

THE FACTORNET

Bleeding Disorders Alliance Illinois

Quarterly Newsletter | Fall 2023



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- NHF has a new name
- Celebrating Camp Warren Jyrch after 50 years

Destacado en este número

- NHF tiene un nuevo nombre
- Celebrando el Campamento Warren Jyrch después de 50 años



NATIONAL
BLEEDING DISORDERS
FOUNDATION
Formerly NHF

A MESSAGE FROM THE EXECUTIVE DIRECTOR



Happy summer! If I haven't had a chance to meet you yet, I'm Kent Sheldon, the new executive director for BDAI. I am very excited to get to know you all and to make a difference in our community. My vision for BDAI is to inform, educate, and connect those in need with resources. My hope is that having strong resources will provide the necessary material needed to make informed decisions. In addition to providing valuable resources, we are continuing our work with partners in the industry to provide education about the newest and most innovative treatments available.

While still new in position, I have had the privilege of meeting several individuals. This experience has been both fulfilling and humbling. I am grateful for the welcoming, informative, and supportive community members that I have connected with, and my excitement grows with each person I meet.

Perhaps one of the most important goals for BDAI is to further our involvement and support in this remarkable community. To support this goal, we are committed to creating new opportunities for fun and awareness. Some initiatives that will be included in this new effort include, but are not limited to, fitness fun for all ages, reliable mental health resources, and a place to celebrate each other's company.

I am really looking forward to our upcoming walk - joining hands and supporting each other is one of the best ways to foster an uplifting atmosphere!

As we move forward, our endeavors to advocate, listen, and understand will continue to be a staple of what BDAI is all about. Our work will continue to reflect the strong and inspiring individuals in the community. I am energized and optimistic about the opportunities that BDAI has, and I cannot wait to connect with more individuals in this community. I believe that your experiences and active participation coupled with advancing technologies in treatment will help us develop solutions to any new challenge that comes our way. We are so excited for the possibilities that the future will bring!

Thank you all for the warm welcome! The support and thoughtfulness of every single person has been touching, and I cannot express my gratitude enough.

"Perhaps one of the most important goals for BDAI is to further our involvement and support in this remarkable community."

UN MENSAJE DE EL DIRECTOR EJECUTIVO

¡Feliz verano! Si aún no he tenido la oportunidad de conocerte, soy Kent Sheldon, el nuevo director ejecutivo de BDAI. Estoy muy emocionado de conocerlos a todos y marcar la diferencia en nuestra comunidad. Mi visión para BDAI es informar, educar y conectar a quienes lo necesitan con recursos. Mi esperanza es que contar con recursos sólidos proporcione el material necesario para tomar decisiones informadas. Además de brindar recursos valiosos, continuamos nuestro trabajo con los socios de la industria para brindar educación sobre los tratamientos más nuevos e innovadores disponibles.

Aunque todavía soy nuevo en el puesto, he tenido el privilegio de conocer a varias personas. Esta experiencia ha sido satisfactoria y a la vez de humildad. Estoy agradecido por los acogedores, informativos y comprensivos miembros de la comunidad con los que me he conectado, y mi entusiasmo crece con cada persona que conozco.

Quizás uno de los objetivos más importantes de BDAI sea aumentar nuestra participación y apoyo en esta extraordinaria comunidad. Para apoyar este objetivo, nos comprometemos a crear nuevas oportunidades de diversión y concientización. Algunas iniciativas que se incluirán en este nuevo esfuerzo incluyen, entre otras, diversión física para todas las edades, recursos confiables de salud mental y un lugar para celebrar la compañía de los demás.

Tengo muchas ganas de que llegue nuestra próxima caminata: ¡unirnos de la mano y apoyarnos mutuamente es una de las mejores maneras de fomentar una atmósfera edificante!

A medida que avancemos, nuestros esfuerzos por defender, escuchar y comprender seguirán siendo un elemento básico de lo que representa BDAI. Nuestro trabajo seguirá reflejando a las personas fuertes e inspiradoras de la comunidad. Estoy lleno de energía y optimismo acerca de las oportunidades que tiene BDAI y no puedo esperar para conectarme con más personas en esta comunidad. Creo que sus experiencias y participación activa, junto con el avance de las tecnologías en el tratamiento, nos ayudarán a desarrollar soluciones para cualquier nuevo desafío que se nos presente. ¡Estamos muy emocionados por las posibilidades que traerá el futuro!

¡Gracias a todos por la calurosa bienvenida! El apoyo y la consideración de cada persona han sido conmovedores y no puedo expresar mi gratitud lo suficiente.

Kent Sheldon
Executive Director, BDAI

"Quizás uno de los objetivos más importantes de BDAI sea aumentar nuestra participación y apoyo en esta extraordinaria comunidad."



Lisa Boggio, MD
Adult hematologist

Mindy Simpson, MD
Pediatric hematologist

Our team will help you and your child pursue full, active lives

If you or your child have a blood disorder, we'll help you understand your condition and manage it. Our comprehensive clinic provides the support, care and tools you need to prevent complications and live a full life. You'll have access to all the medical, psychological, social and supportive services you need, including:

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- Social and emotional support
- Genetic testing and counseling
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- Cutting edge research and clinical trials



To learn more or make an appointment, contact our hemophilia and thrombophilia care team at (312) 942-3034.



