Message From The President

Hello members and friends. What a beautiful morning it is as I draft this missive. There is nothing quite as exciting as the change of seasons and the approach of the holidays. We have covered so much ground in the last few months; and, have so much to do this winter. There are many events to report on, and many scheduled prior to the end of the year. I hope to see all of you at one of our gatherings. From the Coastal Ride in August to Family Camp, scheduled for July 2015, there are ways for all of us to get involved. Let’s use our talents for the greater good. What’s your strong-suit: fundraising; photography; committee work; graphic design? There are volunteer opportunities for all. Please contact any of us to see how you can contribute.

I would like to take this time to congratulate and welcome both our new and returning Board Members to the 2015 CCHF Board. We have much to achieve next year and I have no doubt that the dedication and combined experience that we have amassed will lead to lighter work for all of us. I appreciate each of you graciously offering the gift of your time to the organization. Your sacrifice is well noted and makes a difference to so many.

We will be holding several new events in 2015. Please make sure to be part of our inaugural Salsa Challenge or maybe our first Family Camp. Enjoy a traditional favorite, too. But be sure to be included. Being a part of this community enriches all of our lives. Together, we are stronger.

I wish for you all a warm, fulfilling holiday season. I hope to see you at the next opportunity. I hope you enjoy our news. And, thank you, all.

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

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- Just how does your favorite salsa recipe stand up to the local competition?
- Don’t miss CCHF’s inaugural Salsa Challenge,
- Calendar of Events
- December 6, 2014 Annual Holiday Party
- February 21, 2015 Annual Crab Feed
- March 26-28, 2015 HFA Annual Meeting St. Louis, MO
- April 17, 2015 World Hemophilia Day
- April 18, 2015 Family Golf Day Haggin Oaks Golf Course
- May 11-13, 2015 Future Leaders Days Sacramento, CA
- TBA Salsa Challenge Sacramento, CA
- June 27-28, 2015 Family Education Day/Fun Day
- July 17-19, 2015 Family Camp

The Central California Hemophilia Foundation is dedicated to improving the quality of care and life for persons impacted by hemophilia and other inherited bleeding disorders through education, advocacy and support.

On August 17th, a group of intrepid cyclists and enthusiastic volunteers gathered in San Francisco for the 13th Annual California Coastal Ride for Hemophilia, a weeklong ride down the coast. This 500+ mile bicycling trip was organized by the Hemophilia Council of California, and supported by the four California Hemophilia Chapters. The Central California Hemophilia Foundation was represented by Bill (Wilson) Smith, Ian Corona, Aaron Hermann, Nate Osborne, and Burt Lo. This year’s bike riders included first-time participants and weathered veteran peddlers from California and as far away as Denver, Chicago and Virginia. These riders were grateful to be supported by an extensive group of volunteers, who provided directions, support, cooked, and even did laundry.

The group averaged riding 70 miles per day. Along the way, they were treated to beautiful weather and breathtaking views, including some whale watching near Big Sur. As one of the riders, I was struck by several aspects of the group. First, I was overwhelmed by the dedication of the riders and volunteers. Despite a few scrapes and bruises and sore body parts, every rider enthusiastically supported each other to complete as many miles as possible. Second, I marveled at how much treatments for bleeding disorders have changed over the years, as I noted the number of riders with hemophilia. One of the purposes of this ride was to raise awareness of hemophilia, and these riders showed me how barriers have been reduced for them.

The ride concluded on August 23rd at a Hemophilia Association of San Diego Company picnic in Mission Bay Park in San Diego. One of my favorite memories of the week was being warmly welcomed by family, friends, and chapter members holding signs created by summer campers. I was also thankful that every rider completed a safe and enjoyable trip.

The Hemophilia Council of California was also happy to share that this year’s ride exceeded the goal of raising $120,000. Please consider joining, or supporting (financially or by volunteering) for the 2015 California Coastal Ride for Hemophilia, details can be found at www.ccr4h.org.

Contributed by CCHF Board Member Burt Lo. To find out more about the Coastal Ride 2015, please contact Burt at trubol@gmail.com.
CCHF Donates Outdated Factor to Mexico and Pakistan

The Central California Hemophilia Foundation was able to make a humanitarian donation of outdated or surplus factor to patients with bleeding disorders in Mexico and Pakistan. Because of the thoughtfulness of several people with outdated factor and a patient who had a liver transplant and no longer has hemophilia, we were able to send life-saving product to these two countries. These donations save lives because in many areas of the world, factor is not available. As a result, patients are rendered severely disabled which can prevent them from attending school or finding and keeping employment to support their families. In Pakistan, in many instances, hydrotherapy is often the only available treatment. In both of these countries, our partners save the factor for the most serious cases.

