



Arizona Hemophilia News

2009 YEAR

Year End Report

INSIDE THIS ISSUE:

My Nana's Best Tasting Salsa Challenge and Desert Classic 2009	2
Arizona Hemophilia Statistics	3
Our Programs and Services	4-5
Spotlight: Volunteer Speakers Bureau and Mentor/Advocate Program	5
Lunch on the Lawn	6
Fundraising Sources and Expenses	6
Annual Giving	7

A Message from our Executive Director and the President of the Board of Directors

Dear Friends:

Our mission to enhance the quality of life for those affected by an inherited bleeding disorder continues to drive the efforts of the Arizona Hemophilia Association. This is possible thanks to our volunteers, donors, partners, and staff who work tirelessly each and every day to build a foundation of hope for all those that are affected in our community. Despite this challenging economic year, we have not allowed ourselves to lose sight of our mission and goals. We continue to provide quality programs, to raise awareness about Hemophilia, and to support the unique needs of the inherited bleeding disorder community.

March is Hemophilia Awareness month and culminated in our Lunch at the Capital. This year has been the most successful yet. We had over 40 Legislators join us for lunch and hear the stories of our community and the struggles they face with their bleeding disorder. Continuing to increase awareness about the Arizona Hemophilia Association's programs and services is critical to inspiring actions that will make a difference in the lives of those that are affected by an inherited bleeding disorder.

Since our inception in 1967, we have helped the community survive the complicated world of living with a bleeding disorder. We bring together individuals and families to promote the sharing of experiences and information. We continue to be filled with hope that we are furthering the mission of the Arizona Hemophilia Association, as Emily Dickenson so eloquently wrote:

“Hope” is the thing with feathers –
That perches in the soul,
And sings the tune without the words,
And never stops – at all –

Thank you for your support and dedication.

Alexis Christensen, Executive Director

Steve Helm, Board President



WE ARE HERE FOR YOU!

These programs are currently available to members and families of the Arizona Hemophilia Community:

- Advocacy
- Bereavement Support
- Children's Summer Camp
- Community Education
- DNA Carrier Testing
- Emergency Assistance To Families
- HAPY- Youth Group
- Hospital Visitation
- Hemophilia Based HIV Service
- Medical Mailings and Updates
- New Parent Education
- Mentor/Advocacy

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 Joseph McKenzie, Treasurer
 Sarah Fey, Secretary
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 Melinda Cadena
 Becki Brueggeman
 Ashley Gilliam
 Pronto Parenteau

Consultants

Mary Masters
 Katie Stringham
 Nancy Grace

My Nana's Best Tasting Salsa Challenge and Desert Classic 2009

The 2009 My Nana's Salsa Challenge celebrated its 25th anniversary. The event took place on Saturday, April 25th at Tempe Beach Park from 11 a.m. – 6 p.m. The day featured 75 local individuals, businesses and restaurants competing for best salsa in their categories. The Drunken Jalepenos were crowned grand champion for the first time in their 5 years of competing. The Cazadores Margarita Mix-Off featured 14 bartenders showing off their skills and auctioning the margaritas for the Arizona Hemophilia Association. Over 20,000 guests attended the event which featured live music, great food, a kids zone and over 3,000 pounds of tortilla chips paired with all of that salsa! Salsa Challenge garnered over \$150,000 in marketing value through the event's media partners and over \$60,000 in media coverage of the event. The Arizona Hemophilia Association continues long-standing relationships with My Nana's Best Tasting Tortilla Chips, Casino Arizona, Cricket Wireless, Macayo's, PCH Hope, US Airways, Volvo, the City of Tempe, Pepsi, Cazadores, Coors Light, Corona, azcentral.com, 3TV, KEZ 99.9 and Mix 96.9, plus new partnerships with SCF Arizona and Shamrock Farms. The Arizona Hemophilia Association owns, operates and produces every aspect of the event and receives revenue from sponsorships, ticket sales, contestant registration, margarita auction, food & drink sales and from the People's Choice Award where attendees vote for their favorite salsa with dollars. The My Nana's Salsa Challenge is the largest fundraiser for AHA on an annual basis and the 2009 event saw a net revenue of over \$100,000.

