

HACA News

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Mission Statement

HACA's Vision is to improve the quality of life for persons and their families affected by bleeding disorders.

HACA's mission is to:

- ◆ *Educate, support and advocate for persons with bleeding disorders and their families.*
- ◆ *Network with healthcare professionals.*
- ◆ *Increase public awareness.*

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Celebrate HACA's 40th

40 years ago, HACA was officially recognized as a member chapter of the NHF. The official date on our charter is August 1, 1964. To celebrate this milestone, HACA's Board of Directors extends an invitation to all the members, former members, and supporters of HACA to attend a "family" picnic on the 6th of June. Final arrangements for site and time are currently being solidified. In the meantime, please put this event on your calendar and make plans to attend this family reunion and celebration.



DC Hemophilia Open

Under the able direction of Cliff Krug, Jr., the May 17th DC Hemophilia Open at Ft. Belvoir is shaping up to be a great day of golf followed by a delicious steak dinner and by live and silent auctions. Participation as a golfer includes greens fees, cart, range balls, and course refreshments. The format for the tournament will be best ball scramble with prizes for the longest drive and closest to the pin. This year, Reynolds Auto Center in Orange, Virginia will donate a Pontiac Grand Prix to the lucky golfer with a hole in one. Ruth's Chris Steak House in Fairfax Corner will also be donating a fantastic steak dinner to the winner of our putting contest. You can do your part to help Cliff make this event a success in the following ways:

- 1) On pages 10 and 11 in this issue of HACA News, you will find a letter of invitation and a registration form for this event. Please share the invitation and registration with friends of yours who might be golfers and urge them to take part in this event.
- 2) If you are a golfer, consider taking Monday, May 17th off from work and plan to join us.
- 3) If you are unable to golf during the day, join us at the bargain rate of \$25 for a delicious steak dinner and a fun evening at the auction.
- 4) You could donate items for the auction or the silent auction.
- 5) You could volunteer to help with registration, setting up the silent auction, monitor the hole where the free car contest is held, or a myriad of other activities.

Please contact us at 703-352-7641 to offer your services or if you have any questions.

Blood Buddies

Blood Buddies, a group for young people with bleeding disorders between the ages of 13 and 20 has been revived after a year's hiatus. Under the direction of Paul Brayshaw and John McNeil, the group gathered on February 29th for a Bowling Bash. The next event, a Rock Climbing Expedition is planned for May 2nd from 2:30 to 6 at SportRock 2 on Eisenhower Avenue in Alexandria. Participants will have 2 hours of instruction followed by 2 hours of free climb. Reserve the date on your calendar, call us at 703-352-7641 with your e-mail address, and watch the mail and e-mail for more details.

Chapter News continued

Bruise Brothers

Bruise Brothers, a group for young people with bleeding disorders (and their parents) between the ages of 7 and 12 held their second meeting on April 3rd. While the young people worked with the art instructor at the Children's Studio Charter School, the parents had a chance to address issues that affected them and their children. Future events planned for this group include a trip to the Smithsonian Transportation Museum and a sleep-over with the sharks at the Baltimore Aquarium. If, by chance, you did not receive an invitation to this event and your child fits the age criteria, please contact the HACA office at 703-352-7641 so you can be added to the mailing list.

Lawrence Maderios Scholarship Fund

Positudes, Inc. announces that applications are now available for the Lawrence Maderios Scholarship Fund. Awards will be made to graduating high school seniors, living with a chronic disorder and continuing their educations at an accredited college or university. Applications may be obtained from the Positudes office at 518-863-2668 or from the HACA office at 703-352-7641. Applications must be post-marked no later than *June 16th, 2004*.

Other Scholarship Deadlines

Just a reminder that the deadlines for scholarships are as follows:

Wyeth—Soozie Courter Scholarship—April 15, 2004
 Factor Support Network Pharmacy—Mike Hylton & Ron Niedermann Memorial—April 30, 2004
 Hemophilia Health Services—Memorial Scholarship—May 1, 2004
 Hemophilia Health Services—Scott Tarbell Scholarship—May 1, 2004

2004 Board of Directors Meetings

General Board Meeting
June 7, 2004

General Board meetings begin at 7:00 p.m. and are open to all interested HACA members. Because of security regulations at our meeting place, please notify the HACA office that you will be attending. Directions and site will be shared with you at that time.

NHF's Washington Day

On March 11th, six members of HACA made visits to Senators Allen & Warner, and to Representatives Davis, Moran, and Wolf's offices. The visitors were looking for a senator to introduce a companion bill and asked our representatives to agree to co-sponsor House Congressional Resolution 314 which calls for:

- Appropriate screening for women and girls with excessive menstrual bleeding prior to the initiation of treatment.
- Evaluation prior to hysterectomy to rule out the possibility of a bleeding disorder.
- Referral of women with a bleeding disorder to a federally-sponsored hemophilia treatment center for comprehensive treatment.
- Strengthening of public education and outreach campaigns.
- Increased funding for research to improve diagnostic testing and treatment.

