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The Louisiana Comprehensive Hemophilia Care Center, chased from New Orleans by Hurricane Katrina, has found a wonderful temporary home generously offered to us by the Hemophilia Federation of America. Because the HFA shared their facilities with us shortly after the storm, we were able to bring our staff together and establish a working hemophilia center in Lafayette within a short period of time.

We have been able to regroup as a team and reconnect to our patients, and we very much appreciate the HFA's role in helping us to do that. Because we care for patients from throughout the state, many of our patients were displaced by Katrina and then by Hurricane Rita. Now that we have been able to find most of our displaced patients and let our other patients around the state know where to find us, we're almost back to business as usual.

- Dr. Cindy Leissing, MD

Pictured, left to right: Jennifer Belteau, Accountant; Karen Wulff, RN, Nurse Coordinator; Rebecca Kruse-Jarres, M.D.; Carol deKernion, Medical Technician; Alicia Cole, RN, BSN; Sandra Chiasson, Administrative Assistant; Cindy Leissing, M.D., Director; Sue duTreil, Ph.D., LCSW



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About This Publication

Dateline Federation is a publication of the Hemophilia Federation of America (HFA). It is published four times a year. The material in Dateline is provided for your general information only. We do not give medical advice or engage in the practice of medicine. The HFA recommends that you consult your physician or local treatment center before beginning any form of treatment. Send all comments, suggestions, and article submissions to: Dateline Federation, 1405 W. Pinhook, Ste. 101, Lafayette, LA 70503.

Mission Statement

The Hemophilia Federation of America is a national nonprofit organization that assists and advocates for the blood clotting disorders community.

Vision Statement

The vision of the Hemophilia Federation of America is that the blood clotting disorders community has removed all barriers to both choice of treatment and quality of life.

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Hemophilia Foundation of Maryland
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Texas Central Hemophilia Foundation
Utah Hemophilia Foundation

Remembrance Wall Project

If you are interested in submitting a name for the HFA Remembrance Wall Project, please submit your family member name and year of death to HFA at info@hemophiliafed.org

HFA Steps Up on Behalf of the Community

The mission of HFA as an advocate for the blood clotting disorder's community and its vision, among others, to remove barriers to the quality of life of its constituents, was recently tested by the unprecedented natural disasters that struck HFA's headquarters state, Louisiana.

These disasters had names familiar to all by now—Katrina and Rita. Of immediate concern to HFA were those patients and their families who were immediately impacted along the Gulf coast of Louisiana, Mississippi, Alabama and southeast Texas. In keeping with its history, HFA stepped up and provided immediate response.

As HFA's headquarters in Lafayette, La., were geographically located between the strike zones of both storms, there was no physical damage to our national office, yet lives and landscapes in the entire region have been dramatically changed. The blood clotting disorders community, like nature itself, is resilient and survives no matter what obstacles cross its path. HFA knows that its Gulf coast families and their communities will again flourish and that displaced families, friends and neighbors will be reunited.

In the honored tradition of HFA being all about families in the community, HFA was pleased to offer its family hospitality to the Louisiana Comprehensive Hemophilia Care Center, which was displaced from its traditional venue at Tulane Hospital in New Orleans. HFA learned of this treatment center's need for temporary administrative offices and immediately offered refuge in the HFA office in Lafayette. There is something special about having one's family gather in one location when times call for such support.

HFA has been provided a unique opportunity to learn about and appreciate the type of care and dedication that the treatment center's Dr. Cindy Leissing and her staff extend to their patients. The greatest challenge for the center was locating evacuated patients as well as its inaccessibility to the center's medical records.

Patients are returning to the Gulf coast, and HFA is pleased to have helped facilitate the treatment center in their business of taking care of hemophilia patients. HFA was also successful in procuring clinical space at the Lafayette Community Health Care Clinic for the treatment center professional to meet with and treat their patients in the area. A working hemophilia treatment center in Lafayette was accomplished within a short period of time, and most displaced patients were found. It is almost back to being business as usual, in exile.

THANK YOU to everyone who donated food, toiletries, clothing, dry goods and financial support to HFA and its community in this great time of need. Your response has been unbelievable, and it demonstrates why we are proud to be a part of this community. Evacuation shelters in our area were in desperate need of resources, and you responded with over 100 boxes of goods that were delivered by HFA staff. HFA has dedicated your financial donations to its disaster relief fund to help affected community members with long-term needs and the more costly items as government, emergency and insurance sources become unavailable. Donations to the HFA Disaster Relief Fund may be made via our website at www.hemophiliafed.org.

