



# INTERVIEW WITH VAL BIAS

## NEW CEO OF THE NATIONAL HEMOPHILIA FOUNDATION

BY KYM KILBOURNE

**H**aving devoted the past 28 years to serving the bleeding and clotting disorders community, Val Bias now takes on a new position as the National Hemophilia Foundation's (NHF) Chief Executive Officer. Learn first-hand his plans for NHF and his agenda for the year ahead.

### **What led you to become so involved in advocating for the bleeding disorders community?**

In the late 1980s, I participated in a focus group hosted by the National Hemophilia Foundation (NHF); the focus was for men living with HIV. At that focus group, I met some of the future leaders of the bleeding disorder community: gentlemen like Don Colburn (Mass.), Dana Kuhn (Va.) and Rich Davis (Wash.). Later, we were asked to participate in a planning group for a national men's program which became the Men's Advocacy Network of the NHF (MANN). Although NHF had supported the need for such a group by creating the Women's Outreach Network of NHF (WONN) one year before the start of MANN, the men wanted more than support—they wanted acknowledgement of what had happened related to their HIV infection.

### **How have your other positions prior to this prepared you for your new role as CEO for NHF?**

NHF is a complex organization with 48 members in our chapter structure, and we collaborate and advocate for 148 Hemophilia Treatment Centers (HTC) across the United States. I have served NHF as Chairman of the Board in 1992-1994—there I learned the structure of the organization. In 1994, I was sent to Washington to advocate for compensation for the HIV infected. We succeeded with the passage of the Ricky Ray Hemophilia Relief Act, which ultimately provided \$100,000 to each

infected person or remaining family member. In Washington, I learned about the National Institutes of Health and other agencies that work with and on behalf of the bleeding disorder community; including the National Heart, Lung, and Blood Institute (NHLBI), Centers for Disease Control and Prevention (CDC), Maternal and Child Health Bureau (MCHB), U.S. Food and Drug Administration (FDA) and the Centers for Medicare & Medicaid Services (CMS). Those agencies are essential to research, prevention, clinical care, licensure and regulation, and reimbursement. I also met and worked with the Congressional offices that have traditionally understood and supported hemophilia.

Upon the successful passage of the Ricky Ray Hemophilia Relief Fund Act in 1998, I left Washington, D.C., and returned home to San Francisco. I continued my volunteer work with NHF through my role as Co-Chair of the Blood Safety Working Group. Shortly after my return to the Bay Area, I became President of the Hemophilia Foundation of Northern California, and was instrumental in rebuilding what had become a dormant organization.

During the entire span of my career in hemophilia, I have volunteered at Camp Emotion, a residential summer camp for children with bleeding disorders and known carriers. I have also volunteered or worked at every level of the organization and community, and have a steadfast commitment to service. That dedication has always been bolstered by my experience with the kids and young people in the community.

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### **Summarize your priorities as the new CEO of the National Hemophilia Foundation.**

NHF and the bleeding disorder community face a serious challenge to their standard of care. With reimbursement decisions being made at the state level, hemophilia is being targeted for cost reduction and formulary limitations. With large insurers and Pharmacy Benefit Managers (PBM) moving into hemophilia care, this change is eroding the care provided by Hemophilia Treatment Centers (HTC) and the specialty care pharmacies that serve the community. I believe the bleeding disorders community is at risk of having access to their HTCs limited, and the full array of clotting factors made unavailable to them as an effect of these cost containment measures.

In order to address this and other health care issues, I intend to strengthen our chapter network through the chapter reorganization. NHF has embarked on a collaborative effort to support our chapter network by providing more direct support for staffing, equipment, technical support and training for both chapter staff and volunteers. The stronger the chapter network, the better our ability to address access to care, access to products, and adequate reimbursement in each state.

The reorganization has already succeeded in working with chapters to agree on a set of standards that will ensure similar services and support at the chapter level for each local community. I feel it is an initial step in building a stronger, better-supported, better trained chapter network. Similar services, however, does not mean a cookie-cutter approach to chapters, but rather, valuing current achievements and diversity among our local organizations.

We will renew and strengthen our relationships with the Washington, D.C. agencies who have traditionally worked with the bleeding disorders community. Already, we have worked with Sen. Byron Dorgan (S. 2706) to introduce a lifetime caps bill, which will raise the limit to \$5 million the first two years, and then \$10 million in years three and four with a cost of living increase in the future. Rep. Anna Eshoo (D-Calif.) along with Reps. Betty Sutton (D-Ohio), Jason Altmire (D-Penn.) and James Langevin (D-R.I.) have introduced H.R. 6528 a companion bill in the House.

We have already met with the FDA, and plan meetings with the other agencies while embarking on never before meetings with large insurers and PBMs to discuss appropriate and cost-effective care for people with bleeding disorders.

