

CA State Budget & Legislative Update

State Budget Update: The Budget Conference Committee has wrapped up its work for the year and is sending a revised State Budget to both houses of the State Legislature for a vote this week. The Governor's Dept. of Finance estimates that the shortfall between the need to fund programs and services and the actual revenues available is over \$24 Billion! Thus, the Budget Conference Committee met to address this shortfall and to make additional cuts. They also proposed some revenue options to close the gap including a tobacco tax and an oil severance tax. The proposals impacting people with Hemophilia and other

bleeding disorders include the following:

GHPP Annual Enrollment Fee Increase: HCC Position: Neutral. This fee increase was adopted by the Budget Subcommittees in May. Since fees have not been raised in over 10 years, the HCC felt it was a reasonable proposal, given the state budget deficit fiscal crisis.

GHPP "Crowd Out" Provision; 6 Month Wait: HCC Position: Seek Amendments to change time period to 45 days to notify GHPP of loss of private insurance. Our request was granted and they also added language to involve stakeholders from the bleeding disorders community when making future changes!

State to Pay Premiums for Some of Our Patients. This item was adopted by the Budget Conference Committee to keep some patients on private coverage vs. adding costs to the state budget by adding them to the GHPP. The state will cover those costs. Toby Douglas at Medi-Cal, Luis Rico at Systems of Care Division, Joleen Heider-Freeman at GHPP, Diane Van Maren at Senate Budget Committee, and Andrea Margolis of the Assembly Budget Committee all deserve a round of thanks for work-

ing collaboratively with us on budget issues!

Standards of Services for Home Care Legislation: Due to the state budget shortfall, legislators were asked not to introduce any bills this session with major costs. Because our Standards of Services for Home Care legislation does have a small price tag, we opted not to re-introduce it this session. We instead plan to host educational forums this fall to raise awareness of the issues. Stay tuned to be involved in that process! Meanwhile, the state has used our SB 1594/Steinberg bill from 2008 as a template for the model contracts set to be put in place this summer with the various home care companies that provide clotting factor to our patients. ■

-By Terri Cowger Hill, Legislative Advocate for HCC

Thanks for Your Support!

Nearly 70 people met with Legislators in Sacramento on behalf of the bleeding disorders community on Legislative Day, May 20. Our largest-ever group of Future Leaders did a great job putting their two days of training to use in leading the groups. **Special thanks go to Disabled Adventure Outfitters** for staffing the program, and to **Baxter, CSL Behring, and Grifols** for their generous financial support of the Future Leader Program. We'll see you next year! ■

The HCC was invited by the Governor's office to participate in the **Western Regional White House Forum on Health Reform**, which provided a dialogue on health and wellness. We were proud to represent California's coordinated care model for managing hemophilia, which is an example of a wellness project that reduces costs for a complex medical condition. ■



NATIONAL HEMOPHILIA FOUNDATION

NHF has comprehensively restructured to more effectively serve our chapters. Public Policy will be decentralized and focused in two areas.

Ellen Riker and Johanna Gray of Holland & Knight (formerly MARC Associates) will lead federal initiatives and report directly to NHF's CEO. Ellen's firm provided the roadmap to success for HTC funding, CDC collaboration, and passing the Ricky Ray Hemophilia Relief Fund Act. Requests for presentations and information should be made through the CEO's office and to our Dir. of Special Projects, Robert Wiseman: 212-328-3740 or bwiseman@hemophilia.org.

Michelle Rice (NHF Regional Director & former ED, Hem. of Indiana), Sally McCarty (Consultant & Former Indiana Insurance Commissioner), and Ruthlyn Noel (Manager of Public Policy) will handle advocacy and training for state issues. They will work directly with chapters and manufacturers, as well as provide education and information to state legislators, Medicaid directors, and insurance payers, to address access to care. Chapters should contact Michelle Rice at (317)517-3032 or mrice@hemophilia.org for presentations and information related to these services and initiatives. ■



Committee of Ten Thousand

The FDA Blood Products Advisory Committee met to consider expanded regulations for use of recovered plasma in factor concentrates. Recovered plasma, from whole blood donations, is subjected to less testing, and considered less safe, than plasma collected for manufacture of blood products. The FDA barred its use in factor concentrates in the 1990s, but a regulatory window was left open for its sale.

