

Special Fall Issue 2020



# HANJournal



**After more than 40 years of service to the Hemophilia community, Elena Bostick has retired. See messages to Elena to celebrate her retirement beginning on page 6.**





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The Hemophilia Association of New Jersey was founded in August 1971 by 10 concerned families, and offers assistance to persons with hemophilia and their families from our office located in East Brunswick, New Jersey.

Our mission is to improve the quality of life for persons with a bleeding disorder by providing and maintaining access to highly qualified medical providers and successfully proven medical regimens.

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**Managing the Transition From  
 Childhood to Adolescence  
 Guiding Preteens With Hemophilia**



For more information, visit [b2byourvoice.com](http://b2byourvoice.com) to download *Navigating The Preteen Years*.

This content is brought to you by Pfizer.

Parents of a preteen with hemophilia may have concerns about preparing a child for life with a chronic condition. During the preteen years, children spend time away from family, attend school, and experience additional social influences. This is when children begin to form their own ideas and opinions. Preteens may be exposed to peer pressure to engage in risky behavior and/or forego treatment, making open communication essential.

Proactively educating children about hemophilia can improve their ability one day to begin managing their own medical care. At a young age, children can gather infusion supplies or even decide on the infusion site. This involvement can help prepare them for self-infusing. Dr. Truncale recommends that families attend summer camps where older children mentor younger children.

Preteens are building life experience and taking steps toward independence, and it is important that parents set limits. Preteens may not handle their impulses and desires maturely.<sup>1</sup> Guiding a child to make the right choices can help prepare him or her for the future and the many similar decisions he or she will make. Parents should find a balance between giving a child space to grow and setting boundaries.<sup>1</sup>

**"Encourage your child to focus on what he or she can do, not what they can't do."**  
 — Thomas Truncale  
 DO, MPH

Adolescence lasts longer today than in the past; children begin puberty earlier and leave home later. This gives parents and children more time to learn how to negotiate the transition to independence.<sup>2</sup>

Education helps children living with hemophilia learn to make the right decisions. If a bleed occurs, proper education may help the child identify it as soon as possible so it can be treated early.

**Proactivity is Crucial**

Dr. Thomas Truncale ranks proactivity as the most important factor when managing hemophilia. Anticipating needs and putting together a plan ahead of time can have benefits when treating hemophilia, addressing parenting issues, and in seeking education.

Dr. Truncale adds that proactivity should extend to school, church, and community. Create a package of educational information for the school nurse, teachers, church personnel, babysitters, and other families. Ask the hemophilia care team for materials available for this purpose, and don't forget to add relevant personal contact information.

Reference: 1. Cassis FRMY. *Psychosocial Care for People With Hemophilia*. Montréal, Québec: World Federation of Hemophilia; 2007. 2. Irish Haemophilia Society. Transition. <https://haemophilia.ie/living-with-haemophilia/parents-of-children-with-bleeding-disorders/the-bridge-of-transition-for-adolescents-with-bleeding-disorders/>. Accessed September 17, 2019.

**PATIENT AFFAIRS LIAISONS**  
 Patient Affairs Liaisons are Pfizer employees who are dedicated solely to providing support to the community. Your Pfizer Patient Affairs Liaison is available to help you access the support and information you need. To find your Patient Affairs Liaison, go to [hemophiliavillage.com/support/patient-affairs-liaison-finder](http://hemophiliavillage.com/support/patient-affairs-liaison-finder) or call Pfizer Hemophilia Connect at 1.844.989.HEMO (4366).





## President's Message By Ron Grayzel, Esq.

In 1975, Elena Bostick came to HANJ as a community volunteer. In 1980, Elena became our Executive Director. Elena served as our Executive Director until 2015 when she became Managing Director until her retirement in 2020. When Elena first came to the Association, we were a small group of dedicated volunteers serving the Hemophilia Community in Central New Jersey. There were no treatment centers. Specialized treatment was not generally available to people with blood disorders and a new "miracle product" factor concentrate was becoming the treatment of choice. Currently, with the new products in the pipeline, we stand on the precipice of a cure. HANJ began by serving the Raritan Valley and grew into a statewide operation. Elena helped build the organization brick by brick, and under her watch, it became the financially strong edifice and prodigious service organization it is today.

During Elena's tenure, the product manufacturers, the health care industry and the community underwent tumultuous changes. Elena always championed the right and responsibility of the community to participate in decision-making regarding the health care for persons with blood disorders. Over the years, Elena hammered away at this principle, eventually persuading industry, health care providers and government representatives to provide HANJ a seat at the table where decisions were made.

In the beginning, HANJ ran a small number of fund-raisers and provided a few basic services to its members. Elena presided over a growth in the resources and social services provided to members, including monetary payments for family emergencies and scholarships. Now we have a full-time social worker. Elena made HANJ a second home for its members. From birth to adulthood, the progress of our children was cause for recognition and celebration. Passing around family photographs at board meetings became a ritual. Elena knew all the families and developed strong personal relationships with the members.

The greatest challenge ever faced by HANJ and its members was, of course, the HIV epidemic of the 1980's and 1990's. Elena was a rock that anchored us in this crisis. Illness and death were a daily reality. HANJ combatted prejudice and fought for basic healthcare for its stricken members. Perhaps Elena's most important contribution during these troubling times was the compassion and support she gave to the families who were overwhelmed by the plague.

Elena Bostick transformed the Association into a grassroots powerhouse that advocated for the needs of the Hemophilia community with the New Jersey Legislature and state agencies. Elena became a well-known figure in Trenton. When Elena was in the state house for the votes on one of our bills, she would doggedly pursue legislative leaders down the halls on their way to their chambers. The tap-tap-tapping of her heels on the marble floors became a familiar and foreboding sign to our opponents that she was on the scene.

Elena led efforts in the 1980's to compel major medical health care carriers to pay for factor concentrate. However, such payments were subject to a cap. The next step was to obtain the passage of legislation shifting the obligation to pay for factor concentrate to the basic or in-patient portion of the plan, thereby eliminating the cap. The catch was that each policy holder was subject to a one-year exclusion for the pre-existing condition. The membership mobilized and utilized blood credits and fundraising moneys to assist members who were excluded from coverage.

Under Elena's leadership, HANJ persuaded the State to pick up these costs for uninsured patients, which led to the State grant to purchase health care insurance for uninsured patients ineligible for Medicaid. These efforts assured that persons with blood disorders would receive the expensive but life sustaining medical treatments they needed.

The next target for Elena was the HMO's. The Association secured regulations requiring them to authorize treatment with the HTC's.

Due to statutes of limitations barring claims against the manufacturers, the HIV crisis left persons with hemophilia without an effective remedy to compensate victims and their families for the widespread viral infections caused by untreated factor concentrate products. Elena led the successful efforts in the 1990's to obtain a law providing a window extending the statute of limitations beyond the existing two year statute of limitations for victims to file lawsuits.

The need for a change in the law was a classic David [HANJ] versus Goliath [the blood industry] battle. With Elena at the helm, the fight was fought in legislator's district offices, the legislative chambers and the governor's office. The industry hired powerful lobbyists to oppose the passage of the law. The community petitioned legislators in their district offices and demonstrated in the halls of the State House. HANJ won round one after both houses of the legislature passed a bill. The industry won round two when it persuaded the Governor to veto the bill. Elena rallied the troops and persuaded the State Senate to override the veto. This amazing victory came up short when the Speaker of the Assembly refused to let the Assembly vote to override.

It was back to the drawing boards for Elena and the Association. A new bill was drafted and once again passed the Legislature. The Governor, worn out by Elena's shock troops, finally relented and signed the Bill. Other successful legislative efforts would follow. This included the adoption of Standards of Care for home care companies supplying blood products to patients with hemophilia.

Elena was a champion for the medical rights of women with bleeding disorders. She persuaded the Governor to establish a commission to study the needs of the patient population and to make recommendations. The work of the Commission was the first of its kind.

Elena generously took HANJ's knowledge and experience, and shared it with other hemophilia associations with the annual PACT workshops. Sister organizations traveled to New Jersey from around the country to learn the lessons Elena had learned from decades of grassroots experience.

HANJ will never be the same without Elena. Her legacy is secure as the organization is stronger than ever.





## Elena Bostick

**Retiring After 40 Years of Dedicated Service to the Hemophilia Community .....Elena's friends, family and colleagues in the hemophilia community have sent her notes, stories and well wishes to celebrate her retirement. We will miss her!**



Hello Elena,

We're so happy to hear of your pending retirement. As the parents of Ken Richardson we cannot begin to thank you for all you did for Ken, especially in regard to his summer camping experiences. Recently I came upon a postcard Ken had sent from Traverse City, Michigan. In the postcard he wrote, "My luggage got lost for a couple of days and I had a slight bleed ("DON'T WORRY" he wrote in capital letters), having a great time. Ken's time at camp, both in Michigan and Connecticut were things he always talked about. Experiences that played an integral role in his becoming a successful ATT paralegal.

Thanks again for all you've done for Ken and so many others like him.

Fondest regards,  
**Helga and Chuck Richardson**

"Elena Bostick introduced me firsthand to the trials and tribulations of hemophiliac patients who received tainted blood. She Educated me, and led me on the road to my first lesson in taking on the "big guys"! We weren't always successful, but in the end thanks to her leadership and discipline we won some of the battles to those families who needed it most.

Thank you Elena for your steadfast leadership and constant integrity. All of our constituents will miss you. But I wish you many years of good health, love, and happy adventures. Hopefully we will both be willing to give a few lessons to others on how to take on "the guys".

**Loretta Weinberg**  
**NJ Senate Majority Leader**

Dear Elena;

Congratulations on your well deserved retirement! Your commitment and passion towards the bleeding disorders community is truly remarkable. As a Baxter representative, I always greatly respected your position on the opportunities and challenges facing the hemophilia community. One thing I will never forget, is your response when we would discuss future advances in hemophilia care. You would say something like, " no matter what the cost of new hemophilia therapies, HANJ will always find a way to ensure they are accessible to our members." And, this was always the case. Thank you again for your dedication to the bleeding disorders community and thank you for helping me become a better industry representative.

**Peter O'Malley**

## Elena Bostick

What can I say about Elena. There are no words to express the gratitude we have for her.

When we moved to New Jersey in 1970 there was no place except to take our two sons back to New York for treatment.

HANJ was just starting to grow. As I remember, the fund-raising consisted of Turkey Shoots and Door to Door solicitation.

Things improved greatly when Elena became our Executive Director. The treatment center at Robert Wood Johnson was opened. We no longer had to travel to New York with the boys for treatment. Life was improved for all of our patients.

Sadly, when the AIDS holocaust hit us, everything changed, we were fighting to keep our boys alive. Elena was there night and day, standing by us, searching for anything that might help. In the end nothing worked both our sons died.

I don't know how we would have carried on without Elena. Then the battle against the people that caused all this started. With Elena leading us we fought and finally got legislation passed so that we could get a small amount of satisfaction by taking them to court and letting the public know the price of greed on so many innocent victims. None of this would have been possible without Elena Bostick.

She never stopped, the HANJ grew, it got bigger and better. Life was greatly improved for our members due to the friendships and respect she had from legislators and the pharmaceutical representatives. She gained their friendship and trust and that improved life for our members. With what she leaves us, I'm sure we will continue to grow.

Warmest Regards,

**Elaine & Robert Kelly**  
**Elaine, Board Member & Past President**



Elena and Elaine Kelly at hearings in the early days in Trenton

There was nothing this "duo" could not fight for and accomplish together in the interest of our Hemophilia community.

Elena, your accomplishments in the interest of Hemophilia are too numerous to mention here, but one admirable and consistent quality of yours through the years was that you were a friend and always there for our members and their families.

With our best wishes on your retirement, our love and gratitude.

**The Amitrani Family**



Elena with Paul Amitrani, Past President





# ELENA BOSTICK

Starting as a telephonist HANJ's door-to-door fundraising program and rising to Executive Director, Elena is the mother of the most successful hemophilia organization in the world. Growing from its position as the state with the first hemophilia program, through hard times and troubles, Elena made New Jersey the best place to live if you had hemophilia. She made every volunteer feel as if they were the essential ingredient in every HANJ success when it was Elena who did the work. She made the HANJ the most potent public affairs advocate in New Jersey. When she spoke, politicians, industry leaders, unions, and health care institutions listened. She devoted her life to helping persons with hemophilia because all she ever wanted was to better our lives. We are all eternally grateful and wish her an enjoyable retirement.