We will double our efforts in our role to protect the nation's blood supply for our community and all Americans.

### **What do you hope to accomplish during your tenure?**

I hope to build the NHF into what we have dreamed about; a

responsive, service-oriented national organization that provides the leadership to achieve our collective goals as a community. I believe the bleeding disorders community must measure its progress on successful collaborations between those stakeholders, which will contribute to maintaining and increasing the standard of care. Those stakeholders include individuals living with bleeding disorders and their families, the physicians and clinicians, the government agencies that support, provide funding and lead research, and the industry that makes the products we are all dependant on for treatment of these disorders.

I want NHF to provide leadership for everyone who supports patients and our standard of care. For me, that does not mean control, but support through advocacy, research and education. Leadership is not ownership, but rather the ability to build consensus for a common goal.

With the appropriate leadership from NHF, it is my hope that the bleeding disorders community should be the hallmark for the treatment of chronic disorders—a shining example of how best to meet the needs of a diverse community. We should be supporting and increasing the quality of care from our clinicians while working with governmental agencies and industry partners to create even more effective products for the patients we all serve.

### **What are the NHF's legislative priorities in 2009?**

As you know, lifetime insurance caps have long presented a challenge for people with hemophilia and other bleeding and clotting disorders. With annual costs for some consumers at \$200,000, \$300,000 and more, a \$1 or \$2 million dollar cap just doesn't last very long.

During NHF's Washington Days 2008, with the help of members of our Minnesota and the Dakotas Chapter, Senator Byron Dorgan of North Dakota introduced S. 2706, the Health Insurance Coverage Protection Act, which will ultimately raise all lifetime caps to a minimum of \$10 million, and then continue to provide increases based on inflation. Although our ultimate goal is to eliminate caps, this would be a huge step in the right direction. Right now, we're creating a lot of awareness on this issue, including significant media coverage. By the time this story appears, the House version of the bill will likely have been introduced. Moving this important piece of legislation forward will be the centerpiece of our federal efforts in 2009. We appreciate the support we have received on this effort from our allies in industry including PPTA, and we look forward to continuing to working closely with you as the effort goes forward.

Of course, this is an election year, and there are a lot of important things that will remain unknown until November, including who our next President will be. Our goal is to help keep healthcare

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reform on the front burner, not only leading up to the election, but after newly elected officials at every level take office. In particular, we need to drive home the message that healthcare reform must meet the needs of all Americans, and that includes folks living with high-cost, chronic conditions.

Finally, we know that no matter what happens in the fall, a lot of what impacts access to care will still happen at the state level, so we need to pay a lot of attention to what's happening not only in state legislatures, but also at the agency levels where rules are often made. For these efforts, we rely heavily on our chapters who are on the front lines in the state, and we appreciate as well the information and other resources PPTA and our other industry allies bring to the table. Certainly, we would like to see more legislative ad-

vances on things like standards of care. At the same time, we know this will be a difficult year economically for many states, and we need to establish agendas that are realistic and take the economy into full consideration. What cannot be accomplished in some places through legislation might be achieved through negotiation. In other places, it may be all we can do to hold on to what we have. The important thing is that the entire community works together on a united front, speaking with one voice to ensure that our access to quality care is never taken away.

**How do you see the needs of individuals with hemophilia changing over the next five years?**

As I said before, we have some challenges to our standard of care and how we respond will determine the next five years for the community. People will need more support around insurance issues and access. That means chapter and HTC's collaborating with each to support access to dental care internists for needs other than their bleeding disorder. Adequate reimbursement has always been a challenge for access to physicians outside of the HTC treatment team.

For the first time in the history of this community we are facing geriatric care for people with bleeding disorders, a generation who will live a longer life filled with the complications of older age. We will need to focus on what happens when a person with a bleeding disorder enters long-term care in a nursing home environment.

**How do you believe it is best to work with industry in order to achieve common goals such as open access to all plasma protein therapies?**

I believe we must strengthen that relationship as it relates to advocacy. The community should provide the leadership to ensure reimbursement and work with the industry to inspire the development of new products.

We must look to the future where there are recombinant products for von Willebrand Disease and new treatments developed for rare coagulation disorders. I believe if we don't come together on many levels, states won't pay for the fourth generation products.

I will be proposing a collaborative working relationship with PPTA and its members with state advocacy representatives to form a coalition with an agenda to address key state issues nationwide. We need to collaborate with a comprehensive agenda with solid deliverables that will allow us to protect access to care and products while maintaining adequate reimbursement. During the development of a stronger chapter network, this collaboration only makes sense to address current challenges. Perhaps through a more focused and deliberate agenda we can maintain the current standard of care for people with bleeding disorders across America. ●

KYM KILBOURNE is PPTA's Manager of Communications



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