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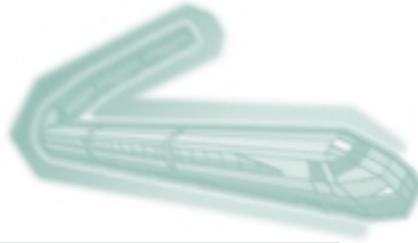
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The following letter was written by a local Delaware Valley Chapter mom who has a 21 year old son with severe hemophilia.

"This summer, while I was away from home, my son (age 21) called me to say that his homecare company (a mail order pharmacy) called him and told him that they would be dropping his factor off, at our home, with a representative of our insurance company. As soon as my son told me that the insurance company was delivering it, I had questions. Never in the twenty-one years that we have been dealing with hemophilia, has anyone from the insurance company come to our home. The factor has always been delivered via Fed-Ex. My son never gave it a second thought, assuming it would be dropped off, as usual, on the front porch.

On that day, the doorbell rang. My son answered the door to find representatives from his homecare company and insurance company on the front steps. My son was about to take the shipment of factor when the insurance company representative told him (heading up the stairs leading to our apartment without invitation), that an inspection of the refrigerator and his remaining factor had to be done. My son objected to them coming in because he had company at the time and is very private about hemophilia. My son was upset because these people were violating his patient confidentiality rights by continuing to debate the situation with him in the presence of his friends and people coming in and out of our apartment building. The insurance rep then told him to go get his factor out of the refrigerator and bring it to them. After inspecting his factor boxes, they said he could only have part of his new factor order. The insurance rep felt he was taking too little factor and wouldn't need his full order.

When I got home, I called the insurance company and demanded an explanation. How dare an insurance company come to my home and insist on entering, then withhold my son's factor after being denied entry? I never did get a definite answer as to why my son was denied his factor. I was furious that we weren't notified about this in advance, nor were we provided a valid reason for it. The insurance company said that they were required by state law to do this. I called the State Department of Health and

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Delaware Valley Chapter News & Notes

National Hemophilia
Foundation

DELAWARE VALLEY CHAPTER

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From the Executive Director

Insurance companies entering your home...determining what factor product you will take, by determining what product they will pay for.....not being able to get your lab work analyzed by the coagulation lab at your HTC (where they get it right, THE FIRST TIME)...insurance companies limiting your pharmacy options to a mail order pharmacy only, with no nursing or supportive services offered...insurance companies not allowing you to stay with the homecare pharmacy provider that has been providing knowledgeable home nursing support to you...WHO WOULD THINK YOU WERE LIVING IN AMERICA?!

If you think you are at risk, after reading this edition of The Winning Spirit, YOU ARE! No doubt about it! Complaints from DVC area patients and medical providers about insurance companies and pharmacies are escalating each day, at an alarming rate. The National Hemophilia Foundation and the Delaware Valley Chapter are currently actively involved in developing a "Standard of Care for Hemophilia Homecare" that will protect the rights of our local patients in many, many ways. This legislative initiative is long overdue...but often, we have to get to the edge of an issue, before it gets the attention it needs. Following is a letter sent to Representative Chris Ross, member of the Pennsylvania House of Representatives and Co-Chair of the Suggested State Legislation (SSL) Committee. It is the first step of many that we will take to protect you, your children and our future patients with hemophilia, not yet born.

*The Honorable Chris Ross
Pennsylvania House of Representatives
P. O. Box 835
Unionville, PA 19375*

Dear Representative Ross:

On behalf of the community of individuals in the Commonwealth of Pennsylvania and the State of Delaware affected by hemophilia, I am writing to urge you to support the adoption of "Standards of Care for Hemophilia Homecare" by the Council of State Governments (CSG) in your role as Co-Chair of the Suggested State Legislation (SSL) Committee. This legislation will be considered by the SSL Committee at its November meeting in Dana Point, California. In addition, because individuals with hemophilia in Pennsylvania and Delaware are experiencing many of the same problems that this legislation addressed in New Jersey, the Delaware Valley Chapter of the National Hemophilia Foundation will be working on similar legislation during the next session of the Pennsylvania and Delaware General Assemblies.

