Happy Retirement to our longtime friend & HANJ Associate, Rita Matagrano! We wish you a healthy and happy retirement!
Message from the President of HANJ

As a new year begins, I hope everyone had a very happy and healthy 2016. As a follow up to the last HANJ newsletter, I did get the opportunity to attend the annual NHF meeting in Orlando in July. As part of their meeting, the NHF continues to focus on providing up to date information on topics from blood safety to longer lasting products to potential Gene Therapy. They offered programs on industry related topics to seminars for adolescents and women with bleeding disorders. There were also a few new industry companies focusing on new research and potential products for the care and treatment of bleeding disorders. It is always great to see the investments and focus that major companies have on meeting the needs and improving the lives of our community.

At HANJ, we also remain committed to providing you with access to timely information and to create opportunities for the membership to interact with each other. 2017 will be no different. Our Blood Brotherhood events continue to be a great opportunity to get together and enjoy different venues. I would encourage those of you that have not attended an event to reach out and participate at least once. In addition to Blood Brotherhood, HANJ has a great schedule of events for 2017. We will be holding our Testimonial Dinner, Dennis Keelty Memorial Golf Tournament, Awareness Walk, Gourmet Dinner, Casino Night as well as other exciting events. Our goal is to continue to increase the turn out from our association and other members of the community. It is always enjoyable to spend time with our industry partners and have an opportunity to hear what's new as well as have some fun. The information for these events can be found on Facebook or our website (HANJ.org). I encourage all of you to share the information with those you know. In addition to a great time, all of the money raised goes back to all of YOU through our programs, events and financial assistance.

I, and the HANJ staff, always enjoy the opportunity to meet new people, new families and members of our community that have not had the opportunity to attend an event in the past. We look forward to seeing you at the next event. If you would like to attend and cannot afford to, please contact the HANJ office. I hope you enjoy the latest information in the current newsletter and I wish all of you a great 2017.

Dave Lechner
President
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.

**President**
David Lechnor

**1st Vice President**
Joe Markowitz

**Vice President**
Ronald Grayzel, Esq.

**Treasurer**
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**Managing Director**
Elena Bostick

**Executive Director**
Stephanie Lapidow

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

**Social Service Coordinator**

**Health Care 2017**

With a new administration in the white house, there is talk of significant changes to health care legislation including the repeal of the Affordable Healthcare Act also known as Obamacare. While the Affordable Healthcare Act is still in place today, there is currently no indication as to how long Obamacare will stay and what will replace it. The Hemophilia Association is vigilantly monitoring changes in legislation particularly with the ACA. We will follow up with our members on the most up to date information on healthcare and how it will affect this community. Stay tuned for our upcoming Fall Educational Symposium that will address any changes and updates to the healthcare legislation. If you have any concerns about your insurance or have any healthcare questions feel free to contact HANJ.

**Insurance Renewal Application**

The Insurance Grant Renewal period for 2017 is here. Members currently receiving insurance assistance through the Hemophilia Association of New Jersey Insurance Grant Program, will soon be receiving their renewal application packet in the mail. Please be aware that the renewal applications are due no later than April 30, 2017. If you are currently receiving assistance, please contact the Association if you feel you have not yet received your application form or need a new form. If you are planning on moving please contact the Association for an update of your most recent address. Applications not received by the deadline of April 30, 2017 will result in termination of participating in the insurance grant program. If you have any questions regarding the application process or have any updates or changes to your insurance please contact the Association as soon as possible. For any questions about the Insurance Grant Program and what additional programs are offered through HANJ, please contact us at any time.

**Scholarship Information**

Every Year the Association provides scholarships to our members who are interested in pursuing an education after high school. We currently offer four undergraduate scholarships and one graduate scholarship. If you are interested in applying for one of our scholarships please log on to our website (www.hanj.org) for a copy of our application and what scholarships we offer. We also have uploaded information on healthcare legislation. If you have any questions regarding the Insurance Grant Program and what additional programs are offered through HANJ, please contact us at any time.