HFA would also like to thank and commend all of the many community organizations and individuals who collaborated in these relief efforts, as it took the tireless efforts of all involved handling the magnitude of the impact of these storms. HFA especially would like to acknowledge the Lone Star Chapter of NHF, Texas Central Hemophilia Association, the Louisiana Hemophilia Foundation, and the NHF for their active roles in this endeavor. 🇺🇸

Susan Swindle
Administrative Director

HFA Board Member Attends Genetic Alliance Annual Conference



I had the good fortune to receive a scholarship to attend the Genetic Alliance Annual Conference held July 29th through the 31st in Bethesda, Maryland.

This was the third year I attend and I must say that every year the topics and presenters get better and the opportunities to meet others who share the same vision and can offer insight as to best practices and up-to-date relevant information increase in quality and quantity.

The Family History Symposia brought new understanding of the needs of the Underserved and Underrepresented Communities and helped develop a network of representatives of these communities and other national organizations. Learning about the tools to use to draw a genetic family history and the importance of gathering this information in order to use it as a diagnostic and screening tool was stressed.

This made me think about my own family's history and how a precious period has probably been lost forever. There is very little my brothers and sisters know about our past generations medical history other than purely anecdotal accounts which may or may not be able to be verified by medical diagnosis. Both sets of grandparents and their siblings are all gone and with them the past history about the inherited disorders which affect one or more members of the present generations. The wealth of untapped medical history may not be able to be reconstructed but we will certainly try to start now to help the current and future generations with whatever information we can gather during our family get togethers.

The Surgeon General's Family History Initiative was presented and everyone was encouraged to make Thanksgiving the day to gather health information while families get together during the holidays. Encourage families to use every opportunity to share any health concerns and health history and keep records of this information. The Surgeon General has created a tool which can be downloaded at www.hhs.gov/familyhistory to help families organize this information and keep it to alert other family members and their physicians of any diseases that may run in the family.

The workshops presented at the Conference offered such an array of choices which made it difficult to choose but they all had a wealth of information. "The Tipping Point: My Family and My Organization" with presenter: Brigid Guttmacher, Licensed Professional Counselor, united a group of tireless advocates who such as myself were having concerns regarding the delicate balance of time working for your organization and the time spent with your family. This was an open forum where everyone had a chance to express their feelings and try to learn from the shared experiences. It made me think that I was not alone with the thoughts of inadequacy, wanting to do more for either my organization or my family and realizing that sometimes priorities need to be set in order to achieve more and keep our efficiency and our "sanity". This workshop gave all the attendees some ideas on how to react to life changes and to accept the emotions and physical sensations that are associated with adjusting to life changing events.

Another excellent workshop was "Effective Participation in Federal and State Advisory Committees" Elliott Hillback, Senior VP, Corporate Affairs, Genzyme and Treasurer, Genetic Alliance

Board of Directors. He was a very energetic presenter and gave simple and to-the-point advice on how to achieve the goal of being effective when called upon to serve in advisory committees. He gave ideas to think about, why are we committing, be realistic, be ourselves, be prepared, trust our judgment, enjoy the opportunities afforded to us to advocate for our group and all groups. What brings us there, what brings others there? Who are we representing, who are others representing? Could they be our allies? Network and build coalitions early. Be well prepared, have data to backup your issues. Be aware of other peoples' issues. Learn from others, stay focused and prioritize goals. Be realistic and be yourself, be prepared to compromise, don't lose control. Be confident and comfortable, trust your knowledge. Know the strength in your position; you represent the patients and the "real world". Think beyond yourself, be ahead of the discussion, interact, be a quality debater. Network, network, network...try to attend all social or informal sessions and talk with people you don't know but you need to know. Lastly, have fun, don't take yourself or others too seriously and enjoy!

I look forward to next year's Conference as it promises to continue the trend of excellence seen for the last three years I have been privileged to attend.

Maria Rubin,
HFA Board Member
Florida Hemophilia Association



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HFA Advocacy in Action

September Visit to the Hill

During the week of Sept. 19, members of the HFA Advocacy Team visited Washington, D.C. On Sept. 19 and 20, Advocacy Director Jan Hamilton was joined by HFA Advocacy co-chair Jim Romano and Gavin Lindberg of our lobbying firm Health and Medicine Counsel of Washington at the meeting of the HHS Advisory Committee on Blood Safety and Availability. The meeting consisted of a review of subjects covered throughout the year plus action in two other specific areas.

The committee put forth a recommendation to the Secretary of HHS regarding the availability of intravenous immunoglobulin (IVIG) products for persons with immune deficiency and other conditions requiring treatment with this vital portion of the blood supply. Some patients are having problems obtaining the product. However, the main reason is not supply, but rather adequate reimbursement for the product in the proper setting. The final recommendation is currently unavailable but will be made public as soon as possible.