Don and Barbara Goldman

Elena, while you will be missed for sure, the legacy and accomplishments that you leave behind will continue to drive HANJ and the incredible work the organization does on a daily basis. I consider myself extremely fortunate to have known and worked with you for almost 30 years. Many of my fondest memories and significant accomplishments were realized while working with you and your staff on behalf of the Hemophilia population of NJ. I also cherish our friendship and professional working relationship. I like to think that we made a pretty good team.

**Mark Scudieri**  
Board Member



Dear Elena,  
First and foremost, we at Saint Michael's Medical Center would like to thank you for your dedication and service to the bleeding disorder community. You inspired all of us with your passion and commitment. We want to acknowledge the contribution you have made to our region. You worked tirelessly for decades and made a positive impact on so many lives, which will always be remembered. We are grateful for the support that you provided to the patients and staff here, at the Nadeene Brunini Comprehensive Hemophilia Care Center.

We wish you all the best in your future endeavors, enjoy your retirement.

**Dr. Gunwant Guron**  
**Dominique Joseph**  
Saint Michael's Medical Center



Mark Scudieri & Elena at his Man of the Year Dinner in April of 2006.

Our family is so grateful to Elena for her years at the helm of HANJ.

Elena's name has been synonymous with HANJ for decades. When we first came to the organization she made sure we knew what was at stake for our son and how our commitment to HANJ would change his life and ours. She wasn't kidding, and we are so happy to be here.

Elena's advocacy on behalf of the bleeding community in NJ, and her overall ability to get us onto committees without us realizing what just happened, were all part of what made our family want to be involved and, more so, work hard for the association and its membership.

It is with great appreciation for her dedication, service, sense of humor and larger than life presence in the bleeding disorders community that we wish her good health and heartfelt thanks as she moves into retirement. We will miss you, Elena. Thank you for everything.

**The Maniaci Family**  
**Chris, Lisa, Christopher and Peyton**  
Chris, Secretary & Past President  
Lisa, Board Member



We extend our gratitude to Elena Bostick upon her retirement for her tireless work to support our patients with bleeding disorders and their families over the past 40 years. Elena has been a relentless advocate for the hemophilia community in her various roles at HANJ. The impact of her legislative achievements to protect the rights of our patients and support their comprehensive care has been monumental. We appreciate all of her efforts on behalf of the bleeding disorder community and providers in New Jersey and her presence will be missed.

With sincerest best wishes in your next chapter, Elena!

From the Rutgers Robert Wood Johnson Medical School Hemophilia Treatment Center

**Claire Philipp, MD**  
**Amanda Kaveney, MD**  
**Susan Murphy, MD**  
**Frances Maceren, RN**  
**Teri Bekos, RN**  
**Lisa Cohen, MSW**

Smart, tolerate, assertive, driven, passionate, never-give up, leads from the front = Will be sadly missed.

**Chris Walsh MD, PhD**

Dear Elena,

Congratulations on your retirement from the Hemophilia Association of New Jersey after 40 years of exceptional service to the organization and its important mission. Your tireless efforts, passion and focus on helping patients with hemophilia and bleeding disorders have been invaluable during your tenure.

On behalf of CSL Behring, I would like to thank you for an incredible career that always centered on advocating for the patient community and ensuring access to care. Your ability to empower others through education, self-awareness and Partnership for Advocacy and Communication Training (PACT) is a true measurement of your leadership. I am grateful for having had the opportunity to know you and work with you for many years. As the CEO of a Values-based company that puts patients at the center of everything we do, I always appreciated your commitment to doing the same – ensuring that the voice of the patient community was loud and clear.

I wish you well in your next chapter and thank you for your leadership and service to the hemophilia community.

Sincerely,

**Paul Perreault**  
**CEO & Managing Director**  
**CSL Limited**

Congratulations on your retirement. Enjoy yourself, you deserve it. Elena was so helpful and an understanding person. Always available to answer questions whenever you needed her. Thank you for all you've done!

♡🙏

**Karen Palaia**

**E**xtraordinary  
**L**eader  
**E**nlightened  
**N**urturing  
**A**damant

**B**right  
**O**utspoken  
**S**elfless  
**T**enacious  
**I**mpeccable  
**C**ompassionate  
**K**indhearted

Elena,

There will never be enough positive words to describe you or to thank you for the forty years that you have so passionately fought for the hemophilia community. If anyone would just take a moment to google your name, they would get a small glimpse of how fortunate and honored the hemophilia community is to have had you at the helm of the Hemophilia Association of New Jersey. It seems all paths to every person's journey with hemophilia have led back to you. New Jersey is nationally recognized as a leader in the hemophilia community due to your powerful voice and leadership of your HANJ team in achieving ground breaking legislation, strengthening comprehensive care for the hemophilia community, fostering team work with insurance companies, pharmaceutical companies and the hemophilia treatment centers to ensure the best care possible for "your community". Through your love you have inspired the various pieces of the community to come together to support each other and to flourish. If anyone had the privilege of being at an event in which you were present, they would have immediately noticed people were encircling you. Adults and children always gravitated to you for your advice and, of course, abundance of hugs and love. Elena, we are so honored to call you our friend and we are glad to have been with you for a part of this ride. We wish you much love and happiness in your continuing journey.

Love,

**The Lessners**  
**Bob, Michelle, Tyler & Jake**  
**Bob, Board Member & Past President**

There are not enough superlatives to describe Elena. Extraordinary, peerless, unflappable and unexcelled come to mind. I've know her for about 15 years. Every time we spoke on the phone or met in person to discuss the organization I was always amazed and humbled by her vast knowledge of every facet of the organization, both locally and nationally. Her ability to draw on her years of experience and always know the right person to contact, have information on the newest innovations, or sometimes just giving the right guidance was unmatched. On a personal note, she is the kindest and most patient person I've met. She never hesitated to answer any questions I had, and was always willing to help. Her dedication to HANJ was unrivaled, and while I know we all wish her well in her new life adventure, she is and will be sorely missed.

**Mary Petti**  
**Board Member**





Dear Elena,

When you said you were actually going to retire and I mean... really retire, I thought back over the years, or probably better to say decades and the many memories we have shared. I can't remember when it was that we first met but, let's say, it was when we were both 'a little' younger. Over these decades the times we spent working together whether it be in your office, at meetings both local or national, HANJ events and just talking on the phone are all part of the collective memories that I will always think of fondly. Of course there was that lobbying 'expedition' where we went to Trenton and waited for 4+ hours to only be given 10 minutes with only one of us was allowed in! I still remember you turning to me and saying 'go for it'...no pressure! I really respect the leadership, focus and commitment you have brought to HANJ over the decades. It was a pleasure to be a part of your 'circle of trusted advisors' and the friendship that has built up over the years. So now your career with HANJ may be coming to an end but our friendship will always remain.

All the best.

**Larry Guiheen**



Dear Elena,

Well we knew it would come to this, but who knew it would be so soon. One of the real joys of my professional and personal life has been the people I have had the pleasure to work with over the years. I would say none of us knew where the bleeding disorders community would take us over the last 40 years. It has been such a tumultuous ride, the highs have been exhilarating, the lows often times unspeakable, but always the desire to do more has been unquenchable. Your retirement marks another milestone in a remarkable era. I have often told people, if I had hemophilia and lived in New Jersey I would rise every morning and thank God for Elena. I wish you all the best in your golden years and hope our paths cross again.

**Joseph Pugliese  
President & CEO  
Hemophilia Alliance**

Dear Elena,

You have always been a fierce champion and true friend of the HANJ families, and we wish you all the best. You have fought hard on our behalf and have touched so many lives; and we have been so fortunate and appreciative of your dedicated and loyal presence over the years.

Mark and I truly wish you all the best in your retirement and **thank you sincerely** for all you have done for us for the past 20+ years.

Hugs, love and sincere best wishes always,

**Sue and Mark Jandoli**

Elena, "say it isn't so" that after more than 40 years of tireless effort and sincere devotion, you are taking a step back from the organization you helped create and lead to the "gold standard" for non-profit organizations. HANJ has established itself, nationally, as one of the leaders in patient support and advocacy.

It seems like only a short time ago that a small group of parents and a young Executive Director gathered around a small table each month to build an infrastructure to support the needs of our children. We were concerned about how do we pay for product and how to support a health system that would enable our "kids" to lead "normal" lives and become productive adults. We weren't worried about who to provide Research Funds to (since we didn't have any funds) or what legislative efforts to support? We have come a long way since then with your leadership and guidance. Every Association President looked to you for inspiration and direction. I count myself as one fortunate enough to benefit from your assistance and friendship over the years. Over the years, you always collected pictures of our kids to post in your office to track their progress.

We lived through the bad years (with hope) and the good years (with promise of things to come). During it all, you became the face of the association and were recognized nationally for your achievement of "what an organization could be".

We are all in your debt and it will be hard to conceive of the Association without your presence. But know that the strong foundation that exists today, exists because of your dedication and the high standards that you set for all to follow.

We love you.....

**Jerry and Barbara Seltzer  
Jerry, Board Member & Past Preident**

Marilyn and I were one of the founding families of HANJ, therefore, I have known and worked with Elena since her tenure when the Association began. She is responsible for our relationships with the government, the pharmaceuticals, the insurance companies and much more. The platform she created is the one we stand on today. It is the reason HANJ was the leading force as the spokesman for hemophilia nationally. Her dedication to our fight to get quick drug approval and combat the AIDS epidemic was epic. I was with her in DC when we went to congress, as well as the FDA seeking help in getting product to market as well as recognition of the problem as it impacted the hemophilia community in New Jersey as well as the entire country.

Her dedication was tireless and as most true leaders she was always in front of the parade. If statues were in order, we should build one.

**George Keelty  
Board Member & Past President**



Elena and Jerry Seltzer in the early days.



Elena with George and Marilyn



Elena,

I write this note with a view from many perspectives – a patient, an HANJ member and a board member. Your vision and contribution to HANJ has been extraordinary. As a hemophiliac that grew up during the formation of HANJ, one cannot appreciate all that you have done until they can look back over time. At the beginning, with no real roadmap to use to guide the community, the challenges that existed with medical care and treatment, no policies or procedures in place, no major funding and no understanding of the difficulties that would lie ahead, you made it your mission to create a community that this association could inform, teach, support and protect. You, and the teams you built, managed to navigate the political roadblocks and uncertainty with unmatched passion, caring, strength and dedication. The lives that you have affected both professionally and personally will always be remembered. There are those, like me, who could not imagine thriving both personally and professionally without all that you have accomplished. You have been a voice that no one could say no to (clearly not me), a shoulder to lean on – cry on – laugh with, a light that no matter what, would always show the way and a person that always put the needs and well-being of others before her own.

I wish you nothing but the very best in your retirement but more importantly – THANK YOU for what you have done. We are stronger people, healthier, more protected and able to accomplish whatever we desire and that is thanks to you!!!

All my love and admiration -

**David Lechner**  
**Imm. Past President**

How do you put into words the impact one individual has in a community? It is difficult to do this seemingly simple task when it is Elena we are honoring. I believe she has been many things to many people. Last year I had the opportunity to work with Elena on fund raising. During this time, I spoke to Elena about concerns regarding health insurance issues at the state level that would negatively impact individuals. She immediately reached out to state level resources and followed through by spreading the word. She is an amazing advocate. I would like to say the following to Elena:

Dear Elena,

Thank you for your years of dedication and service. You have enriched our community. In the words of Fred Rogers, "Often when you are at the end of something, you are at the beginning of something else."

May all the years ahead bring you great joy and relaxation. Wishing you a wonderful, fun filled retirement.

Peace, love, health, and happiness,

**Gina Egidio**

Dear Elena,

A simple thank-you is so inadequate for all you have done in supporting the Hemophilia Association of New Jersey. My parents, Joseph T. and Eleanor Angell, who are sadly no longer with us, have spoken so highly of you.

We thank you for your dedication, support, kindness and dedicated compassion.

Your thoughtfulness will long be remembered.

May the coming years bring you much happiness!

**Lynne Angell**  
**(Joseph and Eleanor's Daughter)**

I first met Elena Bostick over 25 years ago when the Hemophilia Association engaged my firm to provide governmental affairs services. Over the years, we've had our share of success and failure in the legislative arena, but throughout it all, the one constant was Elena's tenacity and unwavering commitment to always doing what was best for the community. Elena's dedication to the HANJ and its members is immeasurable and the lives of so many people are better as a result of her work. It has been an honor and privilege for me to work with Elena on behalf of the HANJ. And I will forever treasure the friendship we developed. Happy Retirement, my friend!