The 2009 Arizona Desert Classic took place on Friday, October 3rd at Legend Trail Golf Club in north Scottsdale. It was a beautiful day of Arizona golf at one of the top courses in the area. The Arizona Hemophilia Association welcomed over 100 golfers for the event who enjoyed a fun day on the greens with the Cazadores margarita hole, the Volvo hole in one, the "use the pro's tee shot" hole, and the "ladies" hole – where participants paid \$10 for their teammate to dress in ladies clothes for the opportunity to hit from the ladies tee. The day ended with a buffet dinner, prize ceremony and conclusion of the silent auction which featured over 60 items. Partners for the event were PCH Hope, Wyeth, Novo Nordisk, Macayo's, Volvo, Cazadores, Corona and Coors Light. The Arizona Desert Classic continues to support AHA as a steady revenue generating event. The 2009 event had a net revenue of just under \$30,000.

Hemophilia Walk 2009



We had a successful second annual Hemophilia Walk last fall on a beautiful day in mid-October. This event is one of our most meaningful ones of the year because it involves not only the community at large but many of our "community" we work with year-round whose families live with a bleeding disorder and turn to the Association for assistance.

Other than having a wonderful time together, we actually met and exceeded our fundraising goal of \$50,000. As a result we qualified for a \$10,000 match grant from the National Hemophilia Foundation.

Another great benefit of putting on a walk is that we not only raise dollars (with very reasonable costs), but we raise awareness in the general popula-

tion. Hemophilia and its challenges were highlighted on the local news as well as in the local paper immediately preceding the event.

If you are reading this and reflecting on the personal experience you had with this event we enthusiastically invite you back for Hemophilia Walk '10 on October 17th. If you haven't experienced our Walk in the past we hope you will consider participating this year. More information will be sent out soon and will reside on our website:

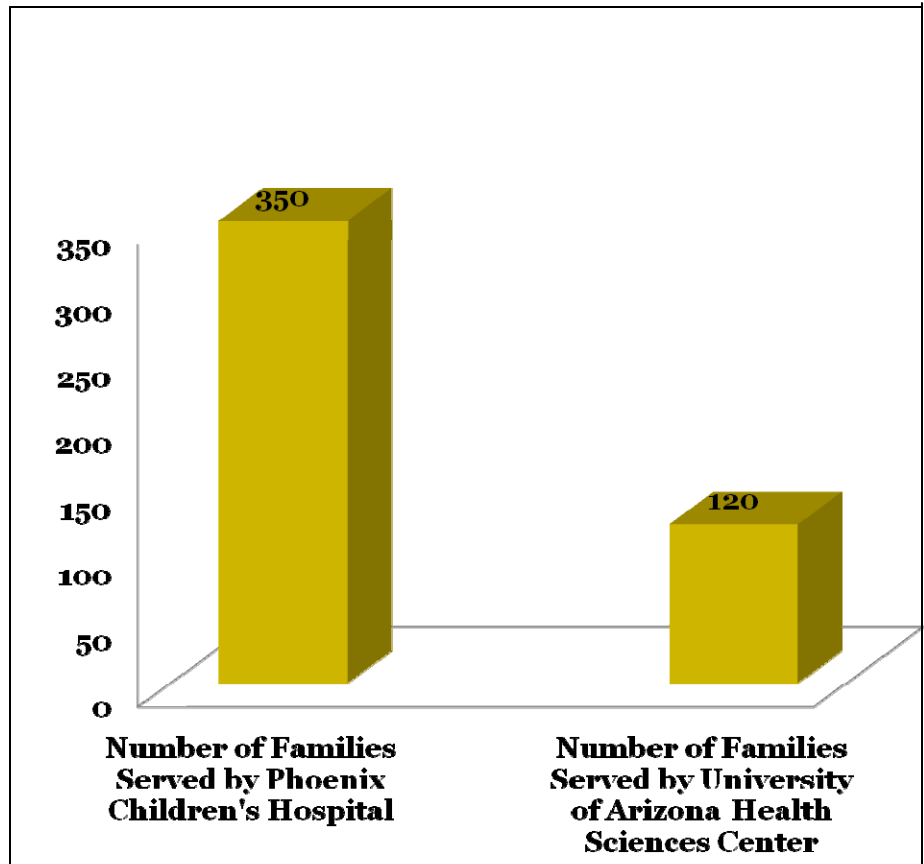
www.hemophiliaz.org.

The team highlighted above exemplifies the spirit and commitment for helping our Association improve the lives of families affected by hemophilia: M.C.B. stands for Manuelito, Carrasco, Brabon, the last names of all of the boys in this family who have Severe Hemophilia B. Thank you, M.C.B. Love & the other 30 teams!

Arizona's Hemophilia Statistics

Phoenix Children's Hospital's estimates as of Oct. 2009

University of Arizona Health Sciences Center estimates are as of 2008.



