Dear Friends,

I completed my second year as the Executive Director of our Hemophilia Center here in WNY and have been so excited to see the evolution of care within the bleeding disorder community. We have also experienced many new developments within our HTC.

Our patients witnessed significant advancement in 2014 with the launching of new “long acting” factor products for Factor 8 and Factor 9. The evolution of these products and further research initiatives are continually exploring pathways for our patients to enjoy a full quality of life.

Our HTC welcomed Dr. Shilpa Jain as our newest addition to the medical staff. Dr. Jain will assume the role of our Pediatric Medical Director.

We saw the emergence of our Hemophilia Foundation of WNY, a subsidiary of the HTC. The Foundation’s mission is to provide community awareness, education, fundraising activities as well as patient assistance to our bleeding disorders community.

We developed a Consumer Advisory Committee made up of consumers of our HTC services with the purpose to provide consumer feedback to the HTC regarding program- ming and operational administration.

Our HTC hosted a tour with Congressman Chris Collin’s office to introduce our local legislators to the HTC model and the benefit of our 340B program. Our advocacy team traveled to Albany and Washington with patient representatives to help educate our elected officials on our community and the impact their governance has on our population.

We continue to look to you for program requests and ideas to help further our mission – “to serve the hemophilia and genetic bleeding disorder community of WNY”. Visit our website www.hemophiliawny.com and like us on Facebook to stay in touch.

Best Regards,

Laurel A. Reger

Laurel Reger
The Hemophilia Center of Western New York, Inc. provides specialized diagnostic and health maintenance services to individuals with Hemophilia and other genetic bleeding disorders requiring lifelong medical management. Through its clinical services, advocacy, education, and research initiatives, the Center strives to improve one’s quality of life.
In 2014, three individuals from our community went to Washington DC, to represent the Hemophilia Center of Western New York during “Washington Days 2014”. Dennis Ruchalski, Russell Newbert and Linda Belling; Clinical Program Coordinator, worked to bring awareness to lawmakers about the many issues that affect those with bleeding disorders and their families.

Advocacy

We are happy to report success on a number of fronts.

Russell summarized the purpose of their advocacy as two fold:

One of our goals was to ask members of Congress to require insurance companies to eliminate Tier 4 in their drug categories. This is the high-expense category where the patient is charged a percentage of the cost of treatment instead of the typical co-pay that applies to the more familiar Tiers 1, 2, and 3. Even a 10% share is too much for most families to handle. The result is patients skipping treatment and ending up in a life-threatening situation or an extensive hospitalization. Moving hemophilia factor to Tier 3 will result in a co-pay that is manageable for virtually all patients.

Another goal was to make our congressional representatives aware of the fact that the typical post-surgery rehabilitation in a skilled nursing facility (SNF) is not available to hemophilia and vonWillebrands patients on Medicare. The result is post-operative patients remaining in the hospital longer, or being sent home too early. The solution the hemophilia community proposes is to have the factor billed separately, over and above the daily rate, under Medicare Part B. This proposal would be revenue-neutral, since the cost of factor would be offset by fewer hospital days and lower hospital bills.

With this being Dennis’s first involvement in Washington Days, he had this to share:

Being my first year attending I was very apprehensive about attending. I was not sure what it was going to like. After a quick flight I found myself surrounded by other’s with Hemophilia that could relate to similar issues I have had and what they are doing in their communities to improve the lives of other People with Bleeding Disorders. I also found that advocating to state leaders about issues of importance to People with Bleeding Disorders to be empowering. A bill that I had a particular interest in was the Patients’ Access to Treatment Act (PATA).

This bill would prohibit insurance companies from listing drugs on a special tier which would require individuals to pay a co-payment from 25% to 33% or even more. After our visit to Congressman Brian Higgins office, he has agreed to co-sponsor the bill!

If I could sum the whole trip up with one word, I would say it was healing. Being with others with the same disorder and being active in improving the conditions People with Bleeding Disorders face has left me with the sensation of growth and greater understanding of my Hemophilia.
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You need a strong organization to support a noble mission.