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WHAT'S HAPPENING
New Jersey Hemophilia Treatment Centers

Rutgers Robert Wood Johnson Medical School
Hemophilia Treatment Center

Rutgers RWJ Medical School 340B Program: In order for the hemophilia program to maintain comprehensive hemophilia care in an era of increasing health care costs amidst dwindling levels of federal and state funding of hemophilia programs, the Rutgers Robert Wood Johnson Medical School Hemophilia Treatment Center has become a 340B covered entity as of October 1, 2015. Participation in the federal 340B program makes it possible for our HTC to continue to serve the hemophilia community with the high level of services and quality of care it expects. If you have questions about this program, please do not hesitate to contact the HTC directly at 732-235-6533.

Educational & Programming Events: The HTC recently hosted an infusion training program. If you or your child were unable to attend this event, please do not hesitate to contact the HTC to set up individual infusion training sessions (see contact information below).

The HTC was pleased to host the annual holiday party this past December which was a great success. Thanks to HANJ for making a contribution to this event.

School Visits: The staff at the HTC continues to provide in-service programs to school personnel about a child’s hemophilia. If you are in need of an in-service program at your child’s school or camp, please contact Lisa Cohen, MSW at 732-235-6533. Please do not wait to contact Lisa, as the slots for these visits fill up very quickly during this time of year!

Ongoing Training: The staff at the HTC continues to provide hands-on training in infusion procedures to parents and their children. A series of thirty minute sessions are held over a period of weeks/months depending on the families’ needs, abilities and schedule. Please call Frances Maceron, RN at 732-235-6542, if you are interested in arranging infusion training.

General Information: For information regarding women with bleeding disorders and/or a family history of hemophilia, clinical trials, genetic counseling, insurance issues, educational sessions or school visits, please call the Hemophilia Treatment Center at 732-235-6531.

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

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 current programs and plans with you.

NEWS
New Staff: We are excited to announce that Dairi Clemente has joined our staff as our new Hemophilia 340B Program Coordinator. Welcome Dairi!

Holiday Party: Our annual holiday party was held on December 18, 2016. Close to 200 patients and family members were in attendance. The holiday party gave families a chance to meet other families and to spend a fun afternoon with great food, a DJ, a Magician, face painting and a visit from Santa.

Hemophilia 340B Program: We are excited to announce that as of October 1, 2016, the HTC now participates in the Federal 340B Program. As a comprehensive care center, we have been improving the quality of life for people 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.

My Life Our Future Carrier Testing: The My Life Our Future program has been providing patients with hemophilia the opportunity to determine the genotype of their hemophilia. The program has now expanded to offer genotyping to potential and known carriers of hemophilia. The carrier testing will be available, for female family members of current participants of My Life Our Future, through the end of 2017. Please contact the HTC for more information.

UPCOMING
Hemophilia Camp: Camp applications will soon be available. Last year, we had several children attend a hemophilia camp at either Double H Ranch or Hole in the Wall Gang Camp. Camp applications are on a first come first serve basis, so in an effort to not be waitlisted, please complete your application in a timely manner.

Depending on your healthcare coverage, patients have a variety of pharmacy options to choose from. Our HTC has contracted with four different home care companies; Accredo, BDRN, Bioscrip, and Option Care. Patients who are not currently using one of these four 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.
manner. Those who attended had a fabulous time and many are looking forward to returning this year. Both camps also offer family programming. Children that have attended camp, and their families, would be happy to share their camp experiences with potential campers or parents. For more information about camp, or if your child is interested in attending, please contact our Social Worker, Erica at the HTC.

**Scholarships:** Be on the lookout for educational scholarships which will soon be available. Please be mindful of the deadlines to submit the applications and the eligibility criteria for each scholarship. Also, please remember to complete your FAFSA forms as early as possible to secure available funds. If you have any questions about scholarships, internships, or coordinating your care away from home please contact us.

**ONGOING PROGRAMS**

**School Visits:** 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. For more information, please contact us at the HTC.

**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, psychological, 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 psychological 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 & Hemostatis Network) Data Set. This is a voluntary program conducted by HTC’s with support by ATHN to improve the health of people with coagulation disorders. Patients with hemophilia can also participate in My Life Our Future to determine the genotype of their hemophilia.

**Manufacturer Factor Programs:** Manufacturers of clotting factor products have programs available to help patients continue to receive factor 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 us at the HTC.

**Diagnosis Specific Programs:** Educational programs can be arranged for patients focusing on specific diagnoses such as hemophilia, von Willebrand disease, and thrombophilia for example. Sessions can cover topics such as living with the disorder, the genetics and testing of family members, nutrition, treatment options, and an overview of the disorder. Sessions can also cover other topics that are of interest to the participants. Please contact us at the HTC, if you are interested, to schedule a program.

