

CCS Program Restructure & Stakeholder Process Update

There is a belief in Sacramento that the California Childrens Services (CCS) program needs to be improved upon and possibly restructured. Thus, as part of the final State Budget negotiations, "Trailer Bill Language" was added to the final State Budget to address CCS. There were no savings attached to the proposal in the short term and Capitol staff in Sacramento made sure language in the bill provided for CCS Stakeholders to be part of the restructure discussions.

The Stakeholder process began this summer and the Hemophilia Council of California (HCC) participated in a group interview with consultants working with the State. HCC also submitted a formal position paper on CCS. For a copy of that HCC position paper, please contact Robyn Ireland at: hccassist@aol.com While HCC believes there is room for improvements in the CCS program, the model of care for people with Hemophilia and other bleeding disorders actually works quite well within both CCS and GHPP. The State of California receives significant rebates from

the manufacturers of clotting factor to help run these two important programs.

The State Department of Health Care Services (DHCS) has contracted with both the CA Healthcare Foundation and a private consulting firm, Health Management Associates (HMA), to assist with gathering information from CCS Stakeholders and in making recommendations to the State. Both groups have submitted their reports to the State based on interviews with various Stakeholders. For copies of those documents, also contact Robyn Ireland at: hccassist@aol.com

There is also interest by state leaders in placing recommendations in the upcoming 1115 Federal Waiver to attempt to secure additional federal funds to assist the CCS program. HCC will continue to monitor that process.

2009-2010 may be a time period of potential changes to the CCS program. HCC will continue to work with the Governor's office and staff, the DHCS, and the State Legislature to ensure that medical

services to people with Hemophilia and other bleeding disorders will be maintained and that access to clotting factor will not be impeded. ■

-By Terri Cowger Hill,
Legislative Advocate for HCC

Join Us for Legislative Day

HCC's 2010 Legislative Day will be on May 12, 2010 at the state capitol. Join us to learn about what is happening in the state that could affect people with bleeding disorders and meet with your representatives to tell your story. May 12, 9:00 am - 4:00 pm in Sacramento. Breakfast and lunch are provided.

Future Leader Program

Young people with bleeding disorders and their siblings ages 14-22 can join HCC for this three-day program. Learn about the world of bleeding disorders, education & insurance, and how to tell your story. On the final day, Future Leaders participate in Legislative Day. Food, travel, and accommodation costs are covered. May 10-12, 2010 in Sacramento.

To register or for Legislative Day or Future Leaders or for more information, contact your local hemophilia chapter or hccassist@aol.com. ■

2009 HCC Supporters

The Hemophilia Council of California and the Chapters would like to recognize our major 2009 donors and thank them for their support. In June of 2009, the grant that supported HCC was discontinued as a result of the state budget crisis.

Baxter & CSL Behring have given generously to HCC to support programs in 2009.

HCC would also like to thank **Baxter, CSL Behring, Grifols and Caremark** for their support of the Future Leaders Program.

IMPORTANT EVENTS...

NHF Annual Meeting 10/29-31

Future Leaders Program . . . 5/10-12/10

Legislative Day 5/12/10

2010 Coastal Ride August, TBA

2009 Coastal Race Superstar Volunteers: We couldn't do it without you! A very special thanks goes out to the volunteers who made the 2009 ride possible! Many hours of planning and preparation went into making this a fun and safe ride.

e Adventure Continues...

Ninth Annual California Coastal Race for Hemophilia raises over \$80,000 in historic statewide event

By Brian Taylor

Climbing a mountain, running a marathon, and sky diving are challenges that require mental and physical endurance. Biking the lifelong challenge of hemophilia.

Combine the two and you have the California Coastal Race for Hemophilia, a bicycling endurance challenge now in its ninth year and perhaps the state's most unique fundraiser for the bleeding disorders community.

On August 23, eighteen cyclists from all over California as well as Arizona, Colorado, Utah, and Virginia began the seven day journey that started in San Francisco and concluded in San Diego. The entire team arrived in San Diego safe, healthy, and with lots of stories about their amazing adventure.



(The riders on the first day of the 2009 Coastal Race in San Francisco)

The group traveled coastal highway, farm roads, city streets and beach avenues through large and small California towns and cities all in the name of hemophilia and raised a combined total of \$83,000. Participants in the 2009 Coastal Race ranged from parents or relatives of family members with hemophilia, bleeding disorders community and industry members, people with hemophilia, and those simply looking for a challenge and an opportunity to fundraise for a great cause.

This year marked an historic occasion for the event as all four California-based Hemophilia Associations & Foundations and the Hemophilia Council of California (HCC) joined together to help support each organization. Cyclists represented the Hemophilia Foundation of Northern California, the Central California Hemophilia Foundation, the Hemophilia Foundation of Southern California, and the Hemophilia Association of San Diego County.

The call to bring all four chapters together stemmed from the need to keep HCC, California's only legislative and advocacy organization for the bleeding disorders community, alive in a challenging budget environment.

CA Coastal Race for Hemophilia Sponsors

The Hemophilia Council of California and the Chapters would like to recognize our ride sponsors and thank them for their support.

Platinum Sponsor: Accredo/HHS

Gold Sponsor: Baxter

Silver Sponsor: Factor Support Network

Bronze Sponsors:

REDCHIP ENTERPRISES • CHOC @ Home 340 B
Home Hemostasis-CHLA • Hope @ Home_City of Hope
Children's Oakland 340B • Orthopaedic Hospital
UCSF Ped's 340B • Heartwood Health

"HCC lost its main source of funding this year due to the state budget cuts, and we were in need of a way to raise funds," said Yvette Bryant, HCC Chair. "The San Diego Chapter held the Coastal Ride for several years and gladly extended the invitation to all chapters to participate to create a statewide fundraiser."

The California Coastal Race for Hemophilia was started in 2000 when US Marine Corps Captain Mike Hudson approached HASDC with the idea of cycling the California coast for hemophilia. As the father of a son with hemophilia, Captain Hudson wanted to raise funds and awareness for his child and the local community. That year, Captain Hudson and two other Marines rode from San Francisco to San Diego in eight days and started the tradition.

Nine years later, the California Coastal Race for Hemophilia has evolved into a major event, and 2009 was certainly the largest group yet with up to 20 riders on a given day.

While the cyclists pedaled all day, a fantastic support crew of over twelve volunteers worked around the clock and behind the scenes to provide food, drinks and mechanical support. The "sag" support crew also provided the necessary daily transport of luggage, equipment and food. This year, two motor homes accompanied the cyclists along with multiple cars and vans that followed the course for rider safety and to provide directions.

"This is an excellent example of chapters coming together and making a difference to support the programs and services of the four Chapters and the Council. This Coastal Ride was a not only success but a historical event for California. This is a tremendous example of what all the California Hemophilia Associations & Foundations can accomplish when we work together," said Bryant. ■

2009 Coastal Race Top Donors

Platinum Donor (\$20,000+): Baxter

Gold Donor (\$15,000+): Novo Nordisk

Silver Donor (\$5,000+): Bayer

Bronze Donors: Wyeth, CSL Behring, Grifols, and the many individual donors!

HCC Board Members

CCHF: Sean Hubbert, Frank Welsch

HFNC: Michelle Gilmore, Brian Ketchum, Brenda Charrete

HFSC: Greg Mermilliod, Edmund Merino

HASDC: Yvette Bryant, Tony Pascucci (Tony Maynard, member at large)