

NHF's 58TH ANNUAL MEETING

The NHF is Coming to Philly!!!

The National Hemophilia Foundation's 58th Annual Meeting will be held in Philadelphia at the Marriott Hotel, 12th and Market Streets, on October 12, 13 and 14, 2006!! The last time the NHF brought this important conference to Philly was 1995!! Here's the low-down!!

This Annual Meeting provides information and networking for patients with bleeding disorders, their families, medical providers, scientists from around the world and industry representatives. You can register on-line at www.hemophilia.org and you should do that right away. As a patient or a parent of a patient with a bleeding disorder, you can request that your registration fee is waived, but the request must be in writing at the time you register. To request a waiver, print out the NHF Annual Meeting registration form from the NHF website, then write the following on the margin of the form... *"I am a patient (or parent of a patient) and am requesting that my registration fee be waived. Thank you."*

You must fax (not e-mail) your form with that request to the National Hemophilia Foundation. The fax number is at the bottom of the form. You cannot request a waiver by e-mail or on-line registration. There is a deadline, so don't delay.

There is a fabulous youth program for your children, boys and girls, regardless of whether they have a bleeding disorder. The kids have fun while the parents attend sessions of interest. You must register for that as well, and it fills up fast. You must pre-register your child by the deadline dates specified on the Youth Program registration form in order to enroll them in the youth program. Advance registration only....no on-site registration for the youth program.

Your best source of complete information, including hotel registration, transportation issues, etc. is on the NHF website at www.hemophilia.org. Don't miss this chance to be a part of the most comprehensive meeting in the United States dedicated to providing the most up-to-date information on bleeding disorders.

Special Invitation

The Delaware Valley Chapter invites you to join us for a great family party on Friday, October 13th at the Franklin Institute, in partnership with Wyeth as the event sponsor. We've had a lot of fun planning this great evening for you. Bring the kids, grandmom, the whole family! If you register for the NHF Annual Meeting, you are entitled to come to the party....FOR FREE!!



The Franklin Institute

The Winning Spirit

Summer 2006

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in
this
issue

- 2 DELAWARE VALLEY CHAPTER NEWS & NOTES**
- 3 CHAPTER HAPPENINGS**
- 3 CHAPTER CALENDAR**
- 4 On the Health Front**
STEPPING STONES TOWARD A CURE
- 6 ON THE HEALTH FRONT**
Von Willebrand disease VWD
- 7 LEGISLATIVE UPDATE**
Update on HB 1705
The Hemophilia Health Care Act
- 8 JUST A THOUGHT**
WE SAY GOODBYE...

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Foundation

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The Winning Spirit

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From the Executive Director

In 1995, the National Hemophilia Foundation (NHF) and the Centers for Disease Control and Prevention (CDC) started a new parent and family program called "First Step." This program was intended to provide families with the information and support needed once parents learned that their children were diagnosed with a bleeding disorder.

"First Step" provides education, support and fun for families with children recently diagnosed with a bleeding disorder.

The Delaware Valley Chapter "First Step Team" was trained in Minneapolis this spring and a new parents' group is forming right here..... starting this summer. Let us know if you would like to attend one or both of the "First Step Events" planned for this area. New parents will have a chance to meet other parents who understand the issues of adjusting to a new diagnosis. This parents' group can provide help, support and networking with other families! Parents from every treatment center in our DVC area are invited!!



Your First Step Team

Jill Abrams, RN, Nurse Coordinator

*St. Christopher's Hospital for Children
Hemophilia Program*

Sue Stinger, Program Coordinator

Delaware Valley Chapter

*Mother of a 23-year-old son with
hemophilia*

Lindsay Pepper, RN

*Mother of a 7-year-old son with
hemophilia*

First Step Meetings

Friday, August 11th, early evening

Saturday, September 16th, at Family
Camp



DVC Board of Directors

We Gratefully Acknowledge...the pledge of support from the following manufacturers for 2006

Baxter Bioscience

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Monoclate-P

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Helixate FS

Humate-P

Stimate

Gammar-P I.V.

August

11 First Step!!

September

15-17 Family Camp!!

18 Golf Classic!!!

October

12-14 NHF Meeting!!

Philadelphia!!!!

November

3 Casino Royale!!

December

9 Holiday Party!!

FOUR VERY IMPORTANT EVENTS THIS FALL!!!