What We DO

- Educate the community and the general public
- Ensure Quality Treatment of the total person/family
- Advocate for the Inherited Bleeding Disorder Community
- Ensure Medical Treatment/Therapy Access

Check Out Our Billboard...



Photo courtesy of CBS Outdoor

This year's Hemophilia Awareness Month Billboard was featured in two locations—Camelback and 3rd Avenue, and 75th Avenue and Camelback. We received several telephone calls from citizens who saw the billboard, who wanted information about hemophilia, as well as information regarding volunteer opportunities.

Thanks to CBS Outdoor for donating the spaces. And a very special thank you to Joe Bridges and the production department for their support.

Our Programs and Services by Melinda Cadena

We offer a variety of programs for families to get together and share ideas and life experiences. Parents or caregivers who share experiences with each other often discover valuable information they can use in their daily lives. Our group activities vary from educational workshops to recreational outings. We offer peer support groups for individuals to get together to share emotions and ideas.

The Hemophilia Association Program for Youth (HAPY) is an educational and recreational component for youth from 8 to 17 years of age. HAPY builds a caring community, along with self-esteem, while increasing our youth's knowledge of bleeding disorders. Attending HAPY is a great way to continue the growth of the relationships established while at Camp HONOR.

Camp HONOR (Hemophiliacs Overcoming New Obstacles Resourcefully) is a week-long summer camp children in the inherited bleeding disorder community, ages 8 – 17 years. This program integrates patients and their siblings in a program of fun, caring, education, guidance, and self-empowerment. Camp HONOR also opens its camp to the Bill Holt Clinic for children with HIV. Children create friendships that will hopefully last a lifetime.

CIT Program (Counselor in Training) is our leadership program focusing on Camp HONOR campers ages 16 and 17. The CIT program's concentration is on preparing our campers to become leaders in camp in the inherited bleeding community and in their immediate community.

Camp HUG (Hemophilia Uniting Generations) is a family camp offered by the staff of the Arizona Hemophilia and Thrombosis Center in Tucson, AZ. Camp HUG was created as a pilot project to develop and implement programming and education for the only family camp in Arizona for people with inherited bleeding disorders. Camp HUG was launched in 2009 and included 16 families statewide. The Arizona Hemophilia Association helps fund this program.

Toddler Group is for community members up to the age of seven. This program is designed for not only the children to socialize and learn from one another but also for the parents. The parents report back that they gain so much by socializing with other parents who have children with an inherited bleeding disorder.

The Women's Retreat is an educational and social program focusing on von Willebrand Disease and addressing issues faced by mothers, wives, daughters and sisters of inherited bleeding disorder patients. The Women's Retreat provides support and education to women while providing a relaxing environment.

The Blood Brotherhood Program is in conjunction with the Hemophilia Federation of America. This program is designed for adult men with hemophilia and von Willebrand Disease. It is a multi-venue outreach program that provides education, social support and a sense of community through online forums, face-to-face local meetings and National Blood Brotherhood Webinars.

Our Annual Meeting and the Annual Holiday Party are family oriented programs which allow our families to get together and have fun, while receiving education, resources for our families, as well as medical updates on the treatment of bleeding disorders.

The AZ Lifeline Pilot Program is a fund that provided individuals with an inherited bleeding disorder modest financial support to help with high insurance premiums, COBRA payments, out of pocket medical expenses associated with the diagnosis and treatment of bleeding disorders. The 2009 program assisted seven families.

Our **Emergency Assistance Program** provides our community members a limited emergency stipend per year to assist our families with housing, clothing, food and utilities. We assist families in increasing their financial independence by offering education on budgeting.

"I self infused my left arm and my right arm this year, I want to be able to do it on my own. I want to be a camp counselor one day. CAMP HONOR is the best!"

*Connor Verdugo
11 years old
Camp HONOR 2009*

Continued on page 5

Our Programs and services continued...

The Resource Center is available to all in the inherited bleeding disorder community. It was designed to be a place where community members can come and utilize the center to look for a job, research their disorder, and apply for school and scholarships. We have a variety of resource books and medical data available.

Our new community member **Family Packet** is sent out to new community members. It contains information about the programs and services offered by the Arizona Hemophilia Association, and (in some instances) a Hemophilia Handbook, which is provided by a grant from Novo Nordisk, as well as a Family Member Update form that can be filled out and mailed back to the association. This Family Member Update is also posted on our website so that it can also be printed, filled out and mailed to the Arizona Hemophilia Association.

We work with pharmaceutical companies and outside agencies to provide educational presentations on topics ranging from health insurance, transition, relationship issues, leadership development, advocacy, joint health, pain management, nutrition and many more.