BDAI

Bleeding Disorders Alliance Illinois
210 S. DesPlaines St., Chicago, IL 60661
bdai.org | 312.427.1495

Mission:

Bleeding Disorders Alliance Illinois (BDAI) exists to improve the quality of life for the inherited bleeding disorders community by supporting individuals and their families with unbiased information and providing them the resources that allow them to live healthy and active lives.

Misión:

Bleeding Disorders Alliance Illinois (BDAI) existe para mejorar la calidad de vida de la comunidad con trastornos hemorrágicos hereditarios apoyando a las personas y sus familias con información imparcial y proporcionándoles los recursos que les permitan vivir una vida sana y activa.

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BDAI- Present and Future

Change is in the air. NHF is how the NBDF. Their mission stays the same as it should but is now inclusive of all Bleeding Disorders bringing the entire community together.

Transition- The hardest part is over. Strong foundation, Great Leadership, People. Having clear and decisive goals for 2024.

What Now? Operational and Financial focus. More Diverse Programming with a focus on all age groups including Programming for downstate Illinois.

Programming and education that is Inclusive to all different types of Bleeding Disorders and Community members.

Fundraising, Advocacy, and Volunteer opportunities for all in the community that would like to participate.

Events that encourage socializing, sharing, and building relationships.

From Executive Director Kent Sheldon's address at the Annual Meeting.

ANNUAL MEETING VISION

"If you change the way you look at things, the things you look at change." –Wayne Dyer

Bleeding Disorders Alliance Illinois has a strong chapter footprint and foundation. Recently there have been some pretty important changes as the national community strives to create a more inclusive environment. These changes began with the National Hemophilia Foundation changing its name to the National Bleeding Disorders Foundation.

BDAI has been innovative and proactive when it comes to inclusivity. We were the first chapter, established in 1949. Proudly serving Illinois for almost 75 years, we are working to bring even more change in 2024. The current core focus on growth encompasses evidence-based programs, educational resources, and support and advocacy for our community. BDAI will challenge the status quo and look for the best partnerships.

Camp Warren Jyrch is one of the oldest bleeding disorders camps in the nation. In the future, camp will continue to evolve in to new heights. Advocacy, fitness, and mental health are key components that are being incorporated alongside networking and social gatherings for all ages.

With 2024 being BDAI's 75th anniversary, as an organization we aim to get back to our roots and the core of what this organization was founded on. Our goals include increased communication, well planned and organized events, and a focus on the youth of the community by honing in on acknowledging those that came before. We have a history! Progress beyond our current 74 years is of the upmost importance. 2024 will start a new and broader journey, bringing together all those with bleeding disorders to be united, to be strong, and to be heard!

VISIÓN DE LA REUNIÓN ANUAL

"Si cambias tu forma de ver las cosas, las cosas que miras cambian." –Wayne Dyer

Bleeding Disorders Alliance Illinois tiene una sólida base y huella de capítulo. Recientemente ha habido algunos cambios bastante importantes a medida que la comunidad nacional se esfuerza por crear un entorno más inclusivo. Estos cambios comenzaron cuando la Fundación Nacional de Hemofilia cambió su nombre a Fundación Nacional de Trastornos de la Sangrado.



BDAI ha sido innovadora y proactiva en lo que respecta a la inclusión. Fuimos el primer capítulo, establecido en 1949. Orgullosamente sirviendo a Illinois durante casi 75 años, estamos trabajando para lograr aún más cambios en 2024. El enfoque central actual en el crecimiento abarca programas basados en evidencia, recursos educativos apoyo, y defensa de nuestra comunidad. BDAI desafiará el "status quo" y buscará las mejores asociaciones.

Camp Warren Jyrch es uno de los campamentos más antiguos del país. En el futuro, el campamento seguirá evolucionando hacia nuevas alturas. La promoción, salud física, y la salud mental son componentes clave que se están incorporando junto con el conecciones y las reuniones sociales para todas las edades.

Dado que en el 2024 es el 75.º aniversario de BDAI, como organización nuestro objetivo es volver a nuestras raíces y al núcleo sobre el que se fundó esta organización. Nuestros objetivos incluyen una mayor comunicación, eventos bien planificados y organizados, y un enfoque en los jóvenes de la comunidad al concentrarnos en reconocer a los que llegaron antes. ¡Tenemos una historia! El progreso más allá de los 74 años actuales es de suma importancia. ¡El año 2024 iniciará un viaje nuevo y más amplio que reunirá a todas aquellas personas con trastornos de la coagulación para estar unidos, ser fuertes y ser escuchados!



SPECIAL THANKS TO OUR DONORS

BDAI gratefully acknowledged our generous donors and sponsors, without whom we could not sustain programming or fulfill our mission. The list below reflects contributions from May 18, 2023 through August 31, 2023.

We do our best to ensure everyone is acknowledged. If you have inadvertently been omitted or your name is listed incorrectly, please contact the BDAI office. Thank you for your understanding

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UN AGRADECIMIENTO ESPECIAL A NUESTROS DONANTES

BDAI agradeció a nuestros generosos donantes y patrocinadores, sin los cuales no podríamos sostener la programación ni cumplir nuestra misión. La siguiente lista refleja las contribuciones desde el 18 de mayo hasta el 31 de agosto de 2023.

Hacemos nuestro mejor esfuerzo para garantizar que todos sean reconocidos. Si lo han omitido inadvertidamente o su nombre aparece incorrectamente, comuníquese con la oficina de BDAI. Gracias por su comprensión.