Save One Life

Through Save One Life, our Foundation has “adopted” two boys in Pakistan with hemophilia. We do not provide them with factor but, rather, contribute a small monthly stipend that can be used to help them attend school, buy food or afford other necessities. Our Foundation works to support not only the families in our area, but to make a difference in the lives of people in other parts of the world.
Are you Ready for Open Enrollment?
This article was originally published in the fall edition of Dateline, Hemophilia Federation of America's quarterly newsletter.

Summer is over and already it is time to start making your list and checking it twice. No, not that list; the list of the things you need to make sure your health insurance plan covers when your open enrollment period starts. An open enrollment period is the time when individuals can enroll themselves and any dependents in Qualified Health Plans for the following year. Open enrollment usually lasts about 30 days. The first step is knowing when your open enrollment period is; the second is finding the right plan.

The Affordable Care Act (ACA) requires insurance companies to provide an easy-to-read chart of benefits for any plan it offers. This is great for the general benefit items, but for patients with chronic conditions, it is the details that count. For example, bleeding disorder patients around the country have found that their hemophilia treatment center (HTC) is in the network of providers their insurance will cover only to learn that the doctor they see at their HTC is not. In addition, many insurance companies now are limiting pharmacy choice for patients, and moving factor from major medical coverage to pharmacy coverage. This allows them to charge a percentage for the cost of factor (20-50%) verses a copay. This is not all. Though the ACA capped annual out-of-pocket costs, some patients have to pay the full out-of-pocket limit in the first month that the insurance policy is effective. For example, the out-of-pocket maximum for an individual is $6,600 individuals and $13,200 for a family. Already, patients with chronic diseases in California are reaching their out-of-pocket maximums in one month and they can’t afford to pay. Legislation is in the works to allow California residents who reach the out-of-pocket max quickly to pay down the balance over 12 to 24 months. Until this legislation and legislation like it around the country becomes law, many individuals and families are at risk for financial hardships should they reach their limit too quickly.

If you are not sure, now is a good time to learn when your open enrollment starts and ends. It is typical to have a 30 day window, often in the Fall. Check with your human resources department, if you can. Some open enrollment dates to keep in mind:

- Medicare plan coverage starting in 2015: October 15 – December 7, 2014
- Medicaid and CHIP are open 365 days a year

Important Things To Know Before Signing Up:
So what can you do? How do you find out if the policy you are considering is the right one? How do you plan for reaching out-of-pocket limits quickly? The checklist on below can help you determine whether the insurance plan you have in mind has what you need to meet your health insurance coverage needs for the coming year.

Create a list of the benefits you need. List the services you used in the past year, then think about what services you may need in the coming year. This includes use of your health care providers such as doctors and physical therapists, specialists, your HTC, your hospital, your prescription drugs, and other treatments you feel your family is likely to need. Don’t forget about optical care and dental care!

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Invest the time to review plans in detail. Allocate time to reviewing the plans to which you have access. Read the plan options carefully but don’t be afraid to ask questions about the plan. Contact your human resources person for help if you have a private plan through your employer, call your insurance provider if you have a self-insured plan, or call 800-318-2596 if you are looking at Marketplace plans.

Check your healthcare providers. Verify that your regular healthcare providers, HTC, clinics, and hospitals are open 365 days a year.
More Than Just Another Line On Your Resume

Making a change in the world begins by making a change in your community! Apply to be an intern through the Bayer Hemophilia Leadership Development Program and begin to learn how to be the change YOU want to see in the world.

Students enrolled full-time in college who are touched by hemophilia can apply now for the opportunity to:

- Engage in leadership training and hands-on business projects
- Learn how to support the hemophilia community as a potential future leader

Apply now for a six-week paid internship at Bayer HealthCare’s U.S. headquarters in New Jersey.

In addition to working directly with leaders at Bayer, selected interns will:

- Collaborate with local hemophilia organizations and learn about efforts to support the hemophilia community and partnerships with business professionals
- Meet with healthcare public policy professionals to experience first-hand how effective advocacy relations impacts legislative decisions
- Be responsible for developing a project that will be presented to Bayer Senior Management

Start shaping your future and your community! Apply today for the Bayer Hemophilia Leadership Development Program.