**Tracie DeSarno**  
**HANJ Lobbyist**  
**& Board Member**

Dear Elena,

Meeting you 30 years ago, in my then brand new position as the HTC coordinator and social worker at TJUH, I was so impressed with you from the start. Your advocacy on behalf of the bleeding disorders community truly knows no bounds. Your fierce tenacity to pursue the unmet needs of the bleeding disorder community, over the past 40 years, despite pushback from politicians, insurance companies, bureaucrats, and federal funders has been awe inspiring. Your courage to speak up and speak out, your ability to collaborate with people from all walks of life, your extraordinary negotiation skills, and your passion and compassion for the bleeding disorders community, patients and staff alike, have enriched so many lives (mine included). You have worked tirelessly on behalf of this community for so long, never leaving any stone unturned, and have always moved on to the next need/barrier facing the community without stopping to bask in your extraordinary achievements.

Over the years, you and I have shared our extreme sorrows over those in our community whose lives were lost to HIV/AIDS and to Hepatitis C. It was the most heart-breaking of times and I know all of those patients knew how much you cared about them and fought for them on so many fronts. We have also shared the joys of our own families and I am glad that you will now be able to spend more time with those you love most. I wish you a very happy and fun-filled retirement, filled with the people and things you love best.

I hope you always remember how honored we all are to have worked with you.

All the best,  
**Sue Cutter**  
**Penn Comprehensive Hemophilia Center**

Dear HANJ,

We wish Elena a wonderful retirement, which is well deserved. She will be remembered to us for always fighting for "our community". I can remember her at national conferences being the strong voice with Julie Frenkel to say what is needed and what is right for "our community". We could never thank either of these wonderful people enough for helping us to navigate the impossible course of hemophilia. Since we started this journey over 35 years ago, we have depended on HANJ with the decisions of our lives with our hemophiliac's and have been lucky to have Elena always in there and "swinging" when it comes to a cause to help. We are eternally grateful and will miss her always in her role. We wish her the best.

Our love and good wishes to Elena and her family,

**Roxanne and Jim Dunkelberger**



I have known Elena for over 30 years. She was a dear friend to my sister Mena, who also worked for Hemophilia Association. Elena has a unique ability to get people to do things that they really don't want to do. I remember back to the time when she called me to sell tickets for the Senator Bill Bradley's Roast. When I told her that I spent time in the Air Force Reserves with him she very gently asked me about my experiences, and then convinced me to take part in the roast, even though I was reluctant. But that's Elena, making it impossible to say no. Another time was when she needed Board members and convinced me to join the Board. The more I said no, the more she convinced me to say yes.

Over the years, I have called upon her for advice and council, and she always found time to point me in the right direction. She is truly a remarkable, concerned individual, who I am honored to call my friend.

Sincerely,

**Michael Piscopiello**

In Honor of  
Elena Bostick

**By Rich Vogel  
Past President of HANJ**

Over the years HANJ and Elena have become family.

Knowing a person for over 40 years there are so many stories to share. Here are a few of my favorites.

When my father was alive, he, Elena and some board members went to California for an NHF convention. My dad loved Chinese food so one night he suggests they all go for Chinese food. He saw a sign for a restaurant. They jump in the car and start to drive. They drive and drive and Elena says, "Ok Walter, where's this restaurant?" "Just ahead" he said. They drive a little further and my dad goes, "There. There's the sign." The whole car burst out laughing for the sign said Ped Xing. It was a pedestrian crossing sign!

My wife Suzanne and I would have some big Oktoberfest parties when we first moved into our house. We would have people park in the field next door and I made a path through the woods that people could easily walk. Elena doesn't do easy. I look up and here is Elena, Julie and Rita coming through the woods, stepping over branches and briars, case of beer in hand. Nothing could stop Elena if she wanted something.

And it's that tenacious spirit of Elena's that has changed the bleeding disorders community in New Jersey these past 40 years. Whether it's legislation to cover clotting factors and blood products or passing legislation to open the statute of limitations for those who contracted HIV through the use of blood products so they could receive compensation and justice. Watching her stand up for the bleeding disorders community all these years was an inspiration, walking with her in the halls of the capital in Trenton was an honor and watching legislators crumble or actually turn away as she walked down the hall was legendary.

It's an honor to know you, testify with you, laugh with you and cry with you and call you my friend. You have helped shape me into the advocate I am today.

Rich Vogel with his Dad, Walter Vogel, Past President. This photo is one that Elena had on her desk over the years.



When you think of Hemophilia and New Jersey - you immediately think of Elena Bostick. Today's families with hemophilia have no idea how lucky they are that for the past 40 years Elena has been fighting on behalf of all people with hemophilia and because of this their child's life will be better. As a HTC we benefited from knowing that because of Elena and the legislation she pushed to get passed, patients had access to care at an HTC with knowledgeable staff.

How hemophilia has changed in the 40 years with Elena.

The late 1980's - 1990's was a difficult time for the Hemophilia patient and their families with the tragedy of the HIV and Hepatitis C. The support she and the HANJ staff gave to the patient, families and the treatment centers was immense.

Product time line: Plasma derived, Recombinant. (first, second, third generation, Monoclonal Antibodies and the future is promising with gene therapy on the horizon.

In the early days when patients had a bleed they would spend days in the hospital or at home in bed. Her support with the NJ Department of Health that she gave to the Hemophilia Centers allowed the HTC to develop a full comprehensive care model and focused healthcare efforts on prevention and education to the patient and their families. Patients now do not have to rely on going to the hospital to receive their factor. Elena worked with the HTC and NJ state legislation to set up homecare standard so patient now treat independently at home in collaboration with homecare companies that meet the standards.

In the 1990's she worked with state law makers to develop a managed care plan to allow patients to obtain their hemophilia care at state recognized Hemophilia Centers.

Patients and their families these days can look forward to a normal life expectancy and excellent health-related quality of life thanks to the relationship between the HTC and HANJ that Elena has developed over the years .

Thank you Elena for all you have done for the Hemophilia Community over the past 40 years. Enjoy the next chapter in your life!!!

**Alice Cohen, MD- HTC Medical Director  
Phyllis Kandl, MA, CSW -Program Manager  
Ellen White, RN, MSN- Nurse Coordinator and  
The entire Newark Beth Israel Hemophilia Center staff**

Dear Elena,

I don't know where to begin to thank you for a lifetime of service to the Bleeding Disorders Community. You are what legends are made of. Throughout my life, you have always been behind the doors of HANJ. Sometimes quiet, sometimes not. To the benefit of all of us with a Bleeding Disorder.

I can say this without a shadow of a doubt, that without you, and your leadership at HANJ, I never would have imagined surviving to sixty-two years of age. And I'm sure I speak for many others. Because of you, there's a ME. May God protect and care for you, the way you have for US.

Love,

**Glenn and Eileen Rosenwald**



One of the attributes of why Elena was so good at running HANJ is that she never lost the desire to fight for what is most important, that the person with a bleeding disorder would be able to get the best possible care. She would go out of her way when a person was in need of treatment or care, to insure that the person received whatever was needed. This aspect of care is written in the mission statement of HANJ.

“Our mission is to improve the quality of life for persons with a bleeding disorder by providing and maintaining access to highly qualified medical treaters and successfully proven medical regimens.”

This is something that Elena endlessly strived to achieve.

I can remember a time when I had a problem. I do not remember all of the details, but some were very clear. I had wakened up as normal to prepare to go to work. I felt dizzy, so I sat at the edge of the bed and passed out and fell onto the floor. When I regained consciousness, I noticed a great deal of a bloody mess on the floor. There were EMT's and police around me trying to determine what happened and what to do. Someone had said that it looked like he bled out. As I was gaining my thoughts, I asked my wife, Barbara, to call the HANJ office, ask for Elena and tell her I was on my way to the hospital and to see if she could get in contact with Dr. Philipp so that she was aware what was happening and that she could be at the ER when we arrived. I do not remember any of the ride to the hospital, however, I do remember waking up in the emergency room and seeing Barbara, Dr. Philipp and many other doctors looking at me and asking questions. What they asked, I do not know. But, in the end, my problems that day were corrected and I am fine. But having Elena available at the ready was a comforting feeling.

**Carl Piercey**  
Treasurer  
Past President

One day during the Fall of 1996, I called Elena to let her know that I would be leaving my job with HANJ's accounting firm, where I had been handling the HANJ account for a few years. Elena then asked me to stop by and see her on my way home one night that week. When I did, of course she asked me to get involved with the Association. And thus began what has now been twenty four years of involvement with HANJ as a volunteer and board member. It has been a great learning experience, provided the opportunity to meet a lot of great people and take part in so many activities that I may never have had the opportunity to take part in. Thanks for inviting me to get involved, for thinking that I could handle it and that I would be a good person to have on board.

Congratulations on your retirement.  
Enjoy it. You've earned it.

**Steven C. Moersdorf**  
1st Vice President

Sorry but my memory is not like it use to be, but what I do remember is Elena having some great interactions with Julie at the board meeting.

Elena went above and beyond helping the hemophilia community for people like myself during the AIDS crisis. She was always there for me when I needed help with my insurance premium during hard times. Elena was truly amazing.

**Regards**  
**Rickford Fooying**

**Elena is:**

Authentic.  
Smart, street-smart, state-smart, DC too.  
Strong, caring, calming, comforter. Advocate—yours and mine.  
Leader, worker. Inspiration, walk-through-fire.  
Strategist. Teacher. Courage. Encourager. Supporter. Connector-of-people.  
Backbone of NJ Hemophilia Movement. National model. Protector-of-blood.  
The answer. The guide. The whole-package.  
Straight-talker, the Brooklyn-way. No-nonsense, great fun.  
Demander of Justice. Julie-friend. Mentor. Lover of families—yours, hers, mine.  
The Best there is.  
The person-you-call-first.

How do you box up into words Elena and her decades of work for people and families with Hemophilia? Elena, who has taken our Community through extreme loss—HIV/AIDS, hepatitis; and extreme joy—the legislative victories, the treatment advances. So, a story about just one of the many life-changing things Elena did for me and my family—this one just over three decades ago.

Home, after work, the phone rings, it's Elena. She knows of a family who recently moved to our Town. The Mom called HANJ. With the caller's permission, Elena asked if I would talk with this Mom of an infant with hemophilia, one of the 30% families who have no-family-history, for whom it's a "spontaneous mutation" (A *lusus naturae* in the sense of a "whim of nature"). Just like our family with our son, Matthew. Yes! I answer. Elena has a way of asking, fervently, and we had been navigating hemophilia for almost nine years. So, Yes, is my final answer.

I called the Mom, new to hemophilia, and arranged to meet her for coffee on Church Street in our Town. We order coffee and muffins, we start talking and talking and talking. And didn't ever stop through our drives together to Board meetings at HANJ, through this Mom serving as President of HANJ, through her intrepid activism, her speaking truth to power for hemophilia and for women's blood disorders. This Mom was Anna DeSimone—best friend, co-volunteer, and co-worker at the NHF. We talked and talked and though we all lost Anna to myeloproliferative disorder in 2012, I can still hear Anna's voice—her philosophy of living, her wisdom—echoing in my heart. You can see why she and Elena would get along so well. There are so many incredible things I thank Elena for, bringing me Anna DeSimone is one of them.

Hemophilia is no easy road—from the time of having no-treatment, through lethal treatment, through the ongoing fight for adequate coverage for care. I don't even want to imagine being on that road without Elena Bostick!

Elena—unique human being, woman extraordinaire—**thank you!**

**Ann-Marie Nazzaro**  
(Matthew Milczarski's Mom)

Elena,  
Best wishes in retirement, but it's hard to imagine you retiring! I've know you for over 20 years, and first met you when I was working for the State. I will always remember your tenacity, preparedness, and compassion. But perhaps most of all I will remember your generosity. Your work with your PACT Workshop, sharing your wisdom and acting as a kind of Johnny Appleseed for advocacy for those with bleeding disorders, no doubt has left a lasting advocacy. Congratulations on a job well done. You will be missed.

**Ward Sanders**



Elena,  
I want to wish you much happiness on your retirement. I will always remember your laugh and smile. The interesting thing is that with that laugh always came a question or a gentle nudge to encourage you to volunteer. Your persuasive smile and wonderful disposition made it difficult to refuse you.

Aside from encouraging volunteering you are a fun loving caring person who has helped numerous patients with bleeding disorders and hemophilia get the help they need. Many pieces of legislation would not have passed if it wasn't for your determination and perseverance.

I remember thinking should I join and become active or not but your kindness and smile won me over in 1997 and I am still here.

You have and will always be a great asset to the Hemophilia Association and to those who know you. I am sure we will continue to see your smiling face even though you are officially retired.

Good luck and enjoy your retirement.

**Jo Ann Howard**

Hello Elena,

Imagine my surprise as I sat on my front porch sipping a cocktail (or two) when I opened my email in box and saw an invitation to join a tribute to you. To say I was delighted would be an understatement.