Dyrella Star Lathan
Dani Macino
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Jodi Zuckerman and Marc Wielansky
Susie Wexler
Melanie Zamora

Your generous gift helps BDAI provide not only educational programming, advocacy, and funding for research but essential care for community members in need. Please consider a gift today. Visit bdai.org or contact the office at 312.427.1495 to make a donation.

Tu generosa donación ayuda a BDAI no solo proporciona programación educativa, promoción y financiación para la investigación, sino también atención esencial para los miembros de la comunidad que lo necesitan. Por favor considere un regalo hoy. Visite bdai.org o comuníquese con la oficina al 312.427.1495 para hacer una donación.



NHF IS NOW NBDF

We at BDAI are very proud to announce the recent name change from National Hemophilia Foundation (NHF) to National Bleeding Disorders Foundation (NBDF)! While NBDF has always supported, educated, and advocated for all types of bleeding disorders, this name change is significant as now all those affected by a bleeding disorder are represented in the title. The whole community can unite in celebrating this change.

BDAI is also working to develop programs that address issues with all those affected by a bleeding disorder. Embracing change and moving to find better ways to educate, develop, advocate, and bring our community together are essential components of our community and organization. We applaud NBDF for listening and acting upon this for the whole community.

The follow is a release by NBDF on how the name change came to be and why:

NHF is now the National Bleeding Disorders Foundation (NBDF)

Because of our longstanding name, the National Hemophilia Foundation is best known for helping people with hemophilia and also for serving the individuals and professionals who care for that community.

However, in the foundation's many decades, we have also long served those facing other blood and bleeding disorders such as von Willebrand disease, rare factor deficiencies, platelet disorders, and more. Over the past 75 years, our



NATIONAL
BLEEDING DISORDERS
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Innovate | Educate | Advocate

NHF AHORA ES NBDF

¡En BDAI estamos muy orgullosos de anunciar el reciente cambio de nombre de National Hemophilia Foundation (NHF) a National Bleeding Disorders Foundation (NBDF)! Si bien NBDF siempre ha apoyado, educado y abogado por todos los tipos de trastornos hemorrágicos, este cambio de nombre es significativo ya que ahora todos los afectados por un trastorno hemorrágico están representados en el título. Toda la comunidad puede unirse para celebrar este cambio.

BDAI también está trabajando para desarrollar programas que aborden problemas con todos los afectados por un trastorno hemorrágico. Aceptar el cambio y avanzar para encontrar mejores maneras de educar, desarrollar, defender y unir a nuestra comunidad son componentes esenciales de nuestra comunidad y organización. Aplaudimos a NBDF por escuchar y actuar en consecuencia para toda la comunidad.

El siguiente es un comunicado de NBDF sobre cómo se produjo el cambio de nombre y por qué:

NHF es ahora la Fundación Nacional de Trastornos de la Hemorragia (NBDF)

Debido a nuestro nombre que se ha mantenido por mucho tiempo, la Fundación Nacional de Hemofilia es mejor conocida por ayudar a las personas con hemofilia y también por servir a las personas y profesionales que cuidan de esa comunidad.

Sin embargo, durante las muchas décadas de la fundación, también hemos atendido durante mucho tiempo a quienes enfrentan otros trastornos sanguíneos y hemorrágicos, como la enfermedad de von Willebrand, deficiencias

powerful combination of research, education, and advocacy has improved the lives of people and families with a range of conditions – yet our name and image has not reflected that.

Now, as the National Bleeding Disorders Foundation (NBDF), we can be more inclusive of everyone we serve. Although hemophilia remains a major focus, our name ensures that all people with VWD and rare and ultra-rare deficiencies know that they can find a home within NBDF.

Although we're adopting a new name and a new look, our work will not change in the short term. We remain dedicated to supporting our network of over 50 chapters across the country and channeling funds into blood and bleeding disorders research. We will continue to educate and support families with these disorders as we work tirelessly to protect access to health care on the state and local level.

Over the long term, our new name will challenge us to explore how we can harness our resources and networks to help people facing other blood and bleeding disorders – because after all, bleeding disorders are blood disorders. In the same way that the National Hemophilia Foundation evolved to help people facing blood and bleeding disorders beside hemophilia, we can evolve once again to assist more families in need. Many rare blood and bleeding disorders don't have a national support and advocacy network like ours—and together we have a historic opportunity to change that.

As the National Bleeding Disorders Foundation, we will use our longtime legacy to inspire a future where even more people have access to the treatments and support they need to thrive. We will remain true to our core vision while raising awareness, expanding reach, and continuing to build upon 75 years of history, hope, and progress.

de factores raros, trastornos plaquetarios y más. Durante los últimos 75 años, nuestra poderosa combinación de investigación, educación y defensa ha mejorado las vidas de personas y familias con una variedad de condiciones; sin embargo, nuestro nombre e imagen no lo han reflejado.

Ahora, como Fundación Nacional de Trastornos de la Sangrado (NBDF), podemos incluir más a todas las personas a las que servimos. Aunque la hemofilia sigue siendo un foco importante, nuestro nombre garantiza que todas las personas con EvW y deficiencias raras y ultrararas sepan que pueden encontrar un hogar dentro de NBDF.

Aunque adoptamos un nuevo nombre y una nueva apariencia, nuestro trabajo no cambiará en el corto plazo. Seguimos dedicados a apoyar nuestra red de más de 50 capítulos en todo el país y canalizar fondos hacia la investigación de la sangre y los trastornos hemorrágicos. Continuaremos educando y apoyando a las familias con estos trastornos mientras trabajamos incansablemente para proteger el acceso a la atención médica a nivel estatal y local.

