

# Hemophilia Herald

Education, Advocacy, Support

Vol. 4 No. 1 Spring 2015

#### **Calendar of Events**

(Complete Calendar is online: www.ccfhsac.org)

#### March 26-28, 2015

HFA Annual Meeting St. Louis, MO

#### **April 17, 2015**

World Hemophilia Day

#### May 5, 2015

Big Day of Giving https://bigdayofgiving.org

#### May 11-13, 2015

Future Leaders Days Sacramento, CA

#### May 18, 2015

CCHF 3rd Annual Golf Tournament Lincoln Hills Golf Club

#### June 6, 2015

Salsa Challenge Old Sacramento, CA

#### June 27-28, 2015

Family Education Day/Fun Day

#### July 17-19, 2015

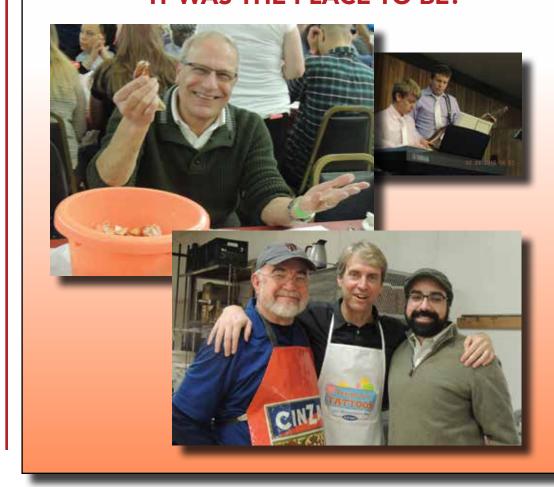
Family Camp

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.

Proudly Affilitated With



# CCHF TURF VS. SURF ANNUAL CRAB FEED TOOK PLACE ON FEBRUARY 21st IT WAS THE PLACE TO BE!



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#### Mark Your Calendar!



Si usted prefiere recibir este boletín en español, por favor llame al 916.202.6204 y pregunte por Tracey. También puede encontrar una copia en español en nuestro sitio de internet (www.cchfsac.org).

# CCHF Welcomes Our 2014/2015 Board

#### Sean Hubbert

President
Seanahubbert@yahoo.com

#### **Tracey Huntington**

Vice President tracey.line2@gmail.com

#### **Greg Brown**

Treasurer cchfsac@yahoo.com

#### **Bonnie Leidheisl**

Secretary bleidheisl@yahoo.com

Dr. Jonathan DuCore, M.D., M.P.H.

Sonia Anguiano

Rebecca Buckmiller

Damia Dillard, L.C.S.W

Muriel Herr

Gail Reed

Elaine Rock

Kim Schafer, R.N., B.S.N.

#### Central California Hemophilia Foundation

Federal Tax ID# 23-7373643

PO Box 163689 Sacramento, CA 95816-9689

Phone: 916.448.0370

Fax: 916.489.1569

Web: www.cchfsac.org

CCHF is an all volunteer organization and 90 percent of all contributions directly support the programs that serve our patient community.

**Become a Member!** 

Sign up online at:

www.cchfsac.org/support

The Hemophilia Herald is published three times per year and is available to its members at no charge.

#### Message From The President

Central California Hemophilia Foundation

P.O. Box 163689 Sacramento, CA 95816-9689 916-448-0370

www.cchfsac.org cchfsac@yahoo.com

March 10, 2015

Dear Friend of the Bleeding Disorder Community;

We would like to take this opportunity to thank you for your continued support in our mission of serving the bleeding disorder community represented by the Central California Hemophilia Foundation. We would also like to take this opportunity to provide insight as to our decision to sever ties with one of our national affiliates. The Central California Hemophilia Foundation was established 45 years ago as an all volunteer organization. We have NO paid employees, no office to maintain and only minimal overhead costs (i.e. phone, post office box, postage, etc.) We are proud to say that over 90% of our proceeds go back into our community. We have successfully fostered a positive and successful foundation over the years and have been able to provide these benefits free of charge to our community for the benefit of our community.

After reviewing the required criteria to maintain an affiliation with the National Hemophilia Foundation by hiring a full time employee, we as your elected Board choose to REMAIN AN ALL-VOLUNTEER ORGANIZATION SO THAT WE MAY CONTINUE TO DEVOTE ALL OF OUR RESOURCES TO SUPPORTING OUR COMMUNITY.

The services that we offer and provide for our community will NOT be affected by our decision not to maintain that affiliation. We are here to continue our mission by supporting and providing for our community.

We look forward to being an active part of the bleeding disorder community for another 45-plus years and welcome walking hand in hand with our community on the path ahead.

If you have any questions, comments, suggestions or would like to volunteer please feel free to contact us by phone or email.