The visitors also asked their Congresspersons to become co-sponsors of S. 1143/H.R. 3539, the Hepatitis C Epidemic Control and Prevention Act. This legislation is needed to promote a comprehensive, coordinated effort for preventing and reducing the impact of hepatitis C. The bills also address the need for improved treatments for hepatitis C.

Calendar of Events

- April 17—vWD Workshop at George Mason University
- May 17—DC Hemophilia Open - Ft. Belvoir-2 pm
- June 6—40th Anniversary Celebration
- June 10-17—Summer Camp in Ashford, CT
- September 18—HACA Annual Meeting/Educational Seminar
- October 16—Hemophilia Half-Hundred

Virginia House Bill 935, Consumer Choice Benefits Plan Act

By *Susan Yamamoto, HACA President*

House Bill 935 was introduced during the 2004 Virginia Legislative Session by Daniel Marshall III, R-Danville, a small-business owner and Virginia Assembly Delegate. Del. Marshall claimed his bill would provide small businesses the opportunity to offer "mandate-light" health insurance to their employees at less expensive rates. This bill was presented as being about consumer choice and cutting health care costs; let the people decide what they want and it will give more Virginians the opportunity for health care coverage.

Virginia law currently requires most health plans to include 27 mandated services, including: cancer screening, diabetes care; hospice care; obstetrical care; childhood immunizations; infant hearing screening and hemophilia care. This bill would allow insurance companies to select which mandated benefits they would cover. On February 17th, this bill flew through the House of Delegates and was approved by a margin of 97-2 and was referred to the Senate Commerce and Labor Committee for action.

HACA and the United Virginia Chapter of NHF joined forces, along with other affected consumer groups, and successfully stalled this legislation for the 2004 session. The bill has been referred to the legislature's Special Advisory Committee on Mandated Health Insurance Benefits for study.

The efforts of many chapter members in writing letters, calling their representatives and the members of the Commerce and Labor Committee, personally making visits to the Senators' offices on March 4th, and presenting testimony at the public hearing of the Commerce and Labor Committee sent a very strong message that this bill was not in the best interests of the citizens of the Commonwealth. An amendment to the bill was approved by the committee continuing hemophilia coverage as a mandated benefit.

After the hearing, Del. Marshall said a lot of the testimony was based on a misunderstanding of what the bill would allow. He plans to work the measure over the summer and bring it back next year.

Our next step is to make our voices heard by the members of the Special Advisory Committee on Mandated Health Insurance Benefits. We will be in touch with chapter members to prevail upon you to once again fight to insure coverage for hemophilia and bleeding disorders.

NHF Update

On February 28, 2004 members of National Hemophilia Foundation's (NHF) Medical and Scientific Advisory Committee (MASAC) sent a letter to the NHF Board of Directors advising the Board that members of MASAC had "grave concerns about the direction of the NHF under the leadership of the Board. They felt that recent decisions by the Board have been detrimental to the NHF—impairing its interaction with various constituents, including government agencies, treatment center, chapters and donors—and compromise the organization's ability to carry out its mission of research, education, and advocacy on behalf of the bleeding disorders community."

MASAC demanded that certain conditions be met before the conclusion of the March 13th Board meeting, or MASAC threatened to "resign immediately and to reconstitute themselves in an alternate venue in order to continue to provide expert medical and scientific advice, issue recommendations for treatment, and set standards for care on behalf of the worldwide bleeding disorders community."

The situation with MASAC was further complicated by the resignation of Gary Henn who was functioning as the interim Executive Director of NHF while a search was being conducted for a permanent Executive Director.

With these scenarios in the background, the NHF Board of Directors met on March 13, 2004 here in Washington, DC. Seven members of that Board of Directors removed themselves from the Board at that meeting. Three members of MASAC who were also sitting members of NHF's Board of Directors also removed themselves from the Board. The following letter from the newly elected president, Richard Metz, M.D. has been posted on the NHF Web Site and sent to all chapters and people who are on the NHF list serve:

On March 13, 2004, the National Hemophilia Foundation Board of Directors voted to expeditiously engage the hemophilia and bleeding disorders community in convening a caucus to effect the reorganization of the governance of the foundation. The caucus will include representatives of the stakeholders in the community. The purpose of the caucus will be the creation of a new board of directors for NHF that will replace the existing board. Some current board members have volunteered that they will not serve on any newly constituted board of directors. These actions are intended to reestablish the confidence of the community in NHF to carry out its mission and vision.

During the meeting of the NHF board on March 13, Richard Metz, MD, was elected president, Andra James, MD, as secretary and Bruce King as treasurer. These officers serve at the pleasure of the board and may be replaced by the new board once it has been constituted.

