



HEMOPHILIA HERALD

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MESSAGE FROM THE PRESIDENT

Sean Hubbert is the President of CCHF.
Her son, David, has hemophilia A.

Welcome to long time friends and new ones. In 2012 the Central California Hemophilia Foundation (CCHF) Board of Directors are striving to do a better job communicating all we are doing to serve the community.

CCHF has been serving patients and families with bleeding disorders since 1969. This includes peer support, education, youth activities, summer camp, scholarships and emergency assistance.

I invite you to please read our newsletter and observe all that is going on in the bleeding disorders community. While these are difficult financial times for many of our families, they are also exciting times in hemophilia research with great advancements occurring. Join us and be part of all that is happening to make life better for all of those affected by bleeding disorders.

Thank you for all your past support. We look forward to sharing all that is accomplished in 2012 through your on-going partnership.

SCHOLARSHIPS FOR HFA

The Hemophilia Federation of America (HFA) is hosting their 2012 symposium in northern California. The annual event is being held at the Santa Clara Marriott on Friday, March 30 and Saturday, March 31. The symposium includes breakout sessions for the following group: Dads in Action; Blood Sisterhood; Blood Brotherhood; Spouses; and, Moms. Childcare, including field trips for teens and young adults and on-site activities for children, is included with the symposium registration.

CCHF is inviting you and your family to join them at the symposium by providing four families with all-expenses paid trips to the symposium, including conference registration, two-nights at the Santa Clara Marriott and reimbursement for travel expenses. Please apply by Friday, February 24th and include your contact information along with the first and last names of up to four family members who would like to attend.

For more information about HFA and their annual meeting see: <http://hemophiliafed.org/>



UPCOMING EVENTS

- February 11—Crab Feed
- March 30-31—HFA Annual Meeting
- April 21—Golf Day
- May 7-9—Future Leaders & Leg Day
- June 17-21—Camp Hemotion

CAMP HEMOTION

is the highlight of the year for the young people in the Central California region. This is a unique opportunity for children with hemophilia and their siblings to be away from home, often for the first time. Campers experience many of the typical camp activities under the watchful eyes of trained counselors and medical staff. Often this is where young people begin to self-infuse, a major step in their independence!



Here is a brief testimonial from one camper named Elizabeth B. (age 12): *“To be a sibling of a boy with hemophilia is hard sometimes, especially when he has a bleed. Camp Hemotion is where I can get to know other siblings of a child that has a bleeding disorder. Camp also teaches me more about what its like to have a bleeding disorder and we get to do activities like rock climbing, swimming, and arts and crafts. I am looking forward to going to camp in 2012.”*

Pictured: Elizabeth & her brother Bradley (age 9) boarding the bus for camp.

ANNUAL CRAB FEED

February 19th we hosted our annual Crab Feed in honor of our dear friend Nathan Slack. Nate passed away on December 20, 2010, and we still miss his energetic smile, but he would have been thrilled with the great turnout out this event, especially the enthusiasm among crowd when we put the specially designed snowboard (featuring Nate’s picture) up for live auction. There

were several other special items also offered for live bidding at the event.

Over 700 participants enjoyed crab and all the sides, plus delicious homemade desserts all served with a smile. Our special thanks to the John F. Kennedy High School ROTC for their gracious and friendly service.

This special event raises money for the important services provided our families, in particular the summer camp described above. Please plan to join us this February!



Purchase your tickets for the **2012 Crab Feed** today!

February 11

Elks Lodge
6446 Riverside Blvd.
Sacramento, CA

\$45

All-you-can-eat crab and
silent auction

*“best crab feed in town—
great service”*

FUTURE LEADERS & LEGISLATIVE DAY



May 16 marked the beginning of the Future Leaders program which culminated in the joint legislative day on Wednesday, May 18th. This program is sponsored by the Hemophilia Council of California, in partnership with the other chapters in the state. Youth aged 13 to 18 participate in advocacy training over two days and then put their training to work, leading groups of patients, families, industry and friends who meet with legislators and legislative staff on

Wednesday. These days are critically important as we seek to maintain funding for important programs and also seek the passage of AB 389 (Mitchell), a measure which will provide standards of service for the treatment of hemophilia.

Mark your calendar for the 2012 days—Future Leaders will be held in Sacramento on May 7-8, culminating in the legislative day on Wednesday, May 9th. Watch for more information and plan to attend. Youth interested in participating in the Future Leaders should contact CCHF to apply for the 2012 class.