Its been 10 years since I retired and I often reflect fondly on my time working with the hemophilia community and the good people at HANJ.

There are many qualities that I admired about you but most impressive was your long standing and unwavering commitment to the New Jersey community. My meetings with you over the years were marked by your strong resolve to make the case for financial support and legislative assistance for important projects to better the lives of your constituents. I knew your requests were heartfelt and the funds would be put to good use. And you did it with such class! Importantly, we always had a few laughs at the end of our meeting.

And now I learn you are retiring after 40 years of dedicated service. Congratulations and as you move into the next chapter of your life, I wish you a long, healthy, and happy retirement. Again, congratulations!

Warm Regards,

**Terry Tenbrunsel**

Our son, Matthew, was diagnosed at 18 months old - about 40 years ago now. There was no family history. We were shocked, and didn't know where to turn. Our doctor suggested we get in touch with HANJ. We spoke with Elena. She was so warm, welcoming and compassionate. The annual meeting was coming up and she strongly urged us to attend. At the meeting she introduced us to other parents in our situation. She knew we needed to make those connections. We feel so fortunate that our doctor had the insight to link us up with HANJ and Elena. Leadership is hard to define. Very few people have the qualities that make a good leader. In my opinion, Elena epitomizes those qualities.

Thank you, Elena, for everything.

**Bill Milczarski**

"Elena has been the driving force in making HANJ the premier Hemophilia advocate in the country. She makes me proud to be part of the organization."

**Richard Keelty  
Board Member**

"I have been told that the definition of GRIT is when passion and perseverance converge. If this is the case, then Elena Bostick epitomizes what true grit is. Her passion for the people living with bleeding disorders is unrivaled in this world. Her perseverance in helping to ensure they get the best care possible is nothing I have ever seen prior. There are no shortcuts to excellence. Developing real expertise, figuring out really hard problems, it all takes time—and longer than most people imagine. Grit is about working on something you care about so much that you're willing to stay loyal to it...it's doing what you love. No one loved and cared for the bleeding disorder community more than Elena. That is why she made it her life mission to ensure that New Jersey was the best state to live in if you had a bleeding disorder – MISSION ACCOMPLISHED!"



**Neal Fitzpatrick**

When I first started volunteering on the HANJ Patient Services committee, Elena handed me a printed copy of the 1995 IOM report on the tainted blood scandal and told me to read it. This was a 350+ page document! But as a longtime leader in the community, she knew that it was important for me, a hopeful future advocate, to know what past community advocates had fought for. It was Elena who encouraged me to fly to Louisville in 2010 and put my name up for an HFA independent board seat. In a very real way, that encouragement led to some of my deepest friendships with blood brothers across the country, as well as a future career path in the pharmaceutical industry. That HFA meeting was my first exposure to the national hemophilia community and I remember having two distinct revelations while there. First, everyone I met who learned I was from New Jersey and a part of HANJ wanted me to send regards back to Elena. The community's respect and appreciation for her as a leader was palpable. Second, I quickly came to the realization...and appreciation...of how well HANJ was run. Prior to meeting lots of folks from other chapters, I had assumed that every chapter was composed of committees that funneled ideas and policies to a functioning board, who then voted on those ideas and policies and worked with staff to implement them. Much to my surprise, that's not the case, and I realized that it was Elena's leadership that had molded HANJ into a model advocacy nonprofit and hemophilia chapter. It's tough for me to imagine a HANJ without Elena at the helm, or at least informing the direction of the chapter. I'll miss her as a mentor, a community leader and a friend.

Best,

**Tommy Russomano**



I was a closet hemophiliac until I was 60, ten years ago. In 2010, after having a spontaneous thigh bleed I went to the ER for treatment. I received my first dose of factor, something I didn't know existed until that moment. When the doctor noticed my surprise that I wasn't being treated with cryo, he told me to contact HANJ.

Unfortunately, I had no idea what HANJ was. When I called I was put through to Elena Bostick, who pretty much changed my approach to my disorder. She introduced me to the HTC model, which was a blessing since I didn't know specialized hospitals existed. She ensured that I was put in touch with physicians and home health care companies that would change my life. I went on prophylaxis and the anxiety of potential bleeds diminished, along with a considerably happier attitude toward life.

Elena then asked me to participate in a HANJ program to write a Strategic Plan. From there I joined the Board, became President, and was then elected to the Executive Committee of HFA. Without Elena I would never have known about the Blood Brothers, and would not have made significant friendships with men with similar issues.

Elena has affected not only my life, but the life of all hemophiliacs, even those not living in NJ. The organization she built, and the legislation she got enacted, are envied throughout our community.

Thank you for all you've done.

**Joe Markowitz**  
Board Member  
Past President

Not often do you get to meet someone responsible for making your life safer and more livable. For a long time I was aware of the HANJ and someone named Elena Bostick working on behalf of the hemophilia community. Luckily in recent years I have gotten to know Elena and watched in awe of her energy and dedication to our membership. When we attend a gathering and see our members doing well because of adequate treatment we can look to Elena as instrumental in making this a reality. She is truly a legendary figure.

So thank you Elena for caring to achieve so much for all of us. You deserve every happiness that comes your way in the future.

**Jeff Lynch MD**  
HANJ Medical Advisor

"Thank you" doesn't remotely come close for all that Elena has done for HANJ, our community and my family. She is/was a relentless and fierce advocate, I'm so glad she was on OUR side of the fence. From the bottom of my heart, Elena, thank you so much for your amazing and faithful years of service and friendship to our community. Love,  
**Bobby, Pam, Kristina and Betty Murdock**

Dear Elena,

I have known you for my whole adult life, you have been a rock for all of these years. You have been to my wedding & watched my kids grow up. I can't express how much I appreciate what you have done for my family, especially through the tough years while my brothers were sick. You are a treasure and we love you, good luck, we will see you, you can't get rid of the Kelly family by retiring.

Love,

**Michael & Dianne Kelly**

Elena,  
Where to start? I will always be thankful to you for welcoming me with open arms when I first started working here 15 years ago. You made me feel like I was part of the family. Not only did you care about me but you also cared about my family. Your sweet spirit and caring self always made me feel comfortable, loved and cared for. I will miss you tremendously but always remember that you have a very special place in my heart. You are amazing, beautiful inside and out with a smile that can brighten someone's day and even an entire room. I want to say that I wish you all the best in this new season of life. This is a new chapter but I'm sure it will be as great as all the other ones. May God continue blessing you and your family today and always.  
With Respect, Love and Appreciation,

**Joanne D. Rodriguez,**  
Social Worker  
Newark Beth Israel HTC

Elena,

Congratulations on your retirement. It was an honor and a privilege to work with you all of those years for the benefit of hemophiliacs and their families. You led us through one of the toughest periods any organization could possibly imagine and you did it with a sense of compassion and professionalism rarely seen. Enjoy your retirement. It was well earned.

**Rachel and Tom Ondreyka, Past President**

I am writing this on behalf of myself, Nicholas Miller, and also my mother, Mary Jo Miller.

"The Miller Family would like to acknowledge and thank Elena for all of the efforts she provided this community for so many years. As a new family entering the Hemophilia community 20+ years ago, we could not be thankful enough to have received the support and education we did. Thank you again to Elena and we wish Elena nothing but the best moving forward."

**Nick Miller**  
Coagulation Sales Specialist

Thank you Elena!

When we were new to the HANJ community, parents of a newly diagnosed baby boy you welcomed us with open arms, and you have always greeted us in the same way. Your warmth and enthusiasm always made us feel special. Early on when we had issues or needed clarification of our options you were there with patience and understanding. Before long we realized you were a warrior for our community, your knowledge and dedication amazed us. Our hemophilia community has been blessed to have you.

For all your hard work and dedication you deserve a wonderful retirement filled with good health, love and cherished moments with family and friends, those are our wishes for you.

~ **Andrea and Aldo Carminio**  
(Daniel and Matthew too)



It was a little intimidating meeting Elena for the first time. I can't remember the exact year, but I want to say either 2009 or 2010. I was asked to represent NHF at the PACT workshop. I must've said something right because I was invited back. Fast forward to 2013. I went to work for Baxter as the Senior Manager of Reimbursement and Advocacy—basically the company's regional point person for patient advocacy relations. The HANJ became one of the key accounts in my portfolio. For the next several years, I spent a lot of time in New Jersey collaborating with Elena and the HANJ team on the PACT program, advocacy, fundraising, and tons of educational programs. We had this running joke that I should just move to New Jersey... In Elena, I found a person who loved policymaking and advocacy as much as I did, so I'd often find an excuse to visit just to talk policy. I remember the first time she called wanting my opinion on a legislative bill, I almost fell off my chair. It was that big a deal!! From then on our relationship blossomed from acquaintances into a wonderful working partnership. What I admired most about Elena was her passion and fierce determination in seeing to it that her members had access. I learned from her the value of staying true to oneself and never forgetting who you represent. Here was a woman who was revered by many—from industry executives to government officials, and even many in the broader hemophilia community. Yet, everything she did was about protecting the members of the New Jersey Hemophilia community. And, she wasn't afraid to let you know that. I can't tell you how often I heard—"what would Elena do?" or "do you think Elena would be okay with that?" That shows the magnitude of her reach. Elena, your record speaks for itself. You are truly a legend and I am forever grateful to have had the opportunity to work with you. The entire bleeding disorders community is better because of you.

Enjoy retirement, my friend!

### Ruthlyn Noel

Elena, my dear, dear friend. 40 Years of service – WOW. You and I have known and respected one another for the last 25 years. I remember walking into your office for the first time with Michael and Rob. I was their new manager after the Legacies of Larry and Pete who were growing in their careers. It was one of the most intimidating experiences of my life! Some of the first words out of your mouth were "Welcome to New Jersey, you've got to be tough and smart to play in this sand box. Larry and Pete wouldn't have put you here unless they believed in you, and believe me, they both know, their lives would become a living hell if they made a mistake"! Net, Net -Your passion and commitment has greatly influenced my career and dedication to the Bleeding Disorders Community. I am proud to say that I fight the good fight every day for the community because of your leadership, guidance and friendship.

Please enjoy your well-deserved retirement, my Friend, and I promise to stay in touch.

With great respect!

### Ken Trader

*Vice President, Managed Markets*

**BIOMATRIX**

Elena has been a lifeline to our family for over 25 years. However, we would like to share one personal story about Elena that is very dear to us.

Over 2 years ago, my son underwent a critical spine correction surgery. Given his severe hemophilia and poor response to factor, Elena recognized the challenges and understood our fear. On a daily basis, Elena reached out to see how he was doing. Her support meant more than she could have ever imagined. At one point, while I was sitting at my son's bedside (just watching him sleep), I took the time to read something that could possibly ease my nerves. I came across a passage that read, "*The next time you feel frightened, stand very still. If you do, you might feel the tip of an angel's wing brush against your shoulder.*" Just then, my son began to stir. Despite the morphine pump being readily available, I felt anxiety rapidly rise within. Without delay, I took a moment to catch my breath and to be very still. Within that moment, I heard a ping from my phone. I looked at my phone and saw that I just received another message from Elena. As I read her note, her words eased my fear and warmed my heart. Knowing that her messages provide strength to my son as well, I looked forward to him waking up so that I could read it to him. That afternoon in the hospital, Elena was the angel's wing that brushed my shoulder.

### The Horbacz Family

Although I was born in 1964, the Hemophilia Association wasn't founded until 1971 and Elena Bostick didn't start working there until much later, I can't seem to picture my life or HANJ without her. It seems as if she's always been there with us. I remember my mother discussing when they hired Elena. I don't remember her exact date or words, but I do remember Mom being very excited and saying something along the lines of, "Ohhhh, we've found a good one!" Mom wasn't necessarily known for her understatement, but in this case, she will be. Elena hasn't been just good. I think one of the highest compliments you can pay someone is to say how integral they were to a program or group. Elena was involved in everything and always fought for US. She was always there in the office, always there when legislation was pending, always there when a recall hit, always there when envelopes had to be filled. Always there, even during a pandemic. She knew local businesses, local politicians, state politicians, lobbyists, reporters. Most importantly, she knew us. All of us. She knew the mothers, the fathers, the sons and the daughters. What her needs or wants were over the years, I'm sorry to say, I don't really know. She wanted to help the hemophilia community and we needed her. We would not be where we are today without her decades of devotion and if anyone is deserving of a long and happy retirement, it is you, Elena!