The Magellan Group is proud to play a part in supporting The Hemophilia Center of WNY in their mission to provide quality healthcare to individuals with hemophilia and other bleeding and clotting disorders.
Linda Belling began her career as a Hemophilia Nurse in 1981 with the Hemophilia Center of Western New York, Inc.

Her earliest experience in treating patients with Hemophilia dates back to the days of the use of Cryoprecipitate in treating bleeds. Linda experienced caring for patients through the freeze-dried (lyophilized) factor VIII and factor IX products available in 1985. These concentrated factor products led to home treatment therapy which greatly changed the lives of people with Hemophilia. With successful cloning of the factor VIII gene in 1984 recombinant factor VIII concentrates became available and factor IX recombinant products became available in 1997.

Linda’s vast experience and compassion in following patients through this ever changing course of treatment regimens and many, loyal years of working at the Center has proven her to be a valuable resource. Her work ethic and professional philosophy continues to make patient needs primary in her service at the Center and is always ensuring that patient care comes first.

Linda has earned, and surely deserves the respect and admiration of the patients she serves, and the medical and administrative staff she collaborated with to continually improve the lives of people with Hemophilia.
Dr. Jain joined the Hemophilia Center of WNY in September of 2014 as the Pediatric Medical Director. Dr. Jain came from the University Of Pittsburgh School Of Medicine and Children’s hospital of Pittsburgh where she was an Assistant Professor with the Pediatric Hematology and Oncology Division. Dr. Jain is board certified in Pediatrics.

Dr. Jain is originally from New Delhi, India where she received her medical degree from Delhi University. She then attended Johns Hopkins University in Baltimore where she received a Masters of Public Health. She completed her residency in pediatrics at Children’s Hospital of Michigan and completed a Fellowship in Pediatric Hematology-Oncology at Children’s Hospital of Pittsburgh in Pa. Dr. Jain has participated in several research studies as Principal and Co-investigator surrounding the field of hemostasis and thrombosis.

Dr. Jain is affiliated with Women’s and Children’s Hospital and Roswell Park Cancer Institute. She is also a member of the American Society of Hematology, American Society of Pediatric Hematology-Oncology; and a member of the Hemostasis and Thrombosis Research Society.

The Hemophilia Center is pleased to have Dr. Jain join the medical staff and is looking forward to expanding services to women with bleeding disorders.

Dr. Jain currently lives in Williamsville with her husband and daughter.
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Samantha Burkett, Coding Auditor

Physicians:
Dr. Steve Ambrusko, Pediatrics
Dr. Shilpa Jain, Pediatrics
Dr. Adam Kotowski, Adult
Dr. Roslyn Romanowski, Adult

Dentists:
Mary Beth Dunn
Timothy Mahoney

Physician Assistants:
Daniel Ford
Jim Miller

Physical Therapists:
Dominique Safar-Riessen
Kevin Jenney

Geneticist:
Melissa Sammons

Pharmacist:
Geoffrey Zielinski

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www.hemophiliawny.com
FDA-Approved Patient Labeling

Patient Information

ELOCTATE™ (‘el ok’ ‘ta te’)
[Antihemophilic Factor (Recombinant), Fc Fusion Protein]

Please read this Patient Information carefully before using ELOCTATE and each time you get a refill, as there may be new information. This Patient Information does not take the place of talking with your healthcare provider about your medical condition or your treatment.

What is ELOCTATE?

ELOCTATE is an injectable medicine that is used to help control and prevent bleeding in people with Hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ELOCTATE when you have surgery.

Who should not use ELOCTATE?

You should not use ELOCTATE if you have an allergic reaction to it in the past.

What should I tell my healthcare provider before using ELOCTATE?

Talk to your healthcare provider about:
- Any medical problems that you have or had.
- All prescription and non-prescription medicines that you take, including over-the-counter medicines, supplements or herbal medicines.
- Pregnancy or if you are planning to become pregnant. It is not known if ELOCTATE may harm your unborn baby.
- Breastfeeding. It is not known if ELOCTATE passes into the milk and if it can harm your baby.

How should I use ELOCTATE?

You get ELOCTATE as a infusion into your vein. Your healthcare provider will instruct you on how to do infusions on your own, and may watch you give yourself the first dose of ELOCTATE.

Contact your healthcare provider right away if bleeding is not controlled after using ELOCTATE.

