



New Kid on the Block The Hemophilia Federation Takes its Place in the Community

Many, many times over the past eighteen months, we have been asked the proverbial question - just who or what is The Hemophilia Federation? Why were we formed? Do we intend to replace NHF? What are our goals? Who do we serve? What will we do that's different?

When we were writing our policies, many hours of deep thought were spent trying very hard to avoid pitfalls and making every effort to "keep our noses clean." In a few instances, we may have erred on the side of safety and a few of these policies have been amended to provide for growth.

In a nutshell, The Hemophilia Federation is "an advocacy for persons with clotting disorders and their families of origin or choice." That means the entire hemophilia community - those with HIV, those with hepatitis those who were lucky enough to come through the holocaust unscathed, and those new patients who have not had to deal with the possibilities. We were formed to fill the perceived gap in services to this community which were not being met.

It has not been our intention to replace The National Hemophilia Foundation. Perhaps the time has come when more than one advocacy group is needed to cover all the bases.

All that it takes to be a viable advocacy organization is time, people power and dollars. Busy people who care can always find the time, people power is becoming increasingly easier to come by - the only stumbling block is money. It takes time to write grants and recognition by the community at large to see them to fruition. Last year we tried for federal dollars, but they are all tied up for an extended period of time by NHF. Short of a fairy godperson it is going to be slow going getting major dollars with no strings attached. All ideas are welcome.

Our intention is to obtain umbrella grants and funnel dollars down to our member organizations. We also offer consultative services in the area of organizational development and have amassed a wide variety of expertise in dozens of pertinent areas from special event fund raising to board development, recruitment of volunteers, family support, patient services, computer support and more. Until the big time money is available, we'll offer the expertise.

The first new project of The Hemophilia Federation is one we're very proud of - The Save our Selves kit which is explained in another article in this issue of Dateline Federation. This was one of the very first ideas our program committee suggested and we are proud to be able to bring it to fruition in less than a year.

Throughout this issue of Dateline Federation, you will see indications of what we are all about. Basically, what we are all about is YOU the members of the hemophilia community - all shapes, sizes, colors, nationalities, and varied health status.

Save Ourselves Kit

Last summer at a meeting in Chicago, the program committee met to outline some possible patient services areas to target. Many ideas were tossed around, but one of the first we felt very strongly about was the situation faced each time we must pay a visit to a hospital emergency room - at home or away. We listed the problems which are faced by patients in the hemophilia community on an emergency visit and outlined a way to overcome them.

The next item was to find funding - enter Hemophilia Health Services of Nashville. As we go to press, the final drafts are being prepared and we hope that distribution won't be far behind.

The SOS (Save Ourselves Kit) was designed to overcome the many obstacles encountered in emergency rooms. While a couple home care companies had similar items, we had specific requirements that we wanted to have included. We also wanted these to be available to the entire hemophilia community and hospitals. Look for a complete introduction of SOS in the next issue of Dateline Federation due in the winter.

"Snowflakes are one of nature's most fragile things, but just look what they can do when they stick together!"

Medical Advisory Board Forming

To say that hemophilia is a complex inherited disease is probably the understatement of the century. In order to have expert assistance in developing appropriate standard of care policies, we are forming a Medical Advisory Board. Members of this panel shall serve two year terms with a maximum of six years.

Members of the Medical Advisory Board would be responsible for their own travel expenses or to have them underwritten by their organization, if appropriate, in a similar manner to members of the Coordinating Council.

Medical Advisory Board members would also be asked to promulgate position papers on healthcare and related issues in partnership with the Coordinating Council. Additionally, they will be asked for opinions on topics of concern to membership of The Federation.

Disciplines would include, but not be limited to professionals with expertise in: Internal Medicine, Hematology, Infectious Diseases, Pediatrics, Family Practice, Orthopedics, Surgery, Genetics, Physical Therapy, Occupational Therapy, Dentistry, Acupuncture, Immunology, Psychology / Social Work, Nursing and Nutrition. Resumes are being accepted at this time.