The legislation that the SSL Committee will be considering in November was enacted into law in New Jersey in 2000 (Senate Bill 786, Chapter 121, Public Laws of 2000) and was fully enacted in 2003. The law was the result of problems with the quality of hemophilia care being provided by homecare companies in the State of New Jersey. The New Jersey law requires that all insurance carriers (including individual and group health insurers, small employer plans, hospital, medical and health services corporations and health maintenance organizations) in New Jersey that provide coverage for home treatment of hemophilia are required to contract with homecare providers that comply with minimum Standards of Care.

Individuals with hemophilia in Pennsylvania and Delaware have expressed similar issues with homecare providers and third-party payers. These issues include: (1) payers limiting patients' access to all blood factor therapies for the treatment of hemophilia, (2) payers establishing maximum allowable charges for these therapies at or below acquisition costs to pharmacies, (3) limiting pharmacy delivery options, based solely on cost and not on a standard of care and (4) sub-standard homecare nursing support contracted by payers. We believe that a patient's access to therapies and homecare services should be determined based on the needs of the patient by the medical team and the patient, not the payer.

Already, the New Jersey Standards of Care law has contributed to an improvement in the quality of hemophilia homecare being provided in New Jersey. I know that individuals with hemophilia in states other than New Jersey, Pennsylvania and Delaware are experiencing similar problems with insurance carriers and homecare companies that provide coverage for the treatment of hemophilia. The Delaware Valley Chapter of the National Hemophilia Foundation believes that one way to encourage other states to adopt laws similar to the New Jersey law is to include this legislation as part of the CSG Suggested State Legislation Program.

I strongly urge you to support the adoption of SB 786 as Suggested State Legislation by the Council of State Governments at its November meeting in Dana Point, CA. In addition, the Delaware Valley Chapter looks forward to working with you on similar legislation here in the Commonwealth of Pennsylvania during 2005.

*Sincerely,
Ann E. Rogers, MS
Executive Director*

We Gratefully Acknowledge...the pledge of support from the following manufacturers for 2004.

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ZLB Behring
Monoclate-P
Mononine
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Humate-P
Stimate
Gammar-P I.V.

November

4 Annual Meeting!

December

11 Holiday party

April

16 Fashion Show!

May

17 Family Dinner!



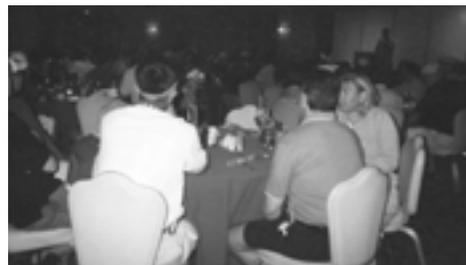
Annual Family Camp 2004

They came from Hershey and Lititz and Reading and Delaware and Philadelphia and...and...and... More than 200 patients and family members attended our **Annual Family Camp** which was held on the weekend of **September 24, 25 and 26, 2004**, at the Variety Club Campsite in Worcester, Pennsylvania, just outside of Philadelphia. What a fabulous weekend! We had perfect weather and wonderful fun activities throughout the weekend. Great food, great fun and the chance to be together with other families sharing the challenges of living with bleeding disorders...it just doesn't get better than that! Many thanks to our wonderful volunteers who helped in every way and to Peter Dyson, a young athlete with hemophilia who talked to our teenagers about participating, in a safe way, in sports and physical activities. Many thanks to Janet Reimund from ZLB Behring for the "Getting' in the Game" program that kept us busy all Saturday afternoon with basketball and fun, fun, fun! See you next year? You bet!!

Our second fall event, the **DVC Golf Classic**, was held on Monday, **September 27, 2004** at the Meadowlands Country Club in Blue Bell, Pennsylvania. Mark Marra chaired this important day and ZLB Behring was once again, the primary sponsor for the day. Mark (from Adima) and Janet Reimund (from ZLB Behring) put together a great day! We had perfect weather and a record number of golfers! We appreciate the efforts of all the volunteers who helped out and a special thank you to ZLB Behring, Mark, Janet and Perry Parker, a "Gettin' in the Game" athlete and pro golfer, who was with us for the day and even helped improve the score of some of our golfers!! And.....a special "thank you" to the many companies that financially contributed through hole sponsorships! What a great day!