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.

**St. Michael’s Medical Center**

**Christmas Celebration:** We are pleased to announce that this year we had another memorable Holiday gathering with our patients. It was another beautiful experience with our patients and their families. We can only ask for this year to bring each and every one of our patients, happiness and health. May this 2017 be another memorable year for each and every one of us!!!

Happy New Year 2017!!!!

**Camp:** The year is just beginning but we are already getting ready to send our kids back to camp. Yayyy, How exciting!!! They look forward to this event every year and we are pleased to help them make this dream come true. For some it might be the first time having this experience but for others it is reuniting with old friends and enjoying time together. If your children are interested, please call The Hemophilia Treatment Center as soon as possible as space is limited and camp deadlines are around April 15, 2017. You can call and ask for Social Worker, Joanne Rodriguez at (973) 877-2967 or Head Nurse, Dominique Joseph at (973) 877-5340. We will be glad to help in filling out the applications.

**Educational Sessions:** We have quarterly educational sessions and invite everyone to give us topics of interest that we can help further explore and educate about. Please feel free to call The Hemophilia Treatment Center at (973) 877-5340 to let us know topics of interest. We are also here to provide the most current information on medical and treatments.

Always remember we are here to provide help and assistance. We look forward to another prosperous and healthy year.

**Blessings to all for 2017!!!**
Rita Matagrano Retires

After 41 years of dedicated hard work, under some of the most unforeseen and tragic circumstances, our longtime employee Rita Matagrano has decided to call it a day. Her retirement conjures up many, many memories, and many mixed sentiments: happiness for Rita, sadness for HANJ. It has been an absolute privilege to know her, and to work alongside her. Rita’s kindness and optimism has been an inspiration to us all.

The HANJ wishes Rita a happy, healthy retirement, and a future filled with joy.

HANJ is providing transportation for two camp sessions:

**Hole in the Wall Gang Camp, Ashford, Connecticut**

**Session 4**     Saturday, July 15th to Friday, July 21, 2017

**DEADLINE:** April 1, 2017

**Double “H” - Hole in the Woods Ranch, Lake Luzerne, NY**

**Session 7**     Wednesday, August 9th to Monday, August 14, 2017

**DEADLINE:** April 15, 2017

You can obtain applications from your treatment center. Once sessions are finalized, you will be sent a transportation schedule. You can send your child to any session. **If it is not listed above, you must provide your own transportation.**

Transportation is provided on a “first come, first serve” basis, dependent on the completed and approved application being received at the camp of choice.

Meet the Board...

Greetings, Please allow me to tell you a little about myself. My name is Carl Piercey, I have served on the HANJ Board for the past twenty five or so years. I have held various positions on the Executive Board, including President, Vice President and Treasurer. I started on the board in the early 90’s when things looked pretty bleak for those within our community. Since then many advances have been made. Now fast forward to today, from a medical point of view, the advances in medicine have made life much easier to deal with. I know for many of our younger members, they have no idea what it was like and can only hope that they never do.

My background is in accounting and I have been employed as a corporate controller for the last thirty years with various companies. I also prepare tax returns during the 1st quarter each year. I have been lucky enough to have been married for thirty-five years and have two children and one grandchild. Both my children are married. I count my blessings for having been able to see them grow and mature.

I enjoy sailing, swimming and doing different types of construction work, including, electrical, plumbing and carpentry.

I cannot encourage you enough to get involved with HANJ and participate in your treatment plan. The world changes too quickly to assume that someone else will be looking out for you.

With my best regards,

Carl Piercey

Happy

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My Camp Experience::
Why you should go too!
By Justin Najimian

Summer camp had always been a constant part of my life when I was a child. I was used to the experience of field trips, scorching summer days, and having a good time with my friends. Summer camp in any capacity is always an excellent thing. However, nothing could compare to the experience that the Hole In The Wall Gang Camp in Ashford, Connecticut has given me.

