

Hemophilia Walk of New Mexico

By Joe MacDonald

Hello Everyone,

My name is Joe MacDonald and I serve as the Walk Chair for our First Annual Hemophilia Walk. All proceeds will go to help further education in the bleeding disorders community. Thank you for setting up your teams. Jean Cole, new to our community and a wonderful member of our Walk committee, will be sending out a week-

ly message from me to you. We have an incredible goal to raise \$50,000. While this looks like a tremendous amount of money, together, we can reach our target.

One way we can help each other is to share our stories about how we are reaching our goals for the Walk. I am going to send out a letter to all of my fellow employ-

ees, encouraging them to be a part of the Walk by either joining my team or forming their own teams. I hope that I am able to surpass the goal that I set for my team. We would love to hear about ways that you are working towards your goal. You never know when your way might help somebody else achieve their objectives. Good luck to everyone!

2013 Hemophilia Walk Facts

WHAT

The Hemophilia Walk is NHF's largest fundraising event. NHF is dedicated to finding better treatments and cures for bleeding and clotting disorders and to preventing the complications of these disorders through awareness, education, advocacy, and research.

WHY

Established in 1948, NHF is the premier bleeding disorders organization in the U.S. serving the bleeding and clotting disorders community.

Now in its 64th year, NHF continues to be a vital resource for prevention education and provides a network of support for Americans living with bleeding disorders and their families.

WHEN

Saturday, April 20, 2013

WHERE

Tiguex Park,
Old Town,
Albuquerque,
New Mexico

Check-in begins at 8:00 a.m.
Walk begins at 9:00 a.m.

DISTANCE

1-mile family fun walk

WALK CHAIR

Joe MacDonald

HOW

Sign up for the Walk on-line by visiting www.hemophilia.org/walk. Everyone is welcome to participate!

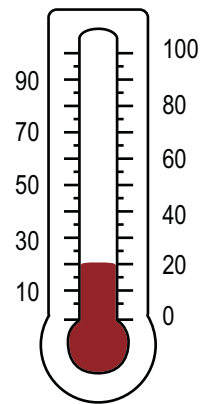
TEAMS

Sign up a team. Choose a team name. Recruit team members from your circle of friends, family, co-workers, and neighbors.

VOLUNTEER

Help us make our event a success. Volunteers are appreciated before and/or during the Walk. Are you unable to do the Walk but still want to participate? Enlist as a volunteer. Call 505-341-9321 for more details.

Goal: \$50,000



Raised: \$10,291
Sponsors: 57
20% of Goal Achieved

CONTACT

- ✉ Joe MacDonald (505-999-0827)
- ✉ nmwalk@sangredeoro.org
- ✉ Loretta Cordova (505-341-9321).



Sangre
de Oro,
Inc.

The Bear Facts

Calendar of Events

March

National Hemophilia Awareness Month

14 Executive/Board Meeting

April

4-6 Region VIII Meeting in Seattle, WA

15-17 NHF Chapter Training, Las Vegas, NV

17 World Hemophilia Day

20 Hemophilia Walk of New Mexico at Tiguex Park in Albuquerque

25-27 HFA Symposium in Dallas, TX

May

3 Executive/Board Meeting

June

3-8 Camp Sangre Valiente at Fort Lone Tree

10 New Mexico Hemophilia Awareness Day

July

11 Executive/Board Meeting

August

16 Caliente Classic Golf Tournament

September

12 Executive/Board Meeting

October

3-5 NHF Annual Meeting in Anaheim, CA

18-20 Patient and Family Education Weekend in Albuquerque, NM

20 Board Meeting

November

8 SDO Annual Planning Meeting

December

TBD Holiday Party (Tentative)



SAVE THE
DATE
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APRIL
25-27

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EMBASSY SUITES
DALLAS-FRISCO
CONVENTION
CENTER

How Do You Keep Moving Forward?

By Cazandra MacDonald

Sometimes living with a bleeding disorder can be a trial.

- ☞ You have flawlessly sterile technique, but your child continues to get port infections.
- ☞ Your child is healing from one bleed and spon-

When you know others out there are facing similar struggles, it's almost as if you can breathe a little easier. Someone else actually understands. They understand what it is like to try and infuse every few hours through the night. They understand what it is like to not be able to take your child's pain away during a major bleed. And they understand what it is like to change plans at a moment's notice because a bleed is taking center stage. You have to reach out because you are not alone.

way you can truly be a part of the decision making for your child's treatment.

But most importantly don't forget hope. When you feel like you have no hope and everything is falling apart, think about the people in the world struggling with medical conditions that have little or no treatment. Many have outlooks that are very bleak at best. Our children have a great future in store. Treatment options are better than they were several years ago, and the fu-

ture for improved product is promising. Individuals with bleeding disorders live happy productive lives, and it is our job as parents and caregivers to empower them.

Don't lose hope. You are not alone. Every day is filled with possibility, and the way you handle each situation will determine whether or not your child will have a positive outlook regarding their bleeding disorder.

"You're braver than you believe, and stronger than you seem and smarter than you think." Christopher Robin to Pooh

taneously starts another.

- ☞ You can't go more than two weeks without being admitted to the hospital.
- ☞ You change product with the best of intentions and your child develops an inhibitor.

The list goes on.

There are seasons of living with a medical condition where things are pretty routine, with few complications, if any. And then seasons of terrific difficulty. Those are the times when you can't seem to catch your breath, and you just can't get a break.