Sending you love and wishing you all the best,  
**John & Terri Thompson**

Dear Elena,

Thank you so much for your tutelage and service to HANJ and the hemophilia community. It has truly been a pleasure to have known you for all these years and I am honored and proud to have known and work with you. The impact you have made throughout the hemophilia community is astronomical and there really isn't anyone I can think of that can replace you.

Good luck in this next phase of your life and rest assured you will surely be missed.

All the best Elena!  
**Peter Marciano**  
**Board Member**



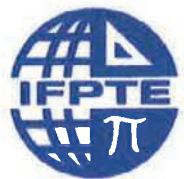


## Local 195, IFPTE

*International Federation of Professional & Technical Engineers*

In Remembrance of Dominick D. Critelli 1977-2006

Donald J. Buchanan, President Emeritus



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Ms. Mary Lou Billings  
Special Events Coordinator  
Hemophilia Association of New Jersey  
197 Route # 18 S. Suite 206 N.  
East Brunswick, New Jersey 08816

Dear Mary Lou,

It is my honor and great privilege to recognize Elena Bostick on her retirement after many successful years of dedicated service to the Hemophilia Community. Local 195, IFPTE has always had a wonderful working association and relationship with Elena starting years ago with the late Dominick Critelli, who worked closely with her & the Hemophilia Association, along with Donald J. Buchanan, Carol Labowicz and Myself.

I especially, have shared twenty-seven (27) blessed years since 1993 working with Elena. Local 195, IFPTE will be forever grateful to Elena Bostick for allowing our organization to be a part of such a worthy cause as the Hemophilia Association of New Jersey.

I extend God's richest blessings, good health and much happiness to Elena on her retirement on behalf of President Emeritus, Donald J. Buchanan, Local 195 Officers, Members and Staff.

Best Wishes for a Happy Retirement.

Sincerely Yours,

Timothy J. Rudolph  
President, Local 195, IFPTE

My Tribute to Elena Bostick

Some history to the formation of the Hemophilia Association of New Jersey with Elena Bostick as Executive Director. Walter Vogel and I were delegates representing NJ as part of the Greater NY Hemophilia Chapter. When we met, and fund raising was discussed, we told the group that the turkey shoot was our major fund raiser. The NY group laughed as they believed that we actually shot the turkeys boxes were printed on large paper poster boards and each box was sold for \$1.00 each box. The posters were mounted at a shooting range and were fired at. The closest to the center of the box for each board won a Turkey. When Elena came to us, things have certainly changed.

Since the NY Chapter did relatively little for our Hemophiliacs in NJ, a group of us got together, and started our own NJ Chapter with Elena as Executive Director. Elena was Terrific, whether it was state legislative action to get better coverage for our Hemophiliacs or working to obtain the benefits of blood clotting factors from corporations, or financial coverage, i.e., compensation during the HIV crisis from the major corporations. Elena reached out to important hospitals in NJ and secured support for our membership, to blood centers, medical staff – anyone that could help our people maintain their quality of life.

Elena saw to it that those who were unable to self-insure received coverage for their factor needs. She was creative at fund raising, especially developing a great staff of workers and volunteers.

Elena has been a true treasure for NJ Hemophiliacs – opening the door for so much more, i.e. Women's bleeding issues, etc.... A book could be written about her accomplishments.

My wish for her future is to have many Happy, Healthy days in her retirement. Thank you Elena for all that you have done for us. We were given a miraculous gift when you came to Hemophilia Association of New Jersey!

**Arthur Reich**  
**Former HANJ President**

Elena, We love you and hope you enjoy your retirement. We missed seeing you this Summer.  
Love,  
**Theresa Sicignano and Bob**

Elena,

Congratulations on your Retirement!! You have put your heart into this community and are an inspiration to many!!! Wishing you all the best and Many Many Blessings!!

Enjoy your retirement!!

**Milinda DiGiovanni**  
**Board Member**

Congratulations on your retirement, Elena. Thank you so much for all you've done for the bleeding disorders community. We always looked forward to seeing your smiling face at the HANJ events. Much love and good wishes for the future!!!

All the best,

**The Najimian Family**

Dear Elena,

Thank you for all of your work, truly. Your friendship with my mother is one of the most powerful memories of my childhood that I have (in addition to all of the gigantic smooches), and reflecting on those memories I want to say thank you for the role you played in allowing my mother to be a confident and potent member of the bleeding disorders community.

Thank you for everything you have ever done for me directly and for everything you have done for all of us.

**Maxwell Feinstein**



To the Members of the Hemophilia Association of New Jersey,

Today we celebrate the tenure of one of the most skilled directors to ever grace a political action committee: Elena Bostick. Elena's service to the HANJ has been instrumental to the protection of its members, the advancement of critical research, and the support from our government officials. She has shouldered many burdens, dealt with the most dire of circumstances, and always had an open ear for tough times. Elena has saved hundreds of lives indirectly through her efforts, and improved the lives of thousands of hemophilia and bleeding disorder patients. Without her aid, many of us would not be here to celebrate her efforts.

Elena has personally been protecting me since before I was a thought. My father, Dennis, was a hemophiliac, and from stories I've been relayed, he was quite terrible at managing it. From jumping off of rock piles, to flipping cars, my father was always finding ways to cause a bleed. My grandmother, Elaine, had a handful managing him, not to mention her youngest son, who also had hemophilia. Upon moving to the Garden State, my grandmother became active with the HANJ, and met Elena. Elena always had a hand in assisting my grandmother in making sure these kids had insurance and access to needed care. Any little thing could be discussed, and every little thing was taken care of. Our family had so much to thank her for in this time.

And then the 80s came. Both Dennis and his brother, Bobby, were infected with HIV from faulty factor. Elena and HANJ now had a tougher road for hundreds of members, including my family. They did not back down; they pushed harder, and fought for the rights of victims. I was born during this time, and never had to suffer to see my family struggle. When both men lost their lives to AIDS in the mid-90s, our family was wounded, but not broken. Elena was always the fire that forged our fight anew, even when it seemed impossible. Consultations with legal teams, condolences on tough days, and cookies at the office on old West Prospect St. were a frequent occurrence in my young eyes. Never a day do I remember going to the old office or the new one and not seeing Elena at the door, or in her office.

Though hemophilia is ended in our family, our partnership with the HANJ is not ceased. My grandparents have continued to support the efforts of the HANJ through membership, leadership, and academic scholarships. We are pleased to see a new generation of young men and women with bleeding disorders have hope for a healthy future, and possible ends to their respective ailments. All because a dedicated few began this organization to provide equity and protection to victims of a terrible disease. All because Elena Bostick led this dedicated few through good and bad. All because it was a fight worth fighting.

Elena, thank you for everything. May retirement be just as wonderful and prosperous as you have been in all your years of service.

With greatest thanks and regards,

**Thomas M. Kelly**



**Dearest Elena,**

**"Your Retirement is...."**

**Relaxation** time for the hard work, compassion, empathy, and 1000% dedication you put in through your 40+ years of service.

**Enjoyment** of your newfound freedom to explore your new journey.

**Time to try** something new and different that brings you joy.

**Imagining** doing all of the things you wanted to do but didn't get a chance to because of your commitment to the people and the cause.

**Reaping** the benefits and joy of knowing how many lives you have personally impacted throughout your amazing career.

**Excellence...**the highest ethical and professional standard that you have set for the rest of us to follow.

**Meaningful...** You are a loving friend, a confidant, and audacious leader, your rich legacy will live on through those you have mentored.

**Ending** this chapter and starting a new one!

**No more stress**, it's time to rest. You can pass your torch for it still shines bright through the next generation of leaders.

**Taking it to the next level!** Whatever is in store for you, embrace it!

So, my friend, I Bid You Adieu, for now. As you exit stage left, basking off of the fruits of your labor, I want you to know that you truly made a difference in all of the lives who were fortunate to be touched by you. Thank you for the time that you have invested in me and my family. I am forever grateful!

Happy Retirement 2020 to the warmest, yet fiercest leader I know! Wishing you happiness and a well-deserved rest indeed!

Love Always,

**Alaysha M. Walker, David E. Walker (son) & Barry R. Jones (father)**



Dear Elena,

We wish you the very best retirement. You truly put your heart and soul into your time here at HANJ. Each of us admire your tenacity, your determination, and your hard work. You've paved the way for many, making a powerful impact within the community. Each of us are lucky to have learned and grown with you. Thank you for your guidance and commitment through the years. Your successes will be remembered for years to come. Enjoy every minute of your well-deserved retirement.

With love,

**The HANJ Staff**





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We would like to thank everyone for sending in your stories, notes and well wishes. You have helped to celebrate Elena's retirement. All items received have been placed in a random order.



*Thank you  
Elena...  
for more than  
40 years of  
service to the  
Hemophilia  
Community.  
We love you,  
You will be missed!*





**Social Worker Update**  
**By Neidy Olarte, MSW**  
**Social Service Coordinator**

**NJ Health Insurance Marketplace**

Did you know that effective November 1, 2020, New Jersey now has an insurance marketplace? For individuals that are currently seeking a new health insurance plan or have insurance through the marketplace, you can log onto the new NJ healthcare website to see if you qualify for a new plan. Open enrollment for 2021 has also been extended. You have until January 31, 2021 to select a plan of your choice. Please note that if you select a plan by December 31, 2020, your enrollment effective date will be on January 1, 2021. If you select a plan January 1, 2021 or after, your insurance enrollment date will be effective February 1, 2021. If you need insurance and you do not enroll between November 1, 2020-January 31, 2021, you would not be able to obtain a health insurance plan unless you qualify for a special enrollment period. Premium tax credits continue to be offered so if you apply for an insurance plan, you may qualify for a premium reduction depending on your income. If you feel that you may qualify for Medicaid, you can always apply through NJ Family Care anytime during the year. For more information on the NJ Marketplace please contact them at:

New Jersey Marketplace  
**1-833-677-1010**  
 or visit their website at  
[GetCovered.NJ.Gov](http://GetCovered.NJ.Gov)

**Find Financial Help For Your Health Coverage.**

[GetCovered.NJ.gov](http://GetCovered.NJ.gov)

**Get Covered NJ**

**Open Enrollment for 2021**  
**November 1, 2020**  
 to  
**January 31, 2021**  
**Enroll by December 31, 2020 to be covered by January 1, 2021**

The following is a list of the participating health insurance plans offered through the NJ Marketplace. You may contact them directly if you have any questions on the plans they offer.

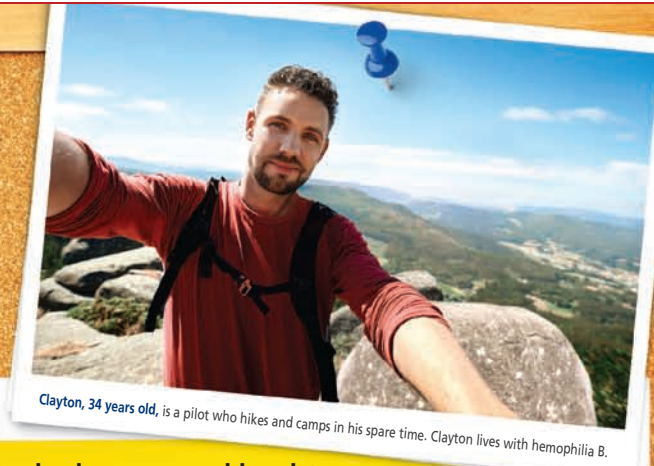
AmeriHealth HMO Inc. and AmeriHealth Ins. Co.  
 259 Prospect Plains Road, Bldg. M, Cranbury NJ 08512  
**1-877-744-5422**  
**www.amerihealth.com**

Horizon Blue Cross Blue Shield of NJ and Horizon HealthCare of NJ  
 Three Penn Plaza East - PP09T, Newark NJ 07105-2200  
**1-800-224-1234**  
**www.horizonblue.com**

Oscar Insurance Corporation (NJ)  
 295 Lafayette St  
 New York NY 10012  
**1-844-672-2766**  
**www.hioscar.com**

Oxford Health Insurance (NJ) Inc. (Off the Marketplace)  
 7440 Woodland Drive,  
 Indianapolis, IN 46278  
**1-800-273-8115**

In hemophilia B  
**TAKE CONTROL TO A HIGH LEVEL WITH REBINYN®**



Clayton, 34 years old, is a pilot who hikes and camps in his spare time. Clayton lives with hemophilia B.



<sup>a</sup>In two phase 3 studies, factor levels were evaluated for 1 week after the first dose of Rebinyn® 40 IU/kg. The average levels after 7 days were 16.8% in 6 adults, 14.6% in 3 adolescents, 10.9% in 13 children ages 7 to 12 years, and 8.4% in 12 children up to age 6 years.

<sup>b</sup>Based upon a 2.34% increase in factor levels per IU/kg infused in adults.

