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## ADVOCATES IN ACTION

### CONNECTICUT ADVOCATES MARK ZATYRKA AND CHRISTINE LIBERTINO: MAKING A DIFFERENCE

Bleeding disorders community members Mark Zatyрка from Connecticut and Christine (Chris) Libertino from Maryland, were instrumental to the introduction and scheduling of state legislation and hearings to benefit the bleeding disorders community.



Chris, a mom with a son who has severe Hemophilia B, became actively involved with the Maryland bleeding disorders community over a year ago. As Advocacy Chairperson of the Hemophilia Foundation of Maryland (HFM), she was instrumental in coordinating efforts for the introduction of House Bill 1127 and Senate Bill 908 (see state advocacy news) in the Maryland General Assembly. She plans the annual HFM Advocacy Day in Annapolis, MD and keeps the Maryland bleeding disorders community educated and informed of federal and state policies issues.

Mark, a resident of Connecticut, has severe Hemophilia A. Mark believes you must pro-actively advocate for what you need, know what you need and recognize if it is being threatened. He recognized the importance of educating policymakers on the uniqueness of hemophilia and other bleeding disorders and established a rapport with his state legislators. Mark's efforts were key in the creation of a Hemophilia Task Force in Connecticut in 2009. His efforts also led to the introduction of House Bill 5212 (see state advocacy news). You can watch a video of Mark speak to the importance of state legislative advocacy on the HFA VOICES web page: <http://voices.hemophiliafed.org/>



Mark and Chris are advocates in the community to emulate; and it is more important than ever to stay involved. Please contact your local chapter or the HFA to learn how. 

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Peter Bayer, 2nd Vice President  
Tom Vaclavik, Treasurer  
Kimberly Haugstad, Executive Director

## CONTRIBUTING STAFF

Kisa Carter, Public Policy Director  
Susan Swindle, Development Director  
Michelle Burg, Programs Director  
Katie Whittle, Voices Coordinator  
Gina Dochnahl, Graphic Design Consultant

## PUBLICATIONS COMMITTEE

Bob Marks, Chair  
Margie Yancey  
Jill Williams  
Barbara Chang

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The Hemophilia Federation of America is a national non-profit organization that assists and advocates for the bleeding disorders community.

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## DISCLAIMER

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# EXECUTIVE'S REPORT

*By Chad Stevens*

Dear HFA Friends,

It is with a full heart that I write this letter to you. It has been my honor to serve as your President for the past two years.

We have been through much and have seen change as a community and as an organization over the years. As I leave this role, I proudly can say that each and every one of the hundreds of people I've met over the years have made an impact on me. I've been inspired in so many ways by so many people. You make a difference. Thank you for your hard work, and thank you for your commitment to the bleeding disorders' community.

I sign off with a challenge to our incoming president and to each of you. We have come so far, and must never rest. We must keep pushing and keep asking for the services we need, asking for improved and safer products, asking for a cure. We must work as a community to achieve and we must never give up. We may be a small community but we have the ability to make big change. 💧

Warm regards,



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# One Man's Story

by John Jarratt, M. Ed., L.P.C.

It is my hope the new millennium will bring about a better understanding of hemophilia and bleeding disorders, along with an improved relationship and collaboration with consumers, chapters, foundations, hemophilia treatment centers, clinics, private practitioners, emergency room personnel, national organizations, and industry. After all, isn't our goal one and the same- an enhanced quality of life for those we serve?

No doubt, we will continue to see and welcome the advances in medical science. Yes, there have been set-backs, but let us remain hopeful that tomorrow is a new day- gene therapy, perhaps a pill to swallow, the elimination of life-time caps, but more importantly, insurance for all persons, making access to care a reality- not merely a dream.

Many of us "kids" have now grown-up. I'm now sixty-one years young. I remember when I was six, a time when there were no chapters, foundations, hemophilia treatment centers, much less care and treatment for hemophilia other than hundreds of pints of whole blood or fresh frozen plasma, combined with weeks in the hospital.

Many of our parents were forced to sign insurance waivers excluding us from their employers' group insurance policy due to our hemophilia. We had no HIPAA, COBRA, federal regulations, or advocacy groups protecting or advocating for us. Some couples were forced into getting a divorce in order to qualify for Medicaid so that those with hemophilia and other chronic and/or terminal illnesses could have access to medical care. How my parents managed, I'll never know. What I do know is that I was blessed with parents who provided me with loving care, their knowledge, wisdom, and courage. Not only did they give me life, but they gave me a sense of self-worth.