Community and communication seem to be important to getting through those difficult times.

Community and communication seem to be important to getting through those difficult times. When you know others out there are facing similar struggles, it's almost as if you can breathe a little easier.

Keep the lines of communication open with your healthcare providers. You want to maintain a strong relationship with the professionals helping to manage your child's condition. If you keep yourself educated about the latest treatments and protocols you will have an arsenal of information to discuss with your doctor. This





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For more information, please visit ChangingPossibilities-US.com.

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James Hamilton Memorial Scholarship Fund

In order to be considered, the applicant must provide evidence of the following by submitting pertinent copies of personal records to the scholarship committee chair or designee.

Scholarship Eligibility Criteria

- ✘ Be a person with hemophilia
- ✘ Be a New Mexico resident
- ✘ Be a U.S. citizen or an eligible non-citizen

Other Requirements

- ✘ Provide a valid social security number
- ✘ Provide proof of application for student aid (FASFA)
- ✘ Demonstrate financial need, as evidenced by the FASFA form
- ✘ Provide evidence of application to two additional sources of financial aid assistance
- ✘ Provide a copy of a high school diploma or GED
- ✘ Provide evidence of enrollment or acceptance for enrollment as a regular student working toward a degree or

certificate in an eligible program

- ✘ Submit completed scholarship application form to Sangre de Oro, Inc.
- ✘ Submit a letter of reference from someone, other than a family member, who knows you
- ✘ Have a personal interview by the scholarship committee or chairperson
- ✘ Must meet deadline for semester of request

Scholarship Renewal Requirements

- ✘ Provide evidence of satisfactory academic progress by maintaining a minimum 2.5 GPA out of a possible 4.0 to be considered for scholarship renewal. Official transcript showing final, current grades must be submitted when requesting a renewal of this scholarship. **If your GPA falls below a 2.5, you can reapply the following semester!**

Application Deadlines

Fall semester deadline: August 1st

Spring semester deadline: December 1st

Scholarship Information

By Candace Cloud

High school seniors may feel that the end of winter is early for finding college scholarships for next fall, but now is the time to apply. People who graduate from college have higher earning potential than those who have some (or no) college credits. Your potential for finding work that provides medical insurance and other benefits that are important to those of us with chronic medical issues, like a bleeding disorder, increases substantially with a college degree. Finding funds for higher education can be challenging, even for thrifty kids with education savings accounts. Some resources for scholarships specific to students who have bleeding disorders are listed below.

The NHF has posted a list of 27 scholarships sponsored by other organizations on its web site: <http://www.hemophilia.org/NHFWeb/MainPgs/MainNHF.aspx?menuid=53&contentid=36>.

For your convenience, these are also listed on pages 14 and 21.

Most of the application deadlines are between March and June, so now is the time to decide which ones to choose and fill out the applications.

The Hemophilia Federation of America offers 10 college scholarships annually to students who have a bleeding disorder, or are the parent or sibling of a person with a bleeding disorder. The application deadline is April 30, 2013. View the eligibility and application requirements: <http://www.hemophiliafed.org/programs/educational-scholarships>.

Other hemophilia support organizations have educational scholarship programs. Be sure to see the list of options on pages 14 and 21.

Family Education Weekend



2012 Patient and



Distinctly you



You share similarities, yet you're all very different from one another.

At Baxter, we're focused on responding to your individual needs and those of the hemophilia B community. We continue to invest in research and development for the promise of tomorrow's breakthroughs.

- **We're committed** to advancing education and resources available to you
- **We're dedicated** to helping provide you with a higher level of support
- **We're devoted** to helping you build a strong hemophilia B community

Recognizing the differences

Connect with a world of hemophilia B resources at DistinctlyB.com

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Essential Health Benefits (EHBs): How Do They Affect Us?

By Jose Guillen



Under the Patient Protection and Affordable Care Act (ACA), aka ObamaCare, all states must have a Health Care Exchange by 2014. An exchange is a “one-stop shop” for health insurance, helping individuals and small businesses decide what type of health insurance plan to buy. The ACA mandates that by 2014 adults must have health insurance or face a tax penalty. Also, every health insurance plan sold in the exchange must cover “essential health benefits” (EHBs).

EHBs refer to 10 general categories of coverage that serve as a baseline for services, treatments, and other benefits required by law. They include the following:

- ❧ Emergency services
- ❧ Hospitalization
- ❧ Maternity and newborn care
- ❧ Mental health and substance use disorder services
- ❧ Prescription drugs
- ❧ Rehabilitative and habilitative services and devices

- ❧ Laboratory services
- ❧ Preventive and wellness services
- ❧ Chronic disease management
- ❧ Pediatric services, including oral and vision care.

The Hemophilia Federation of America (HFA) interprets the word “essential” as any medical treatment, procedure, service, equipment and supplies indicated and approved by the United States Food and Drug Administration (FDA), for the care of patients with that specific diagnosis or that follow generally accepted medical standards. For our state community, will these benefits include the full range of factor treatments? Will we have choice of pharmacy services? Through advocacy, you (we) can make a difference in New Mexico’s EHB decisions. Your Representatives (House and Senate) in Santa Fe need to hear from you to understand your needs and situations.