The **56th NHF Annual Meeting** is planned for **November 4-6, 2004** at the Hyatt Regency in Dallas Texas. This is the only meeting in the United States completely focused on bleeding disorders. It is the one time each year that members of our community, industry, treatment providers, scientists and Chapters attend the same meeting, with specific sessions geared to their individual interests. If you are a patient who is treated in our local area and have never attended this annual meeting before and would like to attend next year (in San Diego), write us a letter to request financial help for the meeting in 2005! It's never too early to make your request!

On Saturday, **December 11, 2004**, get ready, get set for the **Annual Family Holiday Party** at Jefferson Alumni Hall in Philadelphia. Santa will be there, with presents for everyone, a great lunch and a chance to reconnect with old friends and meet some new ones. Please plan to be with us! You can register your family by calling the DVC office @215-885-6500! Everyone must register with us so that we can be sure to have a gift for each child. See you there!!



(above) Supporters at the Golf Classic, (right) Mark Marra, Golf Classic Chairman





Planned Giving

How can I help the DVC and the NHF while securing my own future through a Planned Giving Program?

From Queen Victoria to the Russian Tsars to the struggles and courage of Ross and Betty Griffin (DVC founders) and Robert and Betty Jane Henry in the 1950s, to all of today's heroes participating in the many activities of the Delaware Valley Chapter....we see the long past of hemophilia and other bleeding disorders. Each piece of this history has added to our future.

Now there is another way for everyone committed to our mission to actually affect the well being of future generations...the newly created Lee Ferguson Henry Society, the planned giving program of the National Hemophilia Foundation. It was named in memory of Robert and Betty Jane Henry's son, who died from hemophilia at age 21. The Society was created as a tribute to those special individuals who take the extra steps to insure there will always be funding for research, education and support for those living with hemophilia and other bleeding disorders, by remembering the National Hemophilia Foundation and the Delaware Valley Chapter in their estate plan or with a planned gift.

Through the Lee Ferguson Henry Society, the National Hemophilia Foundation offers a fully comprehensive planned giving program, with opportunities that may enable our members to reach their own financial goals while helping to fund research and important programs. You can designate 100% of your gift to research, or indicate your desire for 50% of your gift to be left to NHF and 50% to our Chapter, to be used as needed.

Additionally, free information and highly qualified professional advice is available to anyone who wants to know:

- the best way to remember us in his/her will or trust;
- how to receive a guaranteed, tax-advantage lifetime income ranging from 6% to 12% with a Lee Ferguson Henry Society charitable gift annuity;
- how to maximize the return on a gift of securities;
- how a gift of appreciated property (real estate, jewelry, art, etc.) can actually improve annual income or a financial situation;
- which assets are better than others for a contributor to donate to charity;
- the most advantageous way to contribute life insurance benefits...



and the answers to many more charitable/financial planning questions.

Lee Ferguson Henry Society members will receive recognition in our newsletter, website and annual report, as well as those of the National Hemophilia Foundation and the gratitude of everyone, present and future, who is waiting for a cure for hemophilia and other bleeding disorders.

If you have already taken the necessary steps to include the NHF and the Delaware Valley Chapter in your estate plans, please let us know so we can officially welcome you as a new Lee Ferguson Henry Society member. Take a minute to review the brochure we have included with this newsletter and let us know what you think. The future health of our organization is dependent on good planning today and the generosity of our friends and supporters who want to make sure that the Delaware Valley Chapter stays in business until bleeding disorders no longer have a place in our lives.

Your gift annuity or charitable trust can be designated 100% for research, or you can choose that NHF split the gift remainder value, 50/50 with the Delaware Valley Chapter, to be applied as most needed.



A Letter from Betty Jane Henry...A Founding Member of the NHF

Dear Member of the Delaware Valley Chapter:

I am writing to tell you about the Lee Ferguson Henry Society, the new honor society for the planned giving program of the National Hemophilia Foundation (NHF). I cordially invite you, as someone who is also committed to a future free of hemophilia and other bleeding disorders, to join me as a member of this important new group. It is named in memory of my son, who courageously lived his entire short life battling this dread disease.

