

8th Annual Symposium

SICKLE CELL DISEASE

Services for Children & Families in California



*An Educational Workshop for Consumers,
Health Care Providers and the General Community*



Friday, April 1, 2011

8:30 am—5:30 pm

Followed by a Networking Reception

Saturday, April 2, 2011

8:45 am—2:15 pm

*Knott's Berry Farm Resort Hotel
7675 Crescent Avenue
Buena Park, CA 90620
(866) 752-2444 or (714) 995-1111*



Sponsored by



Sickle Cell Disease
Foundation of California



CHOC Children's



NORTHERN CALIFORNIA
NETWORK OF CARE
FOR SICKLE CELL DISEASE



Center for the Diagnosis and
Comprehensive Care of Inherited Blood Disorders

PROGRAM DESCRIPTION

This program is designed to bring together health care providers, consumers and the general community to share information about resources available in California for individuals with sickle cell disease and their families. Health care and social service programs for families and affected individuals will be reviewed.

WHO SHOULD ATTEND

Health Care Professionals: Physicians, nurses, social workers, sickle cell counselors, health educators, genetic counselors and other allied health professionals.

Consumers: Parents, guardians and family members of children with sickle cell disease, persons with sickle cell disease and spouses of individuals with sickle cell disease.

OBJECTIVES

At the end of this activity, the attendees should be able to:

1. Explain how advances in sickle cell disease (SCD) clinical care have improved outcomes for people affected by SCD.
2. Give an example of one (1) Healthy People 2020 objective that can improve outcomes for people with hemoglobinopathies.
3. Give two (2) examples of blood borne diseases currently being screened for by blood banks.
4. Name two (2) clinical trials or research studies in SCD.
5. Describe the standard method of screening for identifying stroke risk for children with SCD.
6. List two (2) strategies in a comprehensive treatment plan to help prevent clinical complications of SCD.
7. Describe two (2) health concerns that adults with SCD may face as they age.
8. List one alternative and one traditional method to help with SCD pain management.
9. Describe one strategy for community engagement employed by the California Registry and Surveillance System in Hemoglobinopathies (RuSH).

ACCREDITATION & CONTINUING EDUCATION

Physicians: Children's Hospital & Research Center Oakland is accredited by the Institute of Medical Quality and the California Medical Association (IMQ/CMA) to provide continuing medical education for physicians. Children's Hospital & Research Center Oakland takes responsibility for the content, quality and scientific integrity of this CME activity.



Children's Hospital & Research Center Oakland designates this educational activity for a maximum of **10 AMA PRA Category 1 credit(s)**[™]. Physicians should only claim credit commensurate with the extent of their participation in the activity. This credit may also be applied to the CMA Certification of Continuing Medical Education.

Nurses: 10 contact hours provided by the California Department of Public Health, Genetic Disease Screening Program, California BRN provider number 12857.

LCSWs: The SCDFC is accredited by the California Board of Behavioral Sciences. This course meets the qualifications for 10 hours of continuing education credit for LCSW's as required by the California Board of Behavioral Sciences. Provider number PCE 4141.

ACCREDITATION & CONTINUING EDUCATION, *continued*

Other Professionals: Please check with your licensing agency to determine if this symposium is eligible for continuing education units prior to registration. Upon request a certificate of attendance can be provided without guarantee that continuing education units will be accepted by your licensing agency.

REGISTRATION

Health Care Professionals - \$110.00

Consumers (see listing) or Students w/ID - \$50.00

Children (ages 3-12) - \$20.00

Late registration (postmarked after 03/16/11)

Please add \$20 to the registration fee for \$130.00 for health care professionals and \$70.00 for consumers and students. A late fee will NOT be assessed for children (3-12). A \$10 processing fee will be deducted for refunds before March 16th. **NO REFUNDS WILL BE MADE AFTER March 16, 2011.**

HOTEL INFORMATION & PARKING

The Knott's Berry Farm Resort Hotel is conveniently located in the heart of Southern California and is just 6 miles north of Disneyland and other Anaheim attractions. Parking is included with symposium registration. Room reservations must be made by March 11, 2011 for a guaranteed room rate of **\$99 per night (plus applicable taxes)**. Phone toll free (866) 752-2444 or (714) 995-1111. **Please provide group number "749971".**

ENTRANCE TO KNOTTS BERRY FARM THEME PARK (SATURDAY)

Registered symposium attendees will receive a free ticket for Knott's Berry Farm at Saturday's close of the symposium. Ticket is valid for Saturday, April 2nd, park closes at 10:00 pm. **Additional tickets** can be purchased at a discounted rate of **\$22.00 each (children 2 & under FREE)**. Meal tickets are available for \$8.50 each (*hot dog OR hamburger, chips & soda*).