When I was 12 years old, I was presented with the opportunity to attend Hole In The Wall as a camper for the first time. As expected, I initially exhibited a reluctance to attend. Like many other hemophiliacs my age, I had never attended a sleep away camp before and the notion of being away from home so long was unsettling. The thrills that the experience promised soon wiped away any inhibitions I once had. I was excited to get to live the true summer camp experience with roaring campfires, silly cheers, marshmallow roasting and unbridled camp spirit. A summer camp experience like this had always been inconceivable to me and the chance to immerse myself in it was simply irresistible.

The minute I entered onto the campgrounds, I knew that I was part of something special. Hole In The Wall exudes an aura of positivity and pure love that is incomparable to almost any other place. The staff at Hole In The Wall has a single common goal, that is, to give campers the absolute best week of their lives. Their passion and commitment to this goal is evident in everything that they do. The care they provide, the laughs they cause, and the stories they share reflect who they are as people and reflect their compassion as well.

The camaraderie seen at Hole In The Wall is absolutely astounding. Tolerance and acceptance is the norm here and campers never feel like they are out of place or different. Like the counselors, the campers share a common goal as well. We all want to have the time of our lives and we make sure to create an environment that allows everyone to feel loved and included. I have forged deep connections with many of the campers I have crossed paths with over the years. Friendships that are made here are formed in a matter of seconds and become incredibly meaningful in an incredibly short amount of time.

Hole In The Wall helped me learn to embrace hemophilia as both a part of my personality and character. Before camp, I had yet to come across many teenagers my age with hemophilia. Hearing their stories and bonding over our common struggles gave me a completely new perspective on my condition. I had always seen hemophilia as something that I simply had. After camp, I truly felt that it made me part of something greater. I knew it had made me a part of a community.

Aging out of the regular camp program was a tough concept to grapple with. Leaving behind the loving and nurturing camp I had attended for so many years deeply saddened me. However, I knew my time at Hole In The Wall was not over yet. They offer a wilderness exploration program called Hero’s Journey for campers aged 16 to 18. A week in the woods without running water or electricity gives campers a unique experience to test their limits and get away from all distractions in the real world.

Hero’s Journey was truly an eye opening experience. Hole In The Wall’s summer camp program is designed for relaxation and comfort with typical camp activities. There were not any challenges to be faced there; the point was to escape them instead. Hero’s Journey is designed to challenge you. Being placed in an environment in which I had never been before challenged me both physically and mentally. With vigorous wilderness first aid training, hiking trips, fire-starting and learning how to cook, Hero’s Journey drops its participants into a completely different lifestyle.

A large component of Hero’s Journey is venturing off into the unknown. At regular summer camp, everything is set to a strict schedule and campers know exactly what they are doing at every moment of the day. Hero’s Journey is full of surprises as much of the itinerary and activities planned are shrouded in mystery. The anticipation of not knowing what will come next is always exciting and in the end, it makes the experience more meaningful.

Another key concept of Hero’s Journey is learning how to be emotionally vulnerable. A focal point of the Hero’s Journey experience is self-discovery. Participants are encouraged to open up and share about their struggles, dreams and life in general. It becomes clear that just like regular summer camp, Hero’s Journey is a safe space and provides an outlet for amazing discussions. The conversations had around the campfire are some of the most inspiring and thought provoking I have ever been a part of. They allowed me to learn about the stories of others, but most importantly, more about myself.

These two different programs have shaped who I am as an individual and have played a major part in my maturation. The lessons I have learned there, the advice I have been given and the friendships I have made have all allowed me to become the person I am today. The Hole In The Wall Gang Camp has truly given me everything I needed and more than I could have ever asked for.
The following article is extrapolated from a presentation made at the HANJ’s 14th Annual PACT Workshop, attended by hemophilia chapters across the country. It was presented by Wardell Sanders, President of the NJ Association of Health Plans. We are pleased to share this important information with you.

### In-Network Exceptions for Insured Health Benefits Plans in New Jersey

If a Member is having a difficult time finding a network provider that is available to see the Member in a reasonable period of time or that is within a reasonable proximity to the Member, the Member should call the Member Services number or Behavioral Services number on their insurance ID card (some carriers may have a special number for behavioral health services) to seek assistance in finding a network provider. If the network providers the carrier identifies are unavailable or located too far away, the member may consider requesting an in-network exception. The Q&A below may provide some general background on this process.