The Lee Ferguson Henry Society was created to honor those people who establish a legacy of giving with NHF by remembering the National Hemophilia Foundation with a Planned Gift. This could be a bequest, or beneficiary designation, or by participation in a life-income planned gift, such as a charitable gift annuity or charitable remainder trust. Membership brings special tribute, and NHF's life-income gifts offer interest rates between 6% and 12%, and other tax advantages. We help supporters to improve their own financial situation while securing a better future for those dealing daily with a bleeding disorder.

My son, Lee Ferguson Henry, was born with hemophilia at a time when there were very few resources for families coping with the disease. We wanted to help our son, of course, but it was the plight of others with hemophilia that inspired the founding, in 1948, of what is today the National Hemophilia Foundation (NHF).

During those first years, it was always our hope that a cure would be found. That day has yet to come, but I am proud that in the interim, with the support and hard work of people like you, NHF has grown to become a valuable resource for everyone affected by a bleeding disorder. Fifty-six years later, my commitment to the cause continues, even long after the death of my son at age twenty-one. I have included NHF in my own estate plan as a way of strengthening my support and ensuring NHF's work will continue to assist others like Lee.

There are many ways for you to become a member of The Lee Ferguson Henry Society and I hope that you will accept my invitation to join me in this new and exciting endeavor. While it's impossible to know what tomorrow holds, today it is brighter for people with bleeding disorders—because the National Hemophilia Foundation is here. Planned giving is the best way to ensure that this important work will continue.

Please look over the enclosed materials and complete and return the declaration of intent in the back of the brochure to let us know if you have already included NHF in your estate/financial planning or would like to do so. You can also contact Eddie Pelto, Manager of Individual Giving for NHF, at 212-328-3741 or e-mail epelto@hemophilia.org. Wishing you the very best.

Betty Jane Henry

vCJD RISK ANNOUNCED FOR U.K. PLASMA PRODUCTS

On September 21, 2004, United Kingdom (UK) health authorities informed people with hemophilia and other bleeding disorders that they are considered "at risk" for variant Creutzfeldt-Jacob Disease (vCJD) if they used UK plasma products manufactured between 1980 and 1998. These products were made from plasma collected from donors in the UK who were later identified to have vCJD or possibly from donors who still remain asymptomatic for vCJD.

The UK's products were manufactured by Bio Products Laboratory and Protein Fractionation Centre, Scotland. These companies were not licensed by the US Food and Drug Administration (FDA) to distribute products in the United States, but UK plasma products, particularly factor XI, may have been brought into the US for use in clinical trials or for compassionate or personal use. FDA has not approved any manufacturing claim that the production process for any plasma-based coagulation product elimi-

nates the risk of vCJD transmission. However, to date, no cases of vCJD are known to have been transmitted by any plasma product. The UK health authorities have said their actions are "precautionary" and "the actual risk to individuals is very low."

NHF is seeking to determine if any US clinical studies utilized UK plasma products. Anyone who suspects they may have used a UK plasma product between 1998 and 2001 or anyone who lived or visited the UK during 1980 to 2001 and used UK plasma products during that time should contact their hemophilia treatment center. The last year the UK implicated that the infected product was produced was 1998, but the risk extends to the 2001 expiration date for these products. UK plasma products manufactured after 1998 did not use plasma collected from UK donors.

continued from page 1

Local Insurance Issues For Patients With Hemophilia A Runaway Train.....

was told that no one has the right to enter my home without our permission.

The insurance company rep told me that most people that are on Social Security Income (SSI) are indigent, that they don't have electricity, let alone refrigerators and that it was the responsibility of the insurance company to do routine inspections to see that the patient's needs are met and that this was a new policy of the insurance company. What an insult!

My son received his next month's supply of factor via Fed Ex, but the insurance company called and said they would be coming by to do a home inspection that day. My son told them that they would not be permitted to come in because I wasn't there. The homecare rep insisted on the home inspection. The rep said if they were not permitted in the home, he would not get any more factor next month. They came.

Next month, I was told that the insurance company had to deliver the factor and that I had to allow them access to my home each and every time, or my son would not receive his factor. I took the next day off from work so that I could be home for the "inspection." My son had absolutely NO factor left and I didn't want him to be put in jeopardy.