New Members Wanted

The job description reads: Energetic persons needed to work tirelessly for the hemophilia community. The hours are long, the goals are intense, the emotional rewards are unlimited. The variety of positions available are myriad and the numbers needed are limitless. To apply, call 1-800-230-9797.

The Hemophilia Federation has several categories of membership: Individual memberships are \$25; Corporate memberships are \$5,000; Medical memberships are \$250; Non-profit memberships are \$250; Independent organizations seeking membership on the Coordinating Council are \$2000; and Affiliate memberships for chapters of NHF are \$1500. All dues are payable annually. There are no participation fees.

There's a lot of work to be done and the more people we have to roll up their sleeves and jump in, the quicker we will achieve our goals. The excitement grows with each meeting and each time we reach a milestone, the elation is abundant. If this sounds like an interesting proposition and a challenge, just give us a call at 1-800-230-9797 and hop on board a winning team!

New Organizations

In several areas of the United States new organizations are forming to become independent hemophilia organizations and to join The Hemophilia Federation. Many of these people are in areas not served by any other hemophilia advocacy organization.

Because so many people have come forward to form new organizations, we have formulated a set of "how-to" instructions for people wishing to form a new organization. If you would like to have information on how to form such an organization, just give us a call at 1-800-230-9797.



Federation Participates in CAWG

On July 1, 1994, Ron Neiderman and Jan Hamilton of The Hemophilia Federation's Coordinating Council joined Corey Dubin and Jonathan Wadleigh of The Committee of Ten Thousand, Dick Valdez and Dana Kuhn of PEER, Jonathan Botelho and Val Bias of The National Hemophilia Foundation and Louise and Cliff Ray in forming the *Community Advocacy Working Group*. Over the next few months, this group has worked together to formulate a unified approach to productive legislation for our community.

Prior to this time, the lion's share of efforts to obtain a good legislative package had been produced by The Committee of Ten Thousand and some efforts by The National Hemophilia Foundation. There was concern that the message from the different agencies was different and confusing. Therefore, The Community Advocacy Working Group was formed and has worked toward a unified legislative effort.

The path has not been terribly smooth, but we have managed to finally reach a consensus. If you would like to have information on how to help us get this legislation enacted and working for the hemophilia community, call 1-800-230-9797. We need to contact every senator and representative in Washington and any others who are in places of influence and let them know who we need help.

Hemophilia on the Hill

COTT has been the parent organization for The Hemophilia Federation. We were born from a need seen by COTT leadership as they visited with members of the community across the country. COTT's Government Relations Working Group members have also been Federation members so we have been able to learn about working for legislation from very experienced people.

Corey Dubin's article takes us along the legislative journey to where we are today.

Hemophilia Community Represented on Capitol Hill by COTT

By Corey S. Dubin

For the first time in many years the hemophilia community has a substantial and regular presence with Congress and the Executive Branch. The National Government Relations / Compensation Working Group, led by its Government Subcommittee (Corey Dubin, Dana Kuhn and Jonathan Wadleigh) have for the last thirteen months been working with Congress and the federal regulatory structure to ensure that the interests of persons with hemophilia are well represented. The working group is advocating for those with hemophilia as well as those with hemophilia and HIV.

By building close relationships with members of the House and Senate, COTT is seeking to initiate changes at the legislative and regulatory levels for the hemophilia community. We believe that a sorely lacking advocacy presence at the FDA contributed to the infection of thousands in this community with HIV and are demanding substantial changes in the regulation of the blood and blood products industries.

Congress - COTT is seeking legislation that would provide immediate 100% coverage for persons with hemophilia who lack health insurance. For those with existing coverage, Medicare would become the secondary coverage.

We are also proposing that those with hemophilia and HIV would qualify under the SSI definition of presumptive disability. If passed, this would allow individuals with hemophilia and HIV to be automatically classified as unable to work and eligible for disability benefits without having to subject themselves to the long process of proving that their condition has rendered them unable to be productive. We are also seeking monetary compensation from the federal government regarding the FDA's failure to ensure the safety of blood products. Given the federal regulatory failure to protect the community from HIV. We believe that Washington shares in the responsibility for the infection of half the hemophilia community and therefore should provide monetary compensation for those infected. This does not however absolve the blood products manufacturers from their part in this preventable medical holocaust.