Image of hemophilia B patient shown is for illustrative purposes only.

**INDICATIONS AND USAGE**

**What is Rebinyn® Coagulation Factor IX (Recombinant), GlycoPEGylated?**

Rebinyn® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Rebinyn® is used to treat and control bleeding in people with hemophilia B. Your healthcare provider may give you Rebinyn® when you have surgery. Rebinyn® is not used for routine prophylaxis or for immune tolerance therapy.

**IMPORTANT SAFETY INFORMATION**

**What is the most important information I need to know about Rebinyn®?**

- Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center. Carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing Rebinyn®.

**Who should not use Rebinyn®?**

- Do not use Rebinyn® if you:
- are allergic to Factor IX or any of the other ingredients of Rebinyn®.
  - are allergic to hamster proteins.

**What should I tell my health care provider before using Rebinyn®?**

- Tell your health care provider if you:
- have or have had any medical conditions.
  - take any medicines, including non-prescription medicines and dietary supplements.
  - are nursing, pregnant, or plan to become pregnant.
  - have been told you have inhibitors to Factor IX.

**How should I use Rebinyn®?**

- Rebinyn® is given as an infusion into the vein.
- Call your healthcare provider right away if your bleeding does not stop after taking Rebinyn®.
- Do not stop using Rebinyn® without consulting your healthcare provider.

**What are the possible side effects of Rebinyn®?**

- Common side effects include swelling, pain, rash or redness at the location of the infusion, and itching.
- Call your healthcare provider right away or get emergency treatment right away if you get any of the following signs of an allergic reaction: hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.
- Tell your healthcare provider about any side effect that bothers you or that does not go away.
- Animals given repeat doses of Rebinyn® showed Polyethylene Glycol (PEG) inside cells lining blood vessels in the choroid plexus, which makes the fluid that cushions the brain. The potential human implications of these animal tests are unknown.

**Please see Brief Summary of Prescribing Information on the following page.**

Rebinyn® is a prescription medication. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

**Learn more at [rebinyn.com](http://rebinyn.com)**



Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.  
 Rebinyn® is a registered trademark of Novo Nordisk Health Care AG.  
 Novo Nordisk is a registered trademark of Novo Nordisk A/S.  
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**rebinyn®**  
 Coagulation Factor IX  
 (Recombinant), GlycoPEGylated



**rebinyn®**

*Coagulation Factor IX (Recombinant), GlycoPEGylated*

**Brief Summary Information about: REBINYN® Coagulation Factor IX (Recombinant), GlycoPEGylated**

**Rx Only**

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit [www.novo-pi.com/REBINYN.pdf](http://www.novo-pi.com/REBINYN.pdf) to obtain FDA-approved product labeling
- Call 1-844-REB-INYN

**Read the Patient Product Information and the Instructions For Use that come with REBINYN® before you start taking this medicine and each time you get a refill. There may be new information.**

This Patient Product Information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have questions about REBINYN® after reading this information, ask your healthcare provider.

**What is the most important information I need to know about REBINYN®?**

**Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center.**

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing REBINYN® so that your treatment will work best for you.

**What is REBINYN®?**

REBINYN® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Hemophilia B is an inherited disorder in all age groups that prevents blood from clotting normally.

REBINYN® is used to treat and control bleeding in people with hemophilia B.

Your healthcare provider may give you REBINYN® when you have surgery.

REBINYN® is not used for routine prophylaxis or for immune tolerance therapy.

**Who should not use REBINYN®?**

You should not use REBINYN® if you

- are allergic to Factor IX or any of the other ingredients of REBINYN®
- if you are allergic to hamster proteins

If you are not sure, talk to your healthcare provider before using this medicine.

Tell your healthcare provider if you are pregnant or nursing because REBINYN® might not be right for you.

**What should I tell my healthcare provider before I use REBINYN®?**

You should tell your healthcare provider if you

- Have or have had any medical conditions.
- Take any medicines, including non-prescription medicines and dietary supplements.
- Are nursing.
- Are pregnant or planning to become pregnant.
- Have been told that you have inhibitors to Factor IX.

**How should I use REBINYN®?**

Treatment with REBINYN® should be started by a healthcare provider who is experienced in the care of patients with hemophilia B.

REBINYN® is given as an infusion into the vein.

You may infuse REBINYN® at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your hemophilia treatment center or healthcare provider. Many people with hemophilia B learn to

infuse the medicine by themselves or with the help of a family member.

Your healthcare provider will tell you how much REBINYN® to use based on your weight, the severity of your hemophilia B, and where you are bleeding. Your dose will be calculated in international units, IU.

**Call your healthcare provider right away if your bleeding does not stop after taking REBINYN®.**

If your bleeding is not adequately controlled, it could be due to the development of Factor IX inhibitors. This should be checked by your healthcare provider. You might need a higher dose of REBINYN® or even a different product to control bleeding. Do not increase the total dose of REBINYN® to control your bleeding without consulting your healthcare provider.

**Use in children**

REBINYN® can be used in children. Your healthcare provider will decide the dose of REBINYN® you will receive.

**If you forget to use REBINYN®**

If you forget a dose, infuse the missed dose when you discover the mistake. Do not infuse a double dose to make up for a forgotten dose. Proceed with the next infusions as scheduled and continue as advised by your healthcare provider.

**If you stop using REBINYN®**

Do not stop using REBINYN® without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

**What if I take too much REBINYN®?**

Always take REBINYN® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you infuse more REBINYN® than recommended, tell your healthcare provider as soon as possible.

**What are the possible side effects of REBINYN®?****Common Side Effects Include:**

- swelling, pain, rash or redness at the location of infusion
- itching

**Other Possible Side Effects:**

You could have an allergic reaction to coagulation Factor IX products. **Call your healthcare provider right away or get emergency treatment right away if you get any of the following signs of an allergic reaction:** hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.

Your body can also make antibodies called "inhibitors" against REBINYN®, which may stop REBINYN® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

You may be at an increased risk of forming blood clots in your body, especially if you have risk factors for developing blood clots. Call your healthcare provider if you have chest pain, difficulty breathing, leg tenderness or swelling.

Animals given repeat doses of REBINYN® showed Polyethylene Glycol (PEG) inside cells lining blood vessels in the choroid plexus, which makes the fluid that cushions the brain. The potential human implications of these animal tests are unknown.

These are not all of the possible side effects from REBINYN®. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088.

Tell your healthcare provider about any side effect that bothers you or that does not go away.

**What are the REBINYN® dosage strengths?**

REBINYN® comes in three different dosage strengths. The actual number of international units (IU) of Factor IX in the vial will be imprinted on the label and on the box. The three different strengths are as follows:

Cap Color Indicator	Nominal Strength
Red	500 IU per vial
Green	1000 IU per vial
Yellow	2000 IU per vial

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.

**How should I store REBINYN®?**

**Prior to Reconstitution** (mixing the dry powder in the vial with the diluent):

Store in original package in order to protect from light. Do not freeze REBINYN®.

REBINYN® vials can be stored in the refrigerator (36-46°F [2°C-8°C]) for up to 24 months until the expiration date, or at room temperature (up to 86°F [30°C]) for a single period not more than 6 months.

If you choose to store REBINYN® at room temperature:

- Note the date that the product is removed from refrigeration on the box.
- The total time of storage at room temperature should not be more than 6 months. Do not return the product to the refrigerator.
- Do not use after 6 months from this date or the expiration date listed on the vial, whichever is earlier.

Do not use this medicine after the expiration date which is on the outer carton and the vial. The expiration date refers to the last day of that month.

**After Reconstitution:**

The reconstituted (the final product once the powder is mixed with the diluent) REBINYN® should appear clear without visible particles.

The reconstituted REBINYN® should be used immediately.

If you cannot use the reconstituted REBINYN® immediately, it should be used within 4 hours when stored at or below 86°F (30°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

**What else should I know about REBINYN® and hemophilia B?**

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

**More detailed information is available upon request.**

Available by prescription only.

For more information about REBINYN®, please call Novo Nordisk at 1-844-REB-INYN.

Revised: 11/2017

REBINYN® is a trademark of Novo Nordisk A/S.

For Patent Information, refer to: <http://nvnordisk-us.com/patients/products/product-patents.html>

Manufactured by:

Novo Nordisk A/S

Novo Allé, DK-2880 Bagsværd, Denmark

For information about REBINYN® contact:

Novo Nordisk Inc.

800 Scudders Mill Road

Plainsboro, NJ 08536, USA

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USA17BIO03951 12/2017

**WHAT'S HAPPENING****New Jersey Hemophilia Treatment Centers****Rutgers Robert Wood Johnson Medical School Hemophilia Treatment Center****OPERATIONS DURING COVID19**

The Rutgers RWJ Hemophilia Treatment Center (HTC) recognizes that the global health crisis we are facing today with COVID-19 is of particular concern for patients and their families who rely on clinical coordination of care, factor and home care nursing. We would like to assure you that the HTC remains operational and is able to provide care for our patients with bleeding disorders. In light of the rising COVID cases in New Jersey, the clinic continues to take measures to minimize the risk to patients and staff. The majority of clinic visits are currently being conducted via telemedicine. HTC nurses are present in the clinic and triage calls as is the case during normal operations. Please do not hesitate to contact the clinic with any concerns or issues that you may have.

**Contact can be made with the Rutgers RWJMS HTC at the usual telephone numbers.**

**For Nurses:**  
732-235-6542 or  
732-235-6531

**For Social Worker:**  
732-235-6533

**PROGRAMS & SCHOOL VISITS:**

Currently educational programs & school visits are being conducted via Zoom. Please contact Lisa Cohen, MSW at [cohenlr@rwjms.rutgers.edu](mailto:cohenlr@rwjms.rutgers.edu) or by phone at 732-235-6533 if you anticipate a need for a school visit. Unfortunately, we will not be holding our children's holiday party this year. Hopefully we can resume the festivities in 2021.

We urge all of our patients to abide by New Jersey and CDC guidelines which include wearing a mask, maintaining social distancing and limiting indoor contact. These measures are increasingly important as winter approaches and given the increasing cases throughout New Jersey and the country. Please stay safe!

**Please****Wear your mask****Wash your hands****Social Distance**

**Rutgers RWJ Medical School Hemophilia Treatment Center**  
125 Paterson Street, 5th Flr, Ste5200  
New Brunswick, NJ 08901  
For appointments: (732) 235-7226  
Nurse Direct Line for Medical Issues: (732) 235-6531  
Social Worker: Lisa Cohen, MSW, LSW  
(732) 235-6533  
[cohenlr@rwjms.rutgers.edu](mailto:cohenlr@rwjms.rutgers.edu)



## Newark Beth Israel Medical Center and Children's Hospital of New Jersey



Happy Fall! The staff from the Comprehensive Hemophilia Treatment Center at Newark Beth Israel Medical Center and Children's Hospital of New Jersey would like to share some updates, current programs, and plans with you. We hope you are all doing well!

### STAFF NEWS:

**New Staff:** We are happy to announce that Taina Sampeur, MSHA has joined our team as our new 340B Coordinator. Welcome Taina!

### NEWS:

**Hemophilia Camp:** Unlike previous summers, where campers could physically go to camp, the summer camp programs at both Double H Ranch and The Hole in The Wall Gang Camp transitioned to a virtual format this year. Camp can be an integral part of a patients' journey towards independence. Both camps offer family camps as well. **For more information about camp, or if your child or family is interested in attending camp in the future, please contact Erica, our Social Worker, at the HTC.**

### ONGOING PROGRAMS:

**Insurance Changes:** Please be sure to update the HTC on **any and all** changes to your insurance coverage. **If you have any questions about insurance coverage, your deductibles, co-pay issues, or plan changes please contact our Financial Coordinator, Cassandra.**

**Treatment Logs:** The HTC is aiming to get all patients (who treat their bleeding disorder with medication) to track their infusions and/or treatment in a treatment log. In an effort to provide the best possible care for our patients, it is extremely important that our physicians and nurses can see a patient's treatment logs, in real time, for the management of their bleeding disorder. **ATHNadvoy is a web-based application that allows patients, or their caregivers, to track treatment related to their bleeding disorder in a user friendly way directly**

**through their smart phone, tablet, laptop, or computer.** When user creates an account, they choose their treatment center; linking the patient and the HTC, and allowing the HTC to have access to view patient's treatment log. **For more information, or to sign up, please contact our Social Worker, Erica**

**School Visits:** As students are transitioning back to school, either in person or virtually, we know that you might need forms completed, letters for school, or school visits scheduled. School visits are a wonderful opportunity for our HTC to provide education and outreach to your child's school or daycare about hemophilia and other bleeding disorders. Whether the visit is with the staff at your child's school, the daycare staff, or even the child study team, a school visit opens the lines of communication between the child's school or daycare and the HTC. **If you are going to want a school visit scheduled for your child's school or daycare center, or need a letter for school/forms completed, please contact Erica, our Social Worker.** Erica will make sure that we have a release on file, and will coordinate your needs with the school and schedule a visit. **If you will need any forms or letters for your child's school or daycare center, please be mindful that it may take up to two weeks for forms or letters to be completed.** For more information, please contact us at the HTC.