CONTACT INFORMATION

For more information please contact the SCDFC at (310) 693-0247 or email deborahg@scdfc.org or visit www.scdfc.org.

PLANNING COMMITTEE

Melissa Belvedere, RN, BSN
Mary E. Brown
Jeanne Courtney, LCSW
Mary Evans
Deborah Green
Shellye Lessing, MS, CGC
Eileen Murray

Diane Nugent, MD
Geetha Puthenveetil, MD
Jeanine Renfro-Woods
Helen Rice, RN, MSN, OCN
Ryan Roberts, MS
Marsha Treadwell, PhD
Karen Whitney, MS

Acknowledgements

This educational activity is supported in part by funding or other support from:

Herzog Contracting Corp.

Sickle Cell Community Advisory Council

Sickle Cell Community Health Network

Disclaimer: The Sickle Cell Disease Foundation of California, Children's Hospital & Research Center Oakland, California Department of Public Health, Children's Hospital Orange County, Center for Comprehensive Care of Inherited Blood Disorders, Northern California Network of Care, The Talking Drums Project, Sickle Cell Community Advisory Council, Sickle Cell Community Health Network, Maternal and Child Health Bureau, Health Resources and Service Administration, DHHS and their staffs or affiliates are not responsible for injury or illness resulting from the use of medications or modalities discussed during this educational activity.

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PROGRAM

Friday, April 1, 2011

7:30 am **Registration & Continental Breakfast** (provided)

Plenary Session

8:30 am **Welcome & Meeting Overview**

9:00 am **Historical Overview: 100 Years of SCD**
Elliott Vichinsky, MD

10:00 am **Public Health Position in SCD**
Ellen Werner, PhD

11:00 am **Break**

11:15 am **California Registry and Surveillance in Hemoglobinopathies (RuSH) Update**
Lisa Feuchtbaum, DrPH, MPH

11:45 am **Take Ten Minutes for Your Health**
Guided Imagery
Heather Huszti, PhD

11:55 pm **Lunch** (provided)

1:00 pm **EDUCATIONAL WORKSHOPS**
"Ask The Health Care Provider"

Consumers (ages 0-18)
Melissa Belvedere, RN, BSN & Geetha Puthenveetil, MD

Consumers (age 18+)
Ward Hagar, MD

Nurses
Debbie Harris, PNP & Trish Peterson, PNP

Physicians
Richard Shearer, MD & Keith Quirolo, MD

Social Workers, Health Educators & Other Allied Health Workers
"Social Work Resources & Program Updates"
Ebony Mitchell, MSW

2:05 pm **EDUCATIONAL WORKSHOPS**
Consumers (ages 0-18): Be Prepared
Jeanne Courtney, LCSW

Consumers (age 18+): Be Prepared for the ER
Pat Corley, RN

Nurses: Coping Strategies to Teach Your Patients and Families
Heather Huszti, PhD

Physicians & Nurses - SCD CCS Centers Special Care Center Workshop
Carole Klein, MPH & Shellye Lessing, MS

Social Workers, Health Educators & Other Allied Health Workers
Transitioning from Pediatric to Adult Care
Valentino Walker, MSW

3:05 pm **Break**

3:15 pm **Gene Therapy, Stem Cells & BMT for SCD**
Donald Kohn, MD

3:45 pm **Stroke and Stroke Risk in Children with SCD**
Paula Groncy, MD

4:15 pm **Blood Products & Blood Bank Safety Issues**
Diane Nugent, MD

5:00 pm **Summary, Wrap-up & Evaluations**

5:30 pm **Networking Reception**
Sponsored by Herzog Contracting Corp.

Saturday, April 2, 2011

7:45 am **Continental Breakfast** (provided)

8:45 am **Welcome**

9:00 am **Comprehensive Care in Sickle Cell Disease**
Geetha Puthenveetil, MD

10:00 am **The Adult with Sickle Cell Disease**
Susan Claster, MD & Janice Earl, MSN, FNP

11:00 am **Break**

11:15 am **Pain Management: Traditional & Alternative**
Theopia Jackson, PhD & Keith Quirolo, MD

12:15 pm **Lunch** (provided)

1:15 pm **Talk Into Action: Advocacy & Empowerment**
Action Plan for Consumers & Professionals
Mary E. Brown & Marsha Treadwell, PhD

2:00 pm **Summary, Evaluations & Raffle**

2:15 pm **Adjourn**

FACULTY

Melissa Belvedere, RN, BSN
Children's Hospital Orange County

Mary E. Brown
Sickle Cell Disease
Foundation of California

Susan Claster, MD
Children's Hospital Los Angeles

Pat Corley, RN
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Children's Hospital &
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Valentino Walker, MSW
Children's Hospital &
Research Center Oakland

Ellen Werner, PhD
National Heart, Lung and Blood Institute
National Institutes of Health

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REGISTRATION FORM OR REGISTER ONLINE