The other important task was a session on strategic planning to set a course for actions for the committee for 2006. The next session is scheduled for Jan. 5 and 6, 2006.

On Sept. 21 and 22, the team was joined by Paul Brayshaw, HFA Advocacy co-chair, and Chad Stevens, HFA Treasurer. The team spent two days visiting about 20 offices of key legislators, thanking them for their assistance in the past and asking for their support of our efforts to ease the 20 percent Medicare co-pay. ■



Pictured, Chad Stevens (sitting) with his Congressman Butch Otter (standing) of Idaho



BOARD MEMBER SPOTLIGHT: HFA Welcomes New Treasurer

Chad Stevens joined the Hemophilia Federation of America Board of Directors in 2004 as a representative of HFA's member organization, the Hemophilia Foundation of Idaho.

He has served as interim treasurer since May and was voted on by the Board of Directors at its September 28, 2005, meeting. Chad has Hemophilia B and is the last survivor of seven relatives with the condition. He has worked with several community organizations, including Partners in Education, Habitat for Humanity, and Paint the Town, an organization in his hometown of Newdale, Idaho.

Chad moved back to Newdale from Boise, Idaho, where he spent 18 years in the banking industry. He has been married to his wife, Jolynn, for 14 years. 📌

Ricky Ray Hemophilia Relief Fund Program Administrative Close-Out


On October 3rd, Hemophilia Federation of America(HFA) received a courtesy call from Paul T. Clark, Director Hemophilia Relief Fund Program, notifying HFA of the most current posting of The Federal Register dated September 29, 2005(Volume 70, Number 188, Page 56926).

The following information is reprinted from the posting:


SUMMARY: This Notice announces the administrative close-out of the Ricky Ray Hemophilia Relief Fund Program (the Program). All business concerning petitions and related payment documentation associated with the Program will conclude on October 31, 2005. As of that date, the Program will cease to accept or process any additional documentation submitted by individuals (or their representatives) relating to the eligibility or payment of petitions still pending. Remaining funds will be returned to the United States Treasury, and the Program will archive all outstanding documentation at the Washington National Records Center in Suitland, Maryland, in accordance with the requirements of the National Archives and Records Administration.

The program awarded compassionate payments totaling in excess of \$559 million to more than 7,171 eligible individuals and survivors. 📌

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Dads In Action

a program of the Hemophilia Federation of America, is partially funded by a generous grant from Factor Foundation of America. The program has made a tremendous difference in the way Dads are interacting with their children. Below is a personal testimony from the program facilitator at Gateway Hemophilia Association, St. Louis, Mo.

My son, Jesse, was born on Valentine's Day in 2001. He is now 4 years old and has severe hemophilia. It is hard to believe the amount of emotions that have transpired in the short period since his birth. Life leads us down many paths. The path of fatherhood is filled with untold joys, unbelievable heartbreak and constant education and expectations.

Fatherhood begins from the time of conception. In my case, the months leading up to Jesse's birth were times of doubt and anxiety. In my circle of friends, I was the crazy one. I was the one who shaved my head, rode a Harley and had the majority of my upper body covered with tattoos. What did I have to offer a child? I felt my physical appearance would be a deficit to any child. What kind of father would I be? Could I even be a father? To be quite blunt, I was scared to death. Who was I kidding? Then to top it off, we learned we would have a son and even better, he was going to have hemophilia. Surely, God had a good laugh when he chose me for such a task. Still, life moves on, and my son was born.

Jesse came into this world as the result of a scheduled C-section to avoid any complications that his hemophilia could cause during natural childbirth. They pulled him from my wife's belly kicking and screaming. I saw him and cried uncontrollably. Through the tears I realized that my fears and doubts were gone. It was now crystal clear I would be the best father I could. Instinctively, I knew that I would love this child, fight for him and do whatever was necessary to ensure his well-being.

The first two nights that Jesse was home, I rested on the floor at the foot of his bassinette. I hardly slept at all. I was constantly checking on him by putting my hand on his chest to make sure that he was breathing. So began six months of pure joy. Each day fresh. I was amazed to see how quickly Jesse changed. Each day he learned something new. And so did I. Most nights I would rock him to sleep while singing to CDs that played in the background. Life has few perfect moments, but these were some of my best. Then at 6 months of age, the specter of hemophilia raised its head.