What are the possible side effects of ELOCTATE?

Common side effects of ELOCTATE are joint pain and general discomfort.

Allergic reactions may occur. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, neck, or lips.

Your body can also make antibodies called, “inhibitors,” against ELOCTATE, which may stop ELOCTATE from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

How should I store ELOCTATE?

- Keep ELOCTATE in its original package.
- Protect it from light.
- Do not freeze.
- Store refrigerated (1°C to 8°C or 36°F to 46°F) or at room temperature [not to exceed 30°C (86°F)], for up to six months.
- When storing at room temperature:
  - Write on the carton the date on which the product is removed from refrigeration.
  - Use the product before the end of this 6 month period or discard it.
- Do not return the product to the refrigerator.

Do not use ELOCTATE after the expiration date printed on the vial or, if you removed it from the refrigerator, after the date that was noted on the carton, whichever is earlier.

After reconstitution mixing with the diluent:
- Do not use ELOCTATE if the reconstituted solution is not clear to slightly opalescent and colorless.
- Use reconstituted product as soon as possible.
- You may store reconstituted solution at room temperature, not to exceed 30°C (86°F), for up to three hours. Protect the reconstituted product from direct sunlight. Discard any product not used within three hours.

What else should I know about ELOCTATE?

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ELOCTATE for a condition for which it was not prescribed. Do not share ELOCTATE with other people, even if they have the same symptoms that you have.

Manufactured by:
Biogen Idec Inc.
14 Cambridge Center, Cambridge, MA 02142 USA
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44279-91
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Issued June 2014

Meet your CoRe Manager Sue Cowell
E: sue.cowell@biogen.com
T: 609-602-6303

This information is not intended to replace discussions with your healthcare provider.

Indications

ELOCTATE [Antihemophilic Factor (Recombinant), Fc Fusion Protein] is a recombinant DNA derived, antihemophilic factor indicated in adults and children with Hemophilia A (congenital Factor VIII deficiency). Control and prevention of bleeding episodes, perioperative management (surgical prophylaxis), and routine prophylaxis to prevent or reduce the frequency of bleeding episodes. ELOCTATE is not indicated for the treatment of von Willebrand disease.

Important Safety Information

Do not use ELOCTATE if you have had an allergic reaction to it in the past.

Tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines, supplements, or herbal medicines, have any allergies, are breastfeeding, are pregnant or planning to become pregnant; or have been told you have inhibitors (antibodies) to Factor VIII.

Allergic reactions may occur with ELOCTATE. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, neck, or lips.

Your body can also make antibodies called, “inhibitors,” against ELOCTATE, which may stop ELOCTATE from working properly.

Common side effects of ELOCTATE are joint pain and general discomfort. These are not all the possible side effects of ELOCTATE. Talk to your healthcare provider right away about any side effect that bothers you or that does not go away, and if bleeding is not controlled after using ELOCTATE.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.
NUMBERS 2014

INCOME
- Contributions $448,802
- Grants $38,371
- Operational Income $13,069,262
- Non-Oper. Income $302,250
Total $13,858,685

EXPENSES
- Salaries $700,669
- Taxes/Benefits $191,802
- Contracts $386,488
- Cost of Sales $11,812,348
- Other $902,912
Total $13,994,219

AGENDA 2015
- The expansion of our HTC clinics with concentration on Women with bleeding disorders coordinated by Dr. Shilpa Jain.
- Launching of our Pharmacy services to distribute factor products to our Medicaid Home Therapy population.
- Family visits with legislators in Washington D.C. and Albany NY to advocate for our patient community.
- Annual NHF meeting in Dallas in August 2015.
- Hemophilia Walk for our patient community at Cazenovia Park in August.

At CSL Behring, we are committed to providing treatments and supportive services that make a meaningful difference in the lives of people with bleeding disorders and those who care for them.

We set out on this journey with you more than a century ago, starting with the development of treatments for those with rare and serious diseases.

As we look to the future, we see the promise of new innovations and opportunities—just as we always have.

Over the years, we have never lost sight of what matters most: you and the countless others who inspire our efforts every day.
THE COUNTDOWN HAS BEGUN.

For more information and updates, sign up at ADYNOVATE.com