**Q1: What is an “in-network exception?”**

A: New Jersey regulations require an HMO, service corporation or an insurer (collectively “carrier”) with a network plan to provide or arrange for health care services for its enrollees for specified services, including behavioral health care services. (e.g., N.J.A.C. 11:24-5.1(a)) However, there may be times when the medical services are not available within the network or available within a reasonable period of time or within a reasonable distance within a network as described above. In such cases in instances where the Member and/or the Member’s primary care physician have made reasonable efforts to access the services in network and can reasonably document those efforts, a Member or the Member’s primary care physician may request that the carrier grant what is called an “in-network exception,” where the carrier is requested to provide coverage for medical services rendered by an out-of-network provider at a level of coverage and cost share equivalent to that which would be applied to the same services if rendered by an in-network provider.

**Q2: How do I initiate a request for an in-network exception?**

A: Each carrier may have its own procedures for initiation of an in-network exception, but generally the requests may be made by the Primary Care Physician or the Member to the carrier by calling the carrier’s Member Services number or Behavioral Services number (the phone number will be on the ID Card) or Provider Services if initiated by a provider. Requests must be made prior to the rendering of the services and granted by the carrier in order to be eligible for the exception. Documentation, including a summary of efforts that have been made to access the required services in network must be supplied to the carrier at the time of the request.

**Q3: When will a carrier grant an in-network exception?**

A: The Member will need to consult with the carrier, but generally a Member will need to show at a minimum that: (1) the service sought is a covered service under the Member’s health benefits plan; (2) the service is medically necessary; (3) the Member has provided adequate documentation of efforts that have been made to access the required services in-network, without access and (4) despite the carrier’s expeditiously undertaken efforts to secure an in-network provider appointment for the

Continued to page 17
Blood Brotherhood

For Adult Men with Hemophilia

The NJ Blood Brotherhood program holds free events for men with bleeding disorders. This group is open to anyone over the age of 21 who has a bleeding disorder. Each of our events incorporates a bit of education, socializing and a physical activity, but we typically use the time to get to know other guys in the community. The events are completely free and there is no commitment to attend every event.

If you’d like to join the Blood Brotherhood group and attend one of our events, please reach out to Joe Markowitz (Joe.Markowitz@gmail.com, 201-650-0335) or Peter Marcano (petermarcano@gmail.com, 201-401-7080) or HANJ directly.

HANJ has partnered with the Hemophilia Federation of America (HFA) to offer the Blood Brotherhood program. Blood Brotherhood is a men’s group open to adult men (21+) with bleeding disorders. The purpose of this group is to provide an opportunity for older men with bleeding disorders to connect with their peers in a fun, relaxed setting.

The NJ Blood Brotherhood program holds free events for men with bleeding disorders. This incorporates a bit of education, socializing and a physical activity, but we typically use the time to get to know other guys in the community. The events are completely free and there is no commitment to attend every event. Additionally, transportation assistance (gas cards or pre-paid Visa cards) may be available for each event, depending on our budget.

If you’d like to join the Blood Brotherhood group and attend one of our events, please reach out to Joe Markowitz (Joe.Markowitz@gmail.com, 201-650-0335) or Peter Marcano (petermarcano@gmail.com, 201-401-7080) or HANJ directly.

Built on strength and experience. Powered by our commitment to you.

With over 60 years of dedicated history to the Hematology and rare disorders communities, Shire has, even more, resources to bring to the bleeding disorders community. Supported by the passion, commitment and innovation that make a difference, we will continue to consistently pursue advancements in the treatment of bleeding disorders.

You count on us because we’re here … stronger than ever.

The bleeding disorders community lost a true warrior. Corey Dubin, President Emeritus of the Committee of Ten Thousand passed away on Wednesday, January 4, 2017. Corey, who had severe hemophilia, was the first human infused with factor VIII concentrates in 1968-1969. A tireless advocate, he was appointed to several boards and working groups in the home state of California and nationally working on HIV/AIDS awareness. Corey was a founder of the Committee of Ten Thousand (COTT) and HFA, and along with other bleeding disorders patients advocates, he penned the initial drafts of what became the Ricky Ray Hemophilia Relief Fund Act.

Previous to the HIV/AIDS epidemic, Corey was a successful radio and print journalist covering Latin America and US foreign Policy. He also served in the mid 1980’s as News & Public Affairs Director for KPFK, Pacifica Radio in Los Angeles.