For more information on all of our programs and services, you may call Melinda Cadena at 602-955-3947, or you may log onto our website at www.hemophiliaz.org.

Spotlight: Community Education Volunteer Speakers Bureau by Ashley Gilliam

This year we have launched an exciting new program that will ignite awareness in the public about inherited bleeding disorders. It is our Community Education Speakers Bureau and it is fueled by our passionate and talented volunteers who have stepped forward to be a part of this movement.

These wonderful members of our community are trained and ready to present on hemophilia and von Willebrand Disease, ensuring that more people know about these disorders and what they can do to help. In March, Hemophilia Awareness Month, our speakers led discussions with legislators at our annual Lunch on the Lawn at the state capitol and they have continued our campaign throughout the community. They speak at service organizations, churches, schools and anywhere else that is interested in learning more about bleeding disorders. We are thrilled to have this group of motivated individuals increasing awareness in Arizona and are excited for the great things this will bring to everyone affected by bleeding disorders.

Here are the names of those who are now a part of our Speakers Bureau: Guy Boss, Michelle Brabon, Christian Escalante, Victoria Hartman, Melinda McGuire, Sandra Medina, and Linda Pope.

Spotlight: Mentor/Advocacy Program

Beginning February 2010, the Arizona Hemophilia Association launched a new program designed to meet the ever-changing needs of our young adults with bleeding disorders ages 15-25. Pronto Parenteau is the newest member of our team and is proud to serve as the Arizona Hemophilia Association's Mentor and Advocate. The vision of the Mentorship program is to captivate, motivate and inspire our young adult community members to identify their long term goals and then what steps they need to take to achieve their success. Our goal is to help each community member take action and develop a plan as they become more self-sufficient and function as positive, contributing members of our society. The Mentor program is a team-based approach that involves the young adult community members, their parents, schools, and the Hemophilia Treatment Center social workers, nurses and doctors. Mentor focus areas will include: 10 key areas of personal growth and development, commitment to personal health needs, community services and daily living skills, as well as employment and education opportunities. **Every community member ages 15-25 now has access to Pronto and the mentorship he provides.** For questions please contact Pronto today at pronto@hemophiliaz.org or call 602-955-3947.

Lunch on the Lawn at the State Capitol—2010

This year's Lunch on the Lawn was an overwhelming success. Approximately fifty-one family members, as well as industry representatives and state legislators attended this event. Some of our family members came from as far away as Tucson and Nogales to participate in this event. Our families met with our local legislators to talk about issues and challenges that the inherited bleeding disorders community must face everyday. They discussed such issues as the cost of healthcare, insurance caps, the difficulty to access medical care, as well as the high cost of medication. Each representative received a certificate of appreciation for their participation in this event.



Connie Dow, Admin Assist. from Sen. Braswell's office and Julie Heinrich

We must pay special recognition to one of our community members, Mrs. Julie Heinrich. Not only did Julie attend our Lunch on the Lawn but she also called the representatives from her district and extended them a personal invitation to join our families at this event. Julie also had a copy of "Her Story" which she presented to her representatives, as well as information on a bill that is currently in the House of Representatives in Washington, DC. Julie referenced HR 4846 Bleeding Disorder Screening, Awareness, and Further Education (SAFE) Act of 2010. For more information about this piece of legislation, as well as other issues that impact the bleeding disorder community, log onto the Hemophilia Federation of America's website at <http://capwiz.com/hemophilia/home>, and click on Issues and Legislation.



