



Hemophilia OUTLOOK

A Newsletter of

The Hemophilia Association of New York, Inc.

131 West 33rd Street, Suite 11D, New York, NY 10001

Tel 212-682-5510 Fax 212-983-1114

admin@hemophiliary.com * www.hemophiliary.com

www.facebook.com/Hemophilia.Association.of.NewYork

 **SPRING 2018** 

PATIENT BE PATIENT

By: Linda Mugford

Recently I heard from a few clients who were frustrated in what seemed to be a delay in their factor delivery. Here are my thoughts:

If you have switched your insurance provider or even if your plan has been renewed, it can be a very anxious waiting period. One of the biggest concerns is how your factor will be covered, or even worse, will it be covered. Thankfully with most commercial insurance companies that are not self-funded* (I will refer to self-funded a.k.a. ERISA plans at the end) all factor products have to be covered. New York State Medicaid, New York State Exchange plans, and all Medicaid Plans also cover factor.

The patience on your end would be waiting for authorization and verification. No matter where you are getting your factor, the company that will be dispensing (sending) your product needs to verify that you have coverage. In many cases they will also need to obtain authorization. Authorization is given by the insurance provider following a request by the factor provider (or for that matter the request can be from any provider that would like to be paid for their service) to authorize their providing of the factor (service). The factor provider knows that when the claim is filed with the insurance company they will get paid, as long as the insurance is still active. Some claims will not be paid without an authorization from the insurance company. This is also how the provider finds out if the patient has a co-pay or deductible. Make sure you have enrolled in the assistance programs of your factor manufacturers. Medicaid and Medicare

plans are excluded from the co-pay and deductible assistance plans.

In the insurance environment that exists today the turnaround time for non-emergency authorizations can be as long as a week or two. This is one very good reason you should be ahead of your factor needs by a week or two. If your insurance company will only authorize one month at a time, your provider (whether it is your HTC or for-profit homecare) will need to make contact with the insurance carrier every month and provide them with information. Your responsibility is to make sure that you keep track of your factor levels. And to even communicate with your factor provider of extenuating circumstances, such as: why you need to reorder sooner than usual and if you will be traveling and not have access to home delivery. This is part of the responsibility that comes with a chronic condition.

*Self-funded plans are insurance plans provided by employers. The employer has full control over the benefits plan. The organization funds the risk with its own assets using stop-loss insurance coverage to cover large dollar claims. The organization is excluded from state mandates and is only subject to federal regulations under ERISA. A Third Party Administrator (TPA) is hired to administer the plan. The employer can decide to exclude things from coverage, such as factor. When considering employment with a company it is very important to find out if their insurance is self-funded and if there are any exclusions to coverage.

Many Deserve Credit for Curbing “Fail First”

*By: Rachel Brilliant, DO
Advocacy chairwoman, New York State
Academy of Family Physicians*

The start of the New Year can be exciting, a fresh start, and change. But that change can also bring challenges as patients and their doctors navigate new health care coverage and determine what has changed. This can mean delays in access to critical medications that patients rely on to keep medical conditions under control.

There is hope that 2018 will be different. For many years, patients have faced an insurance industry mandate known as step therapy, or “fail first”. An insurance company was able to require a patient to first fail on alternative medications, prior to getting coverage for the drug initially prescribed. Insurers used this to save money but the cost to patient health was high.

Physicians, patients, and other organizations banded together to change this and succeeded. As of Jan. 1, state-regulated, public and private insurance plans must provide a fair and standardized appeals process when insurers try to require patients to fail first. The appeals process can be used when the alternative drug is not in the best interest of the patient.

This could not have happened without the bill champions, Assemblyman Matthew Titone and Sen. Catharine Young, who achieved unanimous passage of this measure. Gov. Andrew Cuomo should be commended for his leadership in signing this patient centered bill into law. None of this would be possible without the brave patients and providers who came forward to share their stories and convince policymakers that change was needed. Our representatives listened.

The article below was posted by “Transunion”

The Hemophilia Association of New York has been a member of the New York Blood Disorders Coalition since its inception. We are proud to be one of the organizations New York Bleeding Disorders Coalition who “walked the halls of Albany” in support of this bill. Our

gratitude also goes to the many members of the Bleeding Disorders community who made visits to their representatives.

HANY SCHOLARSHIP

2018 SCHOLARSHIP APPLICATIONS ARE NOW AVAILABLE!

In order to qualify for the 2018 scholarship program, applicants must have, or be the child of a person who has a genetic bleeding disorder and is registered with HANY. Applicants must also live within the 14 southeastern counties of New York State.

For applications contact 212-682-5510 or email tconstantine@hemophiliany.com.

DEADLINE APRIL 30, 2018.

PATIENT ASSISTANCE PROGRAMS

The patient assistance programs are offered by factor manufacturers. Manufacturers offer assistance with co-pays and deductible assistance programs. If you would like information about these programs, please contact 212-682-5510.