GOLF!

by Frank Welsch



On May 21 we had a wonderful golf tournament for the kids. The weather was just right! Each of the kids had a golf lesson and then an opportunity for a pitch and putt. Then it was off to the course to see what they could accomplish. Some of the things the kids took away from this tournament was going at the pace of play and also the sportsmanship amongst them, whether they won or lost – that's special. The next Golf Tournament is scheduled for April 21, 2012. Don't miss it!

Did you know CCHF has scholarships called "Lifelong Learning Grants" which can cover the cost of lessons for activities like golf? Contact CCHF for more information.

WOMEN WITH BLEEDING DISORDERS

by Laura Walters

June 4 and 5th, 2011, I was one of the women who attended the vWD retreat in Old Sacramento. I had the most amazing time and it really taught me a lot.

I learned terms I never knew the meaning of, how important advocacy is and how many people can help you in so many ways. It inspired me to be more independent with my health, whether it's renewing my GHPP, keeping track of my treatment plan, or to start advocating for myself.

I met some amazing women this weekend and have a support network to lean on if necessary.



Prefer email communication?

We're attempting to go electronic with our communication. Please make sure we have your current email.

CCHF is a member chapter of the National Hemophilia Foundation and the Hemophilia Federation of America.

We partner with three additional California chapters in the Hemophilia Council of California.

Membership & Volunteers

You can become a member of CCHF by signing up online at:

www.cchfsac.org/support

We also have many opportunities for volunteers. These include:

- Grant writing
- Community events
- Event fliers
- Crab Feed assistance
- Assist with mailings



2011 CALIFORNIA COASTAL RIDE FOR HEMOPHILIA

by Nate Osborne (fellow rider & associate board member)

San Francisco to San Diego, 7 days, 500 miles, Tour of California you ask? Nope, how about the 10th annual HCC Coastal Ride for Hemophilia. 2011 marked two new additions to CCHF's annual coastal ride team, Burt Lo (rider) and Sean Hubbert (SAG Support).

Burt is a new recruit to the world of endurance cycling. A dedicated board member and dutiful dad, Burt undertook the mammoth task of riding 500 miles over 7 days with a whopping 45 days - or so - of training.

Now, before I boast any further about my teammate Burt, I would be remiss if I did not mention the help all of us riders get along the way. There are mechanics and SAG support, amongst many others who help so much during the week. That is precisely where our second CCHF all-star showed her true colors. Whether it was a cold drink on the route, a kind wave to steer us in the right direction, a warm *Cup-o-Joe* at the finish, or the non-stop laundry she did for all of us, Sean was like having a second mother on the trip. She always made us feel safe, well fed, and made the week pass without even so much as a hiccup....just the way she always does!

Burt started off by gliding down the steep grades of San Francisco only to rolling up a 19% grade into Admiral Park in Monterey. He traversed the ups and downs of Big Sur to Ragged Point for 52 miles, climbing 5,500 vertical feet (and that was just the lunch spot). He did his first 100 miles or century in a day, a true bench mark in cycling endurance riding. Finally, Burt safely navigated Southern California traffic to lead the entire ride into Mission Bay Park in sunny San Diego. Man, what a ride. Great work Burt, see you on the road in 2012...

The HCC Coastal Ride for Hemophilia is scheduled for August 19-25, 2012. Start training now!

EDUCATIONAL SYMPOSIUM

The CCHF annual educational symposium was held on Saturday, October 29th at the beautiful UC Davis Mind Institute and offered education and information for all members of the bleeding disorder community.

Community members heard the latest developments in treatment for both hepatitis C and hemophilia – and much of it is good news! Another hot topic was the importance of nutrition and healthy bodies to hemophilia care.

Younger community members enjoyed making new friends in the supervised play-daycare program. One of the highlights was the Halloween costume contest. Throughout the day, all attendees were able to visit participating industry displays to learn more about the products available to treat bleeding disorders and provide home care support.

Save the date for the next educational symposium scheduled for Saturday, October 20th, 2012!

Mark your calendar now:

**Educational Symposium
2012**

Saturday, October 20

UC Davis Mind Institute
Sacramento, CA

Workshops on:

- Trauma prevention & care
 - First aid & safety
 - Research updates
 - Much, much more!

CHRISTMAS PARTY



On December 3rd we gathered with dozens of families, both old and new friends, for a very special holiday tradition—the annual CCHF Christmas celebration. All attendees were treated to a delicious lunch; cookie frosting/decorating; crafts; and a candy-filled piñata.

For the kids, Santa made a special appearance to take photos and deliver presents to each child who attended. Families were treated to special goodie-bags. Thanks to all who attended and especially to our sponsors and supporters who make these special events possible.

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www.cchfsac.org

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