Immediately following the board meeting, a transition team was formed comprised of board members and community members. The team then formed four subgroups with the respective tasks of evaluating the needs of various key constituencies within the community, addressing organizational issues, improving communication and determining and implementing a process for the selection and long-term retention of a new CEO. A tentative date of March 31, 2004, has been set as a deadline for each subgroup to have

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18 TIMES TO CALL A.C.C.E.S.S.

Timing is Everything

As we go about taking care of our families and managing our careers, it's easy to forget that many of the choices we make can have an effect on our health care coverage. All too often, we don't realize that there may be a problem until it's too late. It is critical that we recognize those times and situations where our access to health and disability benefits may be affected.

For more than a decade, Hemophilia Health Services' A.C.C.E.S.S. (Advocating for Chronic Conditions, Entitlements and Social Services) has been helping the bleeding disorders community navigate the often complex maze of state and federal entitlement programs. They will also help you understand your rights to continuation of group health coverage based on federal laws and your eligibility for health insurance through state high-risk pools and other alternatives. They represent people in the community in Social Security Disability and Supplemental Security Income claims without regard to choice of provider and free of charge. Based on their experience in answering questions, they developed the following list of situations where you should consider your options and ask questions.

I quit my job

I lost my job

Most of us get our health insurance through our employer. If you change your employment for any reason, COBRA can help you maintain insurance until you are eligible for a new group policy under your new employer's health insurance plan. In addition, HIPAA may allow you to further continue your health benefits if your new employer does not offer health insurance benefits.

When you quit or lose your job due to your medical condition, disability may be an issue. This is the time to think about applying for Social Security Disability or Supplemental Security Income.

I got a new job

A new job may or may not offer group medical coverage or a new employer's medical benefit package may not provide the same coverage as your prior benefits. COBRA can extend your existing insurance from your prior employer's policy to continue coverage until your new employer's policy takes effect. HIPAA may help by insuring that you do not have to undergo a new pre-existing condition waiting period under your new coverage.

I'm looking for work

Looking for work is often a stressful time, made more

stressful when you are concerned about maintaining continuous health insurance. COBRA and HIPAA may help keep you insured regardless of the time period between jobs. COBRA can provide a vital bridge between employer policies when you have a gap of no more than 18 months between jobs. Even if you are unemployed beyond the 18 months of standard COBRA coverage, HIPAA may help by ensuring the availability of an individual policy.

I am no longer able to work

Deciding that you are no longer able to work full-time due to health concerns is a very difficult decision to make. Before you leave your job, you will need to know how federal disability programs decide if you are entitled to benefits. You will also need to think about how to insure continued access to health care for yourself and your family.

I'm about to lose my health insurance

I'm about to use up my health insurance

I just lost my health insurance

There are many different circumstances that may cause someone to lose their health insurance, from losing a job to capping out on your lifetime maximum. COBRA and HIPAA may protect your rights to an insurance policy, or you may be eligible for a high risk insurance pool or for other entitlement programs. It is always best to investigate your options **before** you lose your insurance to assure continuous coverage.

I can't get health insurance

It is often difficult to obtain a new insurance policy if you have a pre-existing medical condition and are unable to work. When you qualify for federal disability entitlement programs, such as Social Security Disability and Supplemental Security Income, you frequently gain access to health coverage from Medicare or Medicaid. When you cannot get health insurance because your employer does not offer health care benefits, state programs, as well as COBRA and HIPAA may offer a solution for you.

I just got married

Both COBRA and HIPAA provide certain protections to newly married couples and their minor children. Under COBRA, marriage is considered a qualifying event that triggers certain rights. HIPAA also protects a new spouse and minor children under an employer's health insurance benefit package. Getting married may also impact your access to certain state and federal safety net programs, such as Supplemental Security Income and Medicaid. It is important to consider these issues before

your benefits change in order to understand how you and your family may be affected.

I just had a child or adopted a child

Newborns and newly adopted children are specifically protected under both HIPAA and COBRA. Although you must be certain to meet specific deadlines to enroll them in your group health insurance policy, they are guaranteed coverage with no pre-existing condition exclusions. Also, Medicaid may be available for a child in the household where it would not be available for an adult. The criteria for children seeking Medicaid are often different than the criteria for adults seeking Medicaid.

My child has lots of medical bills I can't pay

Finding health care coverage for a child with high medical costs can be a daunting task. Supplemental Security Income and/or Medicaid may be a solution. Many states also offer high-risk pools for those who cannot obtain health insurance elsewhere. It is important to sort through the possible solutions to determine which one works best in your situation.

My child just turned 18

My child is about to leave for college

COBRA provides special protections for continuation of coverage under a parent's group health care policy when a covered minor child loses dependent status. Also, when a disabled child turns 18, their eligibility for Supplemental Security Income may change.