YOU MUST REGISTER EVERY YEAR

SAVE THE DATES

YOUNG WOMEN'S WORKSHOP

Join the Mount Sinai Hospital Treatment Center team for a unique interactive workshop designed for young women ages 22 and younger.

The MSH will be introducing the New Young Women's Clinic and attendees will have the chance to meet the HTC team who will be specializing in gynecological concerns.

When: April 21, 2018

Time: 10:00 am- 4:00 pm

Location: Guggenheim Pavilion

1468 Madison Avenue

Hatch Auditorium- 2nd Floor

RSVP BY MARCH 30, 2018

To RSVP email

Kaitlin.weisman@mountsinai.org

2018 HFA SYMPOSIUM



The 2018 Hemophilia Federation of America symposium will be **April 26-28** in Cleveland, Ohio. We will offer assistance with travel. Those who are registered with HFA are also eligible for first time attendee scholarships.

If you are interested in attending please contact us at 212.682.5510 or visit hemophiliafed.org.

REGISTRATION CLOSES APRIL 2, 2018

NATIONAL HEART, LUNG, AND BLOOD INSTITUTE DIVISION OF BLOOD DISEASES AND RESOURCES FVIII INHIBITOR STATE OF THE SCIENCE WORKSHOP

Researchers will be discussing ways to solicit the hemophilia community into the development of a coordinated US- based blueprint for future basic, translation and clinical research focused on FVIII immunogenicity and FVIII inhibitor prevention/eradication.

When: May 15, 2018

**Where: NIH Natcher Conference Center
Bethesda, MD**

If you are interested in attending contact admin@hemophiliany.com

PAST EVENTS

January 27 – Blood Brotherhood Bowling Night

Michael Zolotnitsky, DPT led a rap session and presented on alternatives to pain management. Following the presentation the Blood Brothers enjoyed a night of good food & bowling at Bowlmor Lanes Times Square.



March 10- Blood Sisterhood Nutritional Cooking Class

Monica Hansen, RD led a nutritional session with our Blood Sisters on healthy cooking. Following Monica's presentation they enjoyed a cooking class at Sur La Table NYC.



HANY UPCOMING EVENTS

May 20- Day at the Races at Belmont Park with Art Therapist making "Derby Hats"
Children ages 5 – 12 with a bleeding disorder with 1 accompanying parent complimentary admission.
For tickets contact tconstantine@hemophiliany.com

June 1- "A Night at the Museum"
*(Ages 6-13) **FILLED***

June 18- 11th Annual Mathew Lee Greer Golf Classic

July 29- HANY 66th Anniversary Gala at Yankee Stadium
Tickets- \$220/Per Person

TICKETS ARE LIMITED

September 14-16- S.A.I.L (Self Advocacy Independence & Leadership) Training at Camp Quinipet at Shelter Island, NY with Guttmonkey
(Ages 13-18)

December 7-9 - Steven L. Margolies, MD Family Retreat at Mohonk Mountain House

HANY's RESOURCE CENTER

MISSION STATEMENT

The mission of the Hemophilia Association of New York is to provide information, education, advocacy and direct assistance to and on behalf of people with bleeding disorders, and to encourage and support scientific research to improve medical treatments and develop cures for hemophilia and related disorders.

About this Newsletter

The Hemophilia Outlook has been around since 1952. It's produced quarterly and distributed to all the members of the bleeding disorder community.

We have an electronic version in our website. If you prefer not to receive a copy please let us know.

HANY does not release any personal information without your consent.

HANY's Contacts

Linda Mugford, Executive Director
Lindamugford@hemophiliany.com

Tyshawn Constantine, Program Director
Tconstantine@hemophiliany.com

Jessica Blanco, Staff Associate
Jblanco@@hemophiliany.com

Website:
www.hemophiliany.com

Facebook:
www.facebook.com/hemophilia.association.of.newyork

Resources Information

Hemophilia Federation of America

800-230-9797

www.hemophiliafed.org

National Hemophilia Foundation

800-42-HANDI

www.hemophilia.org

Coalition for Hemophilia B

212-520-8272

www.coalitionforhemophiliab.org

HEMOPHILIA TREATMENT CENTERS

New York Presbyterian

<http://www.cornellpediatrics.com>

Mt. Sinai Medical Center

www.mountsinai.org

Northwell Health (formerly LIJ)

<http://www.northwell.edu>

Albany Medical Center

www.amc.edu

New Comprehensive HTC

Montefiore Hospital

www.montefiore.org

SMART Women

By: Jessica O'Donnell

From personal to professional, the women profiled here turned their connections to hemophilia into real, life-changing achievements. While many of us set out to complete a task, we may not label it as a goal or plot out a deliberate path to achieve it. But each of these women had a vision, implemented a plan, and plotted a path to reach her goal.