I guess we always knew the day would come, but nothing can fully prepare you for your child's first bleed. It was such a subtle thing. I was giving Jesse his morning bottle when I noticed he would not hold it like he normally did. Then, BOOM! It hit me. I woke my wife. It became clear that something was wrong. Yet to the untrained eye, we could see no visible signs of a bleed. Still, we called his doctor and prepared to go to the hospital. In the short time that it took to get ready, Jesse's pinky and adjoining finger slowly curled up and would not straighten back out. After a brief exam at the hospital, it was confirmed. Jesse would need his first infusion. After several

attempts at hands, arms and feet, it was determined that the best choice was infusing through the scalp. They were going to stick a needle in my son's head. My wife and I lost it. I could hear my wife's frightened screams as she ran out the door and down the hallway. I was sobbing and out of my mind. Unfortunately, it had to be done. And I had to stay. I have withstood much physical pain, but nothing ever hurt me more than to watch them stick that butterfly into my son's head. In a heartbeat, my six months of joy were replaced with the harsh reality of hemophilia.

Over the next 18 months, it was a scene that was repeated on a regular basis. A bleed would occur. Off to the hospital we would go. My wife would leave the room and I would stay with our son while they infused him. Unlike the first time, I no longer cried. I had to be strong for my son. It worked. Over time, he became comfortable with infusions. In a strange way, it has given us a bond that can never be broken. It got to a point where his infusions could only be done if he were sitting in my lap. I was his safety net. As long as dad was there, it would be okay. Although the infusions became easier, the 45-minute drive to the hospital and the constant fights with ER personnel didn't. So we went to home nursing and having Jesse infused in his own environment.

Using home health care gave us more control over Jesse's disorder. It also changed the dynamics in our family. My wife, now a stay-at-home mom, finally was able to participate in Jesse's infusions. The burden of responsibility slowly shifted from me to her. Gradually and almost unnoticeably, I was left out of Jesse's medical care. We still spent a lot of time together playing and exploring the world. Every place that we took him, he was like a sponge, absorbing all the things that I would tell him about his world and environment. I became complacent with his disorder and focused my attentions on just being dad. That would soon change.

From the beginning, my wife had been involved with the hemophilia community. I, on the other hand, shunned it, seeing no purpose. I was a good father to Jesse and felt that I could handle his disorder on my own terms. Then one day it was determined that I was the perfect candidate for a Hemophilia Federation of America program called Dads in Action. Reluctantly, I was shipped off to Lafayette, La., to be trained as a facilitator for the program.

Before leaving, I had predetermined that I would gain nothing from my trip. I decided I would be courteous and affable at the sessions and come back home no worse for wear. Boy, was I wrong!

Almost immediately after our first session began, I could see that I would be affected and changed by this experience. As I listened and talked with the other fathers, I realized that the term “Blood Brothers” not only pertained to hemophiliacs, themselves, but also to us as fathers of affected children. As things progressed, I realized that I had placed myself on an island and that there was a purpose to being involved. All of us, as fathers, brought shared and unique experiences that helped each of us become more complete. As our discussion continued, I soon discovered that I had failed my son for the mere fact that I did not know how to infuse him. This was something that my wife had been doing for over a year.

I had taken away from my experience at Dads what I needed: the motivation to become more responsible for my son’s medical needs. I made a promise to my “brothers” that within six months I would be infusing my child. It took me only three months. A promise had been fulfilled.

As of today, I am still infusing my son. Probably not as often as I should, but I am a work in progress. I have become more involved in our community and regret only that living life does not allow more dedication to my son’s cause. I have determined that each of us should do what we can, when we can, to support the bleeding disorders community. If each of us did just a small part, in the end the whole would be much stronger. I am writing this article in hopes that it can educate and motivate some other father to become what his child needs. It is a part of my commitment to Dads in Action and a moral responsibility to do so.

LESSON LEARNED: Don’t be afraid to expose your emotions to others who may benefit from your experiences. 📌

Signed,
Jesse’s Dad



Major Changes Coming to Medicare Program

People with Medicare are getting ready for the biggest change to the Medicare program in its 40-year history. Are you ready? This article provides some general information to help you start thinking about what these changes may mean to you.