As of January 4, 2013, New Mexico declared the intent for a State-based exchange for 2014. New Mexico obtained conditional approval to consider the partnership option (where both the Health and Human Services Department (HHS) of the Federal Government and the state work together to operate different functions of the exchange) if the state-based exchange is not feasible, even though the Feb 15 deadline for partnership declarations and blueprints is rapidly approaching. The HFA recommends

that each state consider the following when evaluating what will be included in the EHBs: Standards of Care; Comprehensive Care; Medical Necessity Determinations, Appeals and Grievance Processes; Limits on Benefits; State Mandates; Updating EHBs and Cost Sharing.

Since the beginning of January 2013, the New Mexico Legislature has submitted 4 House Bills (HB168, HB262, HB311, & HB366) and 6 Senate Bills (SB48, SB148, SB156, SB221, SB226, & SB403) for debate and consideration. These bills all relate to the New Mexico Health Insurance Exchange and can be downloaded from the HFA website at: <http://www.hemophiliafed.org/advocacy/state-policy/>.

Types of Health Coverage:

There are two types of health coverage: employer-based coverage and individual coverage. How do EHBs apply to these types of coverage? If you are like most Americans, you have insurance health insurance through your employer. Most employers are large firms (with more than 100 employees). In 2011, 18% of employers were small firms (with 2 to 50 employees).

1. What kind of policy does your employer offer?

- ❧ Does the insurance policy cover all claims for the workers? => **fully insured**
- ❧ Does the employer pay claims from their own pocket (insurer administers benefits and processes claims only)? => **self-insured**

Note: Large employer firms are more likely to self-insure and most small firms offering coverage are fully insured.

EHB Rule: Only the fully insured plans must comply with the EHBs.

What is the size of the firm?

- ❧ Small firms have at least 2 and up to 50 employees.
- ❧ The ACA allows states to define the self-employed and firms with up to 100 employees as a small employer firm.

EHB Rule: The EHB rule applies to small employers, not large employers.

What about grandfathered status plans?

- ❧ A grandfathered plan is a plan that was in effect when the ACA was enacted (March 23, 2010).

Continued on page 10.

Advocacy: What Does It Mean if You Live with a Bleeding Disorder?

By Chuck Boberschmidt

Advocacy can be defined as a process by which an individual or a group aims to influence public-policy and resource allocation decisions within institutions.

As an individual, everyone in the SDO community has an interest in access to care. Access to care requires us to know which resources we need to live a healthy and productive life with a bleeding disorder. Continuing to educate ourselves will allow us to be our own best advocates as a first line to dealing with barriers to care that are coming up with increasing frequency.

As an organization, SDO can help to advocate for the bleeding disorders

community by educating our lawmakers.

Here are a few of the resource issues that we are aware of and will be developing initiatives for:

- ❧ Access to a physician for diagnosis and treatment. This could be through the Ted R. Montoya HTC or elsewhere.
- ❧ Legislative awareness of the necessity of access to care
- ❧ Funding for the HTC or other physician.
- ❧ Insurance or reimbursement for bleeding disorder therapies.
- ❧ Safety-net programs for excessive co-pays or gaps in coverage.
- ❧ Physician and patient

choice of therapies for individual needs.

Recently, New Mexico announced that it will develop an insurance exchange to fulfill our states participation in the Affordable Care Act, also known as Obamacare. For those who need to purchase their own insurance, exchanges will offer individuals and their families a choice of private health plans resembling what workers at major companies already get. The government will help many middle-class households pay their premiums, while low-income people will be referred to safety-net programs they might qualify for. Assistance will be available, depending on need, to help pay for the premium rates, which could

be more than a car payment. Affordability could be an issue.

Medicaid is also slated to be expanded so more low-income adults will become eligible, but details are still being worked out.

Now is the time to increase your awareness of the issues that could affect your access to care. SDO is committed to supporting advocacy initiatives in the bleeding disorders community. We currently are in the process of organizing advocacy goals and would welcome any questions, comments, or an expression of the desire to participate in advocacy committee actions.

Essential Health Benefits (EHBs): How Do They Affect Us? (Continued)

- ❧ Plans keep their grandfathered status as long as they do not make significant changes to benefits or the amount of cost-sharing.

Grandfathered, small-employer plans do not have to comply with the EHBs.

Do you have an individual insurance plan?

- ❧ In 2011, 15 million people purchased coverage on their own rather than through an employer.

- ❧ The number of people buying individual coverage is expected to grow due to available subsidized coverage in the health insurance exchanges.


Starting in 2014, all new (non-grandfathered) individual plans must include EHBs.

Visit HFA's web page: <http://ehb.hemophiliafed.org> to learn about EHBs and evaluate plan options. There is a Personal Health Insurance Toolkit, available for download at [\[kit.pdf\]\(#\). It includes a checklist and a series of questions to help individuals evaluate which plan will best meet their healthcare needs.](http://www.hemophilia.org/NHFWeb/Resource/StaticPages/menu0/menu4/menu306/Intro-Tool-</p></div><div data-bbox=)

Both HFA and NHF web sites offer webinars under their Advocacy tabs, which you can attend live or watch later. ❧

CHECKLIST

HEALTH INSURANCE EXCHANGES & ESSENTIAL HEALTH BENEFITS



All states must have a health insurance exchange by 2014. A health insurance exchange is a competitive marketplace where consumers can easily compare and buy health insurance plans.

Every plan must cover "essential health benefits" (EHBs), but will these include the full range of factor treatments? Will we have choice of pharmacy services?

