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NACCHO E-NEWSLETTER APRIL - MAY 2009



Dear NACCHO Participants,

NACCHO 2009 was simply amazing. The planning committee worked diligently to plan an event that would be beneficial to both you and your campers. We hope that you are able to take and apply some newly gained knowledge. We have already started to plan for 2010, and we are so excited to continue to improve this conference. At the end of each conference, I sit and reflect about what we can do better and usually I feel that it is going to be hard to top the last conference. It requires the committee to be creative and to always be thinking out of the box. Well, I think they have done just that. I hope that I have piqued your curiosity!

As you go into your camps this summer, we wish you a safe and wonderful camping experience. Please send us pictures and stories from your camps so that we can put them into the fall NACCHO newsletter!

Thank you for your continued support and enthusiasm!

The Arizona Hemophilia Association

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<http://naccho.com>

Looking For A Few Good National Summer Camp Leaders



The National Future Leaders Exchange Program (aka CEP – Camp Exchange Program) offers Assistant Counselors, Adult Cabin Staffers, Art & Craft Directors, and other Directors the opportunity to:

Learn new skill sets, incorporate established practices and principles into new ventures, as well as further foster and capitalize on your leadership and personal development.

Further polish your National Leadership Potential and infuse your fresh ideas -

- in the planning and execution of the camping experience and programs
- in the acquisition of new skill sets, ideas, concepts and/or best practices

Expand your horizons by assimilating other camp cultures, systems and challenges including the:

- administration of the camp program
- management of an essentially all volunteer staff
- communication tools required to meet the myriad of challenges that arise with campers during the camping experience
- positive impact you will have on youth development
- know-how and when-to, for relying on other key staff members in various situations
- development and execution of risk management and practice

Participants must:

- Be at least 18 years of age
- Undergo fingerprint and/or background check

The Future National Leaders Exchange program matches you with one of the 52 other national hemophilia camps across the country. The goal is to prepare the next generation of leaders to improve the overall Bleeding Disorder Communities summer camp offerings and experiences.

If you are interested in the Exchange program, please contact the Hemophilia Foundation of Northern California at the following:

Merlin Wedepohl, Executive Director 510-568-6634
merlin.wedepohl@hemofoundation.org

Bobby Wiseman, Program Coordinator 415-726-6187
bobbywiseman@yahoo.com

<http://www.hemofoundation.org>

NEWS FROM THE HEMOPHILIA FOUNDATION OF NORTH. CA



June 21st - June 27th Camp Hemotion at Camp Oakhurst, CA
August 23rd - August 29 - HCC Bike Ride from San Francisco to San Diego
For more information visit their website at www.hemofoundation.org.

www.hemofoundation.org

FEDERACION de HEMOFILIA de la REPUBLICA MEXICANA, A. C.

The Hemophilia of México will host its First Leadership and Hemophilia Projects Camp on May 30 - June 2, 2009. This leadership camp consists of

18 to 30 year-old volunteers from local hemophilia associations. There will be 35 participants, who will be coming from 20 of 31 states in México.

NEWS FROM ROCKY MOUNTAIN

Ann Schrader, Lisa Maxwell and staff of the Rocky Mountain Hemophilia Bleeding Disorder Association are busy planning their Family Camp. The camp dates are August 7 - 9, 2009 at Luccock Park Camp in Paradise Valley, outside of Livingston, Montana. This year's theme is "The Amazing Race." Log onto their website for additional information about camp and other programs.

<http://www.rockymountainhemophilia.com>

A Letter From Martin Bohún of the Czech Haemophilia Society

Thanks to NACCHO for new opportunities, ideas and friendship! I am extremely grateful for the participation of people with whom I could meet! Haemophilic camps are extremely important for haemophiliacs and NACCHO is clear proof. I have organized camps since the age of 6 and NACCHO has given me another added incentive for other camps. The conference gives us the possibility to compare our camp with the world.

It is very pleasant for me and motivational to meet with people who do the same camps as I. We are pleased that in our country we find activities (especially children's summer camps) and support. I firmly believe that hemophilic camps will continue to develop and meet the increasing interest of children! In the Czech Republic there will be a hemophilic camp for almost 40 children. This year we have already prepared a rich program including sleeping outdoors in a castle, rafting and many interactive games. The camp will be focused on the training course, infuse and rehabilitation under the guidance of doctors and physiotherapists. The camp will take place from July 11 - 25, 2009!

Finally, I thank pharmaceutical company Wyeth and all NACCHO conference organizers! It was a pleasure meeting you!