A largo plazo, nuestro nuevo nombre nos desafiará a explorar cómo podemos aprovechar nuestros recursos y redes para ayudar a las personas que enfrentan otros trastornos sanguíneos y hemorrágicos, porque después de todo, los trastornos hemorrágicos son trastornos sanguíneos. De la misma manera que la Fundación Nacional de Hemofilia evolucionó para ayudar a las personas que enfrentan trastornos sanguíneos y hemorrágicos además de la hemofilia, podemos evolucionar una vez más para ayudar a más familias necesitadas. Muchos trastornos sanguíneos y hemorrágicos raros no cuentan con una red nacional de apoyo—y defensa como la nuestra, y juntos tenemos una oportunidad histórica de cambiar eso.

Como Fundación Nacional de Trastornos de la Coagulación, utilizaremos nuestro legado que se ha mantenido por mucho tiempo para inspirar un futuro en el que aún más personas tengan acceso a los tratamientos y el apoyo que necesitan para prosperar. Nos mantendremos fieles a nuestra visión central mientras creamos conciencia, ampliamos el alcance y continuamos construyendo sobre 75 años de historia, esperanza y progreso.



A few of the BDAI members who were at BDC: Kent Sheldon, Lily Schwartz, Lucy Ramirez, Maria Herrera, and the DePaz and Schwartz-Newton families.



My Factor Fam

My Factor Fam is the first email program of its kind, dedicated to meeting the unique needs of people using or thinking about using factor to manage a bleeding disorder.

This is a tailored experience developed with input from patients, caregivers, and supporters in the bleeding disorders community.

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MARCH IS NATIONAL BLEEDING DISORDER AWARENESS MONTH

Over three million people in the United States are affected by bleeding disorders. BCDI invites you to join the conversation around issues and experiences related to bleeding disorders.



Dr. Jonathan Roberts
Associate Medical Director/
Associate Research Director

Dr. Michael Tarantino
Chief Medical Officer/
Chief Executive Officer

Dr. Maria Espanol
Staff Hematologist

thebloodexperts.org
309.692.5337

BCDI serves over 7,000 patients, with ten outreach clinics across Illinois.

Arthur
HSHS St. Mary's Hospital Building
525 N. Vine St.
Arthur, IL 61911

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1405 W Park St., Suite 306
Urbana, IL 61820

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320 E. Central Ave.
Decatur, IL 62521

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Medical Arts Building
527 E. Grant St.
Macomb, IL 61455

Moline
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515 Valley View Drive
Moline, IL 61265

Ottawa
Fox River Cancer Center
1200 Starfire Dr.
Ottawa, IL 61350

Peoria
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CAMP WARREN JYRCH CELEBRATES 50 YEARS!

JOHN THORSON, LONG-TIME CAMP VOLUNTEER

Bleeding Disorders Alliance Illinois Camp Warren Jyrch (CWJ) is celebrating a golden anniversary! Fifty years of summer camp began in 1973, when the Illinois chapter went by the name of Hemophilia Foundation of Illinois. The camp was named to honor Warren C. Jyrch (1921-1971) of Chicago, the first person with hemophilia to attempt - and survive - open-heart surgery to replace a valve. The surgery was extremely risky, with 2400 pints of blood used during the operation.

Through the years, there have been a lot of changes, but many things have remained constant. One area that has improved vastly in the past 50 years is the variety of treatment options. Back then, patients spent a significant time in hospitals recovering from bleeding episodes and orthopedic issues. They missed a lot of school and opportunities to bond with other kids. For some young patients, their primary friendships were with hospital staff.



Today's medical advancements and treatment options allow kids with a bleeding disorder to rarely miss school. Most often, they can participate in all sorts of physical activities like rock climbing, cycling, and running and sports such as baseball, basketball, and volleyball, to name just a few.

Fifty years ago, communication with affected families was through a tethered phone line or a stamped letter. It wasn't always easy to make announcements about camp or request information from families. Even getting to camp involved maps and directions rather than an address easily plugged into a GPS. Today our ability to communicate is instant and helps offer a more positive outlook on managing a bleeding disorder.

In those times, only boys were thought to have hemophilia. Girls were not invited to camp. Siblings weren't invited either. Today we have a better understanding of how girls are affected by bleeding disorders, especially as being more than just carriers, and are now included. We also better understand how a bleeding disorder diagnosis affects the whole family, so siblings are also invited to share the camp experience.

Despite the challenges of those days, it was deemed important enough to gather this group of young patients for a week every summer with the purpose of socializing, bonding, and feeling less isolated with their medical conditions while encompassing a safe and fun environment, encouraging peer relationships, and increasing self-confidence and independence, so CWJ was started.

Over the years, we have learned to overcome obstacles and have adapted to and implemented many changes. Plenty of education has been added - kids learn about managing their disorder, and camp is where many first learn to self-infuse.

The first time I volunteered at camp was in 2009. I wanted to bring energy and inspiration and be a mentor. I also wanted to gain an understanding of what kids with a bleeding disorder deal with and why camp is so magical to them. By offering a safe environment and gentle suggestions, camp helps kids *(continued on page 14)*



¡CAMP WARREN JYRCH CELEBRA 50 AÑOS!