If you are receiving this newsletter via your treatment center, you should have received a copy of our **2006 Family Camp** registration form in the envelope. If not, give us a call (215-885-6500). This year, our camp will be held on the grounds of Camp Green Lane in Montgomery County, Pennsylvania. About 20 miles from Plymouth Meeting, this beautiful 200 acre site will provide a great place for our weekend on **September 15, 16 and 17, 2006**. Camp Green Lane has canoeing and small boating on a very small

lake, swimming, mini golf, outdoor activities like ping pong, basketball and even rock climbing and "high wires" with real experts!! There are activities and terrific facilities that will appeal to very young families as well as teens, parents and singles. Send in your registration right away! We want you to be with us!!

On Monday, September 18, 2006, plan to be with us for the DVC Annual Golf Classic. This year's event will be held at the Radnor Valley Country Club (a new site)!! Great day!!! Please join us!

As the host Chapter for **the 58th Annual Meeting of the National Hemophilia Foundation**, we hope that you will plan to be a part of this wonderful meeting that brings patients from around the United States together with medical providers, scientists and industry members. The sessions are very informative and there is "something for just about everyone." **October 12-15, 2006**

◆ Our Annual Fall Gala, "**Casino Royale...A Tribute to Ian Fleming**" will be held on Friday, November 3, 2006 at the Hilton Hotel on City Avenue. A change from past "Oktoberfests," this event will feature a casino theme, grand prizes, gaming, food and dancing!! What a great recipe for a wonderful night of fun and fundraising!! Mark your calendars and plan to join us! **Friday, November 3, 2006!**

REPORT OUT FROM SPRING EVENTS!!!

Moose Night on Sunday, April 30th was a blast! Thank you to Laura and Pat Carlino and their wonderful family of employees from Carlino's Specialty Foods in Ardmore and Kathy and John DiMichele and little Giovanni for providing this great night of food and fun! All proceeds were donated to the Delaware Valley Chapter.

The DVC Annual Family Dinner on Tuesday, May 9th was a great night of information for our families. More than 400 people heard A Community Update, provided by Dr. Barbara Konkle (Penn Hemophilia) about products, treatment and the cure....what's on the horizon? Cindy Fillman, Esquire, from the State Insurance Department addressed some key areas of concern about changing insurance prac-

tices in Pennsylvania and how to stay on top of things and George Levy gave an update on HB 1705. What a great night!

Carlino's Golf Outing, sponsored by Wyeth, on Monday, June 5th had a record turnout and raised more than \$50,000 toward our support of research this year. It was a great day in every way. We are grateful to Megan McEnroe and Wyeth for their support of this event and to the many companies and friends who provided financial support and attended!! Thanks to the Carlino's, the DiMichele's and their families and friends who did such a spectacular job and to the Carlino's employees who continue to work so hard on our behalf at this event!! See you next year!!



Mark Marra (BioScrip), DVC Golf Classic Co-Chair with Mike Keavany (ZLB Behring). Award acknowledging ZLB's event sponsorship.



Dan Levin & Megan McEnroe honored for Wyeth's corporate support of "Oktoberfest" and "Carlino's Golf Outing."

Right: Laura & Pat Carlino, Kathy & John DiMichele Family Dinner 2006



Below: Ukee Washington (CBS 3) with Sue Stinger honoring Black History Month in Philadelphia.



Above: 2006 Fashion Show
L to R: Jen Sawyer, Keith Moore (DVC President), Lynn Lindquist



Left: 2006 Carlino's Golf
L to R: Joe Pugliese, John Rogers, Ed Kelley, Andy Serrill

Stepping Stones Toward a Cure

The Eighth Workshop on Novel Technologies and Gene Transfer for Hemophilia
March 31-April 1, 2006, at the Children's Hospital of Philadelphia

The National Hemophilia Foundation's workshop on Novel Technologies and Gene Transfer for Hemophilia featured some of the world's most respected scientists and experts in molecular biology, pediatrics, hematology, oncology and gene therapy, among other fields.

The forum afforded scientists an opportunity to discuss their findings with those who have deep knowledge of related fields. Several scientists began their presentations by saying, "I've learned a lot more about hemophilia here!"