*Continued on Page 8*

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**GRIFOLS**



HFA welcomes Arizona Hemophilia Association as its newest Blood Brotherhood site. Arizona is one of nine Blood Brotherhood sites around the country. HFA's Blood Brotherhood Program is for adult men with hemophilia and von Willebrand disease to

connect through outreach by providing, education, social support and a sense of community. Each Blood Brotherhood site has a site coordinator. Melinda Cadena will take on this role in Arizona.

Since 2007, Melinda Cadena has been the Director of Programs for the Arizona Hemophilia Association. Melinda has worked with children and families in the non-profit field for the past 10 years. Mrs. Cadena's family has a very long history of hemophilia; Melinda is a carrier and has been a part of the community her entire life. Melinda and her husband's pride and joy is their one-year-old son Robert Antonio. Melinda's love and dedication for the bleeding disorders

community motivates her to empower the bleeding disorders community by providing the best resources available. "The Blood Brotherhood program is a wonderful way to help our community members reach out to others and help improve their quality of lives. The Arizona Hemophilia Association is much honored to be a part of the program. The staff is looking forward to having its first Blood Brotherhood event in March. We plan to go to a Spring Training baseball game and learn about Pain Management. We hope our BB program will help those who have isolated themselves find new "brothers" and help each other in all aspects of life," states Melinda. ♦

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## PAINTING A PICTURE IN THE STATES: STATE LEGISLATIVE ACTION IN 2010

By Kim Bernstein, Michelle Pascucci, Kisa Carter

State legislative sessions are coming to an end, however, the bleeding disorders community has been instrumental in and supportive of a number of bills being introduced around the country. Community members are actively advocating for affordable, quality care and standards-of-care legislation. Below is some of the legislation that has been introduced during the 2010 sessions.

**Nebraska** Senator Abbie Cornett introduced Legislative Bill (LB) 1017 to provide requirements for insurers for prescription drug coverage and LB 1088, the Physicians and Patient Prescription Protection Act. A bleeding disorders community member testified before the legislature regarding the importance of capping out-of-pocket costs for prescription medications. The Nebraska legislature has adjourned, but LB 1017 will be reviewed over the summer.

**Hawaii** introduced House Bill (HB) 2461 and Senate Bill (S) 2494. These bills require health insurers to offer the same drug coverage that an insured individual received under his or her previous plan. These bills have received several hearings in both houses and as of April 28, 2010, are in conference.

The Hemophilia and Bleeding Disorder of **Alabama** association is actively seeking passage of House Bill (HB) 420, standards of care bill.

The **Delaware** Valley Chapter of NHF and the Western **Pennsylvania** Chapter of the NHF are actively advocating for passage of (HB) 620, a standards of care bill. HB 620 passed in the House in 2009, and must pass in the Senate during the 2010 legislative session.

For the last several years, bleeding disorder community members in Missouri have been committed to working with their state legislatures to pass HB 1525. HB 1525 was introduced in the current 2010 session and a hearing was held on March 17, 2010. If passed, it will establish a standard of care for people with bleeding disorders throughout the state.

The **Florida** State Legislature has introduced Senate Bill 516 and HB 275. If passed, the bills will prevent



### ARE YOU A DAD IN ACTION?

Definition: a Dad who continues to improve as a father and wants to strengthen the family unit

HFA's Dads in Action program was created to empower and help dads by offering monthly educational webinars. This program educates dads about the bleeding disorders community and provides information about how to strengthen family ties. Last year several dads participated in six successful webinars, lead by Mark Borowski, professional speaker and author of Big Slick Daddy. Topics range from normal parenting tips to hemophilia-related subjects.

Webinars take place the second Wednesday of each month and last one hour.

So are you ready to become a Dad in Action?

For topic and registration information visit: <http://hemophiliafed.org/programs-and-services/dads-in-action/> 

health insurance plans from limiting choice or access to prescription drug coverage.

**New York** has an active Tier Four Bill (AB 6298) in the Upper House. This bill will deny insurance companies the right to impose drug tiers and cost-sharing for prescription medications.

**California** has made progress with Senate Bill 971, standards of service bill. A hearing was held on April 23, 2010, and another is scheduled for May 3, 2010. The bill will create a minimum standard of service requirement for providers of clotting factor in the state of California.