Corey so was very knowledgeable about our history and community. He could be described as a pacifist champion and grassroots activist. Fearless and outspoken, Corey could be intimidating at times, but was also highly respected. He was a speaker, a writer, and a historian with a passion for truth and justice.

He will be deeply missed. Rest in peace, dear friend, and thank you for your many years of dedicated service.

The HANJ shares these sentiments with love and friendship. Corey, our dear friend, may be gone from our sight but never from our hearts, or our memories. Rest in Peace.
**Gettin’ in the Game Junior National Championship Swimming Champion is...**

We are so proud to announce this year’s Gettin’ in the Game National Swimming champion is our own, KJ Kaminskas. We met with KJ, and his mom Kelli and sister Keira, to ask him about his experience. Here’s what KJ had to say:

**KJ Kaminskas interview by Stephanie Lapidow and Elena Bostick**

**Stephanie:** How long have you been swimming?

**KJ:** I have been swimming forever but have been on a competitive team since I was 6 years old.

**Stephanie:** How many hours a week do you practice?

**KJ:** 6 days a week on average of 2 or 3 hours a practice.

**Stephanie:** Have you been in any individual competitions before going to CSL Gettin in the Game?

**KJ:** Yes, I’ve been in many dual meets, which is just versus another team at invitational, which is versus many other teams at once.

**Stephanie:** So other than practice and being in the pool, are there other things you do to prepare for competitions to be a better swimmer?

**KJ:** Like dry land?

**Stephanie:** Yes, what is that?

**KJ:** I do dry land. It’s sit ups, pushups, working out your muscles outside of the pool to make yourself stronger for the pool.

**Stephanie:** Do you eat any special foods that give you energy?

**KJ:** Anything with protein. Carbs the night before. Protein the day of. I would eat hard boiled eggs at the meet and bring a protein bar for after my race.

**Stephanie:** How does Gettin in the Game swim competition compare to other competitions you’ve been a part of?

**KJ:** This one I felt was easier. Because it wasn’t for swimming outside of Gettin in the Game. I’d swim 200 frees, which is 8 laps in 25 interpool and IM’s which is all the strokes. This was just working on your speed, breathing, and your power. How far you can go in a tether. So it was different but it was still a competition.

**Stephanie:** What is your favorite stroke?

**KJ:** I like the butterfly the best.

**Elena:** How many other kids were you competing against?

**KJ:** There was 3 different teams. Which is age groups. I was on the green team which was 11 – 14 I believe. Then there was 14 to older and 10 and under. There were 20 to 30 kids competing.

**Stephanie:** How did you feel when they announced you were the champion?

**KJ:** I didn’t think it was going to be me. I thought it would be someone from another state. I was really happy because I was the first swimmer to win out of all the swimmers there. I was just really happy.

**Kelli:** It was definitely not expected.

**Elena:** Do you think swimming is important to your hemophilia?

**KJ:** Yes I do. I feel other sports are good for you but I feel swimming works out all your muscles evenly, not like basketball with your arms and soccer with just your legs. It works out all your muscles at the same time and doesn’t put stress on just one muscle.

**Stephanie:** I’m sure being in the water is good for your joints.

**KJ:** Yes, it’s less stress and strain.

**Elena:** If you had to give advice to other swimmers who have hemophilia what would it be?

**KJ:** Don’t give up. Because if you give up and go onto another sport you may have been really good and wouldn’t know it. You should work through and not give up.

**Elena:** Is that how you feel about life in general? Don’t give up?

**KJ:** Yes, practice makes perfect.

**Elena:** I’m sure that’s something your mother drummed into your head.

**Kelli:** Yes, there’s a lot of kids on our team. Me, being on the outside looking in. We swim for the YMCA. So there’s 200 plus swimmers on the team, maybe 8 boys in his age group. In the beginning you’re learning, learning strokes, practicing and putting time in the pool. He would get frustrated because he was maybe underestimated a little bit. I kept telling him to put the time in the pool and prove why you should be in the top group.

**Elena:** Are you going to enter again next year?

**KJ:** Yes, if I am picked to go again.
A Real True Life Saver.....
By Benjamin Cutler

The distinct, reverberating sound of a helicopter invades the somber winter day. Moments later, the passenger side door of my father’s minivan is crunched and torn open by the Jaws of Life. Unable to speak, shivering from the loss of blood and the biting cold, I am carried into the Medivac. As my father in driven away in an ambulance, I realize every layer of my clothing has been cut off by the paramedics. Laying there, exposed, except for a thin blanket, I look down at my wrist and see my bracelet, an engraving of a serpent wrapped around a staff hanging off of a thin chain. Despite the circumstances, my lips form into a smirk as I realize the complete irony of the situation.