Additionally, we are asking Congress to address the issue of the statute of limitations and the impact it has had on the community's ability to seek redress in the courts. Congress can, by statute, create a federal cause of action that

would preempt the various state statutes of limitations thereby allowing people's cases to gain a day in court.

To our surprise, over the last year, we have discovered that this community has been misrepresented as well as under-represented by The National Hemophilia Foundation which claims that it is advocating for this community in Washington. As our infection demonstrates, we have, for decades, not had a presence in this nation's capitol. In one year, we have greatly increased congressional awareness of the HIV Holocaust and the needs of this community which we found sorely lacking on Capitol Hill. Another area where we noted a lack of awareness was the FDA where decisions are made that impact our very existence.

In spite of the current IOM investigation, we are requesting a prospective Congressional investigation into how the FDA regulates blood and blood products with an eye toward Congressional action that would clean up this dirty business.

In the next few months, it will be imperative that people at the local level begin to build relationships with their Congresspersons and Senators in order to create the national momentum needed to accomplish our goals. People should make appointments with their Congresspersons and Senators or his/her staff and begin the process of educating them regarding the hemophilia holocaust, as well as the need to ensure the safety of our nation's blood supply.

Additionally, The Federation along with COTT, PEER Association, NHF, and the Ray family has created a Community Advocacy Working Group to provide a forum for the development and implementation of the hemophilia community's agenda on capitol hill. The role of the working group is to insure that the hemophilia community speaks with one voice. It is designed to at long last insure that the interests of the community at large will be effectively represented in the halls of congress. CAWG will guarantee a continuing grass roots involvement in a legislative agenda for the hemophilia community at large.

The FDA - Since December of 1993, The COTT Government Subcommittee has been meeting with leading officials at the FDA to begin forcing changes in the business of blood. In January of this year, we met with Deputy FDA Commissioner Mary Pendergast and her staff. At that time, we detailed the FDA's role in the infection of thousands in the hemophilia community and demanded substantive changes in the regulatory structure. We informed the FDA that while we wanted to work closely with them in this endeavor, we did not intend to be placated by talk and inaction.

One of our bottom lines continues to be the rampant conflict of interests that permeates the FDA at all levels. From the Blood Products Advisory Committee to the internal departments of the FDA, the blood banks and the blood products industry continue to retain an inordinate amount of influence and power over decisions and actions that impact our lives on a daily basis. This must change if we are to clean up the business of blood in this country and this change is at the center of our whole advocacy program in Washington, D.C.

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Through our friends on Capitol Hill we have been pressuring the FDA to open up the decision making process to serious consume input, something

we find seriously lacking. Specifically, we are asking that three voting seats on the Blood Products Advisory Committee be allocated to consumers. Currently, the FDA considers doctors to represent a consumer perspective on the BPAC, a position that we believe is again allowing the doctors power over our lives.

In July, the FDA requested that the COTT board nominate one of its members for a seat on the FDA's Blood Products Advisory Committee (BPAC). The COTT board forwarded a nomination and is currently awaiting action by the FDA.

With regard to the safety of the blood supply, we believe that there are again warning signals that are being ignored. The gamma globulin recall by Baxter and the Red Cross has provided us with another example of a product considered absolutely safe which, in fact, it is not safe. We have also learned from the IVIG situation that when a recall is voluntary and initiated by the companies, the FDA does not involve itself in insuring that all physicians and clinics using a certain product are notified of the recall. This, we believe, is a situation fraught with danger and requiring immediate change. Again, the FDA is leaving the companies to self-regulate and history informs us that self regulation does not work and has had catastrophic consequences.