JOHN THORSON, VOLUNTARIO DEL CAMPAMENTO DESDE HACE MUCHO TIEMPO

¡El Campamento Warren Jyrch (CWJ) de Illinois de la Alianza de Trastornos Hemorrágicos está celebrando un aniversario de oro! Cincuenta años de campamento de verano comenzaron en 1973, cuando el capítulo de Illinois pasó a llamarse Fundación de Hemofilia de Illinois. El campamento recibió su nombre en honor a Warren C. Jyrch (1921-1971) de Chicago, la primera persona con hemofilia que intentó (y sobrevivió) una cirugía a corazón abierto para reemplazar una válvula. La cirugía fue extremadamente arriesgada, ya que se utilizaron 1364 litros de sangre durante la operación.

A lo largo de los años ha habido muchos cambios, pero muchas cosas se han mantenido constantes. Un área que ha mejorado enormemente en los últimos 50 años es la variedad de opciones de tratamiento. En aquel entonces, los



pacientes pasaban mucho tiempo en los hospitales recuperándose de episodios de hemorragia y problemas ortopédicos. Perdieron mucha escuela y oportunidades de vincularse con otros niños. Para algunos pacientes jóvenes, sus amistades principales eran con el personal del hospital.

Los avances médicos y las opciones de tratamiento actuales permiten que los niños con un trastorno hemorrágico rara vez falten a la escuela. En la mayoría de los casos, pueden participar en todo tipo de actividades físicas como escalar, ciclismo y correr, y deportes como el béisbol, baloncesto y voleibol, por nombrar sólo algunos.

Hace cincuenta años, la comunicación con las familias afectadas se realizaba a través de una línea telefónica fija o una carta estampada. No siempre fue fácil hacer anuncios sobre el campamento o solicitar información a las familias. Incluso llegar al campamento implicaba mapas e indicaciones en lugar de una dirección que se pudiera conectar fácilmente a un GPS. Hoy nuestra capacidad de comunicarnos es instantánea y ayuda a ofrecer una perspectiva

más positiva sobre el manejo de un trastorno hemorrágico.

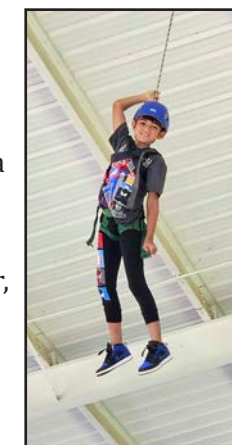
En aquella época, se pensaba que sólo los niños tenían hemofilia. No se invitó a las niñas al campamento. Los hermanos tampoco fueron invitados. Hoy entendemos mejor cómo las niñas se ven afectadas por los trastornos de la coagulación, especialmente porque son más que simples portadoras, y ahora están incluidas. También entendemos mejor cómo un diagnóstico de trastorno hemorrágico afecta a toda la familia, por lo que también se invita a los hermanos a compartir la experiencia del campamento.

A pesar de los desafíos de aquellos días, se consideró lo suficientemente importante reunir a este grupo de pacientes jóvenes durante una semana cada verano con el propósito de socializar, crear vínculos y sentirse menos aislados con sus condiciones médicas, al mismo tiempo que abarcaban un ambiente seguro y divertido, fomentando el intercambio de relaciones entre compañeros y aumentar la confianza en uno mismo y la independencia, así se fundó CWJ.



A lo largo de los años, hemos aprendido a superar obstáculos y nos hemos adaptado e implementado muchos cambios. Se ha agregado mucha educación: los niños aprenden a controlar su trastorno y en el campamento es donde muchos aprenden por primera vez a auto-infundirse.

La primera vez que fui voluntaria en el campamento fue en 2009. Quería aportar energía e inspiración y ser una mentora. También quería comprender a qué se enfrentan los niños con un trastorno hemorrágico *(continúa en la página 14)*





think differently, allowing them to go outside their comfort zones to try new activities, and learn to share with one another without judgment.

I want to leave a legacy of having done the best I could to help kids develop and reach whatever goals they set for themselves. The good stuff is when a camper declares, "I never thought I could, but I can, and I did!" Watching a child grow to adulthood and graduate from being a camper to a counselor is especially rewarding.

On its 50th anniversary, we thank the CWJ pioneers who paved the way with such bravery for future generations of camp goers! We celebrate every attendee, family, caregiver, medical staff, and volunteer who has been associated with the success of Camp Warren Jyrch!

With gratitude and appreciation, I am glad to have been a part of it!

y por qué el campamento es tan mágico para ellos. Al ofrecer un ambiente seguro y sugerencias amables, el campamento ayuda a los niños a pensar de manera diferente, permitiéndoles salir de sus zonas de confort para probar nuevas actividades y aprender a compartir unos con otros sin juzgarlos.



Quiero dejar un legado de haber hecho lo mejor que pude para ayudar a los niños a desarrollarse y alcanzar las metas que se propusieron. Lo bueno es cuando una actividad de campamento se aplica a la vida en casa y un campista declara: "Nunca pensé que podría, pero puedo, ¡y lo hice!". Ver a un niño crecer hasta la edad adulta y graduarse de campista a consejero es especialmente gratificante.

¡En su 50.º aniversario, agradecemos a los pioneros del CWJ que pavimentaron el camino con tanta valentía para las generaciones futuras de asistentes al campamento! ¡Celebramos a cada asistente, familia, cuidador, personal médico y voluntario que ha estado asociado con el éxito del Campamento Warren Jyrch!