Each woman's strategy was unique, but all the goals had something in common: they were all SMART goals. SMART goals are specific, measurable, accountable, realistic, and time-bound. Learn how Mischante, Angelie, Darlene, and Christy and Elise worked hard to get results.

A Better Future for Her Family

After Mischante Cortez's son, Adam, was diagnosed with hemophilia in 2006, Mischante decided to set a goal: to become a registered nurse to better advocate for Adam's healthcare needs. It wasn't easy. Pregnant at age 16, Mischante had dropped out of high school. So before starting her nursing program, she needed to obtain a GED and enroll in community college. After receiving her GED and being accepted into a nursing program, Mischante divided her goal into smaller, specific steps.

But her path wasn't without obstacles. While enrolled in the nursing program, Mischante was often left with no choice but to bring her three young children to school with her because she lacked childcare. Despite the setbacks, Mischante persevered. "I continued to strive toward my goal to be a nurse while raising three kids alone and working full-time as a certified nurse's assistant [CNA]. In May 2010, I graduated from college with my nursing degree. It was the best decision I ever made for my family."

Today, Mischante supports her family as a working nurse and single mother. "I am Adam's number-one advocate, and I get to heal people for a living. I am so grateful that Adam's diagnosis of hemophilia was exactly what I needed to get into gear."

A Son's Diagnosis Prompts a Family Goal

When Angelie Garcia's son Zayden was diagnosed with hemophilia, Angelie recognized that he was unhappy while being infused with factor. So she told her husband, "Once we're taught by home nurses, within two weeks we will start involving Zayden." Then Angelie set a goal to have Zayden take an active role in the infusion process within one year.

Angelie and her husband divided their goal into small, attainable steps: the first was to make sure Zayden wouldn't be afraid of infusions.

On their path to achieving their goal, the family's largest setback was their location. "Our hometown hospitals need education on hemophilia," explains Angelie. "I'm the only one here that can infuse my son, and it terrifies me because they don't know about his condition and we are three hours away from our HTC [hemophilia treatment center]." Angelie learned very quickly that she had to be Zayden's primary advocate for his hemophilia care. Teaching him to help in the infusion process empowered Zayden, now four years old, to be more aware of his condition. His proud mom says, "He is learning ab-out his condition and will tell you what he can and can't do."

Lobbying for Specialized Emergency Treatment

Darlene Shelton founded Danny's Dose Alliance after her ten-month-old grandson was diagnosed with hemophilia. Although Danny always had his factor with him wherever he went, Darlene's family learned that paramedics and ER workers were not allowed to administer the factor due to conflicting treatment protocols and liability fears. So Darlene sprang to action and formed Danny's Dose with these goals in mind: (1) Raise awareness about the current gap in emergency treatment for people with rare diseases, chronic illnesses, and special medical needs; and see current protocols amended. (2) Assist with specialized education for EMS and ER personnel. (3) Provide education for affected families on how to better advocate for their treatment needs.

The organization's first goal was to amend protocols in the Sheltons' home state of Missouri within two years. Darlene says, "Goals can be lofty, but I believe if you don't set goals high, it removes some of the urgency." After their proposed legislation was passed in Missouri, Darlene looked forward to their next goal. "We passed EMS legislation, assisted with the beginning of paramedic education, and are helping that grow in 2018 and beyond. Of course, we can't be sure we will meet our five-year goal, but it looks promising, and we are determined to push hard." Darlene hopes to have improved treatment protocols for ER and EMS in place across the entire US within five years of their first state, Missouri.

The work of Danny's Dose doesn't just benefit people with hemophilia. "It benefits all individuals with special medical needs," says Darlene, "covering rare disease and chronic illness. This covers those with rare, lifesaving meds, those with particular treatments based on their illness, and those with complex medical devices like trachs and heart-pumps."

Never Too Early to Start!

It's never too early to start teaching our children the importance of setting goals and achieving them.

Christy VanBibber's eight-year-old daughter Elise was disappointed by her neighborhood's lack of knowledge and awareness of hemophilia. When Elise began sharing the news about her baby brother Timothy, who has hemophilia, she realized that many people didn't know what hemophilia was. "She came home with a real concern," Christy notes, "and asked, 'Mom, why does nobody know what hemophilia is?'"

Elise made it her goal to generate awareness in her community about hemophilia—by making and selling beaded bracelets and then donating all proceeds to the Southwestern Ohio Hemophilia Foundation.

Christy recounts the initial success: "She made some bracelets and asked me to put them on Facebook. We decided to sell them for \$3 each. Immediately she sold ten!" Elise went on to sell her bracelets at two local farmers' markets and local football games.

Christy was thrilled. "She raised \$880! Also, people recognize Elise and Timothy at school and the grocery store, asking questions and praising her for such a great job. We are really proud of her!"

All these women—and one young girl—achieved their goals fueled by close-to-home, real-life concerns, and you can too! If you want to learn how you can reach your goals this year, check out our cover story and find out how to make your goals SMART.

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By LA Kelley Communications