This is now up to each state to decide, and through advocacy, you can make a difference in your state's decision. Below is a checklist of nine straightforward steps you and/or your organization can take.

1. BECOME INFORMED
2. DETERMINE YOUR PRIORITY INTERESTS AND THE RESULTING PRINCIPLES WITH RESPECT TO EHBs
3. UNDERSTAND ANY COVERAGE MANDATES YOUR STATE HAS REGARDING BLEEDING DISORDERS
4. FIND OUT THE STATUS OF YOUR STATE'S EXCHANGE EFFORTS
5. ASSESS YOUR STATE'S POLITICAL LANDSCAPE WITH RESPECT TO THE EXCHANGE
6. BUILD RELATIONSHIPS CENTERED ON SHARED EHB INTERESTS, AND CONSIDER COALITIONS
7. DEVELOP A BRIEF EHB POSITION STATEMENT
8. START WITH SMALL, FOCUSED ACTION
9. CELEBRATE AND SHARE

LET US KNOW HOW WE CAN HELP:

FOR MORE INFORMATION: advocacy@hemophiliafed.org

We are here to support your Advocacy!

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210 7TH STREET SE SUITE 200B | WASHINGTON DC 20003 | 202.675.6984 www.hemophiliafed.org

9th Annual Camp Sangre Valiente

By Patrick Wagner, Camp
Director 2013

Happy March everyone! After a very cold winter, we are excited to be making plans for summer and our 9th Annual Camp Sangre Valiente. This year, we will once again be at the Fort Lone Tree camp facility in the beautiful mountains outside of Capitan, N.M. The move to this new facility last year was a huge success, and the kids had an amazing week full of activities, education, and fun.

So what is camp all about? Why is this such an important program for Sangre De Oro? Those are great questions and ones that we hear all year long from the community.

Camp is the place where kids and siblings of kids with bleeding disorders can come together for a week of fun, challenges, and education in a safe, controlled, and caring environment. Kids can “just be kids” for a week without worrying about their bleeding disorder and some of the issues that come along with it. It is the major program that SDO raises funds for each year and is something we are all very proud to be part of and support.

SDO provides camp free of charge to children and young adults with a bleeding disorder, their siblings,

and any child of a parent affected by a bleeding disorder. Camp is for kids between the ages of 7 and 12 years, and the camp Leader in Training (LIT) program is for kids 13 to 17 years of age. The LIT program includes education, experiential activities, and challenges to help them prepare to take charge of their future by becoming more involved in their own care. LIT participants are encouraged to return to camp as future camp counselors.

We are thrilled to have Pat “Big Dawg” Torrey join us once again for this year’s camp. Many of you know

him from previous camps, and we always receive requests from our campers to bring him back. Pat will be assisting with camp programs in addition to the LIT program.

You will be able to register on-line again this year at www.sangredeoro.org. Each attending child must be registered. I know some of you out there may have questions or concerns about camp, and I encourage you to reach out to Loretta at 341-9321 with any of those.

See you there!



From Our Past President

Dear Community,

In 2013, SDO will celebrate its 28th year as New Mexico's bleeding disorders chapter by continuing to educate and advocate for our community members. Here is a look at some of the upcoming activities and changes for SDO in 2013.

Each year a delegation from New Mexico attends the North American Camping Conference of Hemophilia Organizations (NACCHO). In January, Loretta and Claudia attended NACCHO 2013 and enjoyed a weekend filled with activities and events designed to help us run our annual youth camp.

NHF's Washington Days is held at the end of February and is an opportunity to meet with senators and representatives to encourage them to fight for health insurance and access to affordable care.

On April 20th we will be hosting our first ever Hemophilia Walk in conjunction with NHF. Please visit www.hemophilia.org/walk to register your team and come out to support SDO. We plan to show the country that New Mexico can pull together as a community to have some fun, raise awareness, and bring in funds to support our community.

The first week of June, we will hold the 9th annual Sangre Valiente youth camp where children and teens with bleeding disorders and their siblings will enjoy a

week of fun, education, and activities. Keep an eye on the SDO web site for more details and on-line registration.

In August, the 10th Annual Caliente Classic Golf Tournament will be held to raise funds that allow us to send youth to bleeding disorders camp at no cost to their families. SDO can use everyone possible to help with this event. If you or someone you know (especially local business owners who play golf) want to have some real fun, please have them contact Loretta. Watch for more information on the golf tournament as well.

Next, we will have our annual Patient and Family Education Weekend. There will be lots of sessions for adults and some fun activities for kids and teens. Most importantly, there will be plenty of time to mingle with others in the community – people with bleeding disorders, their families, and industry partners. Please let Loretta know if you know of someone who might be willing to volunteer for this event.

Our annual board meeting was held in January, and we are pleased to announce some changes in elected board officers and members, each of whom will serve a year term. After serving as President of SDO for 20 years, I decided it was time to step down. The board elected Lori Long to serve as SDO's President. Joe MacDonald was elected Vice President, Eric Marquez as Treasurer, and Jose

Guillen will continue as Secretary. I send best wishes and blessings to you all as you devote your time and energy to our wonderful community. I will continue to serve as a board member and the Past President to assist in any way I can. We have several committees that can use help, so please let Loretta Cordova, our Executive Director, know if you might be interested in volunteering.