Senior Health Insurance
Information Program
Ask SHIIP
Doris Higgins
Area Program Manager
Indiana

Medicare Prescription Drug Coverage: The Basics

Private companies will offer Medicare Prescription Drug plans starting Jan. 1, 2006. Everyone with Medicare, including those 65 and older as well as those under 65 with Medicare due to a disability, are eligible for this coverage regardless of income, resources, health status or current prescription expenses. Here are some of the important points to be aware of:

- There is not just one Medicare Prescription Drug plan. Private companies are contracting with Medicare to offer these plans. There will be many plans to choose from. These plans function as prescription insurance that is subsidized by Medicare. This is similar to when an employer pays part of the cost of your health insurance.
- Since these plans function as insurance, they have premiums, co-pays and deductibles. Remember, you will only be paying part of the cost, with Medicare picking up the rest. If you have limited income and resources, extra help may be available to help you pay for your coverage. Read the “extra help” section to see if you qualify.
- Because there will be more than one plan to choose from, it will be important to choose the one that best meets your needs. Plans will be required to cover many different classes of drugs, but they may not cover your specific medications. To help you decide between plans, Medicare has a search tool on its Web site. Are you not on the Internet? Do not despair! You can call Medicare, Senior Health Insurance Information Program (SHIIP), or Resources for Enriching Adult Living (REAL) Services for assistance. See the “finding help” section for phone numbers and Web sites.
- Because joining a Medicare Prescription Drug plan is voluntary, if you want coverage, you must choose and join a plan to receive the benefits. You can join as early as Nov. 15, 2005, for coverage starting Jan. 1, 2006.
- Just like other insurance, if you choose not to join when you are first eligible and later change your mind, you may have to pay a late enrollment penalty. If you already have prescription coverage that is as good as, or better than, the Medicare Prescription Drug coverage, there will be no penalties.

Extra Help for People with Limited Income and Resources

Almost 1 in 3 people with Medicare will qualify for extra help that will cover between 85 percent and almost 100 percent of the costs of their drugs. Most people who are eligible for this extra help will pay no premiums, no co-pays or deductibles, and no more than \$5 for each prescription.

The amount of extra help will be based on income and resources (including savings and stocks, but not counting your home or car). You may qualify if your resources are less than \$11,500 if you are single (or \$23,000 if you are married and living with your spouse). In 2005, if your annual income is below \$14,335 as a single person (or \$19,245 if you are married and living with your spouse), you may qualify.

What you need to do: If you think you may qualify, you should apply. Complete an application for the extra help as soon as possible. You may have already received an application for the extra help in the mail this summer from Social Security. If you need an application, you can call 1-800-SSA-1213 or visit your local Social Security office. Other organizations such as your Area Agency on Aging and will also have them available.

If you qualify, you will also need to join a plan this fall for your coverage to start Jan. 1, 2006. Getting extra help with paying for a Medicare Prescription Drug plan is a two-step process: Step 1: Apply for help. Step 2: Sign up for a plan that best serves you. Remember, help is available with filling out the application and choosing a plan that best meets your needs.

Mark your calendar

Important Dates for Medicare Prescription Drug Coverage

Oct. 2005: Watch the mail for the “Medicare & You” handbook and for information from any current insurers. Look for community events explaining the new Medicare Prescription Drug plans.

Nov. 15, 2005: First day you can join a plan.

Jan. 1, 2006: Coverage begins for those who join by December 31, 2005.

May 15, 2006: Last day to join a plan and receive coverage for 2006. Last day to avoid any late enrollment penalties.

Nov. 15, 2006-Dec. 31, 2006: Annual enrollment for Medicare Prescription Drug plans with coverage starting Jan. 1, 2007.

Who Am I? How will Medicare Prescription Drug Coverage Affect Me?

Look at the five different statements and select the one that best describes you. Then read the text to learn what changes, if any, you can expect with this new coverage, and what decisions, if any, you will have to make. The decisions you make depend on what kind of health care coverage you have now.

“I have Original Medicare only, or Original Medicare and a Medigap (‘Supplement’) Policy without drug coverage.”

If you use an average amount of prescription drugs, Medicare’s new prescription drug coverage could pay over half of your drug costs next year. If you have very high drug costs, Medicare will pay up to 95 percent of these costs after you spend \$3,600 out-of-pocket in a year.

What you need to do: To get this drug coverage, you can join a Medicare Prescription Drug plan. If you do not opt for prescription drug coverage by May 15, 2006, you will have to pay a late enrollment penalty to get drug coverage later.

“I have Original Medicare and a Medigap (‘Supplement’) Policy with drug coverage.”

Medicare Prescription Drug coverage will generally provide significant savings compared to what you are paying in co-payments for drugs under your Medigap plan, and will generally provide much better protection against high drug expenses as well.

What you need to do: Decide if you want to keep your Medigap policy with drug coverage or join a Medicare Prescription Drug plan. Unlike Medigap prescription coverage, most of the cost of Medicare Drug coverage is paid by Medicare and will never run out if you have high drug costs. Also, if you do not join a Medicare Prescription Drug plan by May 15, 2006, you will have to pay a late enrollment penalty to get drug coverage later. If you opt for Medicare Prescription Drug coverage, tell your insurer, and the drug portion of your Medigap policy will be removed. You may also be able to choose from other Medigap policies. Look for a letter from your Medigap insurer this fall outlining your choices.