Topics included: testing and assessing hemophilia; improving animal research models; viruses as gene therapy delivery vehicles; gene therapy in laboratory studies, including in genetic diseases other than hemophilia; the problems of gene therapy; new clotting factor research; and an update on related clinical trials. This piece highlights a few of the presentations which focused on gene therapy.

The Properties of a New, Ideal Hemophilia Treatment

Compared with other diseases that are believed to involve defects in multiple genes, such as heart disease and many cancers, hemophilia involves just one gene. Mutations of the gene on the X chromosome that produce the clotting Factor VIII cause hemophilia A, while mutations of the gene that produce Factor IX cause hemophilia B.

In contrast with other congenital diseases, a new gene would not need to work perfectly to improve the quality of life for people with hemophilia. Clotting factor levels as low as one percent can restore near-normal function. Dogs with hemophilia have been successfully treated with gene therapy in some cases, for years.

"While these characteristics make gene therapy attractive for this disorder, critical issues should be kept in mind as novel technologies travel from the lab to the patient," said speaker Margaret V. Ragni, MD, MPH of the University of Pittsburgh Medical Center. "Some of these issues include: maximizing safety, affordability, availability in a single dose, easy to administer, completely non-toxic and non-immunogenic and perfectly effective, all at once. Or are certain qualities more vital than others? And who should decide which new therapies move forward?"

"Unlike some rare genetic diseases that are incurable and lethal, hemophilia is controllable with current technology. This affects the risk-benefit assessment of any new therapy," Dr. Ragni noted. "A patient with severe hemophilia might be more open to accepting a greater degree of risk than a patient whose disease is only moderate, for instance."

The Challenge of Delivery Systems

We think of viruses as disease-causing agents, and rightly so. Viruses are adept at invading normal cells and forcing their own abnormal genetic material to take over. The hijacked cells then dutifully replicate the foreign genetic material, and we find out about it later, when we develop symptoms ranging from the sniffles to life-threatening infections.

From the beginning of gene therapy, viruses have been seen as the obvious vehicle (or "vector") for carrying a therapeutic gene—in essence, a gene acting as a medication—deep into cells to treat disease. But success hasn't been automatic. "A major bump on the road to a cure may be related to the vehicle," said Dr. Ragni.

For one thing, the body often mounts an immune response against a viral vector, just as it would against a disease-causing virus, destroying it and perhaps making the patient ill. If the therapeutic genetic material does take hold, its effectiveness may diminish rapidly. Viral vectors are also likely to be expensive to produce and less stable than most drugs. In some cases, researchers worry that the hobbled virus may still be potent enough to cause its own disease. Perhaps most worrisome of all, early studies revealed that some gene therapies can have the potential to activate nearby cancer-causing genes, creating an increased risk of malignancy.

Many strategies are under study to get around all of these problems. For instance, Janneke J. M. Meulenberg, PhD, of Amsterdam Molecular Therapeutics, described her lab's gene therapy work with patients who have familial lipoprotein lipase (LPL) deficiency, which causes very high cholesterol levels. This is a rare, mostly untreatable genetic disease that can be life threatening.

The scientists in her lab chose adeno-associated virus (AAV1), a special member from a family of viruses previously used in gene therapy work to carry genetic material for expressing human LPL into LPL-deficient animals. They used a simple muscular injection to deliver the therapy with this unusual vector.

"We found proof of concept in both models, with up to 99 percent correction in mice and cats," Dr. Meulenberg said. For mice, the treatment cured them for more than a year. The cats developed an immune response to the new genetic material—less of a worry for humans. This therapy is already being tested in people, with findings to be released at a later date.

The Non-Virus Approach

Another strategy for sidestepping the problems of viral vectors is to use something other than a virus. “We’ve been trying to come up with a simpler way to do gene therapy,” reported Michele Calos, PhD, of Stanford University in California. “The advantages of non-viral approaches are very significant.”

For some years now, Dr. Calos has explored using a protein from *Streptomyces*—a family of bacteria that live in soil and contribute to its earthy aroma—as a gene therapy vector. She has used this protein (called “integrase from phage phiC31”) to deliver human genetic material to the livers of mice.

In her experiments, Dr. Calos found that the mice produced therapeutic levels of human Factor IX over their entire lifetimes. “They kept doing so even after two-thirds of their livers were surgically removed,” she added.