I always viewed my MedicAlert bracelet as a scarlet letter I was forced to bear. Ever since I was diagnosed with hemophilia, a rare blood disorder, at a young age, wearing my bracelet at all times became non-negotiable. Every time one would break, I secretly relished the thought of having a naked wrist. Like Hester Prynne, this scarlet letter that had once shamed me now became a symbol of my personal identity and experiences; it saved my life. Removing my bracelet would be like denying I have hemophilia, like denying an entire part of myself that I will always carry with me.

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No one ever thinks that, until, your car skids off an icy road and smashes into a tree. Suddenly, you wake up, defenseless with paramedics hovering over you. The force of the crash had rendered both my father and me unconscious. This was exactly the kind of situation my doctors had warned of, I was bleeding internally and externally with no way of alerting anyone about my condition. After seeing my bracelet, the first responders called the Medivac so that I could be treated as quickly as possible.

I could have died that day. In fact, I would have, if it were not for the thin stainless steel chain I begrudgingly wore on my wrist. Like Hester Prynne, this scarlet letter that had once shamed me now became a symbol of my personal identity and experiences; it saved my life. Removing my bracelet would be like denying I have hemophilia, like denying an entire part of myself that I will always carry with me.

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 your treatment and care.

For more information and to receive an order form, please contact Cindy Hansen at HANJ at 732-249-6000 or chansen561@comcast.net.
It’s Scholarship time at HANJ!

The Publicity and Education Committee of the Hemophilia Association of New Jersey is proud to once again offer scholarships to qualified individuals with Hemophilia or Von Willebrand disease.

If you are interested in applying for a HANJ scholarship for the 2017–2018 school year, please contact HANJ for the requirements of scholarship eligibility and an application form or you may print it from our website at www.hanj.org.

HANJ awards four undergraduate scholarships in the amount of $1,500 per year (renewable for up to 4 years) and one Graduate level scholarship in the amount of $2,000 (renewable for up to two years). Your application must be in on or before April 30th, 2017.

We also have compiled a list of Scholarships Available from Other Sources for individuals with hemophilia or Von Willebrand disease. Please contact us for a copy, or visit our website to print the list at www.hanj.org.

Contact information:

Neidy Olarte  
Social Services Coordinator  
(732) 249-6000  
neidyo@comcast.net

Cindy Hansen  
(732) 249-6000  
chansen561@comcast.net

All Members!

The Hemophilia Association of New Jersey will be hosting several Educational Pharmaceutical Programs throughout the year.

June 2017  
Shire  
Topic: Women, Let’s Talk About Hemophilia  
English/Spanish  
Thursday, June 8th

July 2017  
Pfizer  
Topic: Transitioning Your Child to Early Independence  
Wednesday, July 12th

August 2017  
Shire  
Topic: Bullying Online and Offline  
Teen/Adult  
Thursday, August 17th

October 2017  
Pfizer  
Topic: To be announced  
Thursday, October 12th

December 2017  
Pfizer  
Topic: To be announced  
Tuesday, December 5th

This information could change. Invitations will be sent out to the membership with meeting dates and topics as well as RSVP instructions.
Sunday
APRIL 30, 2017
Rain Date: Sunday, May 7, 2017
Registration 10AM
Start Time 11AM
Raritan Valley
Community College
118 Lamington Road, Branchburg, NJ 08876
FAMILY FRIENDLY EVENT
$20 Suggested Donation includes:
Children's Activities • Refreshments • BBQ Lunch
Students/Children $10 • 3 & Under FREE
http://www.firstgiving.com/hemophilianj/Walk
For Walkers and Teams that don’t design their own T-Shirts,
T-Shirts will be available to purchase for Kids $5.00 – Adults $10

4 WAYS to Get Involved:

• Register as an Individual
• Join a Team - Walk and Raise Donations!
• Make your own Team and recruit friends to Walk!
• Make a Donation to the Walk!

To make a donation visit www.hanj.org. Call 732.249.6000 for a Registration Packet.