We will continue to develop creative ways to raise funds to support the community. As the economy slowly recovers, we still are in need of fundraising for the programs we serve. The cost of camp went up drastically last year, and we expect it will continue to rise with time. The average cost per camper is approximately \$800. SDO provides this camp and our annual Patient and Family Education Weekend at no cost to families. We need everyone's help to continue to provide these valuable programs to the community.

I send best of luck to our 2013 board officers and wish them lots of success for another year of fun, education, and fundraising in New Mexico. Come join us on April 20th for the first ever Hemophilia Walk of New Mexico. We have huge goals for the success of this program. Don't forget to go to the web site to sign up or donate for this great cause.

Warmest Regards,

Johanna Chappelle, Past President

Executive Board Members

Lori Long,
President

Joe MacDonald,
Vice President

Jose Guillen,
Secretary

Eric Marquez,
Treasurer

Loretta Cordova,
Executive Director

Board Members

Chuck Boberschmidt

Johanna Chappelle

Robert Farias

If you are interested in participating on the board, please contact Loretta Cordova at 341-9321.

From Our New President

Dear Community,

After 20 years of serving our wonderful community with so much love and dedication, Johanna Chappell has turned over the President's mantle to me. There is no way to thank her properly for the enormous contribution she has made to us! Without her, we truly wouldn't be here. But don't worry! Johanna will stay with us in an advisory capacity as Past President on the executive board and as a board member and volunteer.

I hope to carry the mantle with just as much dedication and commitment. I really care about this community, and I hope I can do you all proud.

I want to say a very special thank you to our Executive Director, Loretta Cordova. She has been our Executive Director for 8 years! She does a fantastic job of keeping all of our events and efforts on track. We would be lost without her!

We also have new officers on our executive board. I would like to thank Jose Guillen for continuing as our awesome secretary and welcome Joe MacDonald as our new Vice President and Eric Marquez as our new Treasurer. I have already called on each of them to go above and beyond, and they have each come through for us! We are going to continue to accomplish great things together!

I would like to thank Chuck Boberschmidt for his many years serving as our Treasurer. He will con-

tinue as a board member and as a volunteer for camp and other efforts. Thanks, Chuck!

We have several new members on our advisory board. I would like to thank Patrick Wagner (our advisory board chair), Phil Cordova, Melissa Farias, Chris Fenicks, Elvira Guillén, Alfonso Jaramillo, Alison Trawinski, and Ken Waggoner for their continued support on the advisory board. I would like to welcome Carrie Abajian, Jean Cole, Cassandra MacDonald, Sarah Trawinski, and Rea Watson. Thank you all for serving with us. I look forward to relying on your expertise and assistance regularly!

Our Walk Manager resigned in the middle of February. Candace Cloud has stepped in to help us make the Walk happen. We appreciate her assistance in getting ready for this very special event.

We had a great contingent of New Mexico folks headed to Washington Days, including Patrick Cordova, Loretta Cordova, and Johanna Chappell. Thanks to all of you for heading to the Hill to fight for our community's needs!



We also have quite a crowd attending HFA April 25-27. Everyone attending will bring back what they learn and share it while we're all chatting at the Patient and Family Education Weekend in October!

I look forward to seeing many of you at the Walk on April 20th and at the Patient and Family Education Weekend in October.

Land Softly,

*Lori Long
President*

President's Corner

Go to www.hemophilia.org to apply for a scholarship to attend the 65th NHF Annual Meeting in Anaheim, CA, October 3-5. Scholarships are offered to first-time attendees, and this is a great conference. If you haven't attended, please apply!