Dr. Calos is optimistic that this delivery system could provide a safe, long-term therapy for humans with hemophilia. “There isn’t any obvious route to getting a tumor with this system,” she noted. “It’s been used a lot to make transgenic (experimental) animals,” she said. “If this were really a toxic system, this would have been revealed.” For humans, however, the agent would probably have to be injected into the liver’s circulation.

An Update on Clinical Trials

“Regarding gene therapy, as most of you know, there have been five clinical studies to date,” Glenn Pierce, MD, PhD of Bayer Healthcare-Pharma and workshop co-chair told meeting attendees at the outset. “A total of 41 persons with hemophilia have received a new gene.” But despite this progress, clear clinical success has been elusive so far.

Carl June, MD, reported on the first clinical trials using lentiviral vectors. Lentiviruses are a subfamily of viruses found in humans and animals that may offer advantages over other viral vectors.

The most famous lentivirus, HIV, which causes AIDS, is used as the vector source. But before use, the lentiviral vectors are stripped of their genes from the HIV parent to minimize the risk of accidentally giving the patient an HIV infection. Nonetheless, “this work has been done, for ethical reasons, in patients with HIV infection as a first test,” Dr. June explained. “HIV is an acquired genetic disease, and potentially the principles that are learned may be useful in congenital disorders.”

In a preliminary study involving five patients with drug-resistant HIV disease who received one dose of the new agent, Dr. June found that the HIV-based lentiviral vector—ironically carrying the payload of an anti-HIV gene—caused improvement in several measurable signs of HIV infection for most patients. There were no signs of safety problems, and a new study with six doses per patient is now being initiated.

Upcoming Studies with Human Factor IX

Amit C. Nathwani, MD, PhD, of University College

London, United Kingdom, described a planned study in patients with hemophilia. “The vector we propose to use in the clinical trial will be a self-complementary vector, in which the human Factor IX gene is liver specific,” he said. (Blood coagulation factors are manufactured in the liver.) “We want to use this vector because it is much more potent, and raises the possibility of achieving therapeutic gene transfer using lower doses in humans, and this will have important safety implications.”

The viral vector Dr. Nathwani’s lab has selected is adeno-associated virus 8, also called AAV8. He has found that only two to five percent of patients surveyed have immunity to AAV8, compared to 60 percent to AAV2, which has been used in previous studies. “This allows us to exclude the few patients from entering a trial if they have immunity to AAV8. Hopefully, this will reduce the potential for immune-related liver toxicity that was seen in previous clinical trials,” Dr. Nathwani said. Unlike previous trials, researchers will inject the agent into a vein just under the skin, as doing so is safer and more convenient for patients than injecting it directly into the liver’s circulation.

This self-complementary vector—so called because it has parts that repeat themselves—has been studied in animals and found to be very safe. “Over 200 patients have received these vectors,” Dr. Nathwani added, “and some patients have received repeat administration without any [serious] toxicity.” The researchers hope to begin the study in early 2007.

The co-chair of the workshop, Katherine A. High, MD, from the Children’s Hospital of Philadelphia, described another clinical trial. This will be a study that follows earlier work, in which she and Dr. Pierce had found one subject with hemophilia cured for a short time. In this next trial, Dr. High will administer immunosuppression briefly at the beginning, to permit the AAV2 to release its Factor IX genetic material without stimulating an immune response that would terminate the effect.

Her colleague, Valder R. Arruda, MD, PhD, of the University of Pennsylvania School of Medicine and Children’s Hospital, is also planning a follow-up clinical study to a trial in which AAV2 was injected into patients’ leg muscles. He has discovered a better way to deliver the AAV2 to the muscles that, in dogs, cures hemophilia over the long term.

Prospects for a Cure

Many new therapies are being developed to make the quality of life better for people with hemophilia. One of these includes a longer acting Factor VIII, decreasing the amount of infusions needed. As the workshop made clear, gene therapy technology has turned out to be far more challenging than scientists originally expected. Yet many experts believe that if research continues at its current pace, this disease can be cured. In fact, because of its special characteristics, hemophilia may be one of the first diseases completely conquered by gene therapy.

In 1996, the National Hemophilia Foundation convened its first workshop on novel, promising therapies. Gene therapy was not prominent on the agenda back then, as there was hardly any relevant gene therapy research. Previous article published by the National Hemophilia Foundation.