My spouse stopped working

If your spouse is moving from one job to another and you received your health care coverage through your spouse's employer, COBRA can help you maintain coverage until your spouse gets a new job with benefits or until you are considered eligible for the protections of HIPAA. If your spouse stopped working due to a medical condition, you may be able to keep your COBRA coverage for an extended period. HIPAA and COBRA interact to protect you and your family's access to health care coverage when your spouse stops working. If you are disabled but did not meet the financial guidelines for Supplemental Security Income while your spouse was working, benefits may be available to you if only for a limited time while your spouse is not working.

I'm getting a divorce

As with so many life changing events, divorce is often a very stressful time. Both COBRA and HIPAA have provisions to protect the health insurance rights of the persons getting divorced and any minor children in the family. Also, if your household income and assets are affected by the divorce, you or your disabled child may meet the financial guidelines for Supplemental Security Income or Medicaid.

I'm moving

Whether you are moving within the same city or to another state, it is important to notify the appropriate agencies in order to insure uninterrupted continuation of your federal or state entitlement benefits any time you move. Moving may also impact your access to health care under your current insurance policy. COBRA and HIPAA may provide some protections. Before you move, look into how COBRA and HIPAA may be able to help you maintain continuous access to health care coverage.

Where to Get Help

Remember that the protections provided by federal law can only help you if you know what they are and how they work. A.C.C.E.S.S. provides information and counseling to help you understand these issues.

A.C.C.E.S.S. representatives can outline federal disability programs, as well as how COBRA, HIPAA, Medicare and Medicaid intertwine with the disability process. They can help you decide if filing for Social Security Disability or Supplemental Security Income is right for you. They offer representation to persons with certain disorders throughout the disability process. Their program can also explain what protections you may have under COBRA and HIPAA when moving from one health insurance policy to another.

Call A.C.C.E.S.S. toll-free at (888) 700-7010 when you need help understanding how life changes may affect the availability of health care coverage or other important benefits for you and your family. The professional staff will be happy to help you make the choice that is best for you.

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NHF Update (continued)

completed their recommendations and for the entire team to convene as a whole. At that time, a date for the caucus will be set and logistics will be determined and communicated to the entire community. In addition, I am personally committed to keeping you and all members of this community informed as this transition process goes forward.

As a group of individuals entrusted with the responsibility of serving the needs of this community, we understand that we must not lose sight of our mission, vision and goals. A strong, committed and well-organized NHF, working with the entire community, offers the best hope that we will continue to have better treatments, and one day, a cure for hemophilia and other bleeding disorders.

Sincerely,
Richard Metz, MD
President

Another Option for Venous Access in Children with Hemophilia

By: Leonard A Valentino, MD., Beverly D. Dooley, B.S.N., P.N.P, Audrey Taylor, B.S.N., Debra Honig, M.S.W., L.C.S.W., Gladys Lee, M.B.A., Walter J. McCarthy, M.D. From: *The Parent Empowerment Newsletter*, May 2003

Parents of young children with hemophilia face a challenging decision—how best to access small veins? Parents need to determine a plan for therapy with your doctor and nurse and decide how best to administer factor to your child. You may choose episode-based factor infusions in response to each bleed (“on-demand”). Or, you may choose prophylaxis—regular preventive injections when your child isn’t bleeding. Learning to give factor at home can be stressful. Yet, once this skill is mastered, families feel a sense of freedom, independence and empowerment.

Traditionally, parents of children who need regular factor infusions, whether for prophylaxis or immune tolerance therapy, have two options to deliver factor. First, they can use a simple needlestick with a butterfly needle (a process also called “peripheral venous access”). Increasingly, parents have opted for the second choice: the placement of a central venous access device (CVAD), such as Broviac, Hickman or Port-a-Cath. But for many parents, these two traditional choices present a problem. Enter the AV Fistula, a third option for accessing your child’s veins. It’s not a port or other implanted device—it’s a surgical procedure that creates an enlarged, natural vessel that parents can access more easily. It’s new to the hemophilia community, and it’s worth exploring if your child has difficult-to-access veins, and you are not comfortable with the current options for venous access.

Problems with Traditional Options

Unfortunately, even with the best of care, complications may still arise. In newborns, young babies and even toddlers, veins are often difficult to see and enter with a needle. Nevertheless, a group of experts convened in Washington, D.C. to discuss the uses and problems of CVADs concluded that injection in the veins of the arms or hands (peripheral veins) is highly desirable, and should be the first choice for venous access in a child with hemophilia. This conclusion was based mainly on the high rate of infection that occurs with CVADs.

Further raising concerns, deep-vein blood clots related to CVADs are reported with increasing frequency. When peripheral venous access is difficult, and limits the ability to provide optimal care, parents may want to consider an alternative to CVADs. At RUSH Children’s Hospital in Chicago, we have chosen to offer the AV Fistula as an option for families with hemophilia.