Academic Scholarships for Students with Bleeding Disorders

Scholarship	Amount	Candidate	Web Site/Phone
Kevin Child Scholarship	One, \$1,000 award	Individual with hemophilia attending U.S. college/university or vocational school.	www.hemophilia.org 800.424.2634
Alex Lieber Memorial Scholarship	Four, \$500 scholarships	U.S. students with hemophilia or von Willebrand disease accepted by an accredited college, university or vocational/technical school.	https://www.kelleycom.com/AlexLieber/application.html 800.249.7977
Beth Carew Memorial Scholarship	Ten, \$4,000 college awards	Person with hemophilia, von Willebrand disease or other inherited bleeding disorder enrolled in an accredited college.	http://www.colkeen.org/?page_id=123 800.966.2431
Bill McAdam Scholarship Fund	One, \$2,000 award	For persons with hemophilia, von Willebrands, their partners, spouses, parents, children, siblings, or other significant family members, for post-secondary education, including college, trade or technical school, or other certification programs.	313.563.1412
BioRx/Hemophilia of North Carolina Educational Scholarships	Four, \$2,000 scholarships	For caregivers of children affected with bleeding disorders, a person who has been diagnosed with hemophilia, or their sibling. Preference will be given to a hemophilia community member, parent and family members seeking healthcare related education from an accredited college or university or certified training program.	http://www.biorx.net/wp/category/hemophilia (go to "2012 BioRx Scholarship Application") 866.442.4679
Biogen Idec Hemophilia Scholarship Program	\$50,000, ranging from \$2,500–\$7,000 each	Individuals with hemophilia A or B pursuing a vocational or technical certificate, a 2- or 4-year degree program or graduate degree are encouraged to apply.	www.biogenidechemophilia.com/scholarships 855-670-ISTS (4787)
Bob Hersh Memorial Scholarship	\$1,000	Eligible candidates must be high school upperclassmen or graduates or students in good standing who are already enrolled in a post-secondary program, and planning to enroll in a course of study at an accredited 2- or 4-year college, university, or vocational technical school program or certified training program, with priority given to undergraduate study, and a person affected directly or indirectly by hemophilia, von Willebrand disease, hereditary bleeding disorder, or hemochromatosis.	http://www.hemocenter.org/site/PageServer?pagename=programs_scholarships 585.922.5700
Christopher Pitkin Memorial Scholarship	\$500 – \$1,000	All members of the hemophilia and bleeding disorders community, including spouses, siblings and children.	www.hemosocal.org (download link from HFSC home page) 323.525.0440
Comprehensive Bleeding Disorders Scholarship Fund	Two, scholarships at \$2,000 apiece	For anyone with a chronic bleeding disorder and who has attended an HTC's comprehensive clinic annually. Must have maintained a GPA of 2.5 or above and be enrolled or plan to enroll, as a full- or part-time student at an accredited vocational/ trade school, technical school, junior college, or a 4-year college/university.	http://www.communityfoundationci.org/central-illinois-foundation-scholarship-opportunities#cbcdcsa 309.688.1345
Education Advantage	Various awards ranging from \$150 to \$15,000	Individuals with hemophilia A attending university, technical school or passing GED test.	www.myeducationadvantage.com 877.544.3018
"Education is Power" Scholarship	\$500-\$2,500	Individuals living with hemophilia or von Willebrand disease attending college or vocational school.	http://www.medprorx.com/scholarship.html 866.528.4963
SevenSECURE®	\$500 to \$7,000	For people of all ages with inhibitors, acquired hemophilia, congenital factor VII deficiency or primary caregivers.	http://www.changingpossibilities.us.com/SupportPrograms/Education.aspx 856.573.9400
Eric Delson Memorial Scholarship	Three, \$2,500 awards	Students clinically diagnosed with hemophilia or von Willebrand disease.	www.cvscaremarksspecialtyrx.com 866.792.2731
Eric Dostie Memorial College Scholarship	Ten, \$1,000 awards	Student with hemophilia or other related bleeding disorder or a family member. Must be a U.S. citizen and enrolled full-time in an accredited 2- or 4-year college.	www.nufactor.com 800.323.6832
Hemophilia Federation of America	Ten, \$1,500 awards	Person with hemophilia or VWD, including parents and siblings attending any accredited 2- or 4-year college, university or vocational/technical school in the U.S.	http://hemophiliafed.org/what-we-do/programs-and-services/educational-scholarships/ 800.230.9797
Accredo's Hemophilia Health Services Memorial Scholarship Program	Multiple awards of at least \$1,500	A U.S. citizen with hemophilia, von Willebrand disease or other bleeding disorder. Must be a high school student about to attend college, a college student, a college senior planning to attend graduate school or graduate school student.	http://www.hemophiliahealth.com/Scholarships.html 615.850.5210
Joshua Gomes Memorial Scholarship Fund	Multiple \$1,000 awards	Individuals living with HIV/AIDS accepted or enrolled in college in the U.S.	www.joshuagomes.org 303.761.3055
Lawrence Madeiros Scholarship	Multiple awards of \$1,000 or more	Student with an inherited bleeding disorder or other chronic disorder attending an accredited college or university.	http://www.adirondackspintacular.com/pages2/scholarship.html 518.863.8998
Mary M. Gooley Hemophilia Center, Inc. Scholarship Fund	Maximum award of \$2,000	High School seniors, graduates, or students in good standing already enrolled in a post-secondary program, and planning to enroll in a course of study at an accredited 2- or 4-year college, university, or vocational technical school program or certified training program, with priority given to undergraduate study. A person affected directly or indirectly by Hemophilia, von Willebrand disease, hereditary bleeding disorder or Hemochromatosis.	http://www.hemocenter.org/site/PageServer?pagename=programs_scholarships 585.922.5700
Michael Bendix Sutton Foundation	Two, \$2,000 scholarships	Student with hemophilia pursuing pre-law study.	Michael Bendix Sutton Foundation c/o Marion B Sutton 300 Maritime Avenue White Plains, NY 10601
Mike Hylton and Ron Niederman Memorial Scholarships	Ten, \$1,000 awards	Men with hemophilia or von Willebrand disease and their immediate family members.	http://www.factorsupport.com/scholarships.htm 805.388.9336 or 877.376.4968



Excerpted from www.hemophilia.org

Our own Patrick Cordova has applied to NYLI and been accepted. Great job, Patrick!

Program Goal

The goal of the NHF's National Youth Leadership Institute (NYLI) is to provide youth in bleeding disorders community with leadership opportunities to effect change and positively influence others.

Program Overview

The National Hemophilia Foundation has designed NYLI to assist young people from the bleeding disorders community to become well-trained, recognized leaders. NHF works closely with young adults through training and support; NYLI members provide educational presentations and programs to the bleeding disorders community. NYLI provides an amazing opportunity for youth to learn and share experiences of living with a bleeding disorder.

You can apply in May and remain in the program for 3 years.

Program Objectives

- ☒ Increase leadership opportunities for NYLI members
- ☒ Increase education for bleeding disorders community
- ☒ Increase visibility and reach of NHF messaging.