**Hemophilia 340B Program:** Our HTC participates in the Federal 340B Program. As a comprehensive care center, we have been improving the quality of life for individuals with bleeding disorders and providing cost effective care in the long term for many years. In an effort to help HTCs sustain themselves, and provide better care for their eligible

patients, Congress created the 340B Program as part of the Veteran's Health Care Act of 1992. Across the United States almost all of the HTCs participate in 340B Programs. Depending on their healthcare coverage, patients may have a variety of pharmacy options to choose from. Our HTC is contracted with three different home care companies; Accredo, BDRN, and Option Care Health/Bioscrip. Patients who are not currently using one of these three companies may voluntarily switch if their insurance company allows. Participation in the 340B Program is voluntary. **Please contact our Program Manager, Phyllis, for further information.**

**Comprehensive Evaluations:** It is really important to schedule and attend an annual comprehensive evaluation at the HTC. The annual evaluation is an essential component in the provision of an individual's comprehensive care. Members of the HTC treatment team will complete medical, musculoskeletal, psychosocial and laboratory evaluations to assess the patient's current health and to develop a treatment plan for the upcoming year. Education and referrals for medical and psychosocial services will also be provided as needed. At the time of an annual evaluation, patients will be asked to participate in the ATHN (American Thrombosis & Hemostasis Network) Data Set. This is a voluntary program conducted by HTC's with support from ATHN to improve the health of people with coagulation disorders. Patients will also be educated about any other available studies that they might be eligible to participate in. **Please note that any individual receiving medication through the HTC to treat their bleeding disorder must be seen by the HTC on an annual basis.**



### Travel Letters:

Are you going to be travelling? Are you going to need a travel letter? If you answered yes to either of those questions, this information is for you. **Please remember to let the HTC staff know if you are going to need a travel letter at least two weeks prior to your scheduled trip** so you can rest assured that your letter is in your hand as you embark on your journey.

### Manufacturer Factor Programs:

Manufacturers have programs available to help patients continue to receive products during a lapse of insurance coverage. They also offer co-pay assistance programs. Each program has enrollment requirements and many require yearly re-enrollment. Enrollment in these programs can be beneficial. **For more information, please contact your home care company or our Financial Coordinator, Cassandra.**

**Please contact us at the Hemophilia Treatment Center to sign up for one of the above programs or to request further information on available groups or services for children and adults. We can be reached at : (973) 926-6511.**



**Newark Beth Israel Medical Center and Children's Hospital of New Jersey Hemophilia Treatment Center**  
201 Lyons Ave. (E2)  
Newark, NJ 07112  
Main Number: (973) 926-6511  
Social Worker:  
Erica Stuppler, LCSW  
(973) 926-4197  
Erica.Stuppler@RWJBh.org  
Fax: (973) 391-0048





## St. Michael's Medical Center

### Patient Education:

Our Patients are always welcome to ask questions about New Therapies and Insurance updates. If any of you have questions or concerns, please give us a call and we will provide you with the most up to date medical and insurance information. You may call Dominique Joseph, Nurse at (973) 877-5340 or Joanne Rodriguez, Social Worker at (973) 877-2967.



GetCovered.NJ.gov

Get Covered NJ

### Insurance Re-Enrollment:

If you have insurance through the marketplace, please remember that this is the time of year where the **re-enrollment** period is open. If you have any questions or concerns and need assistance, please do not hesitate, and give us a call at (973) 877-5342 and we will assist you as much as we can. If you do not have insurance give us a call as well and we will help you with the enrollment process.

### COVID-19:

We want you to know that as the cases are rising again, we continue following protocols and guidelines to keep our patients safe. We are still open and servicing our patients and community. Always remember to wash your hands and wear a face mask for your protection and the protection of others.

### Mental Health:

We understand that these are difficult times for a lot of people, but we want you to know that you are not alone. If you feel sad, depressed, anxious and need someone to talk to, please call us at (973) 877-5342. If you feel that you need further intervention, please call the suicide prevention hotline at (800) 273-8255 or go to the website at [suicidepreventionlifeline.org](http://suicidepreventionlifeline.org) or call 911.



**St. Michael's Medical Center  
Hemophilia Treatment Center  
111 Central Ave., Bldg. M2  
Newark, NJ 07102  
Patient's call: (973) 877-5340 or  
(973) 877-5341 or (973) 877-5342  
Social Worker: Joanne Rodriguez, CSW  
(973) 877-2967  
JRodriguez27@primehealthcare.com  
Fax (973) 877-5466**

The Hemophilia Association of New Jersey provides MedicAlert Memberships and IDs for patients with hemophilia and vWD. Medical ID jewelry is essential for people with bleeding disorders. Wearing a Medical ID ensures emergency responders and hospital staff have the most up-to-date medical information the moment they need it, to make informed decisions about treatment and care. For more information and an order form, please contact: Cindy Hansen at HANJ at (732) 249-6000 or [chansen@hanj.org](mailto:chansen@hanj.org).



# SAY HELLO TO JAMES

He has hemophilia A and has gone through two major surgeries while keeping to his factor regimen with the support of his hemophilia care team



"RECOVERY WAS TOUGH, BUT I LEARNED I HAD MORE SUPPORT THAN I THOUGHT POSSIBLE."



Read stories like James' in Hello Factor magazine: [BleedingDisorders.com](http://BleedingDisorders.com)

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## COVID-19 Update...

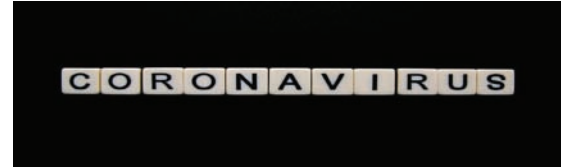
Jeff Lynch, MD  
HANJ Medical Advisor

As winter approaches the COVID-19 pandemic is holding its place as the top concern for our community and the population in general. The number of infections is rising as we begin to move back indoors. It appears that improved treatment has led to less severe outcomes but so far there is no magic bullet.

After filtering out the news and politics it is likely that vaccines will become available around the end of the year with significant use by early spring. According to the CDC vaccine availability will be prioritized in a so far undetermined way. The vaccine will be free with providers able to charge an administration fee that insurers will be required to cover.

In the meantime the often repeated but still valid measures of social distancing, hand washing, masks and avoidance of crowds are the best protections. The CDC website [cdc.gov/coronavirus/2019](https://www.cdc.gov/coronavirus/2019) has an excellent guide to prevention as well as an explanation of the role of testing to reduce spread of the virus. I encourage everyone to check it out.

Lastly, many health experts are concerned with general health effects of living in relative isolation. It is important to maintain contacts, get sunlight and some form of activity. If you are struggling with feelings of depression do not be afraid to reach out. I guarantee you will find others with the same feelings. If



necessary, the HANJ website has links to mental health services or feel free to contact HANJ and we will help find what you need.

Here's hoping everyone has a healthy fall and winter and I hope to see all of you at an HANJ in-person soon.

**Please take all necessary precautions for yourself and your family.**

New Jersey regularly updates local and State information at:  
[www.covid19.nj.gov](https://www.covid19.nj.gov)

HFA (Hemophilia Federation of America) maintains information specific to the bleeding community at:  
[www.hemophiliafed.org](https://www.hemophiliafed.org)

NHF (National Hemophilia Foundation) is the leading/largest/only national non-profit organization dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy, and research. Check their website at:  
[www.hemophilia.org](https://www.hemophilia.org)

## We are here to help you ...

Do you need assistance with your health insurance premium, co-pays and deductibles? HANJ offers assistance to eligible individuals, through our Medical Insurance Grant.

## Impacted by COVID19...

We are also providing assistance to eligible members who have been financially impacted by the COVID19 pandemic through our COVID Relief Fund.

Please contact **HANJ Social Worker, Neidy Olarte** via email at [nolarte@hanj.org](mailto:nolarte@hanj.org) or call **(732) 249-6000** for information about the requirements and how to apply for assistance.

GO SEEK. GO EXPLORE.  
**GO AHEAD.**

PEOPLE LIKE YOU. STORIES LIKE YOURS.  
Explore more at [HEMLIBRAjourney.com](https://HEMLIBRAjourney.com)



Discover your sense of go. Discover HEMLIBRA.

### What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

### What is the most important information I should know about HEMLIBRA?

**HEMLIBRA increases the potential for your blood to clot. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.**

#### These serious side effects include:

- **Thrombotic microangiopathy (TMA)**, a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events)**, which may form in blood vessels in your arm, leg, lung, or head

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects**.





**Medication Guide**  
**HEMLIBRA® (hem-lee-bruh)**  
**(emicizumab-kxwh)**  
**injection, for subcutaneous use**

**What is the most important information I should know about HEMLIBRA?**

**HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.**

**HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:**

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

**If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.**

See “**What are the possible side effects of HEMLIBRA?**” for more information about side effects.

**What is HEMLIBRA?**

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

**Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:**

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

**Tell your healthcare provider about all the medicines you take,** including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

**How should I use HEMLIBRA?**

**See the detailed “Instructions for Use” that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.**

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.

- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

**What are the possible side effects of HEMLIBRA?**

See “**What is the most important information I should know about HEMLIBRA?**”

**The most common side effects of HEMLIBRA include:**

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

**How should I store HEMLIBRA?**

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

**Keep HEMLIBRA and all medicines out of the reach of children.**

**General information about the safe and effective use of HEMLIBRA.**

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

**What are the ingredients in HEMLIBRA?**

**Active ingredient:** emicizumab-kxwh

**Inactive ingredients:** L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,  
 1 DNA Way, South San Francisco, CA 94080-4990  
 U.S. License No. 1048

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 For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.  
 This Medication Guide has been approved by the U.S. Food and Drug Administration  
 Revised: 10/2018



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 A Member of the Roche Group

## Copay Accumulator Adjusters Create Confusion, Obstacles for Consumers

By Mark Hobracz, Staff Writer  
 Reprint from HFA Summer 2020

Health insurers continue to develop new methods to limit access to care for members of the bleeding disorders community. Through Project CALLS, Hemophilia Federation of America has collected more than four years of reports from consumers that help to identify these new barriers.

HFA is using this data to develop resources to educate decisionmakers and community members about the harm caused to consumers by these restrictive insurance company practices. The following case study describes one of the insurance challenges recently reported to HFA through Project CALLS and suggests some ways consumers access to care.

### A Recent Case Study

A young adult male with hemophilia A aged out of his parents' group health plan after age 25. He initially obtained individual platinum-tier coverage offered by the Affordable Care Act Marketplace in his home state. During this time, this enrollee had received cost-sharing assistance from the manufacturer for his factor product. Because this assistance covered his out-of-pocket (OOP) costs, he decided to switch to the bronze plan for the 2020 plan year, since it had the lowest premium.

Before switching plans, the enrollee did his homework to prevent any disruption in care. He confirmed that the provider network for the bronze plan included his physician and providers. He also made sure the new formulary covered the medications he required.

He learned from HFA presentations that health plans were increasingly using copayment accumulator adjusters to contain costs. These accumulators do not allow the value of an enrollee's third party assistance to be applied to the enrollee's annual cost-sharing obligations. As a result, the enrollee could be forced to pay the full \$8,150 amount of the annual deductible under the bronze plan (which is the same as the annual out-of-pocket limit), despite receiving assistance.

This greatly concerned the enrollee and so he also took affirmative steps to determine whether the plan options available to him would apply an accumulator. He went into the local plan office shortly before the end of open enrollment but received conflicting information. Lower-level employees assured him the plan would not apply accumulators. However, a regional manager subsequently stated that the plan would start applying accumulators “across-the-board” for the 2020 plan year.

The enrollee never received any written notice confirming his plan would apply an accumulator. Instead, he was told by the office that the language could be found in “plan documents”. On his own, the enrollee was able to find such language buried on page 123 of a 203 page document. The language in that document merely states that the health plan would apply accumulators at the plan's “discretion.”

As a result, the enrollee decided to go ahead and sign-up for the bronze plan (since it had much lower premiums with only a slightly higher OOP limit). However, when he notified the manufacturer that an accumulator might be applied to his plan, the manufacturer stopped sending checks to the enrollee's insurer to cover his OOP costs.