For many day, I placed calls to the insurance company, but my calls were never returned. After the Delaware Valley Chapter got involved and filed a formal complaint with the state insurance commissioner, the insurance company called to say that they would try to work out a special arrangement with me in which I would have to mail

all of my son's used factor vials back to the insurance company so that they could verify how much factor my son is using. Mailing "biohazard" materials through the US mail? Who ever hear of such nonsense? Details were to follow. I've heard nothing to date.

I feel that what has happened to our family is an invasion of our privacy and a violation of our civil rights. I feel like we are being bullied into submission through coercion, threats, intimidation, extortion and blackmail, to name a few...all against the law. This is the United States of America, not some third world country, where people with power can bully their way into your home, then withhold life sustaining medicine if they are denied entry. I understand that factor is expensive and the insurance company has the right to keep tabs on it, but not this way.

I would like to thank the Delaware Valley Chapter for their time and attention concerning this matter, and for filing a formal complaint on our behalf."

P.S. Complaints are being filed with the Delaware Valley Chapter, at an alarming rate, against the practices of insurance companies in Pennsylvania. If you have had an experience that you are willing to share with us, we will follow it all the way through the proper state channels to advocate for you and your rights as a patient with hemophilia in Pennsylvania and Delaware. Send all complaints in writing to the DVC office.

Legislative Update

Important Issues of Interest to the Bleeding Disorders Community



The following notice was received from TheAccessProject@aol.com about a very serious and important issue. Please help, if you can, by participating in this.

HIV Medicare and Medicaid Workgroup (HIVMMW)

Action Alert!!

Letters are needed now to protect PWAs (Persons with Aids) with Medicare/Medicaid.

Do you know that roughly 60,000 PWAs might lose their comprehensive prescription drug coverage in 2006, when the new Medicare Rx benefit comes into effect?

According to regulations being drafted, Medicare recipients will no longer be allowed to rely on Medicaid for their prescription drug coverage. Instead, they will be forced into the new Medicare Rx plans with limited drug coverage. These plans are not required to provide all FDA approved antiretroviral drugs.

PWAs who have both Medicaid and Medicare are long time survivors, who are treatment experienced and likely to have drug resistance problems. A massive and united response is needed to keep their treatment regimens effective.

The Centers for Medicare and Medicaid Services (CMS), the federal agency that oversees Medicare, is requesting comments on the draft regulation. We need a massive and united response to make sure that people with HIV/AIDS receive protections in the final regulations.

Please take some time to be a part of this response! A sample letter has been provided for your use and personalization. Written comments can be made either online or through the mail.

- To submit comments online, go to <http://www.cms.hhs.gov/regulations/ecomments/>. If you make comments online, please send a copy of these comments to rclary@projectinform.org, so they can track the community response.
- To submit comments by mail, please mail or fax the letter to the address/fax below. The federal government is requesting two copies of all comments. Ryan will make all copies and mail the letters. Send letters to:

Ryan Clary C/O Project Inform
205-13th Street, #2001
San Francisco, CA 94103
Fax: 415-558-0684
- If you need any help crafting your message, please contact Ryan Clary at rclary@projectinform.org

SAMPLE LETTER:

*Centers for Medicare and Medicaid Services
Department of Health and Human Services
Attention: CMS-4068-P
P.O. Box 8014
Baltimore, MD 21244-8014*

To Whom It May Concern:

I am responding to the proposed rule "Medicare Program: Medicare Prescription Drug Benefit," 69 FR 46632. I am concerned that the current rule does not provide sufficient protection for people with HIV/AIDS who will receive their treatment through this benefit.

CMS must designate people living with HIV/AIDS as a "special population" and ensure that they have access to an open formulary of prescription drugs and access to all medications at the preferred level of cost-sharing. This would ensure that HIV-positive individuals would have affordable access to all FDA-approved antiretrovirals, in all approved formulations, as is recommended by the Public Health Service HIV Treatment Guidelines.

{INSERT PERSONAL STATEMENT HERE.} If you are on Medicare, talk about how these regulations will affect you. Otherwise, write a couple of sentences about the need for people with HIV to have full access to treatment, regardless of ability to pay.

Thank you for considering my comments as you finalize the regulations.

