

President's Welcome

Welcome to the first Hemophilia Council of California newsletter. HCC is an education and health advocacy organization that has representation from each of the four California hemophilia chapters. Terri Cowger Hill, HCC's legislative advocate, is our (and your!) eyes and ears in Sacramento when legislation affects people with hemophilia and other coagulation disorders. In these times of budget cuts and economic turmoil it is important that this community is informed and ready to act. Our goal is to educate the hemophilia community about current issues.

- Yvette Bryant, HCC Chair

How you can help:

Legislative Day - May 20

Call your chapter for information.

Future Leaders - May 18-20

A youth leadership program for ages 14-22. Contact hccassist@aol.com or your chapter for information. ■

State Budget Finally Adopted!

Legislators adopted a new State Budget proposal on Feb. 19th. The Governor signed the proposal into law on Feb 20th and also made approximately \$600 Million in "Line Item Vetoes". The new State Budget proposal for the next 17 months, which totals approximately \$40 billion, will include:

\$16 Billion in Cuts (over all)

\$12.4 Billion in Tax Increases

\$11 Billion in Borrowing

There will be a "spending cap" or rainy day fund on the ballot on May 19th.

Health Cuts:

GHPP: There is a \$1.4 million General Fund savings in GHPP by increasing the annual enrollment fees for patients. This reduction would remain on a sliding fee scale and is "pending discussion of statutory changes to occur at a later date." HCC has sent out draft language on this item to our community for review.

There is a \$600,000 General Fund savings in GHPP by utilizing the state's assistance in coordinating enrollment of GHPP eligible patients into commercial insurance product lines and funding the premium payments. This action is also "pending discussion of statutory changes to occur at a later date" according to the Senate Budget Committee.

The state is planning to implement a six month waiting period for people who drop private health insurance to access GHPP. HCC has sent out draft language on this item to our community for review.

Medi-Cal: There are Optional Benefits Cuts for Adults, including cuts to adult dental care. There is also a 10% cut to public hospitals (\$54 Million in Safety Net Care Pool dollars). Both of the above items may get restored or partially restored if federal revenues come through. ■

-By Terri Cowger Hill, Legislative Advocate for HCC



NATIONAL HEMOPHILIA FOUNDATION

Lifetime Caps Bill Introduced

On Friday, February 13, 2009 the Health Insurance Coverage Protection Act (H.R. 1085; S442) was introduced. The legislation will set a \$10 million minimum lifetime cap on health insurance, with future increases based on inflation. The National Hemophilia Foundation (NHF) played a vital role in encouraging the legislation and assembling a coalition of more than 50 patient advocacy and health organizations.

"This bill addresses a critical lack of coverage for those with disabilities or chronic illnesses," said Anna G. Eshoo (D-CA). Increasing the minimum lifetime cap will result in a net savings for federal and state governments because individuals with high medical costs can maintain private health insurance. "

NHF applauds the efforts of the bill's sponsors and co-sponsors. We will keep you informed of further action on this bill after Washington Days. ■



Committee of Ten Thousand

COTT Looks Forward, Seeks Health Reform

The Committee of Ten Thousand (COTT) celebrates twenty years of community commitment in 2009, and is currently planning several events in recognition of this anniversary. While continuing our work on blood safety and HIV/HCV treatment and care, COTT is working in numerous state capitals to address the severe cuts in healthcare. In California we are working closely with HCC and local hemophilia and other disease organizations to address these unconscionable cuts in critical care. In addition, work continues on the citing of a memorial to those in our community lost to the hemophilia AIDS epidemic.

As more states attempt health reform on their own, COTT will be holding Town Meetings at the HFA Symposium in March in Indianapolis and the NHF Conference in October in San Francisco. Watch for COTT's new program on PTSD (Post-Traumatic Stress Disorder) starting up later this year as well! Lastly we are working with FDA on a review of the entire body of regulations that makes up US Blood Policy. ■

HFNC

A Quarter Century of Dedication

Lucy Alviso-Vallejo, a dedicated volunteer for 25 years, retired from the Hemophilia Foundation Northern California board last December. Lucy was initiated into the hemophilia community when her 7-month old son Daniel was diagnosed with severe Factor VIII in 1982. In her many years of service Lucy has volunteered as Secretary and Treasurer of the Foundation, been an outreach coordinator educating the community about AIDS, and has even worked in the office.

“I began to feel really connected to this community and joined the Foundation and later the board,” recalls Lucy. “As a Spanish speaking Latina woman I have felt the power to help other women and children accept the hemo card that was dealt to them,” continues Lucy. “This community is always ready to help, and it has warmed me over and over again. I have returned that favor by supporting those who have come after me.” ■

CCHF

Are You Wearing Your Medic Alert?

By Karen Scott, RN, UC Davis HTC Adult Nurse Coordinator

This should be the number one item on your to-do list! It could even save your life! What is it? A Medic Alert bracelet, necklace or wallet card provides important information about how to treat your bleeding disorder, including medical issues, medication, allergies, emergency contacts, and the phone number of your Hemophilia Treatment Center. This is vitally important if you are ever in an emergency situation where you can't tell the paramedics or other emergency personnel about your bleeding disorder. Having this information all in one place saves valuable time and helps emergency personnel know how to treat you both properly and quickly.

It is easy to apply for a Medic Alert. Ask for an application at your Hemophilia Treatment Center, Foundation, or call Medic Alert directly at (800) 432-5378 or visit them online at www.medicalert.org. The cost is \$39.95 for the application fee and then \$27 per year to renew. If you can't afford the payments, your local chapter may be able to help. ■

HFSC

Handy Tips for Smooth Travel

Colleen Stone, proud grandmother of a child with hemophilia and Transportation Security Administration employee, has these handy travel tips to smooth out the wrinkles on your next flight:

Luggage: In addition to one carry-on and personal item, any passenger with a medical condition is allowed to have all medically necessary equipment to administer treatment on board.

Shoes: If you have a bleed and are unable to remove your shoes or medical orthotic, you don't have to remove your footwear. Allow extra time for screening of the footwear.

Fluids: The limit on liquids and gels for carry-on luggage (3 oz. containers that fit in a 1 quart plastic bag) does not apply to medically necessary liquids. Allow extra time for screening and bring a letter from your doctor stating their necessity. ■

IMPORTANT EVENTS...

CCHF Golf Tournament 5/16

Future Leaders 5/18-20/09
Deadline to Register 5/1/09

Legislative Day 5/20/09
Deadline to Register 4/10/09

Coastal Race for Hemophilia 8/23-29/09
Early Registration 4/17/09

HASDC

HASDC's Tutoring Program

By Teresa Ramirez, Executive Director, HASDC

The Hemophilia Association of San Diego County (HASDC) strives to better assist and strengthen the educational needs of the children in our bleeding and clotting disorder population. With this goal in mind, HASDC launched its Tutoring Program for youth 7-18 years of age. The focus of this program is to assist students in reading, writing, and math. The weekly two-hour tutoring session takes place on Saturdays at the Association's office. Tutors are credentialed teachers who design a customized program following the student's school curriculum. They also introduce a series of effective study and organizational skills to help students achieve success in school and later in life.

The program is now in its third year, and to our satisfaction the number of participants has increased. The Tutoring Program also puts emphasis on the need to achieve a higher education for a realistic job that will provide a good income and health insurance. It is intended to give each child a good educational beginning that will help them earn a better living. ■

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