“I am a retiree and I have drug coverage through my (or my spouse’s) former employer or union.”

Medicare is providing financial incentives to encourage employers and unions to continue to provide retiree drug coverage that meets Medicare’s standards. Your former employer or union may or may not choose to participate. Some employers and unions may also choose to change, reduce or drop their current prescription coverage.

What you need to do: Look for information coming from your former employer or union this fall. This information will explain what changes, if any, they will be making to your prescription drug coverage and what decisions you will have to make. If you do not hear from them, visit their Web site or call your benefits administrator.

“I have Medicare and Medicaid, and I get my drug coverage from Medicaid.”

Starting Jan. 1, 2006, you will get your prescription drug coverage from Medicare instead of Medicaid. The prescription drug coverage from Medicare has no premiums, no deductibles and no gaps, and you will pay very little or nothing for almost all prescriptions.

What you need to do: Starting in the fall, you will need to decide which Medicare plan offers the prescription drug coverage you would like. If you do not sign up for a plan, Medicare will sign you up for one to make sure you do not miss a day of coverage. You can switch to a different plan if you choose.

“I am interested in learning more about Medicare Advantage (Managed Care) Plans.”

Starting in Jan. 2006, everyone with Medicare will have the choice of at least two managed care plans. Private companies will contract with Medicare to provide all your medical services. Medicare Advantage plans usually give you extra benefits and/or lower costs, but only if you use the doctors and hospitals that participate in the plan’s “network.” It is expected that many of these plans will also offer their participants Medicare Prescription Drug coverage.

What you need to do: Look for more information from Medicare and the Medicare Advantage plans this fall. You will then be able to compare the plans to your current coverage and costs.

What You Can Do Right Now to Make an Informed Decision About Medicare Prescription Drug Coverage

- Gather information about your current coverage for health care and prescription drugs. Make sure you know what coverage you have now.
- Gather information about the drugs you use, including their names and dosages.
- Remember the key Medicare dates.
- Apply for extra help if you think you might qualify.
- Watch for the “Medicare & You” handbook arriving in your mail. Read it carefully and ask questions about anything you do not understand.

Finding Help

Got a question? Need someone to walk you through it? Help is available!

Medicare: Medicare has operators available 24/7 to answer your questions at 1-800-MEDICARE. You can also visit their Web site at www.medicare.gov.

SHIIP: Volunteers provide free and local personalized counseling. Call 1-800-452-4800 for the site nearest you.

Sources: Medicare publications #11146 & #11105. ■



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Brian Craft – A Tribute



Brian Craft, a real life inspiration to everyone and particularly to the bleeding disorders community, passed away on July 12, 2005. He was 57.

Brian was born on August 20, 1957, he had severe Factor VIII hemophilia. In the early 80's, he contracted HIV infection from blood products and later on contracted Hepatitis C. Despite this, Brian did not let himself fall into despair. As a comedian, Brian lived his life by finding humor in just about everything. Finding comfort and inspiration in comedy, he first tried his hand at a local Fort Lauderdale, Fla., comedy club in 1979 and was "hooked."

Over the next couple of years, Brian performed regularly, and in 1981 he met Kelly, who later became his wife. Kelly had been living in California and working as a television actress, appearing in such shows as "Archie's Place," "Soap," and "WKRP." She also was a skilled comedy writer and had returned to her hometown of Fort Lauderdale because she was considering starting a comedy school.

While making the rounds of local comedy clubs, Kelly met Brian. Kelly began to teach Brian comedy acting, and later on agreed to manage him. They went on the road together, fell in love and married.

A Partnership With a Vision

One of the couple's goals was to own a comedy club. From 1988-1992, they operated ComedyLand, Inc, in Anaheim, CA. Before this, however, as they crisscrossed the United States (including Alaska and Hawaii) and Canada with Brian's act, they would run fund-raisers for the National Hemophilia Foundation (NHF). They would let local NHF chapters know when they would be in town and made arrangements with club owners to hold benefits.

It was during this time Kelly persuaded Brian to begin including hemophilia material into his act, even though it was risky because it was personal. Taking this risk affected Brian's life in unexpected ways, initiating a period of self-exploration for the couple in which they began attending a series of workshops on leadership, goal achieving and communicating without judgment. This experience led the Crafts to reorient their mission to helping those with difficulties in life, especially chronic conditions such as hemophilia, and deal with their challenges in a positive way.