The enrollee was very confused by the conflicting information he received from the insurer, which forced him to seek out emergency sources of funding (such as family loans) in the event he is forced to incur the \$8,150 deductible. Adding to this confusion is the fact that he had not been billed for any OOP cost following his first shipment of medication in 2020. He is requesting assistance from HFA on how to proceed.







# Jivi<sup>®</sup> Extension Study

Explore the study design and see the safety and efficacy data from patients who were part of the study.

► Dive in at [JiviExtensionStudy.com](http://JiviExtensionStudy.com)



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## Questions that arise with this case:

1. Should the enrollee ask the manufacturer to resume paying his cost-sharing assistance? Does it make sense to make such a request before the plan clarifies whether or not it is applying an accumulator?
2. Because the plan is being offered in a federally-facilitated ACA Marketplace, it must follow federal rules that prohibit midyear formulary changes that substantially increase OOP costs without "reasonable notice." Thus, is it even permissible for the plan to apply accumulators for 2020 since they have not issued advance notice to subscribers? Will Centers for Medicare and Medicaid Services enforce the prohibition against midyear formulary changes in cases such as this one? Or will CMS conclude that the discretionary language appearing on p.123 of the health plan document satisfies the "reasonable notice" requirement?
3. Is the health plan exercising discretion to apply accumulators only for its highest-cost enrollees? Would that violate the ACA's anti-discrimination provision? Will CMS enforce those anti-discrimination provisions?

4. Does the health plan intend to apply accumulators starting with the 2021 plan year, with clearer notice? With the same notice? **How HFA Uses Project Calls** Educate community members about how to identify and receive clear notice of accumulators prior to plan selection.

Educate community members about their rights when accumulators are applied.

Educate community members about other sources of copay assistance that may not be subject to accumulators (e.g., third-party charitable assistance).

Use this case study as an example of how insurers play "hide the ball" with accumulators and how such practices can lead patients astray, even when patients take advance steps to identify whether their cost-sharing assistance will be credited towards their cost-sharing obligations.

Have you or family member experienced an insurance issue?

Share your experience at [www.hemophiliafed.org/projectcalls](http://www.hemophiliafed.org/projectcalls) or by calling (202) 836-2530.



**ADYNOVATE**  
[Antihemophilic Factor  
(Recombinant), PEGylated]  
REAL LIFE. REAL BLEED PROTECTION.\*  
[AdynovateRealLife.com](http://AdynovateRealLife.com)

HEMOPHILIA A IS  
A PIECE OF YOU.  
NOT ALL OF YOU.

ADYNOVATE<sup>®</sup> is a treatment that can be personalized to fit your lifestyle so you have more time to spend doing the other things that also make you, you. It has a simple, twice-weekly dosing schedule on the same 2 days every week.<sup>1,2</sup>

\*In clinical trials, ADYNOVATE demonstrated the ability to help prevent bleeding episodes using a prophylaxis regimen.

No actual patients depicted.

### ADYNOVATE twice-weekly prophylaxis prevented or reduced the number of bleeds<sup>2</sup>

ADYNOVATE was proven in 2 pivotal clinical trials to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis)<sup>2</sup>

- **Children Under 12 Years:** This study evaluated the efficacy of ADYNOVATE twice-weekly prophylaxis and determined the ability to treat bleeding episodes for 6 months in 66 children under 12 years old who received 40–60 IU/kg of ADYNOVATE prophylaxis treatment<sup>2</sup>
  - During the 6-month study in children under 12, those receiving twice-weekly prophylaxis treatment experienced a median<sup>1</sup> overall ABR<sup>1</sup> of 2.0
  - 0 bleeds in 38% (25 out of 66 patients) during 6 months on twice-weekly prophylaxis

- **Adolescents and Adults 12 Years and Older:** This study evaluated the efficacy of ADYNOVATE in a 6-month study that compared the efficacy of a twice-weekly prophylactic regimen with on-demand treatment and determined hemostatic efficacy in the treatment of bleeding episodes in 137 patients. These adolescents and adults were given either ADYNOVATE prophylaxis twice-weekly at a dose of 40–50 IU/kg (120 patients) or on-demand treatment with ADYNOVATE at a dose of 10–60 IU/kg (17 patients). The primary study goal was to compare ABR between the prophylaxis and on-demand treatment groups<sup>2</sup>
  - 95% reduction in median overall ABR (41.5 median ABR with on-demand [17 patients] vs 1.9 median ABR with prophylaxis [120 patients])
  - 0 bleeds in 40% (40 out of 101 per-protocol<sup>3</sup> patients) during 6 months on twice-weekly prophylaxis

<sup>1</sup>Median is defined as the middle number in a list of numbers arranged in numerical order.

<sup>2</sup>ABR—annualized bleed rate, the number of bleeds that occur over a year.

<sup>3</sup>Per-protocol patients were assigned to the prophylactic group and treated with their originally assigned dose for the entire duration of the study.

### ADYNOVATE Important Information

#### What is ADYNOVATE?

- ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital factor VIII deficiency).
- Your healthcare provider (HCP) may give you ADYNOVATE when you have surgery.
- ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

#### DETAILED IMPORTANT RISK INFORMATION

##### Who should not use ADYNOVATE?

Do not use ADYNOVATE if you:

- Are allergic to mouse or hamster protein.
- Are allergic to any ingredients in ADYNOVATE or ADVATE<sup>®</sup> [Antihemophilic Factor (Recombinant)].

Tell your HCP if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

##### What should I tell my HCP before using ADYNOVATE?

Tell your HCP if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are or become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

### What important information do I need to know about ADYNOVATE?

- You can have an allergic reaction to ADYNOVATE. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADYNOVATE unless you have been taught by your HCP or hemophilia center.

### What else should I know about ADYNOVATE and Hemophilia A?

- Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

### What are possible side effects of ADYNOVATE?

- The common side effects of ADYNOVATE are headache and nausea. These are not all the possible side effects with ADYNOVATE. Tell your HCP about any side effects that bother you or do not go away.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

Please see Important Facts about ADYNOVATE on the following page and discuss with your HCP.

For Full Prescribing Information, visit [www.adynovate.com](http://www.adynovate.com).

References: 1. Valentino LA. Considerations in individualizing prophylaxis in patients with haemophilia A. *Haemophilia*. 2014;20(5):607-615. 2. ADYNOVATE Prescribing Information.

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## ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated]

### Patient Important facts about

#### ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

This leaflet summarizes important information about ADYNOVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADYNOVATE. If you have any questions after reading this, ask your healthcare provider.

#### What is the most important information I need to know about ADYNOVATE?

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADYNOVATE so that your treatment will work best for you.

#### What is ADYNOVATE?

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

#### Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)]

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

#### How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

You may infuse ADYNOVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADYNOVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADYNOVATE to use based on your individual weight, level of physical activity, the severity of your hemophilia A, and where you are bleeding.

Reconstituted product [after mixing dry product with wet diluent] must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

You may have to have blood tests done after getting ADYNOVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

#### How should I use ADYNOVATE? (cont'd)

Call your healthcare provider right away if your bleeding does not stop after taking ADYNOVATE.

#### What should I tell my healthcare provider before I use ADYNOVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

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You can have an allergic reaction to ADYNOVATE.

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The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADYNOVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

#### What else should I know about ADYNOVATE and Hemophilia A?

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

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

#### The risk information provided here is not comprehensive.

To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA-approved product labeling can be found at [www.ADYNOVATE.com](http://www.ADYNOVATE.com) or 1-877-825-3327.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

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S47033

## Ask the Expert

Miriam Goldstein

Director for Policy, Hemophilia Federation of America

**Q: "I've seen on Facebook that some insurance companies won't honor manufacturer copay assistance programs. What's going on?"**

**A:** Drug manufacturer copay assistance programs help many in the bleeding disorder community. People who live with bleeding disorders rely on medications—clotting factor or other treatments—to control bleeding and preserve their health. These drugs are essential, but expensive, and are needed on an ongoing basis. As a result, many people with bleeding disorders face the prospect of hitting their health insurance out-of-pocket maximums each year, and can reach that limit all at once with one order of factor. Yearly out-of-pocket maximums include copays, coinsurance, and deductibles, with amounts varying from plan to plan. While the Affordable Care Act (ACA) places an annual cap on cost-sharing amounts, that ceiling, depending on plan type, is high—in 2020, between \$6,900 and \$8,150 for an individual, or between \$13,800 and \$16,300 for a family. And the prospect of hitting it every year is daunting, to say the least.

Manufacturer copay assistance programs protect patients from this financial burden, and sustain their access to essential medications, by covering patients' drug-related copay, coinsurance, and deductible expenses. Many programs will cover \$12,000 and up in cost-sharing expenses per year. Eligible patients typically must have third-party commercial insurance to participate in these programs.

Unfortunately, in recent years a growing number of health insurers and pharmacy benefit managers (PBMs) have begun claiming that copay assistance programs incentivize patients to demand pricey brand name drugs instead of using more cost-effective generics. Citing the need to counter these incentives and contain costs, some health plans have been taking steps to limit the value of manufacturer copay assistance to patients—while maximizing the amount that the health plans themselves collect from those programs—through the use of "accumulator adjusters."

**Q: "I've heard that term, but don't know what it means. What are 'accumulator adjusters,' and how do they affect me?"**

Accumulator adjuster programs are used by health insurance plans to limit the value of manufacturer copay assistance programs. When an accumulator is in place, the health plan accepts the manufacturer copay assistance—which is supposed to pay for the patient's out-of-pocket drug costs—but then doesn't credit that amount toward the patient's deductible or out-of-pocket maximum. The health plan draws down the full value of the copay assistance as prescriptions are filled; but then it "adjusts" or resets what is credited to the patient's cost-sharing obligations back to zero.

As a result, a person with a bleeding disorder will still have to personally pay deductibles, copays, and other out-of-pocket expenses, up to the yearly out-of-pocket maximum. At the same time, the health plan appropriates the full amount of the copay assistance—assistance that was supposed to help the patient!

Accumulators leave bleeding disorder patients in a tough financial bind. If this happens to you, please check out the options listed in Hemophilia Federation of America's (HFA) online Resource Library.<sup>1</sup> You may be able to get financial help with your copays from a third-party, charitable nonprofit patient assistance fund.<sup>2</sup> Health plans sometimes will not apply accumulators to copay assistance provided by charitable organizations, and will still credit the charitable assistance to patient deductibles and out-of-pocket maximums.

HFA is working with other patient advocacy groups to educate health plans and PBMs about the dangers of accumulators. We urged federal regulators to ban the use of accumulators, where patients don't have the option to choose a generic drug (as is the case with bleeding disorder patients). Unfortunately, the US Department of Health and Human Services (HHS) rejected this request. In May 2020, HHS finalized a rule<sup>3</sup> that allows health insurers to continue using accumulator adjusters for the coming plan year.

HFA and allied groups will continue to advocate for federal and state policies that prioritize patient access to their prescription medications. In the meantime, we need to hear from you! If you learn that your copay assistance will no longer be credited toward your deductible or out-of-pocket maximum, please share your story with HFA's Project CALLS.<sup>4</sup>

Collecting data on the impact of accumulators allows us to make a case for change when we ask lawmakers to take action to protect patients from these harmful health plan tactics.

**Miriam Goldstein is director for policy at Hemophilia Federation of America, where her work includes monitoring and analyzing federal legislation and regulations impacting patient access to care; insurance, Medicaid, and Medicare issues; and blood and product safety. Miriam lives in Arlington, Virginia, and is the mother of two adult sons with hemophilia.**

1. [hemophiliafed.org/resource-library/additional-resources/navigating-patient-assistance-programs](http://hemophiliafed.org/resource-library/additional-resources/navigating-patient-assistance-programs) 2. Patient assistance funds that offer financial assistance to eligible bleeding disorder patients include the Assistance Fund, Patient Access Network (PAN) Foundation, and Patient Services, Inc. (PSI). 3. US Dep't of Health and Human Services, Notice of Benefit and Payment Parameters for 2021, 85 Fed. Reg. 29164 (May 14, 2020). 4. [projectcalls.org](http://projectcalls.org)

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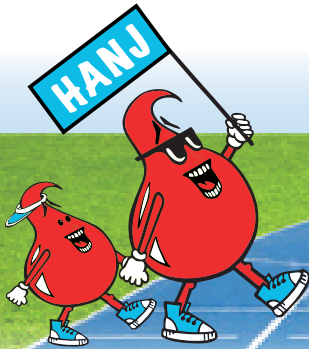
Column: Ask the Expert



Hemophilia Association of New Jersey

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