST**. The featured speakers are from Emmaus Life Sciences, Global Blood Therapeutics, Mast Therapeutics, and Pfizer Inc.

The agenda will include a brief update on California's **SCD Long-term Data Collection program** (the host of the webinar) and an announcement about the fall webinar on creating a statewide SCD plan for South Carolina.

https://attendee.gotowebinar.com/register/2652202739061998081

**June 18, 2016 Sickle & Flow – Atlanta GA** [http://www.sickleandflow.org/about](http://www.sickleandflow.org/about)

Sickle & Flow is a partnership with members of the Atlanta community, including local hip hop producers, DJs, patient advocates, health care workers, and scientists. We’re hosting a sickle cell awareness event as part of World Blood Day, on Saturday June 18, 2016. We want to engage the ATL community to promote patient advocacy and biomedical research. As a part of the evening, we will host a [Be the Match](http://www.sickleandflow.org/about) event, collecting cheek swabs from potential donors, to partner with us in our efforts to more effectively treat and cure sickle cell disease.

**6th International African Symposium on Sickle Cell Disease** July 11th – 15th, 2016  Labadi Beach Hotel  Accra, Ghana

The Symposium website: [www.chop.edu/sicklecellghana](http://www.chop.edu/sicklecellghana) to register online (in English only) or download the Registration Form in French or Portuguese. Please use the French or Portuguese templates to complete the online registration or fax to 215-590-4342.

**Sickle Cell Education Day 2016 –Children’s Healthcare of Atlanta, GA**

"Learning to Live, Love, and Hope with Sickle Cell Disease"

**Date:**  Saturday, September 24, 2016

**Time:**  9:00 a.m. to 3:00 p.m.
**Location:**  Courtyard by Marriott, Downtown Decatur  
130 Clairemont Avenue  
Decatur, GA 30030

Onsite parking is available for $8.

Complimentary parking will be available at the below address:  
First Baptist Church of Decatur  
308 Clairemont Ave.  
Decatur, GA 30030

Registration for this program opens June 22, 2016. Please contact litisha.m.cooper@emory.edu for additional information.

**Sickle Cell Partners of the Carolinas presents, Sickle Cell Disease, “Let’s talk about it” day conference**  
www.sicklecellpartnersofthecarolinas.org

Saturday September 10, 2016  
9 am to 2 pm

Friendship Missionary Baptist Church Conference Center  
3400 Beatties Ford Road, Charlotte NC 28216

**Calling All Abstracts!** Submit your abstracts for the 44th SCDAA annual convention  
Baltimore, MD on September 27-October 1st, 2016

Interested in highlighting your work as a community based member organization, physician, nurse, social worker, or other team working on behalf of people with sickle cell disease and their families? Submit an abstract on the work that you or your team has completed or is in the process of completing for an opportunity to share at the 44th Annual Sickle Cell Convention. This year’s convention will be held in the great city of Baltimore, MD on September 27-October 1st, 2016 at the Hyatt Regency hotel. For more information on abstracts or to submit your application clicking [HERE](http://www.sicklecelldisease.org/index.cfm?page=convention-abstract-submission).

**SCDAA 44th Annual Convention Sept 27 – Oct 1 Baltimore MD**

http://www.sicklecelldisease.org/index.cfm?page=annual-convention
https://www.sicklecelldisease.org/index.cfm?page=convention-registration

Listserv address to join or leave http://scinfo.org/world-wide-resources/sickle-cell-newsletter-listserv

http://listserv.cc.emory.edu/cgi-bin/wa?A0=sicklecell

www.SCInfo.org