NYLI members will meet these objectives through trainings, educational programming and internships. Below is a list of the activities members will be expect to take part in. Each year will include Annual Meeting and Spring Leadership trainings, but responsibilities within each year will differ slightly allowing for growth and unique opportunities.

Applicants should:

- ☒ Be between the ages of 18 and 22
- ☒ Be living with a bleeding disorder, or have a sibling with a bleeding disorder
- ☒ Be willing and able to travel to each of the trainings and

program destinations

- ☒ Be available for monthly communication

What NHF looks for in an applicant:

- ☒ Leadership skills (previous experience with school organizations, sports, etc.)
- ☒ Volunteer experience
- ☒ Academic achievements
- ☒ Strong communication skills
- ☒ A willingness to stay involved and learn
- ☒ Self-starter, reaching out to us with ideas and communicating promptly
- ☒ Ability to work with a team and independently
- ☒ Ability to foster and maintain relationships
- ☒ An eagerness to work with the bleeding disorders community.

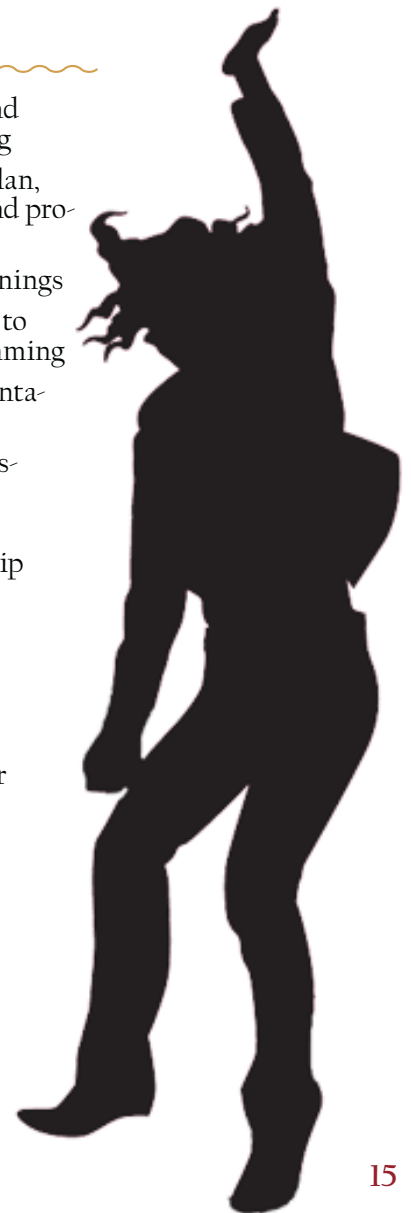
Member Expectations

If selected, you will be part of the face of NHF, and, therefore, there are high expectations of NYLI members.

Responsibilities

- ☒ Attend Annual Meeting and Spring Leadership Training
- ☒ Work with NHF staff to plan, lead and evaluate events and programs
- ☒ Actively participate in trainings
- ☒ Participate and contribute to NYLI educational programming
- ☒ Coordinate and plan presentations for conferences
- ☒ Help NHF to understand issues particular to young adults
- ☒ Complete 3rd-year internship
- ☒ Maintain communication with NHF and mentor
- ☒ 2 e-mails and 1 phone call per month (on average)
- ☒ 4 yearly webinars and/or conference calls with other members
- ☒ Respond to communications from NHF and mentor within 3 days.

For more information or questions, please contact Christie VanHorne at 212.328.3738 or cvanhorne@hemophilia.org



We Will Walk the Extra Mile!

By Joe MacDonald

I thought that I had done my part. I organized a Walk team and have been going about the business of reaching my goal. I struggled to shrug off the idea that there was something I was not doing to ensure the success of our Walk a Thon. As I continued the business of an average day, I finished all of my commitments in time to pick up my youngest son from school.

As I was walking into the school, the idea hit me. I said to myself, "Self, have you asked your son's school to form a team on his behalf?" I grew a little more excited and began to ponder the possibilities of asking my youngest son's school, but what about my oldest son? Voila!

There are two more teams. I didn't even have

to try really hard to increase the success of the Walk. Two new teams. Two new fundraising goals. Wow. It really isn't that difficult!

What are you doing to make your goal a reality? How are you looking beyond your goal to something bigger?

I would love to hear from those leaders who are going the extra mile to ensure the success of our fundraising efforts. Remember, every dollar raised is used to empower a family. Together, we can make a difference in our world.

Peace,

Joe

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NHF's 66th Annual Meeting
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We know that people with bleeding disorders face unique challenges in getting diagnoses, raising awareness, securing access to care, and finding the information and support they need. That's why CSL Behring is proud to support Sangre de Oro Hemophilia Foundation of New Mexico and the *Hemophilia Walk of New Mexico*.

Biotherapies for Life™



Financial Assistance for Factor

By Lori Long and Carnie Abajian

Most or all of us have ended up in a situation where we're having to get creative to fund our medication. After having my own "situation" this year, I started looking into ways to get help paying for my share of our factor. I looked into various options and realized that there is a lot of ground to cover when researching this stuff!

That gave me the idea that there might be others in our community facing a similar situation. I will say that when you participate in any of these programs, you need to read all of the information. Make sure you know the order of the steps they want you to go through to get financial help. (In other words, get a "check in every box" by calling or ensuring that you have activated your registration for assistance. Follow up!) In my case, I did the steps out of order, and I had to backtrack and do a lot of extra paperwork (though I did still get help). It is our responsibility as patients to get ourselves help, and while that's a pain sometimes, it's less of a pain if you follow the directions carefully without having to backtrack!