The Department of Health & Human Services Advisory Committee On Blood Safety & Availability also met to discuss the financial burden of continuing safety initiatives and *the need to consider cost* when considering new and expanded safety regulations. COTT is adamant in our opposition to cost-effectiveness being resurrected as the overriding guidance for critical decisions regarding the safety of our nation's blood supply.

When the blood community, with the apparent support of the government, seeks to resurrect cost effectiveness as a principle guidance for safety related decisions, we in end user communities must again remind all concerned of the magnitude of the failure of the 1970s and 1980s. For more info see the COTT website at www.cott1.org ■

HFNC

Baseball Clinic July 19, 9:00 am - 4:00 pm

We are lucky enough to have partnered with Craig Gianinno to offer a baseball clinic to youth with bleeding disorders and their siblings (ages 7 – 14). The kids will be mentored through the day by young adults (ages 15 – 20). This program is sponsored by Preparing Legends together with the UCSF Hemophilia Treatment Center.

Craig has severe hemophilia and an exuberant passion for baseball. He has played high school and college baseball and has coached in many capacities. Craig will share wisdom and teach game skills such as batting and infield practice, teamwork, and a positive attitude.

Come enjoy this fun-filled day at the College of San Mateo Baseball Field Complex with a BBQ lunch, hats & shirts, trivia, and prizes!

RSVP to Luis E. Galindo by July 15th at 510.658.3324 or luis.galindo@hemofoundation.org ■

CCHF

Exciting New Clinical Trials

This is an exciting time in the history of hemophilia! Companies are actively pursuing the development of Factor products that will prevent spontaneous bleeding when infused only once every 10 to 14 days. If you have hemophilia and want to participate in bringing about this progress, read further about the clinical trials described below, and call your treatment center.

What clinical trials are planned for 2009? There are trials for Factor VIII, Factor IX (Hem. B), and a recombinant preparation for patients with Type III von Willebrand Disease. In addition, two companies are testing long-acting Factor VII products for hemophilia A patients with and without inhibitors.

Each of these new studies needs patients to enroll in clinical trials. What are the potential advantages of participating?

- 1) Helping to develop better products to treat hemophilia.
- 2) These trials provide factor at no cost to the patient.
- 3) These trials often provide reimbursement.
- 4) Access to the new product until FDA approval.

For further discussion and answers to any questions, please contact your Hemophilia Treatment Center staff. ■

HFSC

Lace Up Your Walking Shoes to Bring Attention to Serious Bleeding and Clotting Disorders!

The Hemophilia Foundation of Southern California (HFSC) is proud to invite the California bleeding disorders community to join us in our first-annual Hemophilia Walk-a-thon. HFSC, representing California, and nine other chapters across America are joining with NHF to walk toward a cure and raise awareness of bleeding disorders.

The Southern California Walk will take place at the majestic Los Angeles Memorial Coliseum on Saturday, October 17. Registration is at 9:00 am and the walk begins at 10:00 am. Visit our website at www.hemophilia.org/walk (just choose Southern California from the dropdown menu) to learn more.

There are many different ways to participate... even if you can't make it to LA. Just call 323.525.0440 or email commadv@hemosocal.org. We are calling on all of California to join us now and walk toward a cure! ■

HASDC

2009 California Coastal Race for Hemophilia

The California Coastal Race for Hemophilia is almost here! More than 20 bicycle riders will cover almost 700 miles in seven days, from San Francisco to San Diego.

The riders hope to raise awareness of Hemophilia and other bleeding disorders and raise funds to support programs and services provided by HCC and your local hemophilia chapter. These include advocacy, Legislative Day, Future Leaders, family outreach, summer camp, youth events, and education. All four California Hemophilia Foundations and Associations and the Hemophilia Council of California are collaborating to make this ride a success.

As the coordinating chapter & fiscal agent for the ride, the Hemophilia Association of San Diego County encourages you to support your chapter's riders. You can donate to support your chapter or a particular rider at www.active.com/donate/coastalrace09. You can also support your SAG (Support/Aid/Gear) volunteers here. If paying by check, please make it out to HASDC, note the chapter and rider you are supporting, and mail it to HCC, 1507 21st Street, Suite 206, Sacramento, CA 95811. Thanks for your support! ■

IMPORTANT EVENTS...

HFNC Baseball Clinic	7/19
California Coastal Race	8/23-29
HFSC Walk-a-thon	10/17
NHF Annual Meeting	10/29-31

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)