**TAKE ACTION** in your state and become involved in state legislative efforts that impact the bleeding disorder community. To find out the dates of your state's legislative session, please visit <http://www.ncsl.org/?tabid=18630>. Links to the state bills are located on the HFA Legislative Action Center site at <http://capwiz.com/hemophilia/home>. HFA has also launched a new State Legislative Map tool, that will allow you to follow specific bills in your state. Check it out at <http://hemophiliafed.org/advocacy/advocacy-in-a-box/>. 

## HFA...CONNECTING PARTNERS ACROSS THE COUNTRY

Are you a partner to someone with a bleeding disorder?  
 Would you like support from others who know what it's like to love someone with a bleeding disorder?  
 Are you looking for information/education about bleeding disorders?  
 Could you benefit from efforts to raise awareness about the realities of living and loving in the face of a bleeding disorder?

If you answered "YES", please join us. Future sessions will include:

- guest speakers on educational topics YOU are asking about, open forum discussions facilitated by people like YOU!
- opportunities to connect through shared experiences

No obligation or commitment, just come check it out! Share your thoughts and questions via phone &/or web. We welcome all ideas and perspectives! Please visit HFA's Calendar of Events: <http://hemophiliafed.org/community/calendar/> for more information on upcoming sessions.



Hemophilia Federation of America  
**FOCUS ON THE FEMININE**

**BLOOD** Brotherhood  
 Hemophilia Federation of America

## WELCOME TO HFA MICHELLE PASCUCCI

HFA Welcomes New Team Member Michelle Pascucci, HFA Policy and Administrative Assistant initially joined the staff as a volunteer in January. She graduated from Chapman University with a B.A. in Political Science and brings extensive volunteer experience from her affiliation with the Hemophilia Foundation of San Diego. She has two brothers with Hemophilia.

Michelle's involvement with national community organizations began after attending NHF Washington Days. Her combined interest in the legislative process and personal family experience spurred her passion for advocating on behalf of the bleeding disorders community. Recently, Michelle was in attendance at the House Gallery to witness the historic vote on Health Care. Michelle is a wonderful addition to the office in DC, where she brings her knowledge and compassion to the job every day. 💧

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Kimberly Haugstad, HFA Executive Director, was delighted to learn that we reached our goal so early in the year. "Reaching 2,010 so quickly illustrates an important need we can fill. Even in our age of technology, people are ultimately about connections, relationships and sense of community. Research certainly cites this and now we can demonstrate this through practical use."

We are excited to continue to develop our Facebook page! If you are not a fan yet, you should be ☺. Visit [www.facebook.com/hemophiliafed](http://www.facebook.com/hemophiliafed) to learn more. 🩸

Hemophilia Federation of America

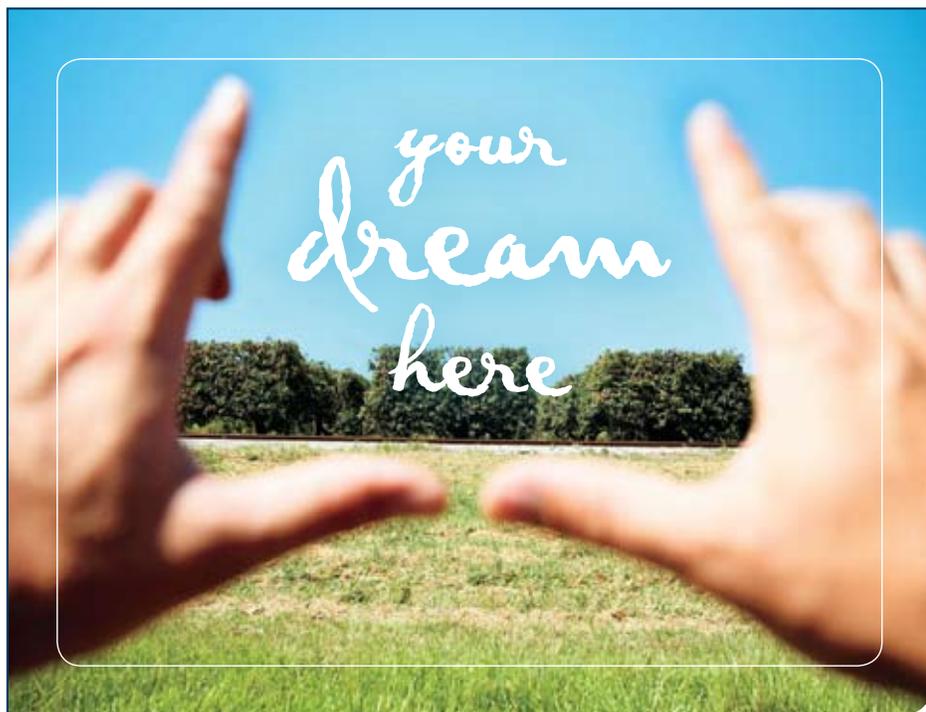
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*Continued from Page 3*

As a result, I have become my own "Chairperson," able to advocate for myself, making my own decisions as I travel this journey of life.