The reason for telling you all this is that I think we have a lot of resources out there that we might not be leveraging for help. Some manufacturers offer discounts. Others offer programs for those of us who are temporarily without insurance. Many offer samples if you are willing and able to try a

new product (discuss this with your doctor if you want to consider it).

In some cases, we might choose not to use a resource. (I have opted out of one potential resource for now because the paperwork to apply and be eligible was really too much. However, if my situation changes, I will be rethinking that!)

I enlisted our newest advisory board member, Carnie Abajian, to help to "data mine" for information on this subject, and she created us this informative table. It contains some of the help that we can get directly from manufacturers. Patient Services Incorporated (PSI), a 501(c)(3) non-profit, charitable organization, is the ground-breaking premium and co-payment assistance foundation for the chronically ill. Some manufacturers and other organizations offer financial assistance through PSI. If you would like more information about the financial help available from PSI, please call 1-800-366-7741.

In the next newsletter, we hope to cover the help that we can get from homecare and some other sources. If you have ideas on ways community members can get help paying for factor, please send them to Loretta Cordova at loretta.cordova@sdoinc.org. She will forward them to me, and we will publish your ideas in the next newsletter!

Enjoy and good luck!

Pharmaceutical Company	Patient Assistance Program	Phone	Web Site
CSL BEHRING	CSL Behring Patient Assistance Program	1-888-415-2167	http://www.cslbehring-us.com/patients-and-families/reimbursement-resource-center/patient-assistance.htm
BAYER	Kogenate Factor Solutions	1-800-288-8374	https://www.kogenatefs.com/webapp/patients/commercial-copay-assistance-program.jsp
BAXTER	The CARE Program	1-888-229-8379	http://www.thereforyou.com/hemophilia-and-health-insurance/
PFIZER	Pfizer RSVP Program	1-888-327-7787	http://www.pfizerhelpfulanswers.com/pages/programs/programdetails.aspx?p=12
NOVO NORDISK	SevenASSIST SM SevenSECURE [®]		http://www.novonordisk-us.com/documents/article_page/document/patient_assistance_hemo.asp
GRIFOLS	Grifols Assurance for Patients/Grifols Patient Assistance Program	1-888-325-8579, option 3	http://www.grifolspatientcare.com/
OCTAPHARMA	Outpatient Reimbursement Help	1-800-554-4440	www.wilateusa.com (click on "Reimbursement" link on left)

A handy web site for getting discounts or financial help with many medications is www.rxassist.org. The site is not always completely up to date, but it is a good place to start.

Academic Scholarships (Concluded)

Scholarship	Amount	Candidate	Web Site/Phone
Millie Gonzalez Memorial Scholarship	Five, \$1000 awards	Women with hemophilia or von Willebrand disease entering or attending college or vocational school.	http://www.factorsupport.com/scholarships.htm 805.388.9336 or 877.376.4968
National Cornerstone Healthcare Services	Multiple \$500 to \$1,000 awards	Scholarship program from \$500 to \$1000.00 per year awarded to a person or person(s) associated with the bleeding disorders community.	http://www.nc-hs.com/services.html (scholarship tab on bottom left of page) 877.616.6247
Rachel Warner Memorial Scholarship Program	Funds are varied and limited.	Person with a bleeding disorder.	www.cott1.org 800.488.2688 or 202.543.0988
Salvatore E Quinci Foundation Scholarship	Two, \$2,000 scholarships	Person diagnosed with hemophilia or other bleeding disorder accepted into an accredited university, college or vocational/technical school	www.seqfoundation.org 781.760.7138
Soozie Courter Sharing a Brighter Tomorrow Hemophilia Scholarship Program	Five, \$4,000 graduate study awards and twelve, \$2,500 undergraduate college scholarships	A student with hemophilia A or B who is a high school senior (or has graduate equivalency diploma), college student (undergraduate or graduate) or vocational school student.	www.hemophilavillage.com 888.999.2349
Statton Family Scholarship	Scholarship to Juniata College in Huntingdon, PA up to 100% of need	Candidate: Students must be accepted and intending to study at Juniata College. Applicants must have been diagnosed with a bleeding/blood disorder and/or HIV/AIDS or have an immediate family member with one of the diagnosis. They must apply to the college and state in the application that they wish to be considered for the Statton Family Scholarship.	www.juniata.edu ennelvj@juniata.edu
Through the Looking Glass Scholarships	ifteen, \$1000 scholarships	Open to all students whose parent has any significant disability or health condition. Although no specific parental disabilities are prioritized for these scholarships, we especially encourage those students who have a parent with an intellectual disability to apply for these scholarships.	http://lookingglass.org/announcements/scholarships 800.644.2666
Together Forward Scholarship Program	Four, \$2,500 awards	Individuals living with hemophilia or von Willebrand disease enrolled in fulltime undergraduate studies at a four-year college or university.	www.coramhemophilia.com/scholarship 800.310.4053

The data in this table is from 2012. For more information, use the web sites and phone numbers listed in the table. Good luck!

Hemophilia Awareness Month 2013



In 1986, President Ronald Reagan signed Proclamation 5442, declaring the month of March “National Hemophilia Month.” We now celebrate it as Hemophilia Awareness Month. Tell someone your story!

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