The Arterio-Venous Fistula

The AV Fistula is a surgical procedure resulting in the enlargement of a vein, usually in a child’s upper arm, so that parents can gain easy venous access by a regular

needlestick. To create an AV Fistula, the surgeon establishes a connection between a selected artery and vein. As the AV Fistula “matures” after surgery, this connection promotes the growth and enlargement of the selected vein.

These AV Fistulas are “natural,” and do not involve synthetic implants. Because no device or foreign body is used, the risk of infection is very low. On the other hand, the vein and artery used are quite small, and occlusion or fistula thrombosis is a possibility. The risk is estimated at not more than 5%, or one in 20 cases.

Once the AV Fistula is created, there is a six to eight-week waiting period, during which the vein matures and becomes ready for use. Until then, factor is given through a PICC line (a tube, or catheter, inserted into an arm vein) that is placed at the time of surgery. The AV Fistula surgery can be “reversed” if there are complications or cosmetic concerns. (An AV Fistulae may be barely noticeable or an obvious lump under the skin.) If the vein fails to mature, no intervention is required.

This procedure requires a skilled surgeon with experience in AV Fistula placement. Your surgeon should carefully explain all the risks, benefits and alternatives. The entire process takes about three hours in the operating room with anesthesia. The surgeon isolates the selected vein and artery, and connects them—creating a “short-circuit” path for blood to flow, so that arterial blood flows into the vein, and to the hand below the AV Fistula. This results in the enlargement and thickening of the vein wall, so that it can be seen, felt, and accessed repeatedly. So far, when used in kidney dialysis patients, there is no apparent problem related to the “mixing” of venous and arterial blood.

The AV Fistula is not new to hemophilia. The first one was placed in a hemophilia patient in the early 1970s. Still, we do not yet know the long-term effects, and whether a patient will experience circulation problems later in life. Currently, this procedure should be reserved for patients who have failed traditional forms of venous access, or are participants in clinical research to collect data on the effectiveness of the AV Fistula procedure.

Hemophilia is an expensive disorder. Families don’t need the financial burden of unnecessary surgical procedures. Therefore, the need for “artificial” venous access (placement of a CVAD or AV Fistula) must be clear. Third party payers have traditionally covered the costs of placing a CVAD or AV Fistula. AT RUSH, the average cost,

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Opening Hearts, Opening Homes

By Nathalie Smith, RN, and Tim Mulherin, MA, MSN

A Mother's Tale

Blood is a special concern for children with hemophilia, but bloodlines don't seem to matter when a child finds acceptance in a loving home. Just ask Pat Lewis, who with her husband Joseph learned 40 years ago of a seven-week-old-boy with hemophilia who was available for adoption. "I called our family physician," recalls Pat, "and he assured me that having hemophilia was similar to being a diabetic, and that the condition is easy to control with medication."

Fortunately, there were few bleeding events for their adopted son, except for a hamstring hemorrhage and a fair number of nosebleeds. Having a child with hemophilia ultimately inspired the Lewises to become activists in the hemophilia community. Pat and her sister Katie founded the Indiana National Hemophilia Foundation Chapter 37 years ago, and the Lewises served on the chapter board for more than 30 years. She says now that the bottom line in becoming adoptive parents, whether to a chronically ill child or not, is "to love children and want to make a difference." And, she adds, "only unconditional love will do."

There's Always Hope

In 1996 Tim and Janet Mulherin became foster parents to a 13-year-old boy named Chris who had severe factor VIII deficiency hemophilia. Chris didn't want to have hemophilia, and he didn't ask to be a foster child, either. He often tried to forget his condition, even to dangerous extremes: once, for nearly a month, he skipped taking his prescribed factor dosage at school. Chris is a talented artist, and often expressed himself through drawing and poetry. Much of this work was dark and painful, but it was the willingness to deal with his demons that counted. In all, the Mulherins cared for Chris for more than three years. Two more years and numerous hard living experiences later, he is now adjusting to independent life as a young adult. Through an assisted living program, Chris lives in his own apartment, but he will never be entirely self-sufficient and now welcomes the support he receives from his foster parents. Foster and adoptive parenting is a calling, says Tim Mulherin. "There is no real glory in it; in fact, the glorious idea of saving a child from a lonely existence outside of the love and security of a family is the wrong motivation for adopting a child."

The Essential Questions

People who are thinking of adopting a child with special needs should give thought to a few issues of central importance. For instance, when adopting an older child, anticipate that a chronic illness may be only one of many challenges the young person contends with. Don

Colburn and Kathy Ann Keenan speak about their experience with their son Miro, who they adopted from a Bulgarian orphanage when he was 10 years old. "As parents we were most worried about the hemophilia, but the disease was not the biggest problem. Behavioral and emotional hurdles were more challenging. In this way, Miro was much more like other adopted children than he was unlike them," the Colburns said. Behavioral challenges are quite common among children who have spent a lot of time in foster care, says Andrea Christy-Glover, a family resource recruiter for Aid to Adoption of Special Kids. "These kids are finally in safe surroundings and able to connect with their many, many years of anger, loneliness, frustration, rejection and fear. Understanding that these are the root causes of problem behaviors is important, and this is the beginning of healing."