Until Brian's passing, the Crafts conducted workshops together on various aspects of chronic conditions, from coping with stressful situations to using humor to deal with grief. The goal of presenting the workshops was to effect positive change in others' lives by lessening stress and creating a positive outlook.

Kelly says, "Brian Craft gave hope (to those with bleeding disorders) in the '80s and '90s when there was none. He showed folks how to laugh when they thought no humor existed."■

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FRIEND

The Coalition for Hemophilia B

Bruise Buddy

Our two-year-old son Nathan, who has severe hemophilia B, was about three months old when he began being cared for by his Granny a couple of days a week. Hemophilia with all of its symptoms was all very new, and in those early, less experienced days, every bump and bruise was cause for us to worry and for Granny to panic.

Every time Nathan went to Granny's house, we would relate the site and status of each bruise so that she would be aware if an old bruise became reinjured or if a new bruise appeared that may need to be iced. This worked well for a time, but as my son grew and began to crawl, the number of bruises sometimes became overwhelming and difficult to keep track of. Bruises in various, colorful stages of recovery often overlapped each other and began appearing in places covered by clothing. Simply telling Nathan's caregiver about his bruises quickly became ineffective. We also began to become concerned about how Nathan would feel as he got older about being publicly scrutinized and inventoried for bruises.

So we created a "bruise buddy." We went online and found a clip art of a simple body outline and printed it out twice. We trimmed the pictures down to about the size of a playing card and taped them together back-to-back, labeling each side "front" and "back." We then had the card laminated and punched a hole in the top corner of the card for a string, which we attached to the diaper bag. With the bruise buddy, we simply used a wax pencil or dry erase marker to indicate the size and location of Nathan's bruises, and we were able to do this in the privacy of our own home usually during his morning diaper change before taking him to Granny's house. Still very young, Nathan never even noticed the card.

In the last two years, Nathan has experienced joint and other major bleeds, which has helped us place bumps and bruises in their proper perspective, but we continue to use the bruise buddy occasionally and it was certainly invaluable to us in those early times. We believe that the bruise buddy has helped Nathan feel more like any other little boy going over to Granny's house to play.

Hope the idea helps you, too!

--Jennifer Mermilliod

Article provided courtesy of

Hemophilia Foundation of Southern California



INDUSTRY NEWS

WYETH Pharmaceuticals Initiates Clinical Trial of Investigational Albumin-Free Recombinant Drug for Hemophilia A

-- Implementation of a Novel Protein-Free Purification Technology

Has Potential to Be an Advance in Pathogen Safety

for Factor VIII Therapy --

Madison, N.J. (August 5, 2005)—Wyeth Pharmaceuticals, a division of Wyeth (NYSE:WYE), today announced the initiation of a new clinical trial of an investigational recombinant factor VIII drug. This investigational drug is produced from a completely albumin-free cell culture manufacturing process. In addition, the production of this investigational drug includes a purification process free of any biologically derived materials, and the addition of a viral filtration step for added viral safety. If you are interested in participating in the trial, contact your local treatment center, or visit www.clinicaltrials.gov.

NOVO NORDISK - Talk about inhibitors

Individuals with hemophilia and inhibitors, their family members, and healthcare providers will soon gather at a much-needed meeting dedicated to making living with an inhibitor much easier for all those affected. With an agenda developed by individuals with hemophilia and inhibitors, advocates, and hemophilia treaters, the meeting promises to educate, generate ideas, and promote greater unity within the inhibitor community. The Inhibitor Patient Education Summit, sponsored by Novo Nordisk, will be held on **November 5–6, 2005**, in Philadelphia, Pennsylvania, at the Courtyard Marriott Downtown. For more information about this educational event, including available on-site childcare and travel grants, call 1-888-706-6867 or visit www.inhibitorsummits.com.

BAYER Receives FDA Approval for Room Temperature Storage of Kogenate® FS

Extended storage labeling provides greater flexibility for individuals living with hemophilia A

BERKELEY, Calif. (Oct. 6, 2005)— The Biological Products Division of Bayer HealthCare, LLC., (Bayer BP) announced today that Kogenate® FS (Antihemophilic Factor [Recombinant], Formulated with Sucrose) received approval to be stored at room temperature (77° F, 25°C) for up to three months. The new storage guidelines for the treatment will provide users with greater flexibility and simplify storage options.