*Sincerely,
Your Name
Your Address*

P.S. The HIV Medicare and Medicaid Workgroup is a coalition of national, state and local AIDS advocacy organizations, community groups, healthcare providers and universities committed to ensuring that people living with HIV/AIDS have access to appropriate, cost-effective health-

care and drug treatment. The HIVMMWG is an affiliated working group of the Federal AIDS Policy Partnership. The working group is committed to protecting and expanding coverage for people living with HIV/AIDS under Medicare and Medicaid.

The Days Ahead *By Elena Bostick and Julie Frenkel*

The following article was excerpted from the HANJournal, Volume VII, Issue 2, August 2004 with permission of the authors. For a copy of the entire article written by Elena and Julie, contact HANJ (Hemophilia Association of New Jersey) directly: 732-249-6000 or e-mail to: mailbox@hanj.org.

The state of the Nation's healthcare and reimbursement systems has reached a very dangerous point, with no solution in sight.

Triple digit federal deficits, federal cuts to state programs, budget deficits in virtually every state—and everyone looking to make it up on the healthcare dollar. As a result, everyone is scrambling.

In December 2003, the federal government enacted the Medicare prescription Drug Improvement and Modernization Act. If this is Congress's view of improvement—we are in big trouble. Among other provisions, the law calls for the following changes:

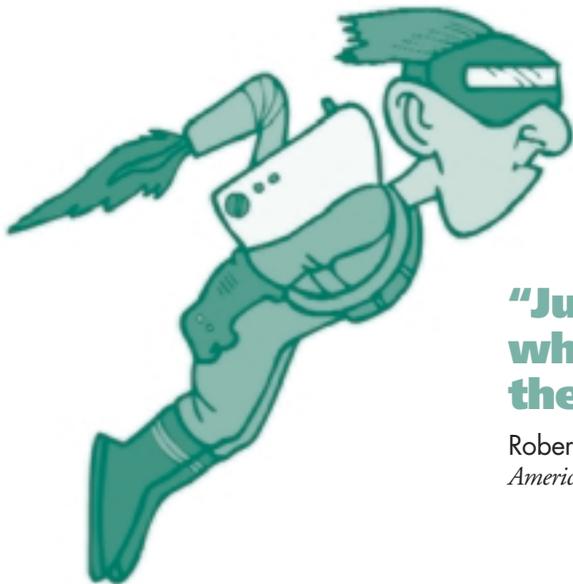
Beginning January 2005, hemophilia therapies will be reimbursed at cost, + 6% + a dispensing fee, yet to be determined. The 20% co-pay that most families cannot afford—remains intact. Homecare companies that had been absorbing the co-pay will no longer be able to do so. The likelihood is that those individuals on Medicare, usually the most vulnerable of our community, will be forced back to the emergency room for treatment.

Beginning January 2006, Medicare Supplemental Insurance policies, also known as Medigap policies, will no longer provide prescription drug benefits. It will be against the law. The federal government's rationale for this is that senior citizens take too much medication. Instead, a prescription drug plan will become available, for a cost, through Medicare. Which drugs will be available on Medicare's formulary is anybody's guess.

Keep in mind, Medicare sets the standard for reimbursement. State Medicaid and private payers usually follow suit.

Government is reducing payments or otherwise restricting access for many healthcare products and services in an effort to balance budgets. Private insurers are doing the same to increase what, in many cases, is an already sizeable bottom line. For the medical insurance industry, the individual policy market is the least profitable of all of their products. Generally, people with chronic illnesses or other health issues, will purchase policies in this market. Some in the insurance industry have reasoned that if they could rid themselves of the individual market, they could maximize profits even further.

P.S. In 2000, strict criteria regarding payers and home-care companies in New Jersey was embraced by the New Jersey State legislature and became law. This is the law which has given the New Jersey hemophilia community protections no other state has. It is the law which has prevented insurance companies from selecting the product you use, from selecting your homecare service provider or from making you switch to a pharmacy benefit manager (PBM), which is a mail order pharmacy providing no support services. This legislation, "Standards of Care for Hemophilia Homecare" is now providing the framework for a national "Standards of Care" that will be adopted, hopefully, in all 50 states over the next years. We thank our dear neighbors and friends at HANJ who have given us the opportunity to build on this model legislation to help others in the United States with hemophilia. YOU ARE INNOVATORS!!



**"Just remember.....
when you think all is lost,
the future remains."**

Robert Goddard (1882-1945),
American Physicist