Angel Ibarra and Rep. Nancy Young Wright

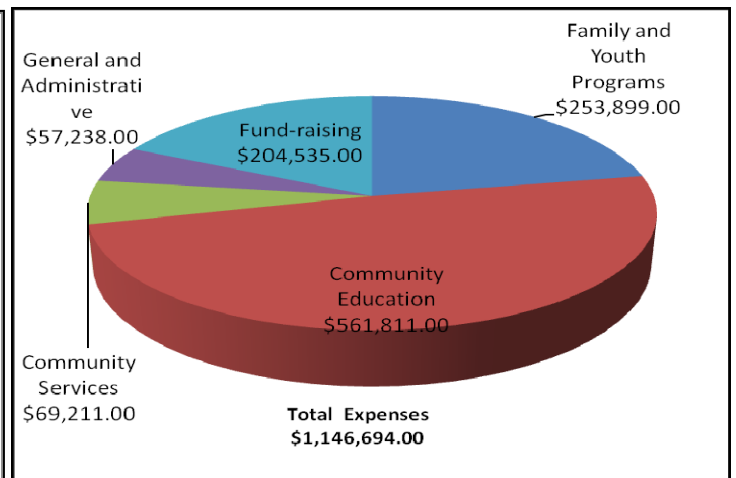
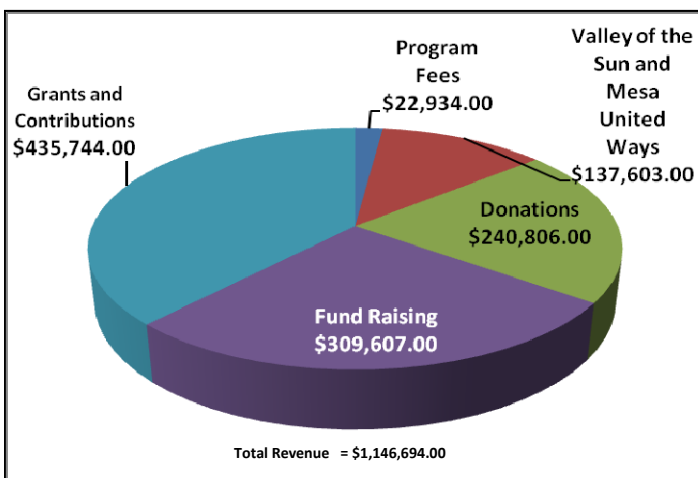


Melinda Cadena, Guy Boss and the Medina Family



The Thompson Family

Arizona Hemophilia Association 2008/09 Significant Funding Sources and Expenses



Information taken from June 30, 2009 IRS 990 Form

Annual Giving—Industry and Private Donations January—December 2009

INDUSTRY, CORPORATIONS AND FOUNDATIONS

Baxter (Fundfusion Grant)	241,250.00
Bayer	8,000.00
Bio RX	1,500.00
Caremark	2,285.00
Coram Hemophilia Svs.	1,000.00
CSL Behring	13,800.00
Novo Nordisk, Inc	19,600.00
Pfizer/ Wyeth (NACCHO Grant)	289,400.00
Factor Health Mgmt.	1,500.00
Grifols	7,300.00
Medco Heal Solutions	150.00
ZLB Bioplasma	300.00
Accredo—HHS	1,250.00
PCH Hope (Camp HONOR, Salsa and Golf Tournament)	120,000.00
Omnicare	1,000.00

Gifts of \$8,000.00

Volvo

Gifts of \$7,000.00

Casino Arizona

Gifts of \$6,000.00

Shamrock Farms

Gifts of \$5,000.00

Cricket Wireless

US Airways

Valley of the Sun United Way

Individual Donations and Allocations

Gifts of \$4,000.00

In Memory of Tracy R. Earl, Esq.

Gifts of \$3,000.00

Armstrong McDonald

Gifts of \$2,000.00

SCF Arizona

Gifts of \$1,000— \$1,999.00

Coleman Dahm

Gifts of \$200.00— \$999.00

Sandra Baird
 Andy Blackledge
 Alexis Christensen
 Dave Cooper
 Rebecca Fitzpatrick
 Nancy Grace
 Steven Helm
 Michelle Holcomb
 B. Horton
 Crystal Klinger
 Lisa LaRoche
 Monty Manuelito
 Donna McGuire
 Oscar Medina
 Vic Ocotillo
 OMACC Logistics
 Peter O'Malley
 Mike Pietzsch
 Lennox Punch
 Julie Pyne
 David Southmayd
 Daniel Statezny

Every effort has been taken to ensure proper spelling and inclusion in our lists. If an error or omission has occurred, we deeply apologize and ask that you contact us at 602-955-3947.

Thank you.



HOW YOUR DONATION HELPS

- \$1,200 allows 30 children to attend a youth group event
- \$1,000 sends a child to camp
- \$350 pays for an entire family support meeting
- \$300 supports a family in crisis
- \$100 provides for Spanish translation services during a clinic visit
- \$55 lets a child have a medical alert bracelet



Arizona Hemophilia Association
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Phoenix, AZ 85014

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602-955-1965 (Fax)
Toll Free 888-754-7017
www.hemophiliaz.org



***Helps Here
Donor Option #1441***

OUR MISSION STATEMENT

The Arizona Hemophilia Association is dedicated to enhancing the quality of life for people with inherited bleeding disorders while advocating for a cure.

HOW YOU CAN HELP

- *Make a financial contribution to help the Arizona Hemophilia Association continue to meet its mission on behalf of the inherited bleeding disorders community.*
- *Volunteer your time and energy to help with community events and advocacy issues.*
- *Learn more about Hemophilia and help create awareness about bleeding disorders.*