Applications are due no later than Friday, March 13, 2015 at 11:59 p.m. ET. To learn more and complete an application, visit www.HemophiliaInternship.com

Explore Bayer HealthCare’s additional leadership opportunities, Step Up Reach Out and AFFIRM, at www.hemophilialead.net.
The following letter was written by CCHF member and first-time NHF attendee, Cristian Anguiano. Cristian’s letter reminds us of the key concepts for which we strive: education; advocacy; and, support.

What I learned at the NHF Washington DC Conference

September 27, 2014

My name is Cristian Anguiano, I live in Olivehurst, California, and I am 15 years old. It was five years ago that I was diagnosed with Von Willebrand Disease (VWD) type 1. This year I was given the opportunity to attend the Conference of NHF in Washington DC. This was my first experience at NHF and I learned a lot about hemophilia and VWD.

VWD is the most common bleeding disorder, affecting up to 1% of the population. The condition is named after Erik von Willebrand, the physician discovered it. There are 3 types of VWD: type 1 is mild and is found in 60% - 80% of patients; type 2 is mild to moderate, and is found in 15% - 30% of patients. Type 3 is severe, and is found in 5% - 10% of patients.

The NHF experience was truly special. I realized that I am not alone, and that I count. I have the support of the Foundation and a large group of collaborators, pharmacists and different companies/scientists who work hard to find the best drugs/factors to help people like me with bleeding disorders. They made me feel part of the event and I was given a very special treatment. I also met other young people who have hemophilia and VWD. Thanks to this experience, I feel safe, and I will take care of myself for a better life.

In the future, I plan on sharing information that I learned at the NHF conference with other young people that have bleeding disorders. Hopefully I get invited to more events to continue learning. After coming back from the NHF Conference, I plan to take my condition more seriously. I am going to understand what types of sports are less risky, take care of my body and try to prevent injury from falling or getting hit hard.

Thank you to all people who helped to make the events possible and for the opportunity to participate.

Open Enrollment

in-network. Remember, your HTC may be in-network but the doctor you see there may not. Look carefully at the details. Call your healthcare provider to find out if they are in-network under any plan you consider.

Check your pharmacy or specialty pharmacy. Like healthcare providers, pharmacies contract with insurers to provide medication and related services. You may have a specialty pharmacy, homecare, or 340B pharmacy that you prefer. It is important to check if they are in-network under the plans you consider.

Know the rules. Find out if you need prior approval to see a specialist. Many health plans require that you get advance permission, called “certification,” in order to have tests, procedures, or surgery that a doctor recommends.

Explore discounts. Health plans may offer discounts for services like dental care or eyewear. These programs aren’t insurance but they can offer savings on services your family needs, and these discounts can add up. You might be able to balance these discounts with out-of-pocket costs.

Once you make a decision, obtain a copy of your Certificate of Coverage, which provides a detailed explanation of your plan’s health benefits in your plan.

Review this carefully and keep it in a safe place as a reference.

In summary, to choose a health plan wisely, think through your needs, build a budget, do your homework, and seek help in making your selection. You are going to be stuck with the plan you choose for 365 days; do all you can to make sure you get everything on your list.

*There are many support services for people with bleeding disorders. Most of the pharmaceutical companies that provide therapies for bleeding disorders have co-pay and patient assistance programs.

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...for the human factor*

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Barbara Harvey | 1 510 367-6867

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When it comes to your factor therapy, you have choices. And at Biogen Idec, we recognize the importance of researching and delivering additional factors to the hemophilia community. See if now might be the right time for you to make a change—learn more about our therapy options as well as our range of financial, educational, and community support programs.

TO LEARN MORE ABOUT THESE OPTIONS, CONTACT YOUR CoRe MANAGER:
Marilyn August | Phone: 925.864.0547 | E-mail: Marilyn.August@biogenidec.com
Calling All Crab-Feeders

CCHF’s Annual Crab Feed will be held on February 21, 2015, again at the Elks Lodge on Riverside Blvd. We already have several unique silent auction items (think “man cave”) as well as the wonderful variety of items our guests have come to expect. This year’s entertainment will be provided by the Capital Jazz Combo, whose bass player is a member of our community. So pull out your crab crackers and get your tickets, which are still only $45. You can purchase tickets on-line through our website; through our Board President, Sean Hubbert; or from any Board Member. But remember, buy early and buy often! Don’t risk a sell-out crowd! This is the Foundation’s biggest and best fundraiser of the year — don’t miss out!