Sincerely,

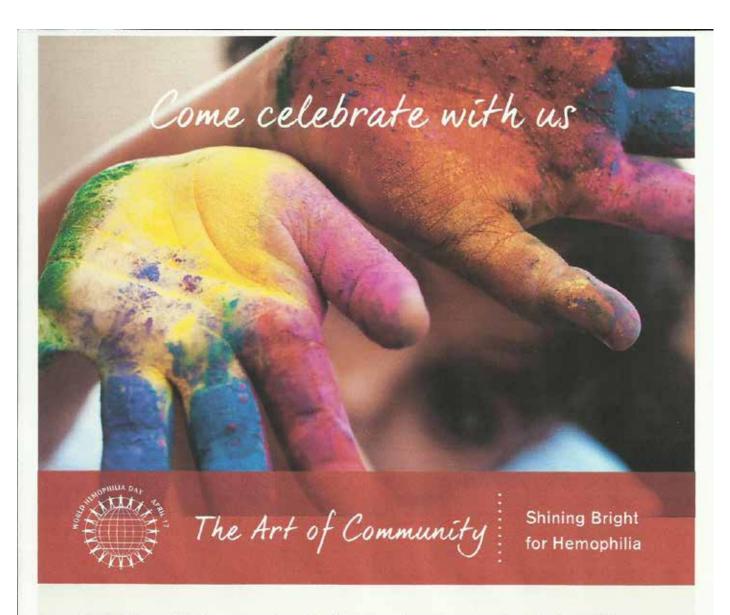
Sean A. Hubbert

President

Central California Hemophilia Foundation

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

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As World Hemophilia Day approaches on April 17, it is a chance to pause to honor the hemophilia community, the road we're on together, and the bright future ahead.

We invite you to join us at *The Art of Community: Shining Bright for Hemophilia*, an evening of art, fun and friendship, as we help raise awareness for bleeding disorders. These exciting painting activities will be accompanied by the illumination of several historic buildings in Old Sacramento in red. Contact us for more details!

RSVP to: Sean Hubbert | seanahubbert@yahoo.com | 916.296.9066



## biogen idec.

Get to know us: BiogenIdecHemophilia.com/CoRes

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# CCHF's Inaugural Salsa Challenge!



# Saturday June 6th 2015

10 a.m. - 2 p.m. in Old Sacramento

Just how does your favorite salsa recipe stand up to the local competition??

Let's find out!

For more information, contact: Tracey Huntington, tracey.line2@gmail.com



HFHEALTHCARE

Infusing health
right to your home

At HF Healthcare, we specialize in the treatment of hemophilia and other bleeding disorders. HF Healthcare provides a personalized one-on-one approach to support the clinical, psychosocial, financial and administrative needs of our hemophilia patients. We maintain our goal by improving each patient's quality of life while ensuring fiscal responsibilities. We are committed to providing anti-hemophilia clotting factor, supplemental prescriptions and other important supplies to patients in an efficient, expedited manner















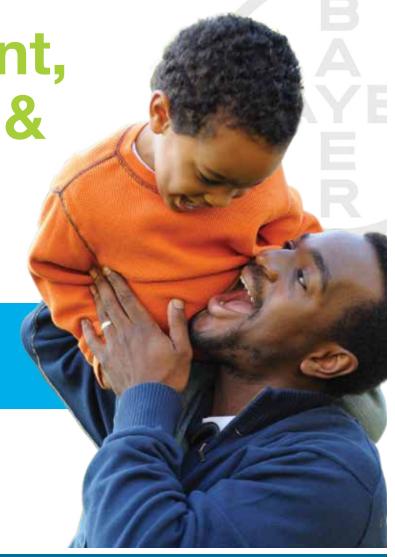
**BAYER HEALTHCARE AND THE HEMOPHILIA COMMUNITY** 

commitment, leadership & innovation

For information on Bayer's Educational Patient and Community Resources, contact your Hematology Account Executive by calling 1-888-79-BAYER.







### **CCHF Christmas Party**

By: Dylan Charamuga



I have a form of hemophilia called von Willebrand Disease and every year the Central California Hemophilia Foundation (CCHF) hosts the children and their families to an afternoon of Christmas food and fun.

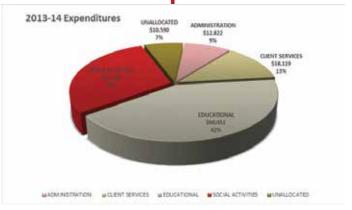
As we walked in I could see off the great food and desserts. My brother and I got in line. There was mac & cheese,

beef brisket, turkey, corn and rolls. After we ate lunch there were some delicious desserts. There was cheese cake, cookies, mountain cake (made by my grandma), cupcakes, brownies, donuts and hot chocolate.