Martin Bohún, Czech Haemophilia Society

"Journey Around the World" by Shelly Mattson



NACCHO has really made an effort to diversify its participants over the past couple of years, with the inclusion of staff from hemophilia camps from countries outside of the United States. More and more international programs and camps are starting up as the hemophilia community begins to look beyond its own backyard to reach out to those in desperate need. Along with this

increasing awareness and more global perspective, at this year's 2009 NACCHO, the World Federation of Hemophilia USA proudly launched its summer pilot program: "Journey Around the World." Participants in this session were given a sneak peek of this exciting new program. A touching video was shown of U.S. volunteers helping others in need in Peru, followed by an informational presentation about "Journey Around the World" along with a Q & A session, and a toast was made with a Russian soda beverage to the health and wellness of all those affected by a bleeding disorder around the world.

This year, the WFH USA has received an educational grant from Wyeth to pilot "Journey Around the World" this summer at hemophilia summer camps across the country. A fun and educational activity, "Journey Around the World" will raise awareness and teach children what bleeding disorders are like in other countries around the world. Only about 25% of the estimated 400,000 people affected with hemophilia receive adequate treatment. So far, over 20 summer camps will be conducting this program representing 2,300 campers and staff!

In "Journey Around the World," children will receive a passport and an airline ticket and will rotate through different stations that each represent a different country. At each "country," children will have the opportunity to do a fun activity to teach them about that particular country (for example, in Japan they will learn how to make origami), and they will also learn about what it is like for someone their age to have a bleeding disorder in Japan. In some cases, factor is not even available as a treatment option, and children have big, swollen joints and painful arthritis. The last stop they visit is the U.S., in which they celebrate and learn how good care and quality of life for bleeding disorders is. By building an awareness of bleeding disorders in other countries, our hope is that children will be able to look beyond their own backyard, and reach out and help others in need. If you are interested, WFH USA will provide your camp with the necessary materials and instructions that you will need to be able to run this program with your camp staff.

If this sounds like something you are interested in, it is not too late to get involved. We are putting the finishing touches on our program and will be packing up the materials to send to you in plenty of time for your camp. To do this, we would need to gather some additional information such as the dates of your camp, verifying a mailing address and contact person to send the materials to, and approximate numbers of the campers and staff at your camp.

If you have any questions, please do not hesitate to contact WFH USA board member, Shelly Mattson, via phone: 414-257-0200 (daytime) or 414-807-4826 (cell), or via email: mattson.shelly@gmail.com

www.wfhusa.org

What Does NACCHO Mean to Me? by Joshua Lunior of Camp Hot to Clot

There are a lot of hemophilia events that I attend every year, however NACCHO is one of my all time favorites. This year for instance I was on an open ended ticket to Israel and I specifically came back just in time for NACCHO.

So why is this conference so rewarding you ask? Well, let me tell you.

As a child I started attending hemophilia camps at the age of seven. It was the highlight of the whole year because I got the opportunity to be around other hemophiliacs who were going through similar struggles in their lives back home as well.

The hemophilia community is roughly comprised of 20,000 in the United States and yet we are a strong community that comes together and creates some of the most remarkable programs like NACCHO because we realize the strong importance of staying connected to others within the bleeding disorders community. Attending camps as a child helped me realize how much I wanted to find a career working with children as well as become a role model to others by becoming a counselor at summer camps.

I travel to several conferences across the country every year where I am able to learn a multitude of ways of working with children. What I realize is the knowledge that I learn at NACCHO sticks with me the most throughout the year. Whenever people ask me what I learn at these conferences, without fail the facts I tend to remember are things I learned here at NACCHO.

The hemophilia community is always looking for young individuals in the community to step up to the plate and teach others. As a participant who has attended NACCHO for several years now, it has taught me a wealth of knowledge on how to improve camp programs I run and to make them

more effective to those who attend. Also, I look forward to the opportunity to teach a workshop on how to help work with children who get homesick and even help out with the NACCHO Planning Committee.

While living with severe hemophilia everyday has its challenges, it's getting the opportunity to attend yearly conferences like NACCHO that make me realize how fortunate I am to be a part of such a remarkable community; a community where I have learned so much about who I am as an individual, and I have met some of my closest friends. I would not give up these experiences for the world.



PHOTOS COURTESY OF GUYTANO LAW OF CAMP HOT TO CLOT



MORE NACCHO CONFERENCE PHOTOS

Thanks to all of you that submitted articles for our first NACCHO E-newsletter. A very special thank you to Guytano Law for submitting the great photos of our NACCHO Conference. We look forward to seeing you at NACCHO 2010.

Sincerely,

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