Starting in November 2005, each package of Kogenate® FS will include a special notification with details on the new labeling. While the new room temperature storage option may be used, Bayer recommends refrigerating (36° – 46°F, 2° – 8°C) Kogenate® FS whenever possible. It also is important to note that product stored at room temperature should not be returned to refrigeration. Kogenate® FS users who may have additional questions about storage requirements for their existing product inventory should call Bayer Clinical Communications at 800-288-8371 (option 3). ■

Chapter Chat



HEMOPHILIA ASSOCIATION OF THE CAPITAL AREA

Upcoming Events:

October 8th Blood, Sweat, & Gears Bike-a-thon along the W&OD. Ride originates from the Reston YMCA. Call 703-352-7641 for more details

December 4th Holiday Party on the Holly Trolley. Tour downtown DC like the tourists--see the National Christmas Tree and the Pageant of Peace Trees and end the day with dinner at Country Buffet. Call 703-352-7641 for more details.

HEMOPHILIA OF INDIANA

Upcoming Events: For additional information, call (800) 241-2873 or log on to www.hemophiliaofindiana.org

TEXAS CENTRAL HEMOPHILIA ASSOCIATION

Announcements:

The Texas Central Yellowjackets from Texas Central Hemophilia Association, Inc. was one of the winners of Camp Superfly and was awarded a \$20,000 grant from Baxter to use for their summer camp program.

Upcoming Events:

Dec. 4: Annual Holiday Party--1 to 4 p.m., Southwest Airlines Corporate Headquarters, Dallas.
For additional information regarding these events, please contact Texas Central at (214) 654-4595.

HEMOPHILIA FOUNDATION OF ARKANSAS

Upcoming Events:

Dec. 10th - Christmas Party - 1 to 4:30 p.m., Catfish Barn , Ratcliff, AR.
For additional information on these events, please call the Chapter at (501) 851-3109.

FLORIDA HEMOPHILIA ASSOCIATION

Upcoming Events:

Swing for the Kids -- Golf tournament November 30, Plantation, FL
Holiday Duo - December 17 Pembroke Pines, FL

LONE STAR CHAPTER OF THE NHF

Announcements:

The Lone Star Chapter of the NHF was the Grand Prize winner of Camp Superfly and the recipient of \$30,000.00 to fund Camp Ailhipomeh.

Upcoming Events:

1st Annual Lone Star Chapter Family Camp
September 30th-October 2, 2005 at Camp for All
in Burton, TX



HEMOPHILIA FOUNDATION OF MARYLAND

Upcoming Events:

Bull & Oyster Roast
Saturday, October 22, 2005
Parkville American Legion

Annual Sylvia Ward Memorial Holiday Party
Saturday, December 17, 2005
Oregon Ridge Park

NEBRASKA CHAPTER OF THE NHF

Upcoming Events:

November 11, 2005 – Golf Tournament – North Forty in Lincoln, NE
Profits will be used for national research & to support community families impacted by recent hurricanes.
November 12, 2005 – Educational Conference – Mahoney State Park

HEMOPHILIA FOUNDATION OF NEVADA

Upcoming Events:

October 15, 2005-Annual Patient Family Information Day Las Vegas
October 16, 2005-5KRun One Mile Fun Run/Walk-Las Vegas
October 17, 2005-Annual Board/Fundraising Committee Meetings
November 4-5, 2005- von Willebrand Women's Retreat Las Vegas
December 2005-Holiday Gathering-Las Vegas (to be announced)
December 2005-Holiday Gathering-Reno (to be announced)

THE HEMOPHILIA FOUNDATION OF ILLINOIS

Announcements:

The Hemophilia Foundation of Illinois held our 8th Annual Driving for Hemophilia on September 21st. Thanks to the generosity of our community, we were able to raise \$90,000 for our programs and services.

Upcoming Events:

The Board of Directors is holding a planning retreat in October. The Board will make a number of decisions at this meeting that will strengthen service offerings to people living with bleeding disorders in the state of Illinois. We will share the results with our constituents in the Winter FactorNet (our newsletter) that will be released on November 15.

HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA

Upcoming Events:

Wednesday, October 5th at 8:00 pm
Theater on High Street
45 E High Street, Moorepark 93021
Tickets: \$25 (tax deductible)
Telephone: 805-529-3786

The Rotary Clubs of Newbury Park, Moorpark and Bucharest-Athenium and S.T.A.R. Children Relief Org. are presenting: INTER-ART – A Romanian contemporary music and dance company on tour in LESS BORDERS; Dancers and musicians interweave with fluidity and drama a show about crossing cultural boundaries. The company is dedicating this special performance to children with hemophilia in Romania

All HFA member organizations are encouraged to post upcoming events and can do so by contacting s.swindle@cox-internet.com. HFA will also post a brief recap or promotion of events occurring in your area.

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IN ONE OF THE FOLLOWING WAYS:

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