The FDA has no mechanism to "look back" at products already approved to reassess their continuing efficacy. A relevant example is that of intermediate purity factor eight products. There are serious questions regarding these products and stable immune function. Studies have demonstrated that for clients with compromised immune systems, intermediate purity products have a negative impact on CD-4 counts. Yet, according to the FDA, they have no process for revisiting these products to re-evaluate efficacy in light of this data.

Given that cleaner products are currently available, we believe that the FDA should revisit their earlier approval with an eye towards removing intermediate purity factor eight from the market. However, no mechanism exists for re-evaluating approved products once new data becomes available. This must change and only this community is in a position to make this happen.

Who Is Driving the Bus? - For the first time, people with hemophilia and their families have a steady voice in the halls of congress. For the first time ever, the interests, needs and aspirations of the hemophilia community are being articulated by those with hemophilia on an on-going basis. This represents a fundamental positive change - and from our perspective - there is no turning back.

Those organizations who have claimed to represent this community in the past have fallen short in their responsibility to provide national advocacy. Now it is time to look to those new organizations and structures, like The Hemophilia Federation, that are persons with hemophilia and their families and not the medical establishment and the drug companies. This is the challenge, to self-identify, self-support and self-advocacy for ourselves and our families.

Who are we?

How Can You Help?????

If you would like to further the mission of The Hemophilia Federation, there are many things that you can do to help. There are a multitude of things that would be of assistance - these are only suggestions.

☎ **Fund our 800 number.** Monthly charges vary due to incoming volume. Any amount is appreciated.

☎ **Fund Conference calls.** Monthly calls run between \$250 to \$350 each depending upon the number of people on the call and the length of the call. Committee conference calls run usually less than \$100 each.

🖨 **Donate computer equipment or the cost of equipment.** IBM compatible 486 . Desk or notebook. Hewlett Packard portable deskjet or HP desktop.

📧 **Newsletter composition and layout.** Do you have skills to offer rather than dollars? We need someone to edit our newsletter four times a year and send it by modem to the printer. No money out of pocket, but a tremendous service.

✉ **Newsletter mailing.** Would you offer to address and mail copies of the newsletter quarterly?

✧ **Airline travel.** Do you have airline miles you're not using? We can always use frequent flyer mile certificates to fund outreach trips, organizational development assistance trips, lobbying trips, etc.

✧ **Benefit.** Sponsor a benefit event - your choice (concert, thon, dinner - whatever) and donate the proceeds to The Federation. We'll help all we can!

✧ **Cash.** We'll even take donations of the green stuff. We really need to establish an office and hire at least a part-time administrator. Either or both of these will take quite a few dollars.

Members of The Hemophilia Federation are often asked, "Who are your members?" The current membership includes:

COTT

COTT, West Coast Affiliate

Hemophilia of Acadiana

Hemophilia Assn. of New Jersey

Hemophilia Assn. of New York

Hemophilia Northwest

HIV/PEER Association

Individual members are: Rick Nagler and Ellis Sulser of the Washington, D. C. area, Wayne Swindlehurst of Michigan; Ken and Ingrid Harper of Beaverton, Oregon, Ed and Pam Maslak, Ohio.

These are the official members. There are other groups who are "in the process" of officially joining and others who are in the process of forming new organizations which will become members.

In the last few weeks we have received scores of telephone calls for information on membership in The Hemophilia Federation.



Booth at NHF Meeting-Dallas

Once again this year, The Hemophilia Federation has rented space in the exhibit hall at The NHF Annual Meeting. We will be available during all booth hours to meet with you and answer your questions.

If you cannot spend time in the exhibit hall, contact one of us for an appointment at your convenience.

Federation Meets in Frisco

January 20, 21, 21, 1994, we will hold a meeting in San Francisco. The actual location will be decided shortly.

If you've been wondering what we do and what we're about...would like to meet the members of the Coordinating Council....or just want to swap ideas for the future of the hemophilia community, we invite you to join us.

The agenda and location will be announced soon and we will be happy to forward information to you as soon as it is available. If you are on our mailing list, you will receive the information.

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