No, "I was never promised a rose garden." We must talk about our past and share the stories which often haunted our earlier lives. We must talk about HIV/AIDS, the "alphabet soup" of hepatitis "A", "B", and "C", and how that has affected the lives of many of our blood brothers and sisters. We must talk about the present and the joy we experience when our six-year-old has learned at camp to self-infuse with a product that has been genetically engineered, with the knowledge of its safety and efficacy, which allows him or her a normal life expectancy. We must look to the future with hope, as opposed to hopelessness, turning challenges into opportunities, and recognize that we are productive citizens, contributing members of society, with strengths and weaknesses no different from the next

fellow. We have become laborers, businessmen and women and professionals in the working world. This was not possible 25, 35, 45, 55, or 105 years ago. It's no accident that I became a counselor by profession, as hemophilia is far more than a medical disorder. Oh, how I could have benefited from psycho-therapy/"talk-therapy" when I was much younger and feeling so alone and isolated at school, in the community, or the workplace. I grew-up in an era when only the "rich and famous" could afford therapy. We must think holistically, with mind, body, and spirit working together, which has brought healing into my life, and the lives of many. Hemophilia, von Willebrand disease, and numerous other chronic illnesses affect one not only medically, but also emotionally, socially, psychologically, and spiritually. We must recognize that without shame. We must also recognize our possibilities as being unlimited. No longer should we be placed in a glass box marked "FRAGILE." Whether

it's hemophilia, von Willebrand disease, platelet dysfunction, or a related bleeding disorder, it is NOT our identity.

Sure, there have been interruptions in our lives, and we will continue to face these. But with continued advances in medical science, coupled with open and honest communication amongst us, our fellow consumers, the medical community, industry, and the community at-large, nothing is impossible. We are not to be feared. Allow us the freedom of knowledge, empowerment and self-advocacy, as we so vividly remember the days when we were told we would not live past our teens. We now have a control, not a cure, but a control that many have learned to self-administer. And with that, I ask you... please allow us the dignity of risk... the dignity to question...the dignity to answer when we question, without becoming threatened or defensive of our knowledge of a disorder for which "we" have become the experts through experience.

*Continued on Page 11*

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On December 2, 2009, Maureen Cook, a loving wife, mother and friend of the community, passed away. She is survived by her husband, Wayne Cook, former HFA board member and current

President of Coalition for Hemophilia B and their children, Wayne III, Shannon and Kasey. Maureen, a retired employee of the New York State Department of Labor, lived her life to the fullest as an avid volunteer, supporting causes of the bleeding disorder community, traveling and most importantly sharing time with those she loved. The HFA was fortunate to have been the recipient of her volunteer service at the annual educational symposium. Maureen was truly an inspiration to others and will be sorely missed by all.

### SHARE YOUR VOICE!



#### CREATING COMPELLING HEALTH CARE STATEMENTS

Sharing your VOICE is more important than ever! To increase public awareness of the community's everyday health care challenges, HFA will share your short, but compelling health care statements with Congress, the Obama Administration and the public. Please visit and complete the short survey to get started!

Link to the survey and examples of compelling health care statements:

<http://tinyurl.com/healthcarestatements> 

HFA extends condolences to the family and friends of Leon Faitek who passed away on February 23, 2010. Leon and his wife Judy have been an inspiration to the bleeding disorder community. Leon was a founder of the Hemophilia Association of San Diego County and remained a tireless advocate and active community member. HASDC could depend on the Faiteks to help and attend each event held in San Diego, from the annual meeting to camp. Leon lived life to the fullest and was always making those around him smile. Each year they would travel extensively, from tours of Europe to cruises and visits to Chicago, they were always on the move. Leon was a great inspiration to the bleeding disorder community and he will be missed very much by everyone who had the privilege of meeting him.



The HFA would like to extend condolences to the family, friends and co-workers of Jim Brown who passed away on March 11, 2010. Jim was an avid volunteer and valued friend to many in the hemophilia community. Locally,

Jim served on the board of directors of the Hemophilia of Iowa, Nebraska Chapter of the National Hemophilia Foundation, Midwest Hemophilia Association of Missouri and the Hemophilia Foundation of Minnesota/Dakotas. Nationally, Jim served as Secretary for the Hemophilia Federation of America for the last two years.