Con gratitud y aprecio, ¡me alegro de haber sido parte de esto!

REGIONAL TREATMENT CENTERS CENTROS DE TRATAMIENTO REGIONALES

ILLINOIS

Northwestern Center for Bleeding Disorders
Chicago | 312.695.4041

Ann & Robert H. Lurie Children's Hospital
Chicago | 312.227.4090

Rush Hemophilia & Thrombophilia Center
Rush University Medical Center
Chicago | 312.942.3034

Bleeding & Clotting Disorders Institute
Peoria | 309.692.5337

INDIANA

Indiana Hemophilia and Thrombosis Center
Indianapolis | 317.871.0000 ext. 236

IOWA

Iowa Regional Hemophilia Center
Iowa City | 319.356.4277

MISSOURI

John Bouhasin Center for Children with Bleeding Disorders
St Louis | 314.577.5332

St. Louis University Hemophilia and Bleeding Disorders Center
St Louis University Hospital
St Louis | 314.977.4340

Washington University Adult Hemophilia and Bleeding Disorders Center
St Louis | 314.362.7216

WISCONSIN

University of Wisconsin Hospital & Clinics Comprehensive Program for Bleeding Disorders
5105 University Avenue
Madison, WI 53705
608.890.9495

Comprehensive Center for Bleeding Disorders
The Blood Center of Wisconsin
PO Box 2178
Milwaukee, WI 53201
414.257.2424

Hemophilia Outreach Center
2060 Bellevue Street
Green Bay, WI 53201
920.965.0606

ADDITIONAL RESOURCES RECURSOS ADICIONALES

National Bleeding Disorders Foundation
hemophilia.org | 800.424.2630

Hemophilia Federation of America
hemophiliafed.org | 800.230.9797

American Society of Hematology (ASH)
hematology.org | 202.776.0544

American Thrombosis & Hemostasis Network (ATHN)
athn.org | 800.360.ATHN

Accessia Health
accessiahealth.org | 800.366.7741

Centers for Disease Control & Prevention
cdc.gov | 800.311.3435

Committee of Ten Thousand (COTT)
cott1.org | 800.488.2688

Lady Bugs
ches.education/ladybugs | 866.981.8815

LA Kelley Communications
kelleycom.com | 978.821.6197

World Federation of Hemophilia
wfh.org | 514.875.7944

HOW A NEEDS ASSESSMENT HELPS

Efficiency and effectiveness are key players in the nonprofit world. To do them well, nonprofits must plan well, and to plan well, nonprofits must understand:

- Who their target beneficiaries are
- How many people need their services/programs
- What other services/programs are already offered
- The actual needs and desires of their beneficiaries

Often, nonprofit leadership has an idea about each of these areas but no concrete evidence to support their gut feelings. Knowing if your target audience actually needs your services and if your services are a good fit is important before spending money, time, and resources on the program. In business terms, if there is no demand for your product, you lose money.

A good analogy here would be building a home without proper architectural blueprints. A “building” might go up, but it may not withstand the first storm. If it’s not what you hoped for or needed, would you want it? Would you live there?

Before starting any new program or initiative, take the time to conduct a needs assessment. Walk through the process of figuring out what people need before spending your resources on a fruitless venture.

Once again, during 2023-2024, BDAI board and staff are conducting a needs assessment which will include a survey of our community and a focus group to ask you what you need and want. We will also look at who else is offering similar programs and services and how they are compared to what we provide. Once we have collected this information from our community, we will develop a report to share with the community. It is anticipated that this report will be available in early 2024.



CÓMO AYUDA UNA EVALUACIÓN DE NECESIDADES

La eficiencia y la eficacia son actores clave en el mundo de las organizaciones sin fines de lucro. Para hacerlo bien, las organizaciones sin fines de lucro deben planificar bien, y para planificar bien, las organizaciones sin fines de lucro deben comprender:

- Quiénes son sus beneficiarios objetivo
- ¿Cuántas personas necesitan sus servicios/programas?
- ¿Qué otros servicios/programas ya se ofrecen?
- Las necesidades y deseos reales de sus beneficiarios.

A menudo, los líderes de las organizaciones sin fines de lucro tienen una idea sobre cada una de estas áreas, pero no tienen evidencia concreta que respalde sus intuiciones. Saber si su público objetivo realmente necesita sus servicios y si estos son adecuados es importante antes de gastar dinero, tiempo y recursos en el programa. En términos comerciales, si no hay demanda para su producto, pierde dinero.

Una buena analogía aquí sería construir una casa sin los planos arquitectónicos adecuados. Un “edificio” puede construirse, pero puede que no resista la primera tormenta. Si no es lo que esperabas o necesitabas, ¿lo querrías? ¿Vivirías allí?

Antes de comenzar cualquier nuevo programa o iniciativa, tómese el tiempo para realizar una evaluación de necesidades. Siga el proceso de descubrir qué necesita la gente antes de gastar sus recursos en una empresa infructuosa.

Una vez más, durante 2023-2024, la junta directiva y el personal de BDAI llevarán a cabo una evaluación de necesidades que incluirá una encuesta de nuestra comunidad y un grupo de enfoque para preguntarle qué necesita y desea. También veremos quién más ofrece programas y servicios similares y cómo se comparan con lo que ofrecemos. Una vez que hayamos recopilado esta información de nuestra comunidad, desarrollaremos un informe para compartir con la comunidad. Se prevé que este informe esté disponible a principios de 2024.