Von Willebrand disease VWD

The History of VWD

A report from the National Heart, Lung and Blood Institute (NHLBI) in 2005 details how the medical community first recognized VWD. It was described in 1926 by Erik von Willebrand, MD, who was treating a five-year-old patient who had already lost three siblings to complications from bleeding. Additionally, her maternal grandmother had bled to death during childbirth. When she was an adolescent, this patient herself bled to death during her fourth menstrual period. Previously, bleeding disorders were considered a male-only disease, but VWD affects men and women in equal numbers. Menstrual periods and childbirth heighten the ramifications of this disease for women.

Since the 1920s, scientists have learned that VWD usually is inherited from one parent who may have an abnormal von Willebrand factor gene. Von Willebrand factor (VWF) is a clotting protein produced in the cells that line blood vessels, composed of small chains that combine to form larger chains called multimers that help the blood to clot. VWF acts as a bridge between platelets at the injury site. This helps blood to clot in the right place.

VWD affects 1 in 10,000 women, according to Andra James, MD, director of the Women's Hemostasis and

Thrombosis Clinic at Duke University and the Chair of the NHF Women with Bleeding Disorders Task Force. Another startling statistic shows that based on the number of women treated at hemophilia treatment centers who experience symptoms of VWD and who have a family history of bleeding, the prevalence of VWD may actually be 1 in 100 women. Symptoms include bruising, nosebleeds, bleeding after injury, surgery or tooth extraction, postpartum bleeding and most commonly, heavy menstrual bleeding known as menorrhagia.

There are currently only two products licensed for the treatment of VWD, Humate P, a factor product and Stimute, a nasal inhalant. Both are ZLB Behring products.

There is ongoing research that holds promise for finding more information about VWD. The CDC, for example, is currently recruiting for a clinical trial that is examining the best medical treatment for women with heavy periods who have VWD. For more information on the trial, visit www.clinicaltrials.gov and search for "bleeding disorders" or by the identification number NCT00111215.

Previous information excerpted from "State of the Art Testing and Treatment of VWD" by Lori Herring, HemAware, January/February 2006, page 52. HemAware is a publication of the National Hemophilia Foundation.

For Your Information



**Anthony J. Tezak, Jr.
Endorsed Candidate for
The Pennsylvania House of Representatives**

Anthony Tezak, from Steelton, Pennsylvania will run for a seat in the Pennsylvania House of Representatives in the fall election (see Spring 2006 issue of *The Winning Spirit*). Anthony is one of three men in the United States with severe hemophilia who is either currently elected to a state or federal congressional seat or hoping to be elected. How 'bout that?

Anthony needs volunteers to help with his campaign. If you or someone you know, would like to help Anthony, give his campaign office a call. Even if you don't live in central Pennsylvania or the Steelton area, you can still provide assistance.

**Committee to Elect Anthony J. Tezak, Jr.
101 S. Front Street
Steelton, PA 17113
717-704-0119
<electtezak.com>**

Update on HB 1705

The Hemophilia Health Care Act



What a busy 12 months it has been for everyone working on HB 1705. We want to thank Representative Roy Baldwin for his dedicated leadership of this important access legislation. Although Representative Baldwin was defeated in the Pennsylvania Primaries on May 16th and won't be championing our efforts in 2007, we appreciate his confidence in us and his belief in our issue to protect patient access to factor therapies, our HTC's and home supportive services.

Our work has continued on this state advocacy project and will move forward this fall as the Pennsylvania General Assembly reconvenes. We are designing our strategy with a new consultant for "Phase Two." It takes, on average, five years to effect legislation, so we are right on schedule with our work.

We need your help as we continue our efforts this fall. Please e-mail us if you are willing to help. We will need

hundreds and hundreds of patients, family members and treatment center staff organized to work at the grass roots level. Let us know if we can count on you!! DVC e-mail: hemophilia@navpoint.com.

As insurance companies continue to restrict our access to medicine and services, we must protect what we really need to be healthy, for the present and certainly for the future. If choice of therapy, pharmacy distribution or our ability to be treated at the eight state-recognized hemophilia programs is restricted, our health and well-being are in jeopardy. Please let us know that you will help in just a small way.....a letter, an e-mail, a visit to your legislator. We need to know that we can count on you as we move forward with HB 1705!