Registration form & registration fee must be postmarked
by March 16, 2011 (add \$20 after March 16th)
Online registration available at www.scdfc.org

Name: _____

Title: _____

Agency: _____

Address: _____

City: _____ State: _____ Zip: _____

Daytime Phone: (_____) _____

Email: _____

HEALTH CARE PROFESSIONALS: Registration Fee \$110.00

- MD/DO NP RN PhD PA Social Worker
 Sickle Cell Counselor Genetic Counselor Health Educator
 Other: (specify) _____
 I will be reporting CMEs or CEUs (Physicians add \$55 for CMEs)

CONSUMERS / STUDENTS (ID req): Registration Fee \$50.00

- Person w/SCD Parent Other: _____
 Student (school ID req.) Field of Study: _____

CHILD (age 3-12): Registration Fee \$20.00 Age _____

ONE DAY ONLY (select day) Friday Saturday (Theme Park incl.)

- Health Care Provider: \$65.00 Consumer/Student: \$25.00

ADDITIONAL THEME PARK/MEAL TICKETS: Registered conference attendees will receive a Knott's Berry Farm ticket for Saturday, April 2nd. Additional tickets can be purchased for \$22.00 each. Meal tickets are available for \$8.50 (hot dog or hamburger, chips & soda).

I would like _____ theme park tickets for Saturday at \$22.00 each
I would like _____ meal tickets for Saturday at \$8.50 each

PAYMENT AMOUNT/METHOD:

TOTAL AMOUNT ENCLOSED: \$ _____ .00

- Check ***Please make checks payable to: SCDFC***
 Visa MasterCard AMEX

Card # _____

Exp Date: _____ / _____

Name on Card: _____

Signature: _____

Send completed form and registration fee to:

Sickle Cell Disease Foundation of California
5777 W. Century Blvd., Suite 1230
Los Angeles, CA 90045
Phone (310) 693-0247 • Fax (310) 216-0307

SPONSORS

Children's Hospital Orange County (CHOC)

For more than 45 years, CHOC Children's has been steadfastly committed to providing the highest quality medical care to children. Affiliated with the University of California, Irvine, our regional pediatric healthcare network includes a state-of-the-art 238-bed main hospital facility in the City of Orange, a hospital-within-a-hospital in Mission Viejo. CHOC also offers many primary and specialty care clinics, over 100 additional programs and services, a pediatric residency program, and four centers of excellence - The CHOC Children's Heart, Cancer, Neuroscience, and Orthopaedic Institutes.

Children's Hospital & Research Center Oakland (CHRCO) Northern California Network of Care for Sickle Cell Disease The Talking Drums Project

The comprehensive sickle cell center at CHRCO is the largest sickle cell program in the Western United States and is internationally renowned as at the forefront of sickle cell treatment and research. CHRCO sponsors patient services grants through the comprehensive sickle cell center, including the Northern California Network of Care for Sickle Cell Disease, a partnership of hospitals, sickle cell centers, other health agencies and community based organizations. The Network of Care goals are to enhance coordination of service delivery and increase knowledge about and participation in the medical home model for people with sickle cell disease across the lifespan. The Talking Drums Project provides sickle cell education, community outreach and patient support.

Sickle Cell Disease Foundation of California (SCDFC)

The Sickle Cell Disease Foundation of California is the first non-profit social service sickle cell disease organization established in the United States. Founded in 1957, the SCDFC provides direct programs and services to persons with sickle cell disease and their families. Programs and services include sickle cell disease & hemoglobin trait education and counseling, summer camp for children with sickle cell disease, sickle cell disease awareness and education to persons with SCD and the general & health care communities as well as other support programs.

California Department of Public Health Genetic Disease Screening Program

California has the largest newborn screening program in the United States, testing all California newborns for multiple metabolic disorders, primary congenital hypothyroidism, congenital adrenal hyperplasia, cystic fibrosis and hemoglobin disorders such as sickle cell anemia. The California Newborn Screening Program screens almost every baby born in the state, which accounts for one-eighth of the babies born in the entire U.S. Since the expanded program began in October 1980 over 15 million babies have been screened.

Through screening, over 11,000 babies with a clinically significant disease have been identified and referred for treatment.

Center for the Diagnosis and Comprehensive Care of Inherited Blood Disorders

The Center provides a multi-functional resource in the community where individuals may come for care, education, or counseling regarding the diagnosis or carrier status for themselves or a family member. The Center works with local educational institutions to teach and train physicians, nurses and other healthcare providers about these rare blood disorders to expand services to our community. The Center, in partnership with healthcare networks, state programs, and our local hospitals, is a referral resource to access diagnostic services, care, genetic and family counseling, education and community based services for patients.

Funding supported in part by grant numbers H46MC00243, H46MC00250, U1EMC16492 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health & Human Services.

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