[von Willebrand factor (Recombinant)]

Making time for what matters most.



Erica
VONVENDI Use: On-Demand & Surgery

- VONVENDI® is the **first and only treatment approved for routine use (prophylaxis)** in adults with severe Type 3 VWD who previously received on-demand therapy
- VONVENDI is **also approved for on-demand and surgical bleed management** in adults with all types of VWD
- VONVENDI **replaces VWF** (the main issue behind VWD), and **may be used with or without recombinant factor VIII** as instructed by your healthcare provider



Are you ready to ask about VONVENDI for your VWD? Visit [VONVENDI.com](https://www.vonvendi.com) to learn more, and talk to your healthcare provider.

VWD=von Willebrand disease; VWF=von Willebrand factor.

VONVENDI [von Willebrand factor (Recombinant)] Important Information

What is VONVENDI?

VONVENDI is used in adults (age 18 years and older) diagnosed with von Willebrand disease to:

- treat and control bleeding episodes
- prevent excessive bleeding during and after surgery
- reduce the number of bleeding episodes when used regularly (prophylaxis) in adults with severe Type 3 von Willebrand disease receiving on-demand therapy

Detailed Important Risk Information

Who should not use VONVENDI?

You should not use VONVENDI if you:

- Are allergic to any ingredients in VONVENDI.
- Are allergic to mice or hamsters.

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

How should I use VONVENDI?

Your first dose of VONVENDI for each bleeding episode may be administered with a recombinant factor VIII as instructed by your healthcare provider.

Your healthcare provider will instruct you whether additional doses of VONVENDI with or without recombinant factor VIII are needed.

What should I tell my healthcare provider before I use VONVENDI?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.

- Are breastfeeding. It is not known if VONVENDI passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if VONVENDI can harm your unborn baby.
- Have been told that you have inhibitors to von Willebrand factor (because VONVENDI may not work for you).
- Have been told that you have inhibitors to blood coagulation factor VI

What else should I know about VONVENDI and von Willebrand Disease?

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

What are the possible side effects of VONVENDI?

You can have an allergic reaction to VONVENDI.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with VONVENDI include: headache, nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, joint pain, joint injury, increased liver enzyme level in blood, hot flashes, itching, high blood pressure, muscle twitching, unusual taste, blood clots and increased heart rate.

Tell your healthcare provider about any side effects that bother you or do not go away.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088. Please see the VONVENDI Consumer Brief Summary on the

Important facts about VONVENDI® [von Willebrand factor (Recombinant)]

This leaflet summarizes important information about VONVENDI. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider.

What is VONVENDI?

VONVENDI is a recombinant medicine used to replace low levels or not properly working von Willebrand factor in people with von Willebrand disease. Von Willebrand disease is an inherited bleeding disorder in which blood does not clot normally.

VONVENDI is used in adults (age 18 years and older) diagnosed with von Willebrand disease to:

- Treat and control bleeding episodes
- Prevent excessive bleeding during and after surgery
- Reduce the number of bleeding episodes when used regularly (prophylaxis) in adults with severe Type 3 von Willebrand disease receiving on-demand therapy.

Who should not use VONVENDI?

You should not use VONVENDI if you:

- Are allergic to any ingredients in VONVENDI.
- Are allergic to mice or hamsters.

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

What should I tell my doctor before I use VONVENDI?

You should tell your healthcare provider if you:

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

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

VONVENDI can cause blood clots particularly in patients with known risk factors for blood clots. Discuss this risk with your healthcare provider.

You can have allergic reactions to VONVENDI. Symptoms may include generalized itching; rash or hives; rapid swelling of the skin or mucous membranes; chest pain or tightness; tightness of the throat; low blood pressure; shock; drowsiness; nausea; vomiting; tingling, prickling, burning, or numbness of the skin; restlessness; wheezing and/or difficulty breathing; lightheadedness; dizziness; or fainting. If symptoms occur, stop using VONVENDI immediately and get emergency treatment right away.

Your body can form inhibitors to von Willebrand factor or factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, they may stop VONVENDI or FVIII from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood

vonvendi
[von Willebrand factor (Recombinant)]

What are the possible side effects of VONVENDI?

Side effects that have been reported with VONVENDI include: headache, nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, joint pain, joint injury, increased liver enzyme level in blood, hot flashes, itching, high blood pressure, muscle twitching, unusual taste, blood clots and increased heart rate. These are not all the possible side effects with VONVENDI. You can ask your healthcare provider for information that is written for healthcare professionals.

Tell your healthcare provider about any side effects that bother you or do not go away.

What else should I know about VONVENDI and von Willebrand Disease?

Consult with your healthcare provider to make sure you are carefully monitored with blood tests to measure levels of von Willebrand factor and factor VIII so they are right for you.

You may infuse VONVENDI at a hemophilia treatment center (HTC), at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or HTC. Many people with von Willebrand disease learn to infuse VONVENDI by themselves or with the help of a family member.