Jim lived his life with integrity and a commitment to serving others. We learned much from Jim and will dearly miss his gentle and kind voice of reason. Jim, may you forever be "Onward and Upward."

## HFA NATIONAL NOTES

by Kisa Carter, HFA Public Policy Director, Federal Affairs



### KEEPING THE COMMUNITY UPDATED

The HFA Advocacy section of the website has a variety of useful tools to educate and assist the bleeding disorders community with its advocacy efforts. Newly added sections include a United States map with relevant state legislation, a list of standards of care/service bills introduced throughout the United States, and updated information on the Bleeding Disorders Screening, Awareness, and Further Education (SAFE) Act introduced in March 2010.

The "Provisions of the Day" blog is another addition to the Advocacy section that was created to educate the community on the new health law and its impact on the bleeding disorders community. The HFA Public Policy team will periodically update the Advocacy section and continue to send Friday Updates with timely information to keep the community on track.

Please visit the HFA website, <http://hemophiliafed.org/>, to learn more about Advocacy web pages. ♦



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# STATE ADVOCACY NEWS

## BLEEDING DISORDERS LEGISLATION AROUND THE UNITED STATES

by Kisa Carter, HFA Public Policy Director, Federal Affairs

### Maryland

Several legislative efforts have been made across the country the last several months that benefit the bleeding disorders community. On February 16, 2010, the Maryland General Assembly introduced standards of care legislation in both chambers. The Health Insurance - Coverage for the Treatment of Bleeding Disorders (HB-1127/SB-908) was introduced by Delegate Marvin Holmes Jr. in the House and Senator Norman Stone Jr. in the Senate.

The bill underscores the importance of standards in the care and treatment of people with bleeding disorders. It seeks to ensure that insurers, non-profit health service plans and HMO's "shall provide coverage for all medically-necessary and appropriate pharmacy care, home nursing services, treatment at Hemophilia Treatment Centers, and clinical laboratory services that an insured's or enrollee's treating physician determines are necessary to prevent, diagnose or treat a bleeding disorder."

A hearing in both chambers was held by the Senate Finance Committee March 10, 2010 and by the House Health and Government Operations Committee on March 12, 2010 (read the HFA Blog for an update) If enacted, the bill will apply to all health insurance policies, contracts, and health benefit plans issued, delivered, or renewed in the state of Maryland on or after October 1, 2010.

To read the entire bill, please visit the Maryland General Assembly website: <http://mlis.state.md.us/>

### Connecticut

Six hours away in Hartford, Connecticut, the Joint Committee on Insurance and Real Estate held a hearing on February 25, 2010 to address several bills including the Insurance Coverage for the Treatment of Bleeding Disorders bill (HB- 5212) House Bill 5212, introduced by Representative Karen Jarmoc and Matthew J. Conway Jr., seeks "to improve access to appropriate medical care for persons with bleeding disorders." The bill was introduced in February 2010 and if enacted will take effect January 2011. Several bleeding disorders community

members testified at the hearing. To watch the hearing please visit: [http://ctny1.ctn.state.ct.us/l/ins\\_2-25-10.wmv](http://ctny1.ctn.state.ct.us/l/ins_2-25-10.wmv). To read the entire bill please visit: <http://www.cga.ct.gov/2010/TOB/H/2010HB-05212-R00-HB.htm>.

To read more about state legislation across the country, please visit the HFA State Advocacy Blog at <http://hemophiliafed.org/topics/state-blog/>. 



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*Continued from Page 8*

So to the new millennium, I ask to be allowed the "risk" of discovering what we can do instead of trapping us with what we cannot do. I, and others like myself, shall always look toward a hope for tomorrow.

My parents were charter members of the Cumberland Chapter National Hemophilia Foundation (now The Tennessee Hemophilia & Bleeding Disorders Foundation) along with a very small group of other committed, dedicated and loving families, with the guidance, direction and leadership of Dr. Jan van Eys and Dr. John Flexner. The TN Hemophilia & Bleeding Disorders FDN, the WFH, the NHF, HFA, the COTT, Save One Life, Inc., chapters, foundations, and comprehensive hemophilia treatment centers throughout the world, manufacturers and home-care companies, along with a lengthy list of supportive agencies;... all with their dedicated, professional, and compassionate staff and volunteers... became and have remained my "life-blood" and "foundation" for hope, health, and happiness.

See this and other stories on the HFA website at <http://voices.hemophiliafed.org/about/>. 

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