For Your Information

DVC Scholarships

The Delaware Valley Chapter awards more scholarships each year to deserving young men and women with bleeding disorders than any other Chapter in the United States. In fact, the DVC has awarded 415 scholarships over the last five years! Here's how to apply.

If you are a patient with a bleeding disorder (hemophilia or von Willebrand disease) who lives within the geographical boundaries of the DVC..... AND you are treated at a local hemophilia program in Pennsylvania or Delaware, you are eligible to apply.

- 1. Write a letter requesting a scholarship, including your name, address, phone and e-mail address. You must state where you are treated and your diagnosis, as well.**
- 2. Include with your letter, proof of current enrollment or acceptance in a post-secondary institution and your tuition bill or proof of payment. We can provide scholarships for colleges or universities, technical programs and trade schools up to \$1,000 each year. You can write each year with your updated request and information and we can continue to help you for up to four years, as long as you stay a student in good standing with your institution.**
- 3. The DVC does not provide scholarships for elementary or high school tuition.**
- 4. We have no deadline dates for scholarship help, but you can only apply once in a 12-month period. We cannot provide financial assistance for any balances for previous semesters.**

Call with Questions!! 215-885-6500

SLOW DANCE

Have you ever watched kids on a merry-go-round?
 Or listened to the rain slapping on the ground?
 Ever followed a butterfly's erratic flight?
 Or gazed at the sun into the fading night?
 You better slow down. Don't dance so fast.
 Time is short. The music won't last.

Do you run through each day on the fly?
 When you ask "How are you?" do you hear the reply?
 When the day is done, do you lie in your bed
 With the next hundred chores running through your head?
 You'd better slow down. Don't dance so fast.
 Time is short. The music won't last.

Ever told your child, "We'll do it tomorrow"
 And in your haste, not see his sorrow?
 Ever lost touch? Let a good friendship?
 Cause you never had time to call and say, "Hi?"
 You'd better slow down. Don't dance so fast.
 Time is short. The music won't last.

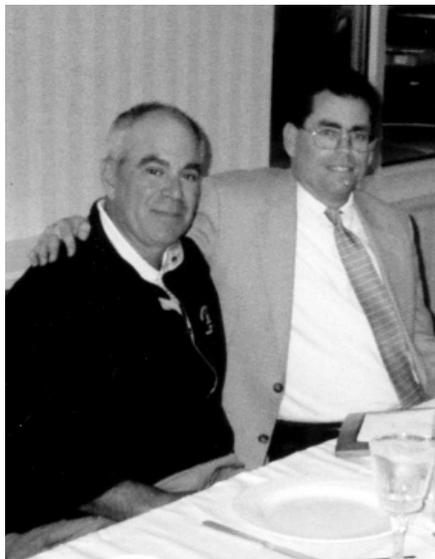
When you run so fast to get somewhere
 You miss half the fun of getting there.
 When you worry and hurry through your day,
 It's like an unopened gift that you've just thrown away.
 Life is not a race. Do take it slower.
 Hear the music before the song is over.

Author Unknown

We Say Goodbye.....

Two wonderful DVC Board Members and friends of the Delaware Valley Chapter have retired. They have both made significant contributions to our organization and they will be missed, no doubt about it.

Bob Romano has served on the Chapter board for five years. Bob chaired the "Oktoberfest" Committee and thanks to his leadership, this great fall event continues to be a huge success for our Chapter. Bob served on the Finance and Investment Committees as well, and has been an outstanding supporter of our mission of service. Bob will continue to be an active member of the Delaware Valley Chapter so we won't say "goodbye," just "best of luck in all that you do.....and we know we will see you at Casino Royale on November 3rd!!"



Carl Lampe, Jr. has served on the Chapter board for 14 years. Carl has been a key leader in board development, finance and he played an important role in the development of "Oktoberfest" with Bob. Carl has been instrumental in helping Chapter leaders stay focused on our mission to support patients and programs. Carl has served the DVC with a generous spirit and a compassionate heart, while helping to strengthen the framework of our Chapter in countless ways. Our work will go on in a better way because of the contributions of Bob and Carl! We are grateful.

*Bob Romano and Carl Lampe, Jr.
Board Farewell*