Christy-Glover also acknowledges the young person's grief, which is experienced intensely by most foster and adopted children. "The majority of children in foster care have been rejected by their parents- and this hurts. Adults move more quickly through grief, but for kids it is a very hard process. They put up emotional walls that must be taken down brick by brick. "This is done with good parenting skills – consistency, structure, patience, a sense of humor- and the ability to love the child and wait a while to be loved back. "All these things," Christy-Glover says, "will bring that child to the point where he can meet you in the middle." Bridgett Morales, program coordinator of Indiana's Adoption Initiative, could not agree more. "People think they are going to go in and help a child by giving him a home that he didn't have before, but they shouldn't expect him to be verbally thankful, at least for a while." She adds, "An adoptive parent's glory comes in different ways."

It is important to consider one's family situation carefully before deciding to adopt. A lifestyle that is flexible enough to include a child with special needs (emotional, physical and behavioral) is the first and most important criteria. Christy-Glover recommends that prospective parents focus on three key questions: (1) Are we emotionally ready to take on a child with extra needs for a lifetime? (2) Are we financially able to care for our existing family, plus the adopted child? (3) Do we have enough physical space in our home for another child, and are we in good physical health, so we can meet his or her special needs? "Make sure you are in a good place with all three," says Christy-Glover, "and if you are, you are probably ready to adopt." After a pause she reflects further, "I can't say enough about how amazing these children are. Not just because they are survivors, but because they are really just great kids.

- from *Hemaware*, Volume 8, Issue 4, July/August 2003

The Birth of a New Technology: Genetics Diagnosis and Pregnancy

By Mike Dougherty

Couples with a genetic history of hemophilia may agonize over whether to embark upon or proceed with a pregnancy. Pre-implantation genetic diagnosis (PGD) is an option for genetic testing of an embryo prior to pregnancy. The advantage of PGD is that it minimizes the need for consideration of pregnancy termination. Mayo Clinic in Rochester, Minnesota, recently began offering PGD in an integrated fashion, relying on experts in each clinical area, including genetics, fertility and hemophilia to ensure the process is smooth and coordinated for the patients. While the approach of Mayo Clinic's PGD Program is not unique in healthcare, Alan Thornhill, PhD, director of Mayo Clinic's PGD Laboratory, said it suits Mayo's philosophy of integrated care. "We have a tradition of quality and we're sticking with that in this model," Dr. Thornhill said. "Everything happens on the same campus. Combining our efforts on a single campus allows us to ensure quality among everyone who is focusing their work on this couple."

Kelle Steenblock, a genetic counselor at Mayo Clinic, claims "Everybody has their own opinion about this area. PGD testing is done prior to becoming pregnant and may reduce the anxiety of waiting 12 to 16 weeks before learning the sex of the child and the potential problems that may result." The process begins with the decision of whether PGD is suitable for particular couples and whether their personal beliefs about when life begins are compatible with PGD. Since PGD is performed before a pregnancy has begun, it may be more acceptable to those who have had an affected child, terminated a previous pregnancy or have objections to termination of pregnancy. "This is about individual choice," Dr. Thornhill said. "Society or even your doctor isn't making this decision for you. For some people, having a child with hemophilia is too much for them in terms of the financial and emotional costs. They might look to PGD as an option."

Hemophilia A and B are Xlinked bleeding disorders suitable for PGD. "Deciding to be parents is a huge undertaking, especially if each male child is at risk for being affected with hemophilia," said Rajiv Pruthi, MD, a hematologist at Mayo Clinic. "People can live fruitful lives with hemophilia; however, handling the economic, physical and emotional toll will vary with individual families."

For example, NHF reports that prophylactic treatment might require about 150,000 units of clotting factor per year for a 65-pound child at a cost of \$85,000 per year. Insurance companies consider coverage for this treatment on a case-by-case basis. Those who choose this treatment face the possibility of reaching their insurance caps much sooner than those who do not. For those who develop inhibitors, the expenses are significantly more. The expense in the short term might seem high for PGD,

but there is potential for long-term savings, according to Prughi. People considering PGD should weigh these long-term costs with the short-term costs of PGD and in vitro fertilization (IVF), the process in which embryos are obtained by combining eggs and sperm in the laboratory. Combined costs for PGD and IVF can run in the range of \$15,000.

At Mayo Clinic, the PGD process begins with a visit to a genetic counselor, such as Steenblock, who says a review of all medical history and records determines whether the potential parents are able to use PGD. There might also be a genetic test to ascertain if the parents carry hemophilia. "Parents need to understand the benefits and limitations and see if it is right for them," Steenblock said. "Every family is going to approach this differently. It's a moral and personal choice to make. Our role is to present things in an open and honest manner and let the patients decide what's most important to them."

Once a decision is made, the mother undergoes a process to obtain her eggs for fertilization. For sex-linked disorders where generally only males will be affected, the embryos are tested and only female embryos are transferred to the uterus. In some cases unaffected carrier embryos may be transferred into the uterus. These carrier embryos are not affected with the disease but could pass it on. The goal is to have a child without hemophilia. At Mayo Clinic, strict ethical guidelines have been established for PGD. These guidelines include the decision not to offer gender determination for social reasons (also known as family gender balancing).

"We're choosing the most reliable diagnostic method where there is likely to be no ambiguity in determining the sex," said Ian Tummon, MD, clinical director of Mayo's PGD Program. In terms of fertility potential, Dr. Tummon notes that in general, younger women have a better opportunity to become pregnant. But even if a woman has become pregnant in the past, IVF does not guarantee a successful pregnancy. The IVF procedures for couples in whose families hemophilia is a factor are the same as those for routine infertility patients. On the morning of the third day after egg collection, the embryo should have reached a stage in development where there are six to eight cells. One or two cells are removed from the embryo for testing, then the embryo is placed into the incubator to continue development. Studies have shown that cells can be removed at this stage without affecting the normal development of the embryo.

Individual cells are tested using a procedure called Fluorescence In-Situ Hybridization (FISH), which is sensitive enough to detect abnormalities in a single cell. When all

the test results are gathered, a decision is made as to which of the unaffected embryos are most suitable for transfer to the uterus. A pregnancy test is performed two weeks after the embryo transfer. If the patient becomes pregnant following the embryo transfer, Mayo Clinic likes to remain in contact with the couple for the duration of the pregnancy and beyond. Although diagnostic accuracy is high, the demands of PGD are such that the result can never be 100%. For this reason, some patients may wish to consider prenatal testing (amniocentesis or chorionic villus sampling) to confirm the pre-implantation diagnosis result. "Mayo Clinic is known for its work in longitudinal studies and we would like to be able to follow up with the families and their children in the years to come," Dr. Thornhill said. "We're not just interested in getting people here for the treatment. Our goal is helping couples who want to have children find a safe way to do so. We care about the long-term health of the family.

-from **Hemaware**, January/February 2003

(Continued from page 6)

Another Option for Venous Access (continued)


including factor, in 2002 for the placement of an AV Fistula in a boy with hemophilia was \$29,000 compared to \$40,000 for a Port-a-Cath.

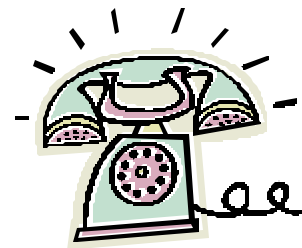
The Decision Process

For some families, beginning with peripheral venous access—regular needlesticks with butterfly needles—is a good option. With positive training by HTC staff, parents usually gain skill and confidence.

Some parents opt for a CVAD. Subcutaneous (below the skin), totally implanted devices like the Port-a-Cath are most frequently used. They have the advantage of low visibility, and are easy to access. However, they may become infected and need to be removed. External central venous catheters like the Broviac or Hickman are typically reserved for children whose hemophilia is complicated by inhibitors, or for short-term venous access—for example, to treat a troublesome target joint. They carry an increased risk of infection, and may be accidentally extracted. Both external and subcutaneous devices carry a risk of blood clots.

Creating an AV Fistula may combine the advantages of using peripheral veins with the benefits of a CVAD. However, all three options require surgery and are expensive. Parents need to do their homework when it comes to selecting an option for venous access.

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LOOKING FOR VOLUNTEERS!!

Would you be willing to answer questions from other affected persons or parents about issues involving blood disorders? We're hoping to establish a rotating referral list to field questions about subjects such as surgeries, joint replacement, discipline, ports, self-infusion and so on. If you'd be willing to have your name on the list, please call the HACA office at 703-352-7641 or email us with your name and number at haca-cares@aol.com. Thank you for sharing your knowledge with others.



Hemophilia Association of the Capital Area

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Fairfax, Virginia 22030-1504
Tel: 703-352-7641
Fax: 703-352-2145
Web: www.hacacares.org
Email: hacacares@aol.com

Dear Potential Golfer:

The Hemophilia Association of the Capital Area (HACA) invites you to join them for their 9th annual DC Hemophilia Open. The tournament will take place on Monday, May 17, 2004, at 2:00 p.m. at the beautiful Gunston Course on Fort Belvoir.

HACA's golf event raised nearly \$30,000 last year and with your support and participation this year, we can reach our goal of \$40,000 and significantly impact more lives. These dollars support many important programs that directly impact the lives of people with bleeding disorders. Children went to summer camp, families had a chance to meet others similarly affected at our educational seminar, and a "hands on" resource was provided to affected families.

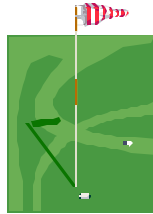
Participation as a golfer includes greens fee, cart, range balls, course refreshments, and a delicious steak dinner. The format for the tournament will be a best ball scramble with prizes for longest drive and closest to the pin. This year, Reynolds Auto Center in Orange, Virginia is donating a 2004 Pontiac Grand Prix for anyone lucky enough to get a hole in one and Ruth's Chris Steakhouse in Fairfax Corner will be sponsoring a putting contest with a delicious steak dinner for the "top putter".

To reserve your spot for this year's exciting golf event, please complete the enclosed form and return it in the self-addressed envelope. About a week before the tournament, we will send you a packet with all the details. In the meantime, if you have any questions or might be interested in the sponsorship of a hole or in donating items for the silent auction, please don't hesitate to call us at 703-352-7641.

We look forward to seeing you at the Gunston Course on Fort Belvoir on Monday, May 17, for what promises to be a very fun day of golf.

Sincerely,
Cliff Krug

Cliff Krug, Jr.
Chair-DC Hemophilia Open



Registration Form HACA Golf Tournament 2004

- ____ Yes, I would like to participate as a golfer. Enclosed please find \$150 for my registration.
- ____ Yes, I would like to register a foursome. Enclosed please find \$600 for our registration. (Include additional names below.)
- ____ I would like to support HACA through the purchase of a tee sign. Enclosed please find \$200.
- ____ I am unable to golf in your event, but would like to show my support. Enclosed please find my tax-deductible donation of \$_____.
- ____ Non-playing guests' dinner at \$25 each. Please provide names for front gate clearance:
Names _____

Registration for the 2004 HACA Open implies consent that any photos taken during the event may be used by HACA for coverage and promotional purposes, including but not limited to, newsletters, brochures, media coverage and web sites. Please notify the photographer if you do not want your picture taken or used for promotional purposes.

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Please make checks payable to **HACA** – For charges, complete the following:

Mastercard Visa Credit Card # _____ Exp. Date _____

Amount \$ _____ Name on Card _____

Billing Address _____

To reserve your space(s) more timely, forms may be faxed to: 703-352-2145
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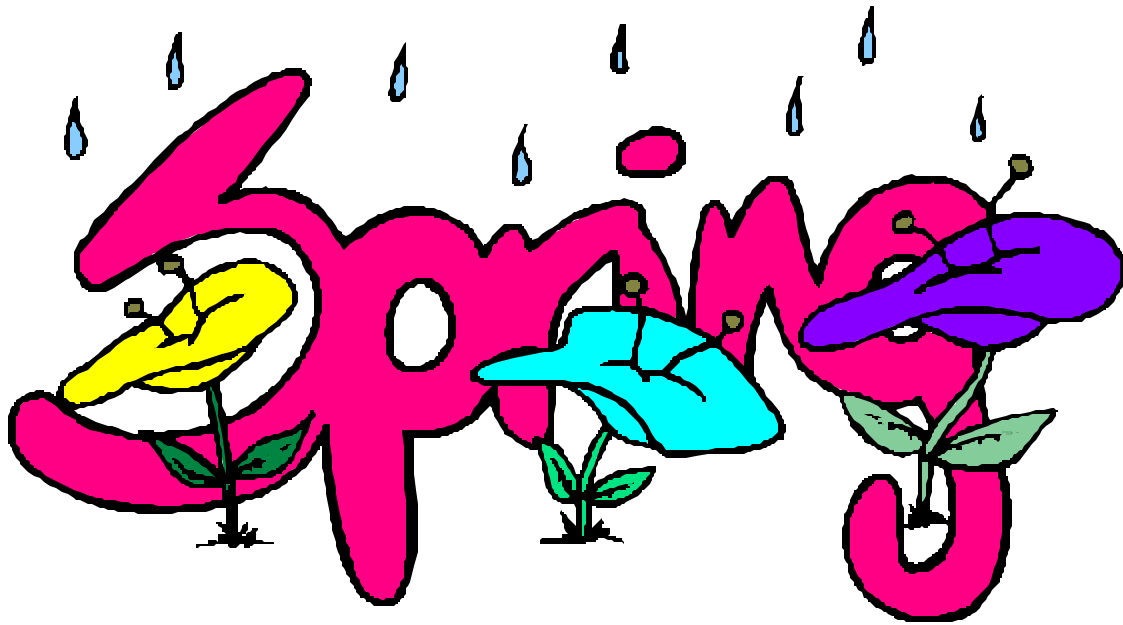

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