After all the great food, it was time for some fun. Some of us went outside and threw around the football I had brought. When we came back inside, my brother and I went straight to the cookie decorating stations. We each chose a tree to decorate. There were all kinds of decorating stuff; frosting, sprinkles and candy snowflakes. Our cookies came out great. We then went over and made some decorated coffee mugs. There were pens to write messages and foam stickers to help make these mugs look festive.

The most fun of all was when Santa came and delivered presents to all the kids. I received a train, which I came home and placed around our tree. My brother got an Airhogs Helicopter which works by remote control and my cousin received a stuffed dog, which I am sure she loves. When it was time to leave, each family was given a bag with lots of stuff in it. Ours had lip balm, a first aid kit, deodorant, a necklace, a stuffed dinosaur, coffee mugs, a water bottle and lots of pens and pencils. I love going through all the stuff. In the end CCHF put on another very nice event which was fun for all.

## **CCHF Annual Report**



#### **CCHF Welcomes Social Media Coordinator**

We are so excited to introduce our new volunteer Social Media Coordinator, Ciera Leidheisl! Ciera is a Communications Major at Sonoma State University and she will be graduating in May of this year. She has built a very strong resume over the last 4 years at Sonoma State with ASP Event Planning for the Campus, Social Media coordinator for ASP and new student orientation just to name a few items.

Ciera has been a part of the CCHF Bleeding disorder community for the past 18 years and she is very excited to be giving back to our foundation and promote our foundation.

For updates and facts like our Facebook page at Central California Hemophilia Foundation or follow us on Twitter at @cchf\_sac.





From midnight to midnight on May 5th, go to

### bigdayofgiving.org

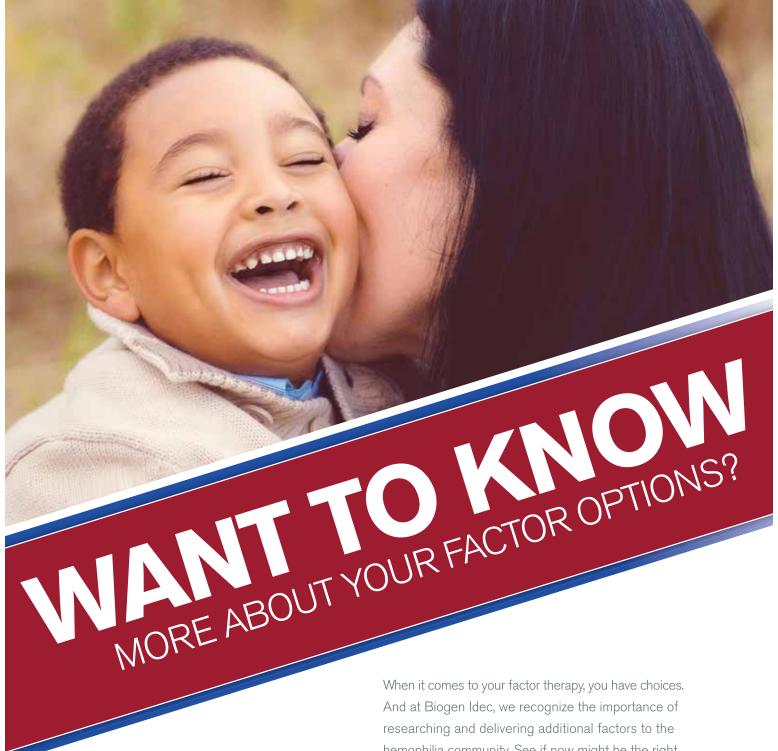
and give to the nonprofits that lift up lives and make this the place we call home.

**Give Local Now!** 

24 HOURS TO GIVE WHERE YOUR HEART IS

bigdayofgiving.org

www.cchfsac.org Spring 2015



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



Ne do not give any legal or medical advice

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alifornia 📗

Foundation

**CCHF** 

95816

P.O. Box 163689 Sacramento, CA

## How Can I Help... There are lots of ways to get involved!

Fundraising; Gwenn Welsh, Chair – gvwelsch.cchf@outlook.com

Help with the annual Crab Feed; the inaugural Salsa Challenge;

We are always looking for new opportunities to spread the word. or bring your suggestions for a new fund raiser.

• Communications; Tracey Huntington, Chair; 916.202.6204 or

It's easy! Fill out the Volunteer Sign-Up sheet on-line!

Membership; Tracey Huntington, Chair; 916.202.6204 or

Take pictures at a social gathering. All hands welcome.

Making a few phone calls is all we need!

Help us to get the word out and increase our

Try your hand at reporting one of our events.

www.cchfsac.org

membership base.

tracey.line2@gmail.com

tracey.line2@gmail.com

This newsletter mailed to you courtesy of BloodSource. Thank you BloodSource for your continued support.

The Foundation is currently looking for volunteers for these committees: