Matrix Health Group

A BIOMATRIX SpRx Company

NEWS

DEDICATED TO MAKING A DIFFERENCE

> **The best way to cheer yourself up is to try to cheer somebody else up.**
>
> Mark Twain

FALL 2017

VOLUME 12 | ISSUE 4
FALL 2017

MISSION + VISION

The **MISSION** of Matrix Health Group is to provide individualized, focused pharmacy and support services to people with chronic conditions nationwide.

Our **VISION** is to enhance the lives of those we are privileged to serve.

Our mission and vision are realized through the value we place in our five guiding principles. These principles represent our commitment to our employees, patients, and the community – driving our organization to excellence.

Integrity - Our professionalism, strength, and stability come from our resolve to operate honestly, morally, and with a higher purpose to meet and exceed the expectations of all.

Dedication - Our dedication is evident in our close attention to detail, personal touch, and resolve to advocate from the heart, giving each relationship a close family feel.

Compassion - We are sensitive to each individual's unique situation. Our ability to listen, empathize, and support those we work with distinguishes our business practice.

Enrichment - We understand that in order to perform at our best, we must always seek to learn and grow, while using our knowledge to assist and empower others.

Enthusiasm - Our confidence in the services we provide is illustrated by the energy, drive, and passion we exhibit in all we do.

FINE PRINT

Editor-in-Chief: Maria Santucci Vetter
Editors: Susan Moore and Justin Lindhorst

The purpose of Matrix Health Group News is to provide information such as current news, upcoming events, educational matters, personal stories, and a variety of opinions and views on topics of interest to the bleeding disorders community.

The information and opinions printed in this newsletter do not necessarily reflect the views and opinions of the partners, employees, others associated with Matrix Health Group News or that of Matrix Health Group.

Health related topics found in Matrix Health Group News are for informational use only and are not intended to take the place of treatment or medical advice provided by your health care professionals or hemophilia treatment center. Please consult with your health care professionals when medical questions arise.

A NOTE FROM THE EDITOR

Welcome to our Fall issue! Personal stories, advocacy, education, and more. We have it all!

6.

DISASTER RELIEF

How to help our community members in hurricane affected states.

7.

ALEXA, TRIGGER AN INFUSION!

The future of managing hemophilia through artificial intelligence.

8.

RELIEVE YOUR STRESS

Examining alternative ways to reduce stress.

12.

EXPLORING THE NEW FRONTIER

A review of NHF's Annual Meeting in Chicago.

18.

BLOOD WORKS 2017

Bringing together artists, musicians, makers and creative folks in the bleeding disorders community.

22.

A BOND OF BROTHERS

A look at HFA's Blood Brotherhood program.

23.

SPOTLIGHT ON RESEARCH

Mobile phone health apps (mHealth) are changing the landscape of healthcare.

25.

THE HEALTH ADVOCATE

The Health Advocate discusses self advocacy.

30.

ADVOCACY TEAM

A call to ACTION:
Get screened and treated for hepatitis C.

32.

MATRIX ON THE MOVE

Check out where we've been!

28.

UPCOMING EVENTS

Looking forward to seeing you at events in our community!

52.

THE GREAT AMERICAN ECLIPSE

A historic siting.

54.

"A MOMENT IN YOUR SPECTACULAR LIFE" 2018 CALENDAR

Order your complimentary calendar today!

54.

TIME FOR FUN!

Hi Kids! Learn about bleeding disorders while having fun!

55.

A NOTE FROM THE EDITOR

Dear Readers:

Matrix Health Group stands with those affected by recent natural disasters this hurricane season. At Matrix Health Group, along with our generous employees, we have provided monetary and in-kind donations to the areas hardest hit. We would like to encourage you, if you are able, to do the same.

The Hemophilia Federation of America, HOPE for Hemophilia, and the National Hemophilia Foundation are collecting ongoing donations to provide relief to families still trying to recover. To find out how you can help make a difference, please see the information listed on the next page.

Those who are veteran readers of our newsletter know we have a tradition of featuring a collection of bleeding disorder camp stories from camp-goers and leaders in our Spring edition. If your child or young adult attended camp this past summer, please consider asking him or her write a couple paragraphs describing their experience and what being able to go to camp means to them. If you are an adult involved with camp leadership or medical services, please consider submitting your story as well.

Our readers, especially those with soon-to-be campers, have expressed their appreciation of these articles. Please consider sharing your story and be sure include photos. We look forward to hearing from you!

Maria Santucci Vetter
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Informative quarterly newsletter, MATRIX HEALTH GROUP NEWS

MESSAGES FROM ORGANIZATIONS OFFERING DISASTER RELIEF

HEMOPHILIA FEDERATION OF AMERICA

Since 1997, HFA has worked with thousands of families in the bleeding disorder community to provide emergency assistance through our Helping Hands program. Twelve years ago, HFA assisted families struggling in the aftermath of Hurricane Katrina. Today, HFA is here to help the families of recent natural disasters. Our hearts go out to our brothers and sisters impacted, and we will continue to work with our member organizations to identify families in need to provide emergency assistance. There is much work to be done. Thank you for your support of the Helping Hands program at HFA since 1997. Because of you, thousands in our community breathe a little easier.

If you would like to help the relief effort through Helping Hands, you can give online:

www.hemophiliafed.org
info@hemophiliafed.org
Toll Free 800-230-9797

HOPE FOR HEMOPHILIA

Hope for Hemophilia is well accustomed to helping families during a crisis and serving the needs of people living with hemophilia with their unique needs.

We have a disaster relief fund and are actively reaching out to the patients who are the most affected throughout the Houston, South Texas, and Florida areas. We have already heard from families who are living with hemophilia and have evacuated, and we are supporting them the best we can. If you are interested in getting involved in helping these families who are juggling life-saving medications, administering treatments all while losing their personal belongings and homes, please donate or sign up today to volunteer to serve these families.

We will do our best to communicate and send you updates as we understand the ever changing dynamics of the local needs.

www.hopeforhemophilia.org
info@hopeforhemophilia.com
Toll Free 888-529-8023

NATIONAL HEMOPHILIA FOUNDATION

Hurricane Irma brought destruction to Florida, resulting in loss of life and property. 6 million residents are without power; parts of Miami and Jacksonville are recovering from floods; and the damage to the Florida Keys is devastating. The total economic damage could be between $70-90 billion. You can help our community affected by the storm by making a donation today!

All donations made are being collected by the National Hemophilia Foundation and 100% of all donations will be turned over to the Hemophilia Foundation of Greater Florida and the Florida Hemophilia Association. The chapters will then distribute these funds to families who have been impacted by Hurricane Irma and are in need.

For donations of cash, checks, or gift cards please send to:

National Hemophilia Foundation
7 Penn Plaza, Suite 1204; New York, NY 11577

Please include a note specifying that the donation is for Hurricane Irma relief and include address and contact information for a donation receipt.

On behalf of our families in the bleeding disorders community thank you for your generosity.

www.hemophilia.org Phone: 212-328-3700

ALEXA, TRIGGER AN INFUSION!

The future of managing hemophilia through artificial intelligence

BY DIANE HORBACZ

CAROUSEL OF PROGRESS

If you have ever been to Disney World's Magic Kingdom, you may be familiar with the popular audio-animatronic attraction known as the Carousel of Progress, in which you travel through the 20th century celebrating the wonders of technology. During each era, revealed in 4 separate vignettes, you learn how previous advances in technology, or "modern conveniences" made life easier for the American family. As you transition between each scene humming along to the tune of "There's a Great Big Beautiful Tomorrow," you can see how former progress has led to future innovations.

The first three scenes depict a time of inefficiencies, while the final scene was intended to be a glimpse into what the future has in store: forward-thinking amenities such as a high definition television, virtual reality gaming, and voice activated household lights and appliances.

During a recent visit to Magic Kingdom and my favorite attraction, the Carousel of Progress, I realized the last scene is no longer a preview of futuristic technologies, but rather an image of present-day. With the inception of digital assistants and smart speakers, the final scene on the Carousel of Progress has taken on new meaning.

Despite my preconceived notions that I could never see myself talking to my appliances, today I find myself doing just that. Living in a "smart home," meaning most things are controlled through a digital assistant, if I want to turn on my bedroom lights (maybe dim them to 10%) or turn on my television (probably adjusting the volume or changing channels), all I do is ask Alexa or Google Home.

If I need to vacuum my home, all I need to do is say, "Alexa, tell Roomba to clean." Then Roomba, controlled through iRobot and linked with Alexa, will depart from its base, clean all my floors and find its way back to its base after completing the job. Smart technology is changing the way we live our lives, including how we track and manage bleeding disorders.

WHAT ARE DIGITAL ASSISTANTS?

A digital assistant, also known as a virtual or artificial intelligence (AI), is a program that understands natural spoken language and completes tasks for an end-user using simple voice commands. Popular digital assistants currently include Apple's Siri, Google's Assistant, Microsoft's Cortana and Amazon's Alexa. Users can access these digital assistants through their mobile phone, desktop/ laptop computers, tablets and smart speakers.

WHAT ARE SMART SPEAKERS?

A smart speaker is a Wi-Fi connected speaker controlled with voice commands. To use the hands-free device, the user speaks a trigger phrase, also known as a wake word (Hey Siri, Alexa, OK Google), and then asks a question, for example, "What's the weather?" or makes a request like, "Order a Lyft." The speakers are powered by digital assistants such as Siri, Alexa, and Google Assistant that talk back.

Smart speakers were only introduced 3 years ago; however, they seem to have become the preferred medium to interact with digital assistants. Examples of smart speakers include the Amazon Echo/Echo Dot (released November 2014), Google Home (released November 2016), and the Apple HomePod (expected release December 2017). Around 14% of U.S. households use a smart speaker. Amazon's Echo/Echo Dot, using the Alexa digital assistant, has over a 70% market share. [1]

USING ALEXA

Alexa has so many capabilities that serve to automate life. With Alexa, you can order from Amazon Prime and track packages, play music, get news, traffic and weather, ask questions, play games, control smart home devices to further automate your home, and even settle an argument. To use Alexa, you need to have an Amazon account. Add your account to your Alexa profile using the Alexa app, which can be downloaded to your mobile device. Within the app, you can set up lists, alerts and reminders, connect to smart home devices and explore all the amazing skills Alexa offers.

WHAT ARE ALEXA SKILLS?

Alexa skills are applications made for Amazon's Echo. Initially, only Amazon could create and publish Alexa skills, but Amazon recently permitted developers to build

third-party skills. The number of Alexa skills has skyrocketed in response, rising from 950 in 2016 to over 10,000 as of June, 2017. [2] Some of the more popular third-party Alexa skills include making interactive purchases (Domino's Pizza, Amazon Prime orders), using ride-hailing services (Uber and Lyft), and playing music (Sirius XM). Unfortunately, substantial programming experience is required to create and publish an Alexa skill, although the Amazon developer kit is free and comes with numerous tutorials.

You don't have to be a tech guru to create commands to help log infusions. So, how can I create a command if I don't have the programming background to create an Alexa Skill? Fortunately there are easy to use web tools that when connected through Alexa, allow users to create simple and customized commands.

USING WEB TOOLS AND APPLETS TO MANAGE BLEED LOGS.

There are several web tools that help the end user automate simple tasks by connecting many of our favorite mobile phone apps, internet connected devices (smart bulbs, outlets, television, etc.) and digital assistants. The most popular of these web tools is IFTTT (If This, Then That).

IFTTT currently supports more than 110 services including Android devices, Apple iOS apps and the major digital assistants. Users create "applets," with no programming skills required. An IFTTT applet is a simple program that combines different web services. While I have no programming background, I created an IFTTT applet that logs an infusion into an Excel spreadsheet through a simple voice command to Alexa. As my son sits at our kitchen counter doing his infusion, to log a treatment all he needs to do is say, "Alexa, Trigger an Infusion." The word "trigger" is used by Alexa to execute the applet within IFTTT. A prophylaxis treatment is then uploaded onto a spreadsheet stored on my Google Drive.

HOW CAN DIGITAL ASSISTANTS AND SMART SPEAKERS MAKE LIVING WITH HEMOPHILIA EASIER?

Creating a digital infusion log through a simple conversation with Alexa eliminates the need to manually enter treatment information on paper or through a mobile app and saves time as it can be completed during the infusion process. With regard to adherence to keeping logs, for those individuals who don't want to be bothered with the task of keeping a log, recording a treatment through a digital assistant and voice commands is the next step in managing hemophilia through digital technology.

WHAT IS THE FUTURE OF DIGITAL ASSISTANTS?

The objective of a digital assistant is to help organize our lives and make our devices easier to use. A 2016 study by Stanford researchers showed speech input is three times faster than typing on mobile devices.[3] Thus, digital assistants are primarily used in applications that are best suited for very basic voice-driven queries. The same study also noted that the fastest way for a machine to provide information to a user is through a screen display. Therefore, to expand the capabilities of digital assistants, manufacturers are including a digital display and webcam along with a smart speaker.

The Amazon Echo Show was released on June 28, 2017 and is intended to allow an end-user to maximize use of Alexa's voice recognition capabilities. Amazon Echo Show skills include: video calls, viewing security cameras, playing music while viewing on-screen lyrics and eventually employing facial recognition to distinguish multiple users in the same household. This new digital technology may have future implications for the hemophilia community. With the ability to pull up different menus or screens, record a bleed using virtual images, share reports with our primary care physician and access resources all through voice command, "Alexa, record an infusion," is just the beginning of how digital technology will influence the way we manage bleeding disorders.

Life is indeed a carousel of progress. However, "that great big beautiful tomorrow" has become today's reality and is no longer "just a dream away." As this new era of technology is upon us with new skills, apps and devices developing at a rapid-fire pace, one can only imagine what the future has in store. As they say in the last scene of my favorite Disney World attraction, "We've got a whole new century waiting for us out there."

RESOURCES:

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2 Kelly, H. (2017, June 8). Smart speakers 101: What you need to know about the Amazon Echo, Apple HomePod and others - Jun. 8, 2017. Retrieved from http://money.cnn.com/2017/06/08/technology/gadgets/apple-homepod-smart-speaker-faq/index.html

3 Ruan/Stanford University, S., Wobbrock/DUB Group, J. O., Liou/Baidu, K., NG/Baidu, A., & Landay/Stanford University, J. (2016, August 23). *Speech is 3x faster than typing for English and Mandarin text entry on mobile devices.* Retrieved from http://hci.stanford.edu/research/speech/paper/speech_paper.pdf

BY SARAH HENDERSON

Living with a chronic condition such as a bleeding disorder adds many stressors to an already demanding world. The stress and pain that come with a bleeding disorder are things that should not be taken lightly. We need to find ways to reduce the stress in our lives and learn how to deal with that which cannot be avoided. There are many types of therapies that can help in coping with stress and in turn, aid in reducing pain. Read on to learn!

ANIMAL ASSISTED THERAPY

"Animal assisted therapy (AAT) uses trained animals to enhance an individual's physical, emotional and social well-being, thus improving self-esteem, reducing anxiety and facilitating healing."[1]

The simple act of interacting with an animal has been shown to reduce stress. There are many ways people make use of pet therapy; through time spent with a personal pet at home, visiting and playing with animals in

RELIEVE YOUR STRESS

a shelter, participating in equine therapy, and even by owning a therapy or support animal. Interaction with pets can reduce stress and anxiety, increase endorphins, lower blood pressure and cholesterol, provide a distraction to pain, as well as provide companionship and social well-being. These are only a few of the many benefits found through animal assisted therapy!

If you are interested in seeking animal-assisted therapy, contact a veterinarian in your area for a local reference. For information on volunteering with your pet, visit *Pet Partner*s https://petpartners.org/

WHAT IS A THERAPY DOG?[2]

Therapy dogs must undergo training, and in some areas must pass the Canine Good Citizen (CGC) test and therapy dog certification test. The training is not as extensive as service dog training and often includes taking a basic manners/ obedience class and exposing a dog to a variety of people and situations.

Therapy dogs and their handlers have no special access rights under the ADA. They visit hospitals and other facilities with the permission of the facility.

Therapy dogs visit hospitals, nursing homes, schools, and libraries to engage in "therapeutic contact" (petting or just spending time with people).

Therapy dogs are pets who generally work with their owners on a volunteer basis.

People are encouraged to pet therapy dogs (that's part of the dog's job!).

Therapy dogs often wear vests or bandanas with patches identifying them as therapy dogs.

Almost any animal can be a therapy animal - dogs, cats, horses, birds, rats.

ART THERAPY

Painting, drawing, sculpting or art of any kind can be used to reduce stress. Working with an art therapist can help guide one to work through stressful issues. This can be done in an individual or group setting.

"Art therapy has the unique ability to unlock emotional expression by facilitating non-verbal communication. This is especially useful in cases where traditional psychotherapy has been ineffectual. Art and art making are inherently perceptually and sensory based and involve the brain and the body in ways that verbal language does not. Art therapy provides an alternative means of communicating for those who cannot find the words to express anxiety, pain or emotions as a result of trauma, combat, physical abuse, loss of brain function, depression and other debilitating health conditions."[3]

To locate a credentialed art therapist, visit *Art Therapy Credentials Board, Inc.* https://www.atcb.org/Home/FindACredentialedArtTherapist

COUNSELING

"When the stress of life leads to drug abuse, chronic physical ailments or pain, an absence of pleasure or relaxation in life, or when it affects one's well-being negatively in any way, it may be helpful to meet with a mental health professional or medical doctor to receive treatment for the manifested symptoms of stress and work through the issues causing it. Cognitive behavioral therapy is often an effective form of therapy for stress, as the technique can help change negative thought patterns that develop as a result of stress, helping the person in treatment find new ways of thinking about stressful events that may not have such a negative effect."[4]

Working with a therapist or counselor in a private setting is a safe, non-judgmental way to help retrain the brain's negative thought processes. Your therapist/counselor can help find new ways to approach common problems and stressful situations.

To find a therapist, check with your health insurance provider or visit *Psychology Today – Find a Therapist* https://therapists.psychologytoday.com/rms/

FLOTATION THERAPY

In flotation therapy, a person literally floats in a tank filled with sterile, body temperature water and 800 lbs. of Epsom salts for 60 to 90 minutes per session. With feelings of weightlessness, a person experiences sensory deprivation, entering a deep state of relaxation that helps with stress reduction, pain relief, increased blood flow and a release of endorphins. In addition to stress relief, many people report experiencing increased creativity, better problem solving skills and mood enhancement.

"Flotation Therapy is a luxurious way to soothe and heal the body from the constant stress of life's daily pressure; you can leave the noise and confusion behind and perhaps, for the first time in your life, experience total relaxation and deep healing in your private, peaceful space... it is truly the ultimate ESCAPE!" [5]

To locate a flotation tank in your area, visit
Where to Float
http://www.where-to-float.com/

LAUGHTER THERAPY

Yes, laughter therapy is a real thing! Laughter has been shown to reduce stress, lift spirits and promote general well-being while providing a multitude of physical and mental benefits.

"We need to laugh more and seek stress reducing humor in our everyday lives. Laughter is the human gift for coping and for survival. Laughter ringing, laughter pealing, laughter roaring, laughter bubbling. Chuckling. Giggling. Snickering. Snorting. These are the sounds of soul saving laughter, which springs from our emotional core and helps us feel better, see things more clearly and creatively weigh and use our options. Laughter helps us roll with the punches that inevitably come our way. The power of laughter is unleashed every time we laugh. In today's stressful world, we need to laugh much more." [6]

"A good, hearty laugh relieves physical tension and stress, leaving your muscles relaxed for up to 45 minutes after. Laughter boosts the immune system. Laughter decreases stress hormones and increases immune cells and infection-fighting antibodies, thus improving your resistance to disease." [7]

There are places that provide laughter therapy, even online; but if not locally accessible, consider attending a comedy club, watching a funny movie or just spending time with amusing family and friends.

To learn more about laughter therapy, visit
Laughter Therapy Enterprises
www.laughtertherapy.com

MASSAGE THERAPY

Receiving a relaxing massage can help reduce blood pressure, stress levels, decrease pain and increase your body's production of endorphins.

"Virtually every symptom listed by the American Psychological Association can benefit from massage. Research has shown that it can lower your heart rate and blood pressure, relax your muscles and increase production of endorphins, your body's natural "feel good" chemical. Serotonin and dopamine are also released through massage, and the result is a feeling of calm relaxation that makes chronic or habitual as well as acute or short-term stress much easier to overcome. Clinical studies show that even a single 1½-hour session can significantly lower your heart rate, cortisol levels and insulin levels – all of which explain why massage therapy and stress relief go hand-in-hand." [8]

There are a variety of massage types available including Swedish, deep-tissue, hot stone, shiatsu, reflexology, just to name a few. Before undergoing massage therapy, bleeding disorder patients should consult with their physician and massage therapist to determine which type of massage would best suit the desired outcome. There are a host of places to get a massage – health spas, gyms, chiropractic offices, even mobile therapists who will come to you!

To search for massage therapists in your area, visit *Massage Finder* www.massagefinder.com

MINDFULNESS-BASED STRESS REDUCTION

"The reality is that we all deal with stress on a daily basis, whether we're old or young, large or small, lofty thinkers or practical doers. Even the most practiced meditator and the yogi who simply radiates peace experience this inevitable portion of being human. It's inescapable, and it brings with it a host of uncomfortable and distracting symptoms. Stress isn't just a feeling or a mental state; if you don't address it, it seeps into every aspect of your life." [9]

The practice of being mindful is especially beneficial in focusing on one's physical and emotional state during times of high stress. By learning to focus and accept today without distressing about the past or the future can be a very effective method of reducing worry and stress.

Often times while practicing mindfulness, yoga stretches and breathing exercises are utilized. Learning to focus on a particular part of the body and relaxing specific muscles and joints can reduce pain.

There are several ways to learn Mindfulness-Based Stress Reduction, such as taking a live or online course, or purchasing DVDs and guided workbooks.

Check out these online options
Center for Mindfulness
http://www.umassmed.edu/cfm/stress-reduction/
Palouse Mindfulness
http://palousemindfulness.com/

MUSIC THERAPY

A music therapist evaluates how a person would best benefit from this type of therapy. Listening, creating, singing or moving to music can lessen stress. Any genre of music can be employed, and best of all, no type of musical skill is needed to participate!

PsychCentral [10] shares interesting facts about music therapy that include:

- Music's form and structure can bring order and security to disabled and distressed children. It encourages coordination and communication, so improves their quality of life.
- Listening to music on headphones reduces stress and anxiety in hospital patients before and after surgery.
- Music can help reduce both the sensation and distress of both chronic pain and postoperative pain.
- Listening to music can relieve depression and increase self-esteem in elderly people.
- Music therapy significantly reduces emotional distress and boosts quality of life among adult cancer patients.

To search for a music therapist in your area, visit *The American Music Therapy Association* https://www.musictherapy.org/about/find/

Life with a bleeding disorder can often be challenging. Learning to keep stress levels low and knowing how to deal with unavoidable stress when it occurs can help individuals with a bleeding disorder better manage pain. Keeping stress and anxiety in check has been proven to also help reduce the incidences of bleeding episodes.

When stress hasn't reached a level of requiring professional assistance, there are many things we can do to keep it from growing. Identify activities that provide feelings of joy and calm. Whether you enjoy gardening, playing golf, swimming, going for walks, crafting, or spending time with people that make you laugh, find what you love, stay active and, most importantly, make time for it in your daily life.

RESOURCES:

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9 MBSR: 25 Mindfulness-Based Stress Reduction Exercises and Courses. (n.d.). Retrieved from https://positivepsychologyprogram.com/mindfulness-based-stress-reduction-mbsr/

10 The Power of Music To Reduce Stress | PsychCentral. (n.d.). Retrieved from http://psychcentral.com/lib/the-power-of-music-to-reduce-stress/

There are many great changes coming to the bleeding disorders community. Changes in treatment, new therapies and research bringing us closer to a cure means a lot on the horizon for individuals living with a bleeding disorder. As we plot a path forward together, the National Hemophilia Foundation's 69th Annual Meeting provided the perfect opportunity to learn, connect and share experiences.

EXPLORING THE NEW FRONTIER

Matrix Health Group proudly continued our tradition of supporting the annual meeting, and our presence in the exhibit hall was the largest to date! We were particularly delighted to share exciting developments at the company, representing the organization for the first time as BioMatrix SpRx.

BioMatrix is the parent organization for all of the pharmacies within our growing family of companies. We are uniting leaders in the specialty pharmacy field who share in our commitment to individualized patient care and services centered on improving lives for people with bleeding disorders and other chronic conditions.

There were plenty of engaging activities at our booth as participants had the opportunity to interact digitally via Twitter and Instagram using the hashtag #HemoUnity. Photos posted to either platform with the #HemoUnity hashtag appeared on a live social media feed at the booth, and participants were also able to pick up a printed copy of their photo.

Check out all of the amazing photos by searching the hashtag #HemoUnity. But that's not all! As

Photo by C|R Prints & Photography, LLC

NHF IN REVIEW

BY JUSTIN LINDHORST

photos were printed, they were strategically placed on a large mural depicting some very special bleeding community members. While the meeting may be over, be on the lookout for future #HemoUnity posts! Be sure to "Like" us on Facebook and follow us on Twitter @matrixhealthgrp.

After the meeting, we checked with a few attendees regarding their experience. Tracie from Wisconsin shares, "This was my first NHF meeting. I really enjoyed getting to know other families and hearing their stories. There was also a lot of good information from the vendors. It was great learning about what is available to us and developing an understanding regarding our future, and what it holds. My son Zach really enjoyed

> **It was great learning about what is available to us and developing an understanding regarding our future, and what it holds.**

hanging out with other kids who are affected. We don't often have that opportunity! Meetings like this are important because it helps raise awareness among other families and gives us the opportunity to share experiences. Seeing other kids, meeting other families, helping or mentoring where I can is great."

Jameelah, a first time attendee from South Carolina explained, "I really enjoyed the breakout sessions, especially the ones regarding women and bleeding disorders. I always lived a certain way, thinking it was just normal for me to have some of the symptoms I do. Meeting other women helped open my eyes and allowed me to learn more about myself. I learned so much, and I'll be bringing all this new information directly to my primary care provider. I think meetings like this are important because of the opportunity to learn new things. I learned a lot about the options that are out there, and you might miss out on some of this stuff if you don't get involved! I also really enjoy the camaraderie and forming bonds with other people who share similar experiences. It helps you feel like it's not just you getting through this alone."

Taylor came all the way from the Pacific Northwest for the meeting. He comments, "I really enjoyed the breakout sessions. There were so many directly applicable to me and my experiences. I think this type of meeting is important for a variety of reasons. I grew up in a small town, other than the summer camp program I participated in, I did not know very many people with hemophilia. It's great being able to network with others who understand, while gathering and sharing information. It's a great opportunity other

Kelly H. (center) accepts an Amazon Kindle and $50 Amazon gift card raffle prize for winner Brett H., with Danny Hicks and Eva Kraemer.

Rania Salem (left) presents Renee J. with the #HemoUnity contest prize, a Fitbit. Renee's efforts added the most photos to the BioMatrix mural!

than your once-a-year treatment center visit to gather information. It's incredible seeing all the new therapies being developed!"

Congratulations to the National Hemophilia Foundation for hosting another great event! Every year, the annual meeting provides a venue for community members, healthcare providers and chapter staff from across the country to come together and share hope, inspiration and the promise for a bright future. We will explore this "New Frontier" as a community, and grow stronger in the experiences we share together.

Thank you to all who stopped by the booth and a hearty welcome to our new readers. Hope to see you next year for NHF's 70th Annual Meeting in Orlando, Florida!

JUSTIN LEVESQUE

Now in its fourth year, the Blood Work art exhibition was again on display in the Exhibit Hall at National Hemophilia Foundation's 69th Annual Meeting. This exhibition brings together artists, musicians, makers and creative folks from across in the community. With over thirty submissions of artworks and music, Blood Work was able to showcase and represent diverse perspectives that represented many groups connected to bleeding disorders; from bleeders to caregivers to siblings and more!

The Blood Work art exhibition was started by FOLX, a small collection of programs that focuses on diverse backgrounds in bleeding disorders. FOLX wishes to support additional versions of success from arts and music to activism and ingenuity. This recognition is important in remaining diligently inclusive of individualized approaches to living with a bleeding disorder.

A BOND OF BROTHERS

BY RICHARD VOGEL

Blood Brotherhood

The word *blood* can be defined as a group of people regarded as a source of energy, vitality, or vigor, a passionate disposition, i.e. "fired up their blood" or "let's get some new blood to this meeting."

The word brotherhood can be defined as all those sharing a quality, the relationship between brothers. It is also a belief that all people should act with warmth and equality toward one another, regardless of differences in nationality, creed, ethnicity, etc. It is an association, society or community of people linked by a common interest.

Put the two together and you get *Blood Brotherhood*. That's exactly how I would define our company of guys who comprise the Blood Brothers – a fantastic group of men who share a bleeding disorder diagnosis and who are regarded as a source of energy, vitality and vigor within our community.

We come together regardless of differences in our background or age. Our common interest is to support one another in good times as well as bad. We get together to discuss the challenges of living with a bleeding disorder – the aches and pains, injuries and bleeding episodes, upcoming surgeries, or just the day-to-day occurrences of having a chronic condition. Some in our group are more vocal than others, while some prefer to just listen. It doesn't matter, we are there for one another through thick and thin.

There are many organizations across the country partnering with the Hemophilia Federation of America (HFA) to offer the Blood Brotherhood program. Open to adult men, age 21 and over, with a bleeding disorder, most groups hold several events throughout the year.

Each event includes an educational, a physical, and a social component. Educational speakers in the past have included state legislators discussing advocacy, nutritionists discussing diet and health, legal counsel

Blood Brotherhood is a national program for adult men, diagnosed and living with bleeding disorders. It is designed to be a multi-avenue outreach, to provide education and support, promote good health, and establish a sense of community for adult men. — HFA

discussing job discrimination, and most recently, a certified yoga and Reiki instructor discussing methods of pain management. The physical component of our meetings depends on the social activity, whether it is hauling in the catch of the day on a deep sea fishing trip, lifting pans and chopping vegetables at a cooking class, taking a food tasting walking tour of a city, or just strolling around a ballpark or hockey arena. There is no obligation for members to attend every event and there is no cost to participate.

Blood Brotherhood is a very successful program because it provides an opportunity for guys with a bleeding disorders to connect with their peers in a fun and relaxed setting. When I was growing up, I felt alone with my hemophilia. There were no bleeding disorder camps available to attend and there was no other person in my family with hemophilia. For me, the Blood Brotherhood program has been a way to share a commonality with others walking in my shoes. These are the guys I can share my feelings and thoughts with. I don't have to explain myself – they know first hand what I'm going through and dealing with. We share a special bond that only exists between men that live with a bleeding disorder.

If you're feeling alone, isolated or just don't have someone to talk with, please come out to an event and join your fellow blood brothers. We make every member feel welcome. I guarantee you will enjoy it and will look forward to the next event!

For help in locating a Blood Brother group near you, please contact your local bleeding disorder chapter, Hemophilia Federation of America, or feel free to email me at richard.vogel@matrixhealthgroup.com. For those not located near a group, HFA offers webinars and live online chats. For more information, visit http://www.hemophiliafed.org/programs/blood-brotherhood/

SPOTLIGHT ON RESEARCH

BY DIANE HORBACZ
BIOMATRIX RESEARCH & EDUCATION
DEVELOPMENT SPECIALIST

APP CLOSE AND PERSONAL:

INVESTIGATION INTO THE USE OF HEMOPHILIA MOBILE APPS

"Every once in a while a revolutionary product comes along and changes everything," announced Steve Jobs, Apple's former Chief Executive Officer at the 2007 Macworld in San Francisco. In front of a captivated audience, Jobs made history with his groundbreaking product presentation introducing three revolutionary products: a widescreen iPod, mobile phone and internet communication device. However, all three devices were combined into one single gadget termed "iPhone." Five months later, iPhone hit the market, initiating the dawn of a new era.

One decade following Job's iconic presentation, 77% of Americans own a smartphone and half the public owns some sort of tablet.[1] According to IMS Institute for Healthcare Informatics, "Most smartphone users have more than 20 apps on their phone device at present; in many cases this is closer to 30 apps."[2] While the highest percentage of app usage is associated with social media and gaming, 58% of smartphone users gather health-related information through mobile apps related to health care.[3]

Mobile phone health apps (mHealth) are changing the landscape of healthcare and are showing promise to improve the lives of individuals with hemophilia. The influx of mobile apps within the bleeding disorders community provides an alternative to manual record keeping and can help patients better manage their bleeding disorder. However, limited data exists regarding consumer usage and the perceived value of these apps.

BioMatrix SpRx, the parent company for a family of industry-leading specialty pharmacies, has conducted a study investigating the use of current hemophilia mobile apps. The purpose of the study was to systematically evaluate current hemophilia mobile apps (hemophilia mHealth), investigate the potential benefits of usage, and identify the barriers to broader adoption and use.

A three-phase process was followed:

Phase 1
A review of published research of the use of general (non-hemophilia related) mHealth.

Phase 2
A survey of the bleeding disorders community.

Phase 3
A systematic evaluation of current hemophilia mobile apps.

This Spotlight on Research provides results from Phase 1- review of published research. Phase 2 and 3 findings and recommendations will be published in the next issue of Matrix Health Group News.

ADVANTAGES OF mHEALTH

According to the FDA, "The widespread adoption and use of mobile technologies is opening new and innovative ways to improve health and healthcare delivery." [4] The FDA has issued guidelines for the development of mHealth to create standardization and to encourage consumer protection; yet, these guidelines are only suggestions.

As the number of available mHealth apps increases, the consumer has more choices. However, these apps are often complex and may not adhere to FDA guidelines. The result is often a confusing array of choices with little guidance regarding app recommendations. Researchers are carefully examining the role these apps play in transforming healthcare with the hope of highlighting the ultimate benefits of mHealth and eliminating some of the confusion that has ensued.

In 2013, Quantile IMS conducted an extensive review of mHealth. This was the first study of its kind to investigate a wide range of healthcare apps including functionality and barriers that might limit usage. The study highlighted the promising impact of mHealth used by consumers/ patients as part of a wellness, prevention or treatment regimen. The study concluded there was a need for insurance companies and providers to become more engaged in the mHealth field to help guide consumers in their choice of an appropriate app.

The study identified an mHealth user was more engaged, better focused on their health, and took more responsibility in managing their healthcare. Researchers further suggested "healthcare apps have the potential to bring efficiencies into healthcare systems by reducing the frequency and cost of direct interventions by healthcare professionals with patients." [5]

Other studies investigating advantages of using mobile

healthcare apps have also supported the use of this technology in preventative care and the treatment of chronic illnesses.[6]

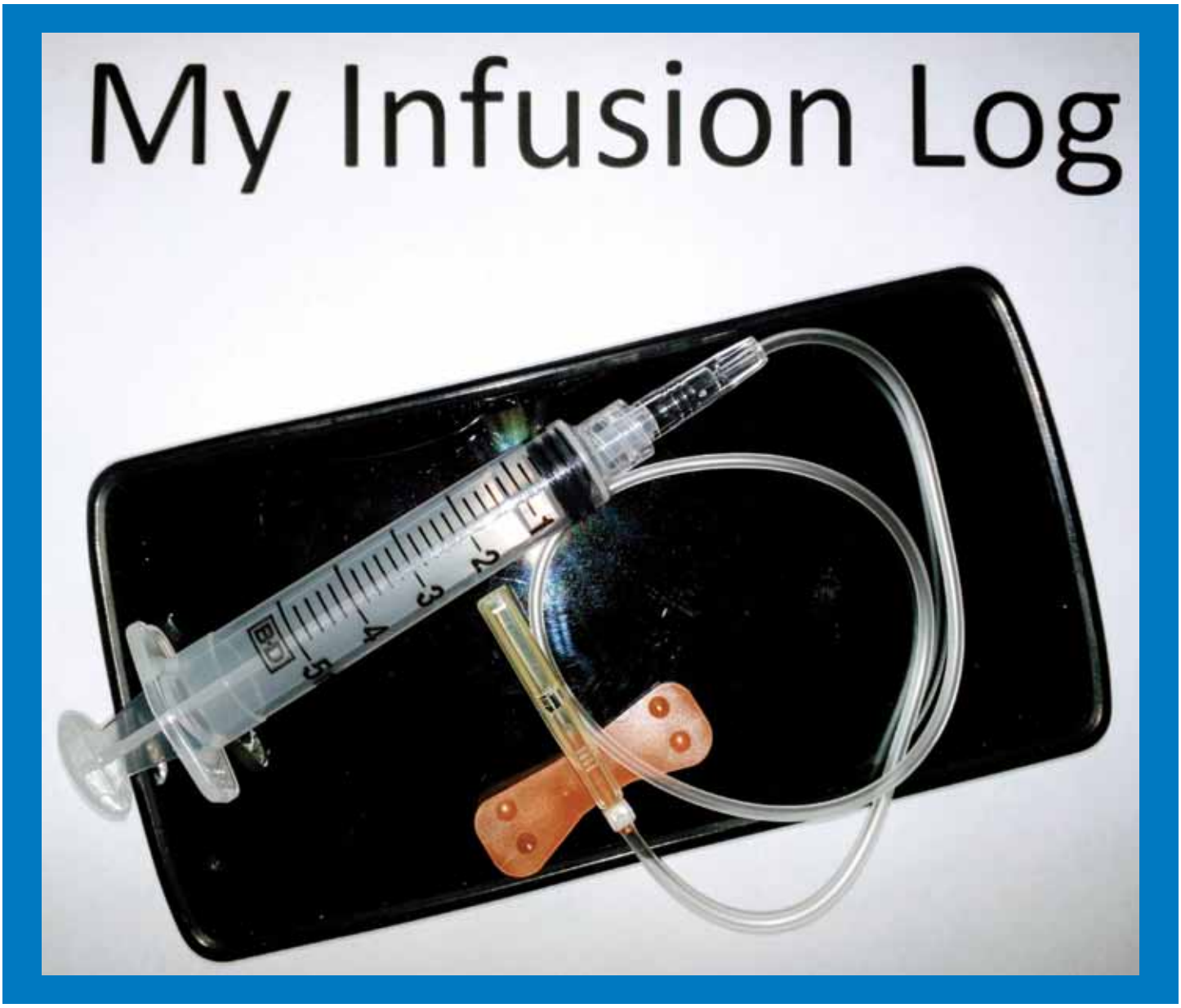
The benefits of transforming mobile apps from "novelty to mainstream" include the following:

- Greater patient engagement
- Improved adherence to treatment through reminders or alerts
- Improved record-keeping of vital health information
- Assistance with transition of care
- Improved communication with physicians
- Improved quality of life for patients [7]

HEMOPHILIA: THE NEED FOR ADHERENCE AND THE POTENTIAL OF mHEALTH TO IMPROVE ADHERENCE

Considerable clinical evidence has shown prophylaxis prevents bleeding from an early age, allowing those living with hemophilia to lead a fuller life with minimal restrictions. In fact, prophylaxis has become the evidence-based first-choice treatment recommended for children with severe hemophilia.[8] Yet, despite medical recommendations, many patients don't always remain adherent to their prophylactic schedule. According to the National Hemophilia Foundation, "Lack of adherence is a common pattern seen in people with chronic medical conditions that don't always have a visible impact on daily health."[9]

An individual is more likely to adhere to treatment when experiencing pain due to a bleed rather than treating in the absence of pain or bleeding.



Additionally, since prophylaxis results in minimal bleeding episodes, patients on this regimen don't fully experience the discomfort associated with internal bleeding and often don't appreciate the importance of regular and timely treatment.

According to the World Health Organization, as quoted in *Hemaware*, "Individuals who have chronic illnesses in industrialized nations stick to their treatment plans only half the time. But for individuals with severe hemophilia, the price of nonadherence can be high."[10] Failure to adhere to a prophylactic schedule often results in additional medicine to control a bleed, thus leading to higher medical expenses. Additionally, continual internal bleeding can result in joint damage, resulting in even higher medical costs.

"Individuals who have chronic illnesses in industrialized nations stick to their treatment plans only half the time. But for individuals with severe hemophilia, the price of nonadherence can be high."

World Health Organization

A report by Managed Market Network in April 2016 states, "Hemophilia is associated with staggering direct costs from hospitalizations, outpatient visits, and drug treatments, as well as high indirect costs from diminished work productivity and absenteeism from work and school. Additionally, hemophilia incurs tremendous intangible costs, including reduced quality of life, pain and suffering, and the emotional and physical toll on the patient and caregivers."[11] Therefore, long term adherence to prophylactic therapy results in optimal treatment outcomes, lowers healthcare expenses, and enhances the quality of life, while failure to adhere results in the opposite.

Lack of adherence isn't limited to maintaining a prophylaxis regimen but also extends to appropriate treatment record-keeping. As stated in *Managing Hemophilia: The Role of Mobile Technology*, "Good record-keeping is an essential component of home-based hemophilia care. Well-kept treatment diaries can help health care professionals to ensure optimal factor use, adherence with treatment regimens and timely infusion practices."[12] However, many individuals find record-keeping to be a hassle. People with bleeding disorders lead very active and busy lives, which makes adherence to overall medical management a challenge.

Some researchers have found that a missed prophylactic treatment is more often due to inconvenience and lack of time rather than simply forgetting about the need to treat.[13] Unfortunately, adequate record keeping is often a low priority for those living with a bleeding disorder; the failure to maintain proper records often results in sub-optimal outcomes.

A NEW ALTERNATIVE: MANAGING HEMOPHILIA HEALTHCARE THROUGH HEMOPHILIA mHEALTH

mHealth has enormous potential to impact chronic disease management around the globe.[14] The World Health Organization's adoption of mHealth initiatives (appointment reminders, treatment compliance, and patient monitoring) are accelerating awareness of the inherent potentials in mHealth. According to WHO, "If implemented strategically and systematically, mHealth can revolutionize health outcomes."[15]

With the emergence of hemophilia mHealth, individuals with hemophilia are provided a new alternative to manual treatment diaries. Individuals can set reminders, track their treatment, record information related to bleeds, generate logs, access additional resources, and even locate a hemophilia treatment center while traveling.

Hemophilia mHealth has the potential to lead to mAdherence: any use of mHealth tools by patients and healthcare providers to improve adherence to chronic disease management.[16] However, the potential for mAdherence goes beyond adherence to taking medication and can include better monitoring and understanding of symptoms, improved patient-provider communication and relationships, better transition of care and education through added resources. Experts predict overall medical care would improve if more people adhered to the use of mHealth.[17]

BARRIERS TO BROAD ADOPTION OF mHEALTH

Mobile healthcare apps can vary in capabilities and functions and, for a community of users to develop, an individual must be able to evaluate existing apps to ensure a match between user needs and app functionality. Without reliable measures of app verification, "Consumers are reliant on numbers of downloads and individual reviews as a guide to usage by the wider public, and hence become involved in a self-reinforcing cycle of most downloads continuing to inspire future downloads." [18]

Information regarding each app's utility is often limited and several barriers exist to broad adoption. Barriers to initial app use noted throughout research: cost of the app, concerns over privacy, security of personal health information, and lack of regulatory approval. Barriers related to continued and consistent app usage include difficulty in understanding and using healthcare apps due to unnecessary complexity and demanding or burdensome data entry requirements. Responses from a national survey, reported in the Journal of Medical Internet Research, revealed a strong interest in simplified apps that allowed users to track data without manual entry. [19]

Finally, patients and physicians fail to understand the potential significant health benefits that result from adopting mHealth, and this lack of understanding is one of the central challenges to broader implementation of mHealth. The selection and consistent usage of a mobile healthcare app is impeded by a shortage of clinical evidence regarding its efficacy in improved health outcomes, by a lack of clarity around regulatory approval, and by minimal recommendations from physicians. According to Quintiles IMS, more "curation and evaluation" of mHealth is needed in order to guide physicians and patients in making smart decisions when selecting a particular app. [20]

Research on this subject is based upon the review of published literature, an analysis of survey results, and conclusions reached from the evaluation of currently available hemophilia mobile apps. Recommendations to increase hemophilia mHealth usage to encourage improved bleeding disorder management are offered within the full report. The report is available by request: diane.horbacz@biomatrix.com.

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Paul R. Brayshaw, M.P.H.

Director of
Healthcare Advocacy and Programs
Matrix Health Group

THE HEALTH ADVOCATE

SELF ADVOCACY

According to Wikipedia, "Self-advocacy refers to people with disabilities taking control of their own lives, including being in charge of their own care in the medical system."

When individuals affected by a disability or a chronic illness seek to improve their quality of life by asking questions or seeking a second opinion, they are exercising the right to speak up for themselves. Whether the setting is a hemophilia treatment center, a pharmacy consultation, a support or peer group, or testifying before Congress or government agency, anyone and everyone has the capacity to be a self-advocate.

In personal experiences, I have sought to advocate for my personal health by participating in rallies like the Ricky Ray Rally in 1995, through countless visits to Members of Congress in Washington, and General Assemblies in various States, as well as through testimony in government agencies.

Throughout each of my experiences, I have had the honor to witness and share in the experiences of other members of our bleeding disorders community toiling as self-advocates. These people are champions of access to care and whom seek to share their own personal challenges to overcome disparities. The benefit of their successes are ultimately protective of all people with bleeding disorders and other chronic conditions.

Mr. Christopher Templin is one of these champions whom I deeply respect and appreciate for his determination, persistence and dedication to all people living with hemophilia, and those who will be born with this rare condition.

Last July, Christopher participated in the Office of Health and Constituent Affairs (OHCA) 13th Annual FDA Patient Representative Training Workshop. This workshop brought together both newly recruited and experienced patient representatives to share their own personal experiences regarding the development of drugs and therapies. Please read an article Christopher wrote in the August edition of the FDA Patient Representative Newsletter (next page).

Christopher also serves in various other capacities as a Special Government Employee, in which he has maintained a critical voice for the bleeding disorders community through his various roles as a participant in advisory meetings and discussions in Washington D.C. and throughout the United States.

People like Christopher inspire me to fulfill my own personal form of self-advocacy, not only for myself but the entire bleeding disorders community. The ability of people living with chronic illness to achieve an optimal existence relies on our individual and collective ability to overcome inequity and attain equal access wherever health care is provided.

Thank you for your efforts, Christopher!

NOT YOUR AVERAGE WORKSHOP:

PATIENTS DO TRULY HAVE A VOICE

BY CHRISTOPHER TEMPLIN, FDA PATIENT REPRESENTATIVE

On July 12-13, I had the honor and privilege of attending the *13th Annual FDA Patient Representative Workshop*, hosted by the agency's Office of Health and Constituent Affairs (OHCA). Upon arrival, it was clear to see the level of commitment and dedication by OHCA staff as we heard first-hand their backgrounds that led them to their current roles. I, personally, felt their encouragement that underscored the important role I have as an FDA Patient Representative.

To say it was an exciting experience to be in a room filled with such dedicated and compassionate patients and advocates committed to making a difference in the lives of persons with lifelong chronic medical conditions, is an understatement. It didn't take long for me to recognize the knowledge and expertise that was demonstrated by my fellow colleagues, which served as a major motivation for my own efforts.

As I listened to each heartfelt story detailing a different journey to becoming an FDA Patient Representative, I couldn't help but be touched by their candidness and courage as they shared openly their experiences with a disease, disorder, or condition. I was in awe from the time I arrived at the meeting to the time that I left--this experience will forever be with me in memory and spirit.

The honest conversations I had with my fellow FDA Patient Representatives will continue to be a driving factor in my life to ensure that the decisions, testimony and actions that I take as an FDA Patient Representative will benefit the patients I represent and be based on facts and evidence.

The agenda was well planned and thought out, very comprehensive and informative; the information learned and the friendships made will be extremely beneficial and cherished well into the future. It is very encouraging to know that the patient truly has a voice when it comes to the FDA Patient Representative Program. Although I've been active in other agency-sponsored roles, I look forward to what lies ahead in this special role by serving as an important ambassador for the agency and for the patient communities I represent.

ADVOCACY TEAM

CALL TO ACTION

GET TESTED AND TREATED FOR HEPATITIS C IMMEDIATELY

PLEASE LISTEN:

It's time to save your life by getting screened for hepatitis C, and if diagnosed, begin treatment immediately.

According to The World Health Organization (WHO), you have an 80% chance of not being properly diagnosed with hepatitis C. More so, if you are diagnosed, you have a 93% chance of not being on therapy for the virus. And here is where the sad lost opportunity arises, for treatment is now available for all genotypes of hepatitis C. Moreover, virus clearance rates on these new therapies are upwards of 90% for 8-24 weeks of therapy with minimal side effects, as opposed to previously available therapies that were frequently 48 weeks with often, unbearable side effects.

We're going to hit you with some facts. We want you to mull these over and consider what they are telling you. We also want to add that some of our hemophilia community members lived with the virus for over 30 years. One man became a fast enemy with hepatitis C when it took up residence in his blood and drove his liver into cirrhosis. In 2005, he tried to shed it with the only available therapy, PEGylated interferon and ribavirin. This failed and he gave up—there was nothing else.

A decade slipped by, and hepatitis C continued its onslaught, but then, in 2013, he tried again with newer medicines. They worked; they saved him. While damage was done to his liver, he has cleared hepatitis C and stopped further cirrhosis. He can never gauge how many years this gave him back, but that extra time is immeasurable. So, let's check out these facts:

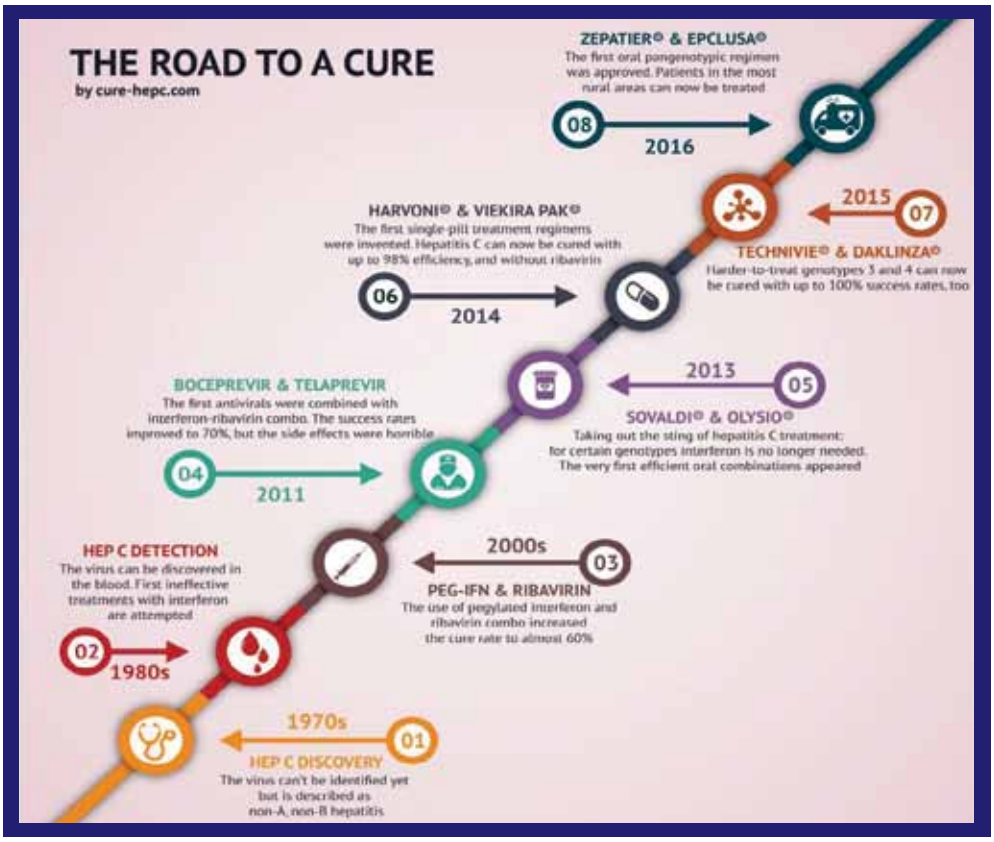
Worldwide, over 71 million people are living with hepatitis C; 3.2 million of those are in the United States. Yearly, approximately 1.75 million people are newly infected and approximately 1.34 million die as a result of hepatitis C-related complications. In 2014, when effective treatment was made available, the U.S. saw over 2,000 new diagnoses, and lost over 38,000 citizens to liver disease resulting from hepatitis C.

As you've likely heard, persons with a bleeding disorder who received plasma products in the 1970s and 80s are at a much higher risk of having contracted hepatitis C. Sources estimate that 6,000-10,000 hemophiliacs contracted the virus in those decades. Additionally, persons with hemophilia who contracted hepatitis C were likely co-infected with HIV, which further complicates the likelihood of liver disease and now, ultimately, leaves us a community where, as NHF states, "Hepatitis C is now the leading cause of mortality in individuals with hemophilia." This does not need to be the case.

MASAC, an NHF treatment advisory council, sets clear guidelines regarding hepatitis C:

1. All persons with bleeding disorders should be evaluated and tested by December 2016. That date has passed; you are behind the curve if you have not been tested.

2. All persons with bleeding disorders diagnosed with hepatitis C "should be treated by December 2017." Have you?



Currently available medicines for treating chronic hepatitis C are as follows:

- **Sovaldi** (sofosbuvir): Once daily pill. Treats genotypes 1 (the most common HCV genotype in the US), 2, 3, and 4. 12-24 week treatment depending on genotype and physician recommendation. Genotypes 1 and 4 often used in conjunction with interferon and ribavirin Genotypes 2 and 3 treated interferon free. 91% cure rate in clinical trials.

- **Harvoni** (ledipasvir/sofosbuvir): Once daily pill. Treats genotype 1, 4, 5, and 6. Interferon free. 12-week treatment. Sometimes used in combination with ribavirin, especially for persons with cirrhosis and/or liver transplant. 94% cure rate in clinical trials.

- **Olysio** (simeprevir): 1x daily pill used with sofosbuvir. Treats genotype 1. Interferon free. 12 weeks. 94% cure rate in clinical trials.

- **Viekira Pak** (ombitasvir/paritaprevir/ritonavir; dasabuvir) or Viekira XR (single pill): 1 x daily pill. Treats genotype 1. Interferon free. Approved for persons co-infected with HIV and/or those with liver transplant. 12 weeks. 97% cure rate in clinical trials.

- **Technivie** (ombitsavir/paritaprevir/ritonavir): 1x daily pill with ribavirin. Treats genotype 4 for person without cirrhosis. Interferon free. 12 weeks. 100% cure rate in clinical trials.

- **Daklinza** (daclatsvir): 1x daily pill with sofosbuvir (and sometimes with ribavirin). Treats genotypes 1 and 3. Interferon free. 12 weeks. 98% cure rate for treatment-naive without cirrhosis; 58% cure rate for treatment-naive with cirrhosis; 92% cure rate for treatment-experienced without cirrhosis; 69% cure rate for treatment-experienced with cirrhosis.

- **Zepatier** (elbasvir/grazoprevir): 1x daily pill. Treats genotypes 1 and 4. Interferon free. Approved for persons with cirrhosis and/or co-infected with HIV. Also approved for those with kidney disease and/or on dialysis. 12-16 weeks. 94%-97% cure rate in genotype 1; 97-100% cure rate in genotype 4 in clinical trials.

- **Epclusa** (sofosbuvir/velpatasvir): 1x daily pill. Treats genotypes 1, 2, 3, 4, 5 and 6. Interferon free. 12-24 weeks. 98% cure rate without cirrhosis; 83%-86% cure rate with cirrhosis; 94% cure rate with cirrhosis with ribavirin.

- **Mavyret** (glecaprevir/pibrentasvir) (Pending availability): 1x daily pill. Treats genotypes 1, 2, 3, 4, 5, and 6. Interferon free. Approved for persons with mild cirrhosis and those on dialysis. 8-16 weeks. 92%-100% cure rate.

This call to action is something you can do to save and prolong your life. Please listen. And please, let us help.

For more information or to sign up for step-by-step support to live HCV free, visit www.matrixhealthgroup.com/hcv or call our Corporate office toll free 877-337-3002.

If you have, or are suffering from hepatitis C and would like to share your story in Matrix Health Group News, please send it to Maria Vetter, Editor in Chief, for consideration: maria.vetter@matrixhealthgroup.com. We look forward to hearing from you!

MATRIX ON THE MOVE!

LOUISIANA

LeAnn Wilson

"What's the red tie for?" was the question of the day May 16th at the Louisiana State Capitol in Baton Rouge. As advocacy was taking place across the country, it was quite the same in Louisiana with double the attendance from previous years at our ***Louisiana Capitol Hill Day***. With HFA and NHF by our side, Louisiana Hemophilia Foundation (LHF) led the efforts in addressing the bleeding disorder community's concerns regarding the repeal and replacing of the Affordable Care Act.

Brenden P. proudly displays Senate Concurrent Resolution No. 96.

LHF was recognized by both the House and Senate, with Senator Fred Mills, Jr. (R District 22) sponsoring a resolution recognizing the bleeding disorder community: "SENATE CONCURRENT RESOLUTION NO. 96 — BY SENATOR MILLS A CONCURRENT RESOLUTION: To recognize and commend The Louisiana Hemophilia Foundation for its work to improve the quality of life and assist persons affected by rare inherited bleeding disorders, the absence of clotting proteins in the blood which are often painful and debilitating, and to designate Tuesday, May 16, 2017, as *Louisiana Hemophilia Foundation Day* at the legislature."

Representative Reid Falconer (R District 89) shared a bit of history on the art deco-inspired building, showing us a bullet hole reputedly from the 1935 assassination of Louisiana Senator Huey Long. Throughout the day, people stopped us in the halls of the 34-story, tallest capitol building in the United States, to ask the meaning of our red ties. We relished the opportunities to explain our cause and hand out symbols of our effort, spreading awareness one red tie at a time.

CALIFORNIA

Heather Messerly

The Crosby at Rancho Santa Fe in San Diego was the place to be Tuesday, May 23rd for the Hemophilia Association of San Diego County's (HASDC) ***24th Annual Charity Golf Tournament***! Players enjoyed an exciting round of golf and bidding on silent auction items in their fundraising efforts to benefit the worthy programs and services of HASDC.

As a volunteer, I was lucky enough to spend the day at hole 16 with Perry Parker, a professional golfer also affected by hemophilia. Perry had recently returned from playing the Australian Masters. He is a true inspiration to the bleeding disorders community and a great spokesperson. The fun and rewarding day wrapped up with awards given to the best performing teams. Thank you to all HASDC personnel and volunteers dedicated to hosting this awesome event!

ILLINOIS

Eva Kraemer

Shire partnered with Matrix Health Group to provide an ***Educational Dinner*** for families entitled, *Making the Grade* Tuesday, May 23rd at Pappadeux Seafood Kitchen in Westmont. We had a very lively discussion and informative presentation about opening the lines of communication between school personnel and children with a bleeding disorder. The roles and responsibilities of everyone working with a school child so he or she are afforded, under the law, equal access to education were discussed. The evening was packed full with valuable information about 504 and IEP Plans, and personal stories from parents discussing their experiences with their schools.

Cortez, Shari, Genny and son, Johnny, John, Eva Kraemer, Kelly, baby Native with dad, Alfonso, and Clemencia (front).

Parents gaining knowledge from one another is so incredibly powerful and, arguably, the most important part of learning. We at Matrix are pleased to do our part in arming parents with insightful information to live successfully with a bleeding disorder.

TENNESSEE

Stephen Lawrence and David Tignor

An eager audience gathered at Legends Steakhouse in Smyrna on Tuesday, May 23rd as Bayer and Matrix Health hosted an ***Educational Dinner***. Angela Lambing MSN, ANPC, GNPC, a Bayer Clinical Support Specialist in Hematology, directed a constructive presentation, *Being Prepared for a Hemophilia Emergency*. The program discussed the various ways people in the bleeding disorders community can be prepared for emergencies and emergency room situations. Angela discussed medical identification such as Medic Alert jewelry, preparation of a go-pack with factor, supplies, and documentation, as well as tips on how to assertively communicate with emergency room staff.

Looking comfortable! Ryan and his dad, Michael.

Bayer rep, Gina visits with Kevin and Robert.

An open discussion followed where attendees shared their personal tips and tricks for emergency preparations and told stories of emergency situations they had experienced. In addition to enjoying a satisfying dinner, the evening was exceptionally enlightening.

NEVADA

Kelly Gonzalez

On a warm Sunday afternoon, May 28th, patients from Nevada gathered in beautiful Reno at the Reno Aces baseball field to watch a minor-league game against Sacramento River Cats. Half the ticket sales proceeds for this event went to the Nevada Patient Assistance Program, which helps under-insured and struggling patient families overcome obstacles to proper care.

Lisa and Becki of Nevada HTC enjoy the game!

Families enjoyed the ***Community Gathering,*** the snacks, and some good ole' baseball fun! Special thanks to HTC of Nevada and NHF Nevada Chapter for supporting this event and to Lisa Cervantes, Medical Assistant at the Reno HTC, for organizing the enjoyable afternoon!

OHIO

Shelia Biljes

After a week of rain, the sun was shining brightly May 31st at Rinky Dink Family Fun Center in Medina. A group of 36 gathered for ***Dinner and a Presentation*** by Kelly Gonzalez, Educational Development Specialist, on *Summer Fun and Travel Safety.* The discussion included navigating out-of-town hospitals

Carter takes his shot!

Chandra's smile says it all!

Shiv and Garth check out the competition.

along with knowing what your insurance will cover while traveling, what to pack, and tips on carrying factor through airport security. After the interactive session and dinner, everyone was dismissed for some fun! Bumper boats seemed to be the biggest hit with go-karts a close second. The Matrix team had a friendly competition at the batting cages with Kelly taking the lead. Family members took turns in the batting cages and played miniature golf until the sun set. It was an amazing event to end the school year and kick off summer!

SOUTH CAROLINA

Peggy Klingmann

Hemophilia of South Carolina Chapter (HSC) held their ***44th Annual HELLO (Helping Embrace Life's Learning Opportunities) Conference and Annual State Meeting*** June 2-3. As happy families arrived at the Embassy Suites Greenville Golf and Conference Center in Greenville, they registered and took part in a fun icebreaker, followed by a delicious dinner buffet. Executive Director, Sue Martin introduced new board members and acknowledged those rotating off, announced special chapter awards, shared HSC's annual report featuring the year in review and vision forward, along with advocacy awareness and research updates. The evening gave way to a delightful *Community Hospitality Ice Cream Social* on the hotel terrace.

Saturday morning began with NHF's Brendan Hayes presentation of *The Evolution of Advocacy in the Bleeding Disorder Community*. Katie Verb, of HFA followed with *Healthcare Policy Updates*. The afternoon offered attendees a variety of breakout sessions with options such as *Understanding von Willebrand Disease*, *Social Media in the Bleeding Disorders Community*, *Persistent Pain*, *Encouraging Champions with Choices*, *Advocacy Coalition Panel*, and *Infusion Workshop*. Following the breakout sessions, everyone was encouraged to return to the exhibit hall for additional conversations with industry reps to learn more about products and services offered.

Dinner started at 5:15 p.m. with an outdoor barbeque meal and raffle drawing. Cornhole Toss and more games closed the event with folks saying their goodbyes until the next gathering Hemophilia of South Carolina bleeding disorder families.

TENNESSEE

LeAnn Wilson and David Tignor

The Tennessee Hemophilia and Bleeding Disorders Foundation (THBDF) held their ***Annual Meeting*** June 9-11 at Cools Springs Marriott in Franklin. Featuring a fitting theme, *Honoring the Past, Treasuring the Present, and Shaping the Future*, over 350 people were in attendance!

The event opened Friday evening with a welcome dinner and a chance to visit with industry exhibitors. Following dinner, a session for new families and several rap sessions were available. Saturday highlighted a variety of great sessions to attend, and industry booths to visit after breakfast and lunch. The sessions offered covered a range of topics such as *Grief*, *Dental Care*, *INHIBITORS: The Most Common and Most Severe Complications of Hemophilia A Treatment: SIPPET Study*, *vWD - How to Become a Strong and Confident Self-Advocate*, *Bleeding Disorders in Children with Special Needs*, and *Hemophilia Q & A Panel,* to name a few. In addition, Matrix Health Group's Regional Care Coordinator and Educational Development Specialist Kelly Gonzalez gave a presentation on *Transition to School-504 Plans*.

David Tignor and LeAnn Wilson visit with Celia (center).

Team Matrix Health Group!
Regional Care Coordinators - LeAnn Wilson, Shannon Cassada, David Tignor, Kelly Gonzalez and Cyndy Coors

The kids/teens program was located off-site at Deer Run Retreat Center in Franklin. They enjoyed outdoor activities including a giant swing, zip lining into a lake, and swimming! On Saturday evening, dinner was served outside where people enjoyed fellowship and live music performed by country music artist, Raquel Cole.

THBDF promoted their youth programs, Camp Freedom and Teen/Young Adult Summit throughout the weekend with fun and informative pictures and video testimony from the youth that have attended these invaluable programs. Before departure on Sunday morning, the last session was held during breakfast on one of the Foundation's most important programs, Camp Freedom. The THBDF Annual meeting was a wonderful, fun, and educational time for families in the bleeding disorders community!

VIRGINIA

Terry Stone and Michelle Stielper

The sun was warm and strong, the air was still and calm, and the explorers from the Virginia Hemophilia Foundation were excited as they anticipated the journey ahead. What was lurking beyond the trees? Will the animals know that we are at the top of the food chain? So many questions unanswered as we passed out goodie bags, put on our safari hats and animal masks, and prepared to embark on a journey through the rolling hills and flatlands of the Virginia Safari Park Saturday, June 10th in Natural Bridge.

There were so many free-range animals eager to make friends and dig into everyone's feed bucket. WATCH OUT...INCOMING! We saw reindeer, white tigers and kangaroos, to name a few. Oh, and if your bucket list included a selfie with a giraffe? Nailed it! The morning was spent on a tram ride that took us deep into the park to view hundreds of animals roaming freely. The group also had time to take a leisurely stroll through many of the habitats of some very unique creatures!

Families ready for a break around noon headed over to the National Bridge Hotel where Bioverativ's Sue Cowell provided lunch and an interesting ***Educational Discussion*** on the Importance of Genotyping. Lunch was perfect as it was like an indoor picnic with fried chicken and all the fixings!

After lunch, those folks with a full tummy and the true adventurer spirit returned to Safari Park to finish the day in the wild and experience all the park had to offer. Partnering with Bioverativ, Matrix Health Group was delighted to sponsor this unique family outing at the Virginia Safari Park. Great people, fresh air, lots of animals and the Blue Ridge Mountains in the backdrop... What's not to love?

FLORIDA

Marcy Foertsch and Peggy Klingmann

Sea World Ports of Call in Orlando was the place to be for the Hemophilia Foundation of Greater Florida ***Annual Family Event*** 2017 June 10th. Michael Rosenthal of Hemophilia Innovations was the featured speaker of this fantastic event! Michael is well known in the bleeding disorder community for his past accomplishments including being a former national director of the World Federation of Hemophilia USA (WFHUSA) and former Executive Director of the Arizona Hemophilia Association, as well as the recipient of eight NHF awards of excellence. Michael's interactive presentation titled *Independence Day*, focused on ways to cope with and take charge of your own care as a person with a bleeding disorder. Michael had everyone up and moving, learning about themselves, and each other.

This year's event boasted an impressive turnout of approximately 500 community members. The educational portion of the meeting was followed by a day full of fun as guests enjoyed all that Sea World has to offer.

OHIO

Enrique Morey

Yet another fun-filled ***Family Education Day at Coney Island*** was hosted by the Tri-State Bleeding Disorder Foundation June 10th. Everyone gathered for a picnic style lunch, met with vendors who service the bleeding disorders community, and spent time mingling with one another. Then it was time for some fun in the sun. Some families headed for the hugely famous Sunlite Pool, while others chose between classic amusement park rides, golfing, or boating on Lake Como. A big thanks to Lisa Raterman, Executive Director, and Helen Lamping, Executive Assistant, who never fail to bring a great time and help make lasting family memories.

NEW JERSEY

Rich Vogel

"Hot town, summer in the city… "While New Jersey experienced an unseasonable heat wave, it looked like the whole town of East Hanover came out to support the Cirelli family for the ***9th Annual Hemophilia Walk-a-Thon*** in Lurker Park. A sea of tie-dyed t-shirts filled the park for this family friendly event. When the music started, I thought I was back in Woodstock. While we waited for the walk to begin, the community enjoyed food, four bounce houses, face painting and games galore. In the 95-degree heat, there were a lot of volunteers for the dunk tank. Snow cones were also a big hit!

Bounce House Heaven!

Team BiologicTx - Julianne, Rich and JoEllen

What makes this walk unique is that Erin and Dino Cirelli host this event year after year with help from family and friends. Another unique aspect is that all the funds raised benefit the Nicolas Cirelli Family Research Fund and every penny goes to assist in funding the NHF Judith Graham Pool Fellows. This year's pennies added up to over $82,000 - an amazing feat! With dedication to research, the Cirelli family is ensuring we have quality hematologists working in the hemophilia community for years to come.

TENNESSEE

David Tignor

Over the past 10 years, parents of Ian Bates, Michael and Sarah Bates, their extended family, church and local community have joined talents to organize a local fundraiser to benefit the Tennessee Hemophilia & Bleeding Disorders Foundation and Hemophilia Research at St. Jude. ***Race for Ian*** was held at Trinity Baptist Church in Jonesborough June 17th. This year's race was special as it celebrated its 10th anniversary. People from around the northeastern Tennessee area and beyond showed up for the race to support

and participate.

The Tom Taylor Sports Show broadcast live, promoting the event and educating listeners about bleeding disorders. Tom interviewed several participants and key players in the community from runners to Ian's father Michael, the Executive Director of THBDF, and Ian himself to highlight on air!

The grounds of Trinity Baptist church is well known for its hills, which make it quite a challenge, but that does not hinder the participants. One by one, runners of all ages crossed the finish line with cheers and support of visitors, volunteers, and fellow runners. The camaraderie was amazing! After the race, an awards ceremony and drawing for door prizes followed. Race for Ian continues to grow every year, and Matrix Health Group is proud to support this wonderful cause!

ILLINOIS

Eva Kraemer

June 20th, the gorgeous Ruffled Feathers Golf Course in Lemont was the place to be for the Bleeding Disorder Alliance Illinois' (BDAI) well attended ***20th Annual Golf Fundraiser - Driving Fore Hemophilia***! The day began flawlessly and BDAI's Executive Director Bob Robinson, staff and volunteers provided 18 challenging holes of golf. Revelry was had by all as donations were made to help the Illinois bleeding disorders community. Regrettably, Mother Nature had other plans. About 5 holes in, stormy weather drove the golfers to the clubhouse, where the revelry continued unabated! Rain did not deter anyone's generosity as we all made our way back to the clubhouse for food and raffled sports paraphernalia. Matrix Health Group sponsored new faces in our foursome this year and their contribution to the day, especially with the rain, only enhanced its success.

NEW JERSEY

Richard Vogel

Ever wonder about the science behind bleeds? How does a clot form and what is needed for it to form and stay in place? What is the difference or mechanism of action between all the new therapies and clotting factors? These questions and many others were answered at an ***Educational Event*** with Bioverativ and hosted by Matrix Health Group. We presented in two parts on two different days, Sunday, June 11th and Thursday, June 22nd. Both were held at the Spanish Tavern in Newark, a Portuguese restaurant in the heart of the Ironbound district.

On Sunday, June 11th, we discussed what happens in the body during a bleed and what causes bleeds to start in the first place. We covered some of the new hemophilia therapies and how they are thought to work or their mechanism of action. FC fusion is believed to help eliminate factor from the body more slowly. Naturally occurring FC proteins are fused with factor proteins to help the body recycle infused factor. Albumin fusion uses albumin and fuses it to the factor. Again, this is thought to help the body retain and recycle infused factor. PEGylated products use polyethylene glycol or PEG to attach to factor proteins to make infused factor last longer.

We talked about ACE910, which is still in clinical trials. ACE910 acts like factor VIII mimetic and helps bring factor IX and factor X together to create thrombin, which is needed for clotting. Gene Therapy was also on the agenda. In this therapy, corrected copies of the mutated hemophilia gene are inserted into a vector, usually a non-infectious virus envelope. There are many vectors being investigated because some people will have anti-bodies to various vectors.

This discussion helped us with the next session on Thursday, June 22, an interactive educational experience with MyELOCTATE Peer, Lane H. who

talked about his journey with hemophilia, and the clinical data and the science behind the product he represents.

This was the first of several events I plan to host regarding products and the science behind them. It's an area that needs to be better understood so consumers can make educated decisions when exploring new therapies. Matrix Health Group shares this information for educational purposes only – we do not endorse any treatment, product, protocol, manufacturers, or individual medical providers. Always speak to your medical team to determine the best course of treatment for you or your loved one.

MARYLAND

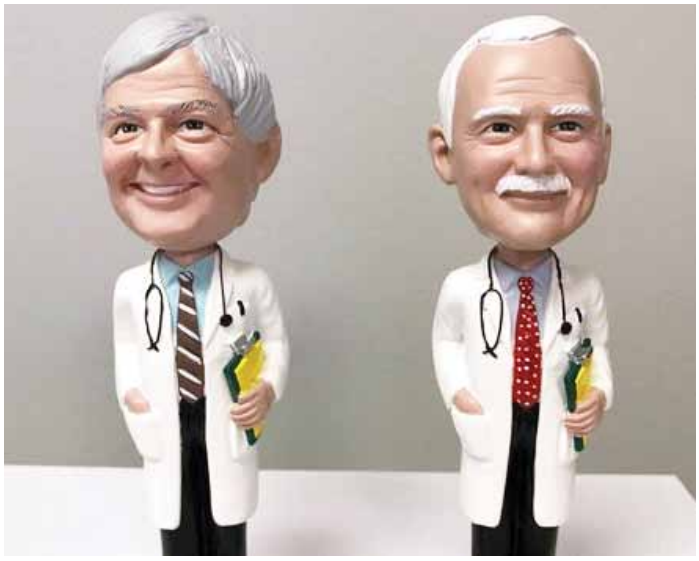
Paul Brayshaw

The Hemophilia Foundation of Maryland (HFM) hosted its 5k/10k ***Race to Stop the Bleeding Annual Run and Fun Walk*** at Quiet Waters Park in Annapolis June 24th. The event also included children's games, a complete picnic lunch and industry exhibit booths where numerous give-a-way items were available. The first 150 registered participants received a free t-shirt, and every $5 of donations provided one entry into a fun-filled raffle for cash prizes. This exciting event is the largest annual fundraiser dedicated to raising needed funds with 100% of entry fees going directly to support the mission of HFM

OHIO

Rania Salem

June 24th brought friends and families of the Tri-State Bleeding Disorder Foundation (TSBDF) together to sing the praises of our wonderful clinicians at the ***Dr. Terry Weiss Memorial Fundraiser Honoring Dr. Ralph Gruppo and Dr. Joseph Palascak***. A special thanks to Bob Herzog, anchor from our local News Channel 12, who co-emceed the evening, along with T.D. Hughes, a long-time supporter of TSBDF. Several patients, nurses and other colleagues paid tribute to the doctors, giving testimonials of how their lives were touched by their care and compassion. Together, they have given 80 years of service to the bleeding disorders community in Cincinnati. Each doctor was presented with engraved wine chillers and awesome personalized bobblehead dolls.



This night not only celebrated our talented clinicians, it was a chapter fundraiser as well. Funds raised will help aid children in attending summer camps and offer emergency assistance for families in crises, among the many other offerings of the chapter. Silent auction items and a great fun game of Heads or Tails was played to help raise money. Lucky winners of the Heads or Tails game graciously donated their winnings back to the chapter. Dinner, drinks and dancing concluded the night. A special thanks to all who help make this a memorable and amazing night!

VIRGINIA

Michelle Stielper and Terry Stone

The Virginia Hemophilia Foundation held their ***Annual State Education Day*** Saturday, June 24th in the shadow of the state capitol at the classic colonial Wyndham Virginia Crossings Hotel in Glen Allen. Flash back 10 years at this very same hotel, the chapter welcomed Executive Director Kelly Waters to the organization, and she has been on the run ever since! Thanks to her hard work, compassion and sensitivity to the needs of VHF members, she has grown membership and participation to a new and impressive level. Happy 10th anniversary, Kelly!

Regional Care Coordinators Michelle Stielper and Terry Stone with Connie Montgomery, Culture Event presenter and favorite community member!

Kelly has the recipe for a fun and effective VHF Annual Meeting! First, you start with a beautiful venue fitting of Virginia's Colonial history, add in some hot topic breakout sessions unique to certain audiences, then add in happy members and a keynote speaker with time sensitive insurance updates and VOILA! A perfect dish to feed the "information hungry" and enrich the soul, all with zero calories!

NHF's Senior VP of Public Policy & Stakeholder Relations Michelle Rice kicked off the day with an "Advocacy and Healthcare Update." She gave an overview of where Repeal and Replace was at this snapshot in time, how to stay on top of updates, and to make your concerns heard. The next presentation was a fun and interactive *Culture Event* compliments of Connie Montgomery called *Patchwork Quilt*. It was a great exercise to help us connect with one another and celebrate our uniqueness. Each piece of a patchwork quilt is different, but together they make something special! Connie serves on the NHF Cultural Diverse Working Group.

The last group presentation was given by Jeannette Cesta, National Bleeding Disorders Educator for Octapharma, who led an interactive discussion of *To Tell or Not to Tell*, which is a question that comes up throughout many of the stages of life.

Breakouts included an HFA rap session for the guys, *Let's Get Fit* program, and a women's session, *Finding Strength through the Struggle*. It was a wonderful weekend to learn, celebrate accomplishments and network with old friends and new faces. Thanks to Executive Director Kelly, and Program and Communications Director Heather Conner for another great event!

CALIFORNIA

Cindy Picos

A fantastic opportunity for families to get away from everyday responsibilities and take time to enjoy themselves with special events, education, crafts, games and family time was hosted by Central California Hemophilia Foundation July 14-17. Held at the Cal State Maritime Academy Campus in Vallejo with each family staying in dorm style rooms, ***Annual Family Camp*** began Friday evening with plenty of pizza, games and a family movie! Saturday's line up included educational classes, crafts, time to swim, and a special surprise visit from Disney characters. The evening brought sports on the campus football field, and more games and movies.

One mom expressed her appreciation of the weekend as her family's annual opportunity to get away from all the electronics, the pressure of preparing meals and taking care of the house, and just having time for her to enjoy her family. A dad

Hanging with super heros!

noted it was just nice to get away with other families that share similar issues and hear about their coping mechanisms. The fun-filled weekend drew to a close with breakfast on Sunday morning. Families then were free to roam the campus and enjoy the ocean view and beach front setting.

GEORGIA

Cyndy Coors and Peggy Klingmann

With open arms the city of Albany welcomed the United Hemophilia Foundation July 14-16 for their We are Family themed Inaugural Family Education Day & Launch Gala. The summer heat didn't stop anyone from gathering at the Hilton Garden where they were welcomed, visited the industry booths, and had dinner sponsored by CSL Behring with Shonda Joshua speaking on Encouraging Champions with Choices.

The next day, children visited the Albany Welcome Center, the Aquarium and Ray Charles Museum while parents participated in sessions presented by HFA's President Kimberly Haugstad *Your Voice Matters*, Katie Verb speaking on *Policy and Government Relations Policy Update-Staying Covered*, Cathy Tiggs-Johnson discussed *Women's Blood Sisterhood* and Ruth Mulvaney presented *Men's Brotherhood Session*.

HFA speakers, Kimberly Haugstad and Stanford Murray led a Moms and Dads in Action session while Carletha and Harvey Gates led Women's and Men's Rap Sessions. An ice cream social brought the evening to an end. Sunday morning consisted of breakfast and plenty of hugs until we meet again! It was an honor to be part of something so uplifting and empowering. We left with the feeling of unity, and we all are family in the bleeding disorders community!

OHIO

Rania Salem

Friends and families of the Central Ohio Chapter of NHF gathered for a weekend of learning and fun for the annual ***Education Retreat*** at the Cherry Valley Lodge in Newark July 14-16.

Diane Horbacz, BioMatrix' Research and Education Development Specialist, also known as Slime Lady, was on hand to conduct a class on My Amazing Blood. The kids had loads of fun thru a hands-on, slime-making experience as Diane led a demonstration of how blood works. Her class was interesting and amusing, but most importantly, left the children with a better knowledge of how important factor is in the clotting cascade.

As a registered nurse, I led a class on self-infusion. While veterans of the process picked up new pointers, others were infusing themselves for the very first time! This weekend wasn't all just about education though. It was also an opportunity for families to get together for fellowship with others who walk in similar shoes. Many thanks to the Central Ohio Chapter for another amazing retreat!

WEST VIRGINIA

Tina McMullen and Michelle Stielper

The West Virginia Chapter of NHF (WVNHF) held their annual ***Family Camp*** July 14-16th at Ace Adventure Park in Oak Hill, and what an adventure it was! Although the day proved to be a stormy, soggy day, families still managed to enjoy time at the water park and zip lining through the forest. After fun at the park, everyone was treated to a down home-style dinner prepared by community member, Chef Drew.

Omari shares a sweet smile with Regional Care Coordinator, Tina McMullen

The next day was a busy one – full of educational symposiums, visiting vendor exhibits, having more time at the water park and enjoying the performances of the first annual kid's talent show. After such a full and exciting day, everyone looked forward to the evening where they settled down around a campfire for stories and s'mores. More adventure followed on Sunday with everyone going on a white-water rafting excursion! Executive Director Amber Tichnell orchestrated an exciting, fun-filled weekend that we're sure will be remembered for years to come!

NEVADA

Kelly Gonzalez

The tone was set early as 20 couples gathered in a private room at Hilton Garden Inn in Henderson July 15th for Nevada Chapter of NHF's ***Couples Retreat***. A young lady named Ali from Inalex Programming spoke with her father and began the presentation by sharing her history. Paralyzed from age two, she learned to appreciate life and flip the proverbial switch to optimism when negative things came about.

Throughout two meals, and hours of activities and lessons, couples grew closer to each other and to those in the group. The lessons learned during this time applied to bleeding disorder-affected couples and parents of chronically ill children. As the day ended, couples were invited to stay the evening to practice the connection and communication skills learned. Attendee feedback on the retreat included words such as inspiring, thought provoking, and life changing. Thank you to the Nevada Chapter of NHF for holding this unique event!

OHIO

Shelia Biljes

As the Cleveland Zoo celebrated its 100 year anniversary, the Northern Ohio Hemophilia Foundation (NOHF) gathered for its highly anticipated ***Annual Zoo Event*** July 15th. With over 120 in attendance, Matrix Health Group shared in the festivities along-side Bayer and Grifols as event sponsors. Families visited the booths and received a free gift from each sponsor: free step trackers from Grifols, cool compression sleeves from Bayer, and awesome *America's Best Recipes* Cookbook and spatulas from Matrix Health Group.

Rhea, Timea, Savannah and Kya having a wonderful day!

The sunshine made for a relaxing day to walk and visit each of the interesting animal exhibits. Zoo-goers enjoyed seeing kangaroos and wallabies roam in Wallaby Walkabout as they made their way to lunch at the Australian Adventure pavilion.

My personal favorite exhibit is of the polar bears that seem to have so much fun in the icy water despite the humid 88-degree Cleveland temperature. It was great to see many new faces join the fun this year!

VIRGINIA

Michelle Stielper

The wonderful ladies of Hemophilia Association of the Capital Area's (HACA) Women's Group came together on a Sunday afternoon in Fairfax to talk and share advice and experiences in an open discussion program ***Advocating for Yourself as a Woman with a Bleeding Disorder*** facilitated by NHF's Corinne Koenig. The range of topics and emotions covered took everyone from misty eyes to hysterical laughter.

The ladies enjoyed a yummy lunch from Noodles & Co. while Corinne led them through a mindful journaling exercise. They were led through the steps of how to organize thoughts and feelings while experiencing difficult times in order to bring some clarity and stress management techniques to the challenges they face while living with a bleeding disorder themselves, or caring for someone who has

Kirstin, Michelle and Dana show off their necklaces.

one. It was a wonderful icebreaker allowing everyone to open up, share true feelings and create an opportunity for the women to understand and embrace one another in common struggles.

The journaling session was followed by our facilitation of Matrix Health Group's *Bead Your Journey* program. Each woman made a lovely necklace that served as a visual representation of her journey with, or caring for, someone with a bleeding disorder. Every bead added to their jewelry piece had a special meaning and emotional significance to their personal journey. It was a day filled with happy tears, laughs, hugs, sisterhood and most of all, love.

PENNSYLVANIA

Shelia Biljes

A room noisy with conversation, laughter, hugs and smiles, surrounded by many friends, old and new is the perfect place to be! Dave and Busters in Homestead has been the venue for several years as the Western Pennsylvania Chapter hosted their ***Annual Meeting*** July 19th. Sponsors welcomed over 30 families as they toured the exhibit booths prior to dinner. Over dinner, manufacturer representatives were given the opportunity to update everyone on their new products. Meanwhile, the kids were anxious to use their game cards to check out the new Spider Man game. Kudos to Allison Yazar, Chapter Director and her team as they hosted another flawless meeting!

Paul says, "Games aren't just for the kids!"

OHIO

Shelia Biljes

Add a little LOVE...and a tennis match or two to shake things up at Northern Ohio Hemophilia Foundation's (NOHF) ***27th Annual Golf Outing and Ladies Tennis Tournament***! Hosted at Shaker Heights Country Club in Shaker Heights, this year's addition of *Ladies Round Robin Tennis Tournament* where 8 teams of very serious players competed while sporting broad smiles to show their enjoyment.

Bryant contemplates his shot.

Eighteen teams of golfers along with the tennis players came out to brave the super hot, humid weather of July 20th. It was already 90 degrees at the 9:30 a.m. shotgun start!

Lunch and awards followed the games, and everyone participated in raffles. NOHF exceeded their goal by raising $30,000! The initiative of including tennis matches added variety to an already successful event!

MISSOURI

Dan Hicks and Eva Kraemer

Families from across Missouri gathered in fellowship to stand united and support the Gateway Hemophilia Association (GHA) as the Association hosted its annual ***Family Education Weekend*** July 21st-23rd at the Chesterfield Doubletree in Chesterfield. Many sensational and startling stories were shared showing the challenges the bleeding community faces and could be attributed to why this chapter has such a strong backbone.

There were a remarkable number of educational paths to choose from at this event. Breakout sessions included *Newly Diagnosed, What's Life Going to be Like*, *Sibling Support for Parents*, *Alternative Treatments*, *Managing the Pain*, *Aquatic Therapy*, *Factors to Consider When Choosing a Product*, *Recognizing and Treating Bleeds*, *Food and Fitness Basics*, *Recognizing Signs of Bullying in Your Child*, and a *Victory for Women* session.

OHIO

Justin Lindhorst and Rania Salem

The ***Family Annual Meeting of Hemophiliacs in Ohio*** (FAMOHIO) has been bringing together members of the bleeding disorder community since 1992. The tradition continued August 4-6 at the newly renovated Columbus Marriott Northwest in Dublin. *Hit it Out of the Park* was the theme for the weekend, and with the opportunity to attend a Columbus Clippers baseball game in addition to a plethora of educational programs and networking opportunities, the board and planning committee hit a homerun! FAMOHIO attendee Jermaine even had the opportunity to throw out the first pitch at the Clippers game! Thanks to new and old friends alike who stopped by the Matrix Health Group exhibit booth. We look forward to next year!

Jermaine was chosen to throw the first pitch!

Hunter, Jennifer, Allison, Rocky and Rocky, Jr. pose for a photo with *Krash*.

Anne P. (center) visits with Danny Hicks and Eva Kraemer at the Matrix Health Group both.

As the final night came to an end, everyone gathered at the pool for an exclusive party and to listen to a song written by one of the members about the struggling and embracing of adversity within his family's life, and the obstacles encountered along the way. It was a truly magical experience to be part of something so great and full of passion. Matrix Health Group looks forward to being part of it all again next year!

NEVADA

Kelly Gonzalez

Although a serious heat wave was floating through town July 21-23, families from various parts of Northern Nevada arrived at the Elko Convention Center to partake in ***Northern Nevada Family Education Weekend*** hosted by the Nevada Chapter NHF. Friday began with dinner and an educational session on *The Unaffected Sibling* by Bioverativ's Jessica Klass, CORE Manager.

Hamming it up for day camp!

In the morning, families gathered for breakfast, then went their separate ways. Kids attended "practice camp," which included arts and crafts, swimming, park activities and a carnival. Meanwhile, adults attended educational classes on topics related to having a bleeding disorder. The groups came together for dinner and more carnival fun.

Sunday morning, guests attended an infusion class led by Becki Berkowitz, NV HTC Nurse Educator. Thereafter, families were on their way home, happy and well informed! Northern Nevada Family Weekend is a special opportunity for our bleeding disorder

TENNESSEE

David Tignor and Shannon Cassada

Shane expertly takes aim.

Every year, the parents of Caleb Wood organize a one-of-a-kind event in his honor with the help of volunteers, sponsors, and the Tennessee Hemophilia and Bleeding Disorders Foundation (THBDF). For the 11th year running, the ***Pitchin' for Caleb Corn Hole Tournament*** was held August 5th at Centennial Park in Crossville.

The fun day began with time to hone corn bag tossing skills. Choosing numbers out of a bucket randomly paired teams of two. It doesn't get more random than that! With plenty of spectators cheering on the participants, 21 teams competed, including THBDF Executive Director Tim Diffenderfer along with several members of the bleeding disorders community from middle and eastern Tennessee.

Following a lunch break generously provided by local community members, Scotty and Ronnie Webb, it was time for eliminations. The competition was fierce as teams tried to reach a score of 21 before their opposition. The day wrapped up with winners announced and door prizes drawn.

As in previous years, participants and spectators alike enjoyed this exclusive fundraising event, which raised nearly $12,000 to help support THBDF! Matrix is a proud sponsor of this unique fundraising tournament, and we look forward to it again next year!

Korbin and Taylor

Maddie Lynn and Malia get ready for the carnival!

community, spread out across our state, to come together. We are grateful to Nevada Chapter of NHF for this wonderful opportunity!

TEXAS

Felix Garcia

As the saying goes, "Everything in Texas is bigger," and that goes for the annual ***Texas Bleeding Disorders Conference*** as well! August 4-6, the Lone Star and Texas Central Chapters NHF brought together approximately 900 community members from all over the great state of Texas to The Woodlands, a fantastic area 30 miles due north of downtown Houston. On the first day of the conference, not only were local folks pulling up to Woodlands Waterway Marriott, but so were large charter buses from locations around the state including El Paso and the Rio Grande Valley at the southernmost tip of South Texas.

Regional Care Coordinators Felix Garcia and Cyndy Coors with Ray Dattoli, Community Advocate.

Community members were eager to hear the latest advancements in hemophilia treatment, medications currently in the pipeline, information on school resources like *Section 504* - part of the Rehabilitation Act of 1973 that prohibits discrimination based upon disability, and several other topics in breakout sessions designed to spark interest for everyone.

It was a Texas-sized family reunion of sorts! I teamed up with my good friends and fellow coworkers, Cyndy Coors, Ray Dattoli and Troy Howell. We set out to meet as many families as possible, hear their stories and share ours as well. The chapters are to be applauded for all their hard work in organizing this monumental event! I speak on behalf of the entire Matrix Health Group team, we can't wait until the next family reunion, er..., I mean, Texas Bleeding Disorders Conference!

CALIFORNIA

Cindy Picos

Central California Hemophilia Foundation's annual ***Family Education Weekend*** August 5-6 started at the Hilton Double Tree in Sacramento and concluded with a family Fun Day at Six Flags Discovery Kingdom in Vallejo. The event began with breakfast and time to visit industry booths. Throughout the day, several presentations were available including, *Show Me Your Pearly Whites*, *Winning with Bleeding Disorders: Strategies for Raising Happier Healthier Kids*, *504 School Plans*, and more. Meanwhile, children had special workshops just for them and participated in an art contest. The first day concluded with dinner and a presentation on *Healthy Choices for Those with Bleeding Disorders*.

The second day was pure fun... at Six Flags Discovery Kingdom in Vallejo, where families enjoyed rides, animal presentations, a group barbeque and more rides!

Sweet smiles from Robby melts his mom's heart.

Ashley loves the merry-go-round!

OHIO

Shelia Biljes

It was a night for romance as Matrix Health Group paired with Shire to present a couples-only ***True Identity Dinner***. Main Street Cafe is never a let down and as usual, the food was exceptional as we gathered on August 9th in Medina. It just happened to also be the wedding anniversary of True Identity speaker Rhea and her husband Tim, making the evening even more of a celebration!

Rhea led the conversation in parenting a child with hemophilia. We enjoyed many belly laughs, sharing stories about sending our kids off to hemophilia camp. Would you believe It - no one was surprised to learn that several parents had thrown away duffle bags full of camp clothes that were just too stinky to wash!

Bob and Charlene enjoy their date night.

Guests enjoyed a scrumptious dinner with steak, salmon and chicken - so filling that no one had room for the triple chocolate cake dessert! A romantic walk around Medina Square followed, and we then headed over to All Fired Up, a local paint your own pottery and creative arts studio.

Bringing the evening to a fantastic close, Matrix sponsored a painting class, and each couple chose a piece to work on together. Artistic juices were flowing, as was the laughter, especially as one couple squabbled over their anniversary date. Upon investigating the facts, it was found they were both wrong! A suggestion was made to add both dates to the piece of pottery and to celebrate twice each year. After a wonderful date-night evening, couples left hand in hand, walking back through the square to their cars with a new-found appreciation for each other.

NEW JERSEY

Richard Vogel

The exchange of information between young and old, novice and experienced can be extremely beneficial and so Matrix Health Group brought together a small group of people August 10th to partake in a new program titled, *Reciprocal Relationships - Exploring the Reflective Relationship Between Port Experts and Masters of Vein Access.* Over pizza at Original Attilios, a NJ shore staple in Tinton Falls, our discussion included growing up with a port, the port graduation, vein access challenges and contemplating a port return if one has trouble accessing veins as he or she grow older.

In an informal group setting, participants were able to share experiences and learn from one another. Our first ***Lunch and Learn Education Session*** led by Diane Horbacz, BioMatrix's Research and Education Development Specialist, investigated how to preserve veins for the future while sharing individual journeys to vein access.

Our audience consisted of a mother with two port-experienced sons, having had 8 ports between them, and a group of older guys with no port experience, but having trouble accessing veins as they have gotten older. We discussed rotating infusions with various vein sites to preserve veins from overuse, various venous access sites, pros and cons of ports, the body's response to being poked, and how scar tissue building up over the years can make accessing a vein more challenging as the years go by. We all came away from the lunch with a better understanding of our veins and how to protect them.

Adrian examines a venous port system.

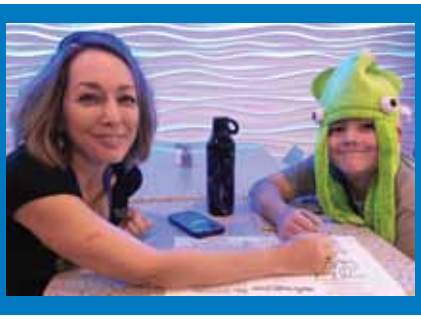
SLEEPING WITH THE FISH

BY TERRY STONE

Haven't got your fill of sharks from Shark Week? Are Nemo and Dory two of your favorite Disney characters? I thought so! To help this chronic need for all things "fishy," The Hemophilia Foundation of Maryland (HFM) and Matrix Health Group hosted an ***Immersion Tour*** at the National Aquarium in Baltimore Saturday night, August 13th. Woohoo! A sleepover!

Schools of families arrived around 6 pm loaded up with sleeping bags and pillows, ready for a great adventure. After settling in the meeting room, our expert marine biology guides sent us to the dolphin house for an exciting display of show-stopping dolphin behaviors. Two different families of dolphins live together in the tank and love to show off their natural talents.

Then it was off to dinner for our inside picnic complete with a puzzle-filled placemat for everyone to warm up his or her brainpower before our adventure began. When our "fishies" were full, we separated into two "schools" and swam off to explore many exhibits, which included numerous sea creatures, sharks, jellies, stingrays, and the magical humid environment of the



tropical rain forest. The moist spa air was a definite value-added benefit...complimentary facial!

After a full evening of exploring and marine life education, it was time for all little fishes to find a coral reef and go to sleep. Everyone received a super cool pillowcase designed especially for this event. Sweet dreams!

Morning came quickly, and it was time to grab some breakfast and head over to see the various species of jellies. But wait, there's more! The guides gathered all explorers to the window at the dolphin tank. It was time to do something so fun, so rare, so awesome, that we all waited with wide eyes and a quiet whisper. Then it happened... here it comes! Time to wake the dolphins! As the guide drew open the curtains, joyful dolphins swam to greet us and we all eagerly said hello and waved.

Not only did the kids love it, but it was astonishing to realize we had a "dolphin whisperer" among us! A member of our group made friends with one dolphin in particular. Several times, the dolphin put his face right up to the glass for her to "pet" him and then made a show of blowing air out of his blowhole!

To wrap up this exciting, interactive event, we all played *Shark Jeopardy*. Can I just say I knew our HFM families were smart, but wow! Only one question was missed. Looks like EVERYONE was paying attention!

Matrix Health Group was delighted to sponsor this unique community event for HFM families. Thanks to everyone who joined us and an extra big THANK YOU to Emma Miller, Executive Director, for her help and dedication to bringing FUN-tastic events like this to the community!

VIRGINIA

Terry Stone and Paul Brayshaw

The ***Annual Chapter Family Picnic/Walk Kickoff*** at Algonkian Regional Park in Sterling was hosted by the Hemophilia Association of the Capital Area (HACA) August 13th. Chapter members and guests enjoyed a wonderful barbeque lunch in a park overlooking the Potomac River, upstream from Washington, D.C. The gathering was followed by a visit to Volcano Island Waterpark, located just adjacent to the picnic site for a refreshing afternoon and cool down in one of the many pools. The picnic also included a kick off announcement for the 2017 HACA *Fall Festival and Walk*, which is the Chapter's biggest fundraiser of the year. Come join us October 14th at Lake Accotink in Springfield, Virginia!

Paul Brayshaw, Porter and Jens

OHIO

Shelia Biljes

What could be sweeter than candy and ice cream? A delectable event at b.a. Sweetie Company in Cleveland! Matrix Health Group partnered with Bayer August 16th for an evening of friendship, education and tasty treats! Packing the room, over 60 members of the northern Ohio hemophilia community were present as Kelly Gonzalez, Matrix's Educational Development Specialist, led a presentation titled, *Back to School Safety*.

Beginning with pizza and chips, and veggie and fruit trays for those more health conscious, the group eagerly anticipated the ice cream sundae bar yet to come. Children could not keep their eyes off the candy bar set up for them to later fill their bags.

A *Factor Storage and 504 Plan* trivia game had everyone participating to win jazzy school supplies. With bellies full and children on sugar highs, the group moved outside to work off some of the energy at Sweeties Golfland, where everyone played miniature golf on the nightglow course. Much fun was had by all, and more importantly, we also learned a lot!

Owen carries an over-sugared Griffin

FLORIDA

Hector Heer

The Foundation Hope and Life USA held a ***Back to School*** event made possible through support from factor manufactures and pharmacies like Matrix Health Group. On August 17th, 120 people gathered to socialize and learn the latest community information from the vendors in attendance. After a brief presentation from each sponsor, families enjoyed dancing and lively music. The foundation provided participants with backpacks full of goodies perfect for the Back to School season. The event was a tremendous success and the foundation plans on hosting a similar event next year.

KENTUCKY

Brenda Montgomery King and David Tignor

The Kentucky Hemophilia Foundation's (KHF) ***Summer Family Event/Annual Education Meeting*** was held August 19th at the Hyatt Regency in Louisville. Executive Director Ursela Kamala warmly welcomed the group and presented the KHF annual report. Board member elections were had and recognition was given to Foundation volunteers for their unselfish support within the community. The 2017 ***KHF Walk Kick-Off*** was also announced. The much-anticipated Walk will be held at Wetherby Park in Middletown October 14th. Information was given on how to form a team and how to sign up for the Walk. An exciting raffle was held and several happy families had winning tickets!

Nicholas and Veronica visit with Brenda Montgomery King (left), Matrix's Patient Resources Specialist.

In addition to time for visiting industry booths, several educational sessions were available such as *Women: Let's Talk About Hemophilia*, *The Evolving Landscape of Hemophilia*, and *INHIBITORS: The Most Common and Most Severe Complications of Hemophilia A Treatment: SIPPET Study*. CSL Behring *Getting' in the Game* presenter Tim Grams spoke on *Fit 4 Life: Extolling the Long-Term Benefits of Exercise in the Bleeding Disorders Community*. As a former record-setting swimmer at University of Denver, Tim also led a swim clinic in the hotel pool.

Following a tasty dinner, everyone headed to the Louisville Slugger Field for a rousing game between the Louisville Bats and the Rochester Red Wings. Matrix Health Group is happy to be a supporter of the KHF Summer Family/Annual Education Meeting!

NORTH CAROLINA

Peggy Klingmann

Hemophilia of North Carolina (HNC) held its annual ***Family Day Out*** August 19th at Tanglewood Park - a 1,100 acre recreation center and park in Clemmons. This laid back, social event gave families a chance to spend time together and get to know one another. Executive Director Charlene Cowell greeted guests as they arrived, then during lunch, spoke about the up-and-coming HNC programs.

HNC's Gillian Schultz, Program Manager, and Charlene Cowell, Executive Director, greet guests as they arrive

Families enjoyed splashing and cooling off at the newly renovated Aquatic Center with its pools, waterslides, and tubing river. What a perfect day for a picnic and water park activities. We very much look forward to this day of summer fun next year!

ILLINOIS

Eva Kraemer

The Board of Directors and Executive Director Bob Robinson hosted the 2017 Bleeding Disorders Alliance Illinois (BDAI) ***Annual Meeting and Awards Dinner*** August 28th, at the William Tell Holiday Inn, Countryside. David Green, MD, Emeritus Professor of Medicine at Feinberg School of Medicine at Northwestern, as well as a hematologist with nearly 60 of working with the bleeding disorders, gave the keynote address, touching on his book, *Linked by Blood: Hemophilia and AIDS.*

Board President Daniel Contreras gave a report on the state of the organization and 2018 endeavors.

Eva Kraemer and Robert Johnson, Social Worker at Stroger Hospital of Cook County, take a moment to catch up.

Awards were graciously accepted for the following contributions: *Walk in Our Shoes Award* to Dr. David Green; *Award of Excellence* to Clemencia Casas-Byots; The *Cibula Award* for outstanding volunteers was given to Giselle Mills and Gilbert Russell. Four students were presented the *Bradley Krueger Scholarship* for 2017-2018 school year by the family of Bradley Krueger. This annual event is a nice way to acknowledge the people in our community making a difference!

CALIFORNIA

Cindy Picos

The Central California Hemophilia Foundation hosted their ***1st Annual Family Fun and Fit Day September 9th*** at the Nimbus Flats State Park - Sacramento State Aquatic Center. Families enjoyed a great day – having lunch, visiting with industry representatives and obtaining autographs from the Sacramento Kings Basketball Team Dancers.

The event highlight was a presentation by Bryan Stow, the Giants fan who was beaten up by Dodger fans outside a Los Angeles game. After lying in a coma for nine months, Bryan is living with partial paralysis and lifelong disabilities. Bryan spoke to our group in a powerful voice about anti-bullying, and standing up to bullying.

The afternoon found families also kayaking, paddle boating, going down water slides, and much more!

UPCOMING EVENTS

OCT. 13-14, 2017 UTAH
Utah Hemophilia Foundation
801-484-0325, hemophiliautah.org
vWD Conference
Homestead Resort; Midway

OCT. 14, 2017 CALIFORNIA
Hemophilia Assoc. of San Diego County
619-325-2570, hasdc.org
Hemophilia Walk
Liberty Station Park; San Diego

OCT. 14, 2017 CALIFORNIA
Valley Children's Hospital
559-353-3000, valleychildrens.org
Family Education Day
Valley Children's Place; Madera

OCT. 14, 2017 IDAHO
Idaho Chapter of NHF
208-351-4785, idahoblood.org
Hemophilia Walk
Kleiner Park; Meridian

OCT. 14, 2017 KENTUCKY
Kentucky Hemophilia Foundation
502-456-3233, kyhemo.org
Kentucky NHF Annual Walk
Wetherby Park; Middletown

OCT. 14, 2017 NEW JERSEY
Hemophilia Assoc. of New Jersey
732-249-6000, hanj.org
Casino Night, Pines Manor; Edison

OCT. 14, 2017 NORTH CAROLINA
Hemophilia of North Carolina
800-990-5557, hemophilia-nc.org
Family Festival & 5K Walk for Bleeding Disorders
Lake Crabtree County Park; Morrisville

OCT. 14, 2017 TENNESSEE
TN Hemophilia Bleeding Disorders Found., 615-900-1486, thbdf.org
Fall Festival, Shelby Farms; Memphis

OCT. 14, 2017 VIRGINIA / DC
Hemophilia Assoc. of the Capital Area
703-352-7641, hacacares.org
Fall Festival and Walk
Lake Accotink Park; Springfield

OCT. 14-15, 2017 CONNECTICUT
New England Hemophilia Association
781-326-7645,
newenglandhemophilia.org
Fallfest
Hartford Marriott Downtown

OCT. 16, 2017 CALIFORNIA
Hemophilia Found. of So. California
626-765-6656, hemosocal.org
34th Annual Gerry Green Memorial Golf and Tennis Tournament
La Canada Flintridge Country Club

OCT. 20, 2017 ILLINOIS
Bleeding Disorder Alliance Illinois
312-427-1495, bdai.org
Autumn Wine Auction and Dinner
Columbia Yacht Club; Chicago

OCT. 20, 2017 PENNSYLVANIA
Eastern Pennsylvania Chapter of NHF
484-445-4282
hemophiliasupport.org
An Evening of Wine and Beer Tasting
Crossing Vineyards and Winery
Newtown

OCT. 20-22, 2017 CALIFORNIA
Central California Hemophilia Found.
916-448-0370
www.cchfsac.org
Women's Symposium
Embassy Suites; Sacramento

OCT. 21, 2017 INDIANA
Hemophilia of Indiana
317-570-0039, hoii.org
Mystery Bus Tour, Indianapolis

OCT. 21, 2017 OHIO
Tri State Bleeding Disorder Found.
513-961-4366, tsbdf.com
Family Day at Cincinnati Zoo
Cincinnati Zoo

OCT. 21, 2017 WEST VIRGINIA
West Virginia Chapter of NHF
681-212-9255, wvnhf.org
Hemophilia Walk
Waterfront Place Hotel/Marriott
Morgantown

OCT. 22, 2017 KANSAS
Midwest Hemophilia Association
816-479-5900
midwesthemophilia.org
Game On
KC Pumpkin Patch; Olathe

OCT. 22, 2017 TEXAS
Texas Central Hemophilia Found.
972-386-3865, texcen.org
Bloody Fun Marathon and Walk
Cedar Hill State Park; Cedar Hill

OCT. 28, 2017 ARIZONA
Arizona Hemophilia Association
602-955-3947
arizonahemophilia.org
Arizona Zombie Walk
Phoenix Zoo

OCT. 28, 2017 VIRGINIA
Virginia Hemophilia Foundation
804-740-8643, vahemophilia.org
Trick or Trot 5K Monster Dash
Robious Landing Park; Midlothian

OCT. 28, 2017 FLORIDA
Hemophilia Found. of Greater Florida
800-293-6527, hemophiliaflorida.org
Orlando Creepy Crawl 5K & Fun Walk
Harbor Park; Orlando

OCT. 29, 2017 PENNSYLVANIA
Eastern Pennsylvania Chapter of NHF
484-445-4282
hemophiliasupport.org
Adventures in Learning
Warehouse Hotel at the Nook
Manheim

NOV. 3-5, 2017 MARYLAND
Hemophilia Foundation of Maryland
410-661-2307, hfmonline.org
Family Weekend
Hyatt Chesapeake Bay
Cambridge

NOV. 4, 2017 CALIFORNIA
Hemophilia Found. of So. California
626-765-6656, hemosocal.org
Annual Bleeding Disorders Walk
Griffith Park; Los Angeles

NOV. 4, 2017 NEW YORK
Bleeding Disorders Association of Northeastern New York
518-729-3577, bdaneny.org
Annual Meeting, Great Escape Lodge and Water Park; Queensbury

NOV. 5, 2017 ARIZONA
Arizona Hemophilia Association
602-955-3947, arizonahemophilia.org
Arizona Hemophilia Walk
Phoenix Zoo; Phoenix

NOV. 8, 2017 OHIO
Central Ohio Chapter of NHF
614-985-3752, nhfcentralohio.org
Der Dutchman Annual Dinner
Der Dutchman Restaurant; Plain City

NOV. 9-11, 2017 FLORIDA
FL Assoc. of Pediatric Tumor Programs
813-396-9528, faptp.epi.usf.edu
40th Annual Advances in Pediatric Hematology/Oncology
TradeWinds Island Resort
St. Pete Beach

NOV. 10, 2017 TENNESSEE
TN Hemophilia Bleeding Disorders Found., 615-900-1486, thbdf.org
Royal Gala, Loveless Barn; Nashville

NOV. 10-12, 2017 NEW MEXICO
Sangre De Oro Hemophilia Found.
505-341-9321, sangredeoro.org
Patient & Family Education Weekend
Crown Plaza; Albuquerque

NOV. 11, 2017 ILLINOIS
Bleeding Disorder Alliance Illinois
312-427-1495, bdai.org
Celebrating Hispanic Heritage Month
Ntl. Museum of Mexican Art; Chicago

NOV. 11, 2017 PENNSYLVANIA
Eastern Pennsylvania Chapter of NHF
484-445-4282, hemophiliasupport.org
Turkey Trot 5K Run/Walk
Lancaster City Bible Church; Manheim

NOV. 13, 2017 FLORIDA
Florida Hemophilia Association
305-235-0717, floridahemophilia.org
Swing for the Kids
Lago Mar Country Club
Ft. Lauderdale

NOV. 15, 2017 CALIFORNIA
Hemophilia Found. of No. California
510-658-3324, hemofoundation.org
HFNC Volunteer Orientation
Chapter Office; Emeryville

NOV. 17-18, 2017 WEST VIRGINIA
West Virginia Chapter of NHF
681-212-9255, wvnhf.org
Annual Meeting
Stonewall Resort; Roanoke

NOV. 19, 2017 NEW YORK
New York City Hemophilia Chapter
212-382-2974, nyhemophilia.org
Education Day
Crowne Plaza Times Square; NYC

NOV. 23, 2017 INDIANA
Hemophilia of Indiana
317-570-0039, hoii.org
Thanksgiving Day Run
Dillon Park; Noblesville

DEC. 1, 2017 ARIZONA
Arizona Hemophilia Association
602-955-3947, arizonahemophilia.org
Arizona Golf Tournament
Wigwam Golf Club; Litchfield Park

DEC. 2, 2017 CALIFORNIA
Central California Hemophilia Found.
916-448-0370, hemophilia.org
Holiday Party
Gibbons Park; Sacramento

DEC. 2, 2017 PENNSYLVANIA
Eastern Pennsylvania Chapter of NHF
484-945-4282
hemophiliasupport.org
Holiday Party
Canstatter Volksfest Verein
Philadelphia

DEC. 2-3, 2017 MAINE
Hemophilia Alliance of Maine
207-631-7550, mainehemophilia.org
Winterfest
Samoset Resort; Rockland

DEC. 3, 2017 KENTUCKY
Kentucky Hemophilia Foundation
502-456-3233, kyhemo.org
Holiday/Year-End Family Event
Clifton Center; Louisville

DEC. 3, 2017 NEVADA
NHF Nevada Chapter
702-564-4368, hfnv.org
Family Conf. & Holiday Celebration
Henderson Convention Center
Henderson

DEC. 3, 2017 VIRGINIA
Hemophilia Assoc. of the Capital Area
703-352-764, hacacares.org
Holiday Gathering
Falls Church Community Center

DEC. 6, 2017 NEVADA
NHF Nevada Chapter
702-564-4368, hfnv.org
Elko Family Day and Winter Celebration
Hilton Garden Inn; Elko

DEC. 6, 2017 TEXAS
Lone Star Chapter of the NHF
713-686-6100, lonestarhemophilia.org
Winter Education Event
Marriott Plaza Hotel; San Antonio

DEC. 7, 2017 TEXAS
Lone Star Chapter of the NHF
713-686-6100, lonestarhemophilia.org
Winter Education Event
Embassy Suites Arboretum; Austin

DEC. 9, 2017 CALIFORNIA
Hemophilia Found. of So. California
626-765-6656, hemosocal.org
Snowflake Festival
Santa Ana Zoo

DEC. 9, 2017 ILLINOIS
Bleeding Disorder Alliance Illinois
312-427-1495, bdai.org
Holiday Party
William Tell Holiday Inn; Countryside

DEC. 9, 2017 OHIO
Northern Ohio Hemophilia Found.
216-834-0051, nohf.org
Holiday Event
Cleveland Zoo Primate Building

DEC. 9, 2017 TEXAS
Texas Central Hemophilia Found.
972-386-3865, texcen.org
Family Education Day
Southfork Ranch; Parker

DEC. 10, 2017 TEXAS
Lone Star Chapter of the NHF
713-686-6100
lonestarhemophilia.org
Winter Education Event
Doubletree Suites; McAllen

DEC. 16, 2017 TEXAS
Lone Star Chapter of the NHF
713-686-6100
lonestarhemophilia.org
Winter Education Event
Sugarland Marriott; Houston

A MOMENT IN YOUR SPECTACULAR LIFE 2018 CALENDAR!

Our 2018 Spectacular calendar highlights just how amazing life can be, even with a bleeding disorder! It will soon be available just for the asking - provide us with your name and address and we will be happy to send our special calendar to you free of charge!

Interested in obtaining a calendar? Just do one of the following:

- Contact your Regional Care Coordinator
- Visit www.matrixhealthgroup.com
- Email your request to Maria Vetter maria.vetter@matrixhealthgroup.com
- Call our Corporate Office: toll free 877-337-3002
- Mail your request to: Matrix Health Group Calendar 3300 Corporate Ave., Ste. 100; Weston, FL 33331

THE GREAT AMERICAN ECLIPSE

On August 21, 2017, the United States experienced a historic siting, a total solar eclipse, also referred to as the Great American Eclipse. A total solar eclipse occurs when the Moon covers the face of the Sun as seen from Earth.

The eclipse passed from the Pacific to the Atlantic coasts covering the continental United States. With special glasses in hand, BioMatrix employees took a break from their busy schedules to witness the historic event.

If you missed it, fret not. The next solar eclipse for North America will come in April of 2024...so get ready!

ANSWERS TO PUZZLES ON PAGE 55.

ACROSS:

4. Bandage
5. Tourniquet
6. Infusion
7. Tape
13. Hemophilia
14. Huber
16. Royal
17. Syringe
18. vWD

DOWN

1. Gauze pad
2. Saline
3. Butterfly
8. Alcohol
9. Prophy
10. Sharps
11. Christmas
12. Factor
15. Bleed

6	9	1	3	2	4	8	5	7
3	2	7	8	5	6	9	1	4
5	4	8	7	9	1	6	2	3
7	6	5	1	4	8	2	3	9
9	3	4	6	7	2	1	8	5
1	8	2	5	3	9	4	7	6
2	1	3	4	6	7	5	9	8
4	7	9	2	8	5	3	6	1
8	5	6	9	1	3	7	4	2

5	3	9	6	1	8	7	4	2
2	6	8	9	4	7	1	5	3
7	4	1	3	2	5	8	6	9
8	9	6	1	5	4	2	3	7
3	1	5	7	9	2	6	8	4
4	7	2	8	6	3	9	1	5
6	8	4	2	3	9	5	7	1
9	5	7	4	8	1	3	2	6
1	2	3	5	7	6	4	9	8

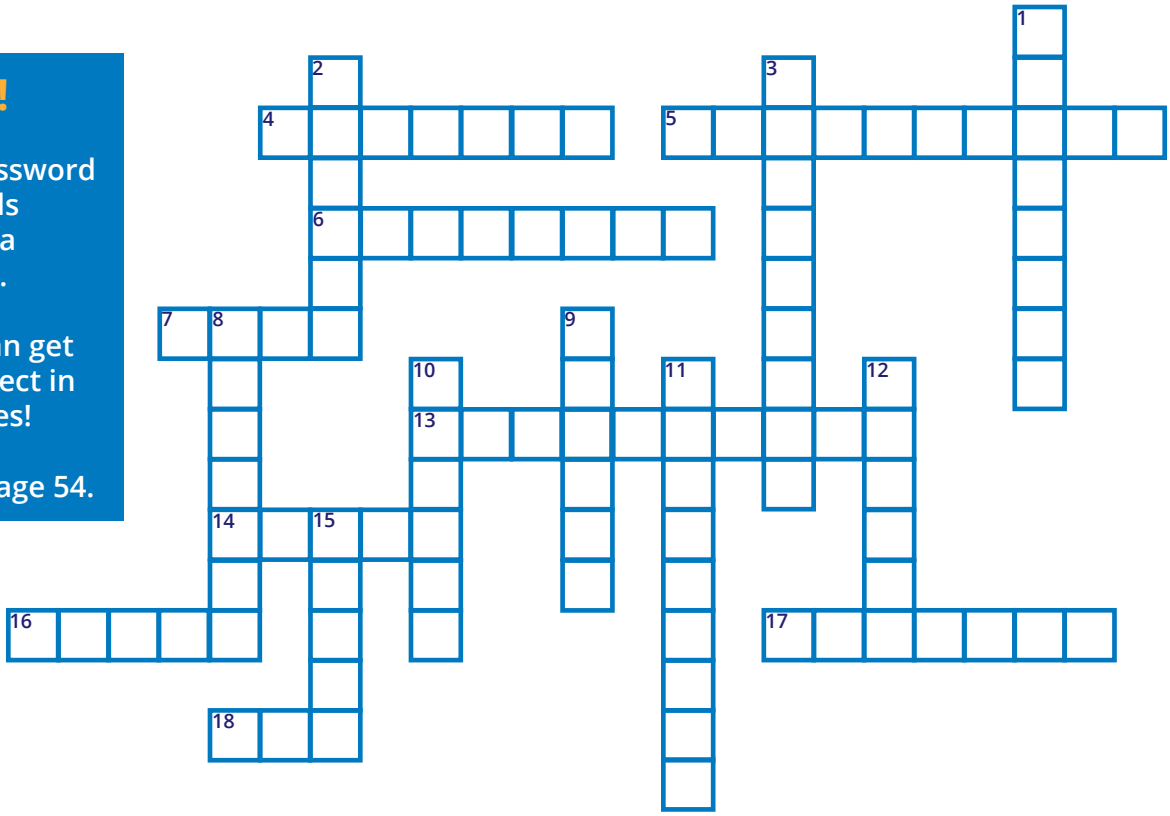
TIME FOR FUN!

HI KIDS!

Complete the crossword puzzle using words related to having a bleeding disorder.

Then see if you can get the numbers correct in the Sudoku puzzles!

Answers are on page 54.



ACROSS

4. Used to add compression to a joint bleed
5. Stretchy band used to help veins pop up
6. The process of getting factor into your body
7. A flexible strip to hold down a gauze pad
13. A male-dominated bleeding disorder
14. Type of needle used to infuse with a port
16. Hemophilia was once called The _____ Disease
17. A tube used to hold the mixed factor
18. Bleeding disorder equally affecting males & females

DOWN

1. A small square pad of cotton cloth (2 words)
2. Sterile water that is mixed with factor
3. A type of infusion needle
8. Type of disinfectant
9. Infusing on a regular basis
10. A special box used to throw away needles
11. Another name for Factor 9 hemophilia
12. Blood clotting medicine
15. Factor is used to treat a _____

			6	1			4	2
2	6					1		3
		1			5			
		6			4		3	7
		5	7		2	6		
4	7		8			9		
			2			5		
9		7				3		6
1	2			7	6			

Sudoku!

Fill in the grid so every row, every column, and every 9 by 9 box contains the numbers 1 through 9.

6				2			5	7
		7		5				4
	4	8		9			2	
7		5			8	2		
	3		6		2		8	
		2	5			4		
	1			6		5	9	
4			2		5	3		
8	5			1	3			2

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DEDICATED TO MAKING A DIFFERENCE

Matrix Health Group values your privacy. We are committed to keeping your information secure and confidential. We take your privacy very seriously by complying fully with HIPAA regulations and employing a team of IT experts whose job is to keep our data safe and secure. Our mailing list is private and will never be sold or shared with a third party. If you have any questions or would like to review our Privacy Policy, please contact our corporate office 877-337-3002.

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Fax: 805-482-6324

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Bartlett, TN 38133
Toll Free: 800-962-6339
Office: 901-380-5899
Fax: 866-755-6339

BiologicTx

40-D Commerce Way
Totowa, NJ 07512
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Office: 973-774-0954
Fax: 877-567-8089