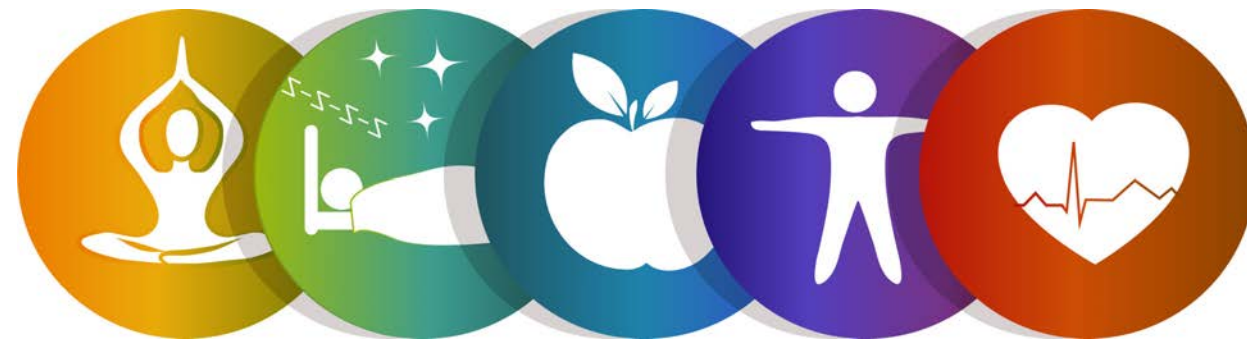
Call your healthcare provider right away if your bleeding does not stop after taking VONVENDI.

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

The risk information provided here is not comprehensive. To learn more, talk with your healthcare provider or pharmacist about Vonvendi. The FDA approved product labeling can be found at https://www.shirecontent.com/PI/PDFs/VONVENDI_USA_ENG.pdf or call 1-877-TAKEDA-7 (1-877-825-3327).

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

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THE THREE P_s

The following is taken from an article I read on the NBDF website in regards to playing sports. I am a sports fan for sure—football, soccer, ping pong, golf, swimming, bowling...you name it. Here at BDAI we are working on programming for 2024 that includes getting involved in fitness. My request to the community is to share what you love to play, watch, or do for a fun fitness activity. Please email me at ksheldon@bdai.org with the fitness activities you love playing or watching most. I look forward to hearing from you! –Kent

- **Physical therapist.** Before beginning a new sport, talk with your physical therapist and health care team about the risk of having a bleed in a target joint. A physical therapist can help you plan a conditioning program to get you in shape for a sport or exercise.
 - **Protective gear.** This includes: helmets, knee pads, and mouth guards. Protective gear helps prevent dangerous head, mouth, and joint bleeds. Bleeding in or around the brain can be life threatening or result in permanent nerve damage.
 - **Position.** Play a position in a sport or game that's less likely to lead to an injury. For example, be the outfielder rather than catcher or shortstop in baseball or a point guard rather than a center in basketball
- Don't play through injuries! You could end up with long-term or permanent joint damage. If you get hurt, take care of yourself right away. Tell your parents, coach, or teacher immediately if you are having a bleed or you think you've injured yourself! Be certain to treat a bleed immediately, then use the R.I.C.E. plan (Rest, Ice, Compress, and Elevate) and contact your bleeding disorders treatment center (HTC).
- Stop playing or exercising if it hurts a muscle or joint. Injuries take time to heal, so talk to your treatment center team about how long after a bleed you should wait to exercise. You can exercise other parts of your body while the injured joint or muscle is healing.

SCREEN TIME ISN'T JUST DOWNTIME

Sure, watching TV or playing video games is fun, but so is biking, swimming, playing Frisbee, or even walking your dog. Staying physically active can help cut down on the number of bleeds. The next time you download a song, get up and dance! Like video games? Try a motion-controlled video game to get you moving!

Taken from NBDF's Steps for Living <https://stepsforliving.hemophilia.org/next-step-kids/maintaining-a-healthy-body-kids/physical-activity-kids#take-precautions>

LAS TRES P_s

Lo siguiente está tomado de un artículo que leí en el sitio web de NBDF sobre la práctica de deportes. Seguramente soy un fanático de los deportes: fútbol americano, soccer, ping pong, golf, natación, bolos... lo que sea. Aquí en BDAI estamos trabajando en una programación para 2024 que incluye involucrarse en salud física. Mi petición a la comunidad es que comparta lo que le gusta jugar, mirar o hacer como actividad física divertida. Envíeme un correo electrónico a ksheldon@bdai.org con las actividades físicas que más le guste jugar o ver. ¡Espero saber de usted! –Kent

- **Fisioterapeuta.** Antes de comenzar un nuevo deporte, hable con su fisioterapeuta y equipo de atención médica sobre el riesgo de sufrir un sangrado en una articulación clave. Un fisioterapeuta puede ayudarle a planificar un programa de acondicionamiento para ponerse en forma para un deporte o ejercicio.
- **Equipo de protección.** Esto incluye: cascos, rodilleras y protectores bucales. El equipo de protección ayuda a prevenir hemorragias peligrosas en la cabeza, la boca y las articulaciones. El sangrado dentro o alrededor del cerebro puede poner en peligro la vida o provocar daño nervioso permanente.
- **Posición.** Juegue una posición en un deporte o juego que tenga menos probabilidades de provocar una lesión. Por ejemplo, estar en la posición de campo abierto en lugar de ser el receptor o el campocorto en el béisbol o el guardia de punto en lugar del centro en el baloncesto.

¡No juegues con lesiones! Podría terminar con daño articular permanente o a largo plazo. Si te lastimas, cuídate de inmediato. ¡Dile a tus padres, entrenador o maestro inmediatamente si estás sangrando o crees que te has lesionado! Asegúrese de tratar un sangrado inmediatamente y luego use R.I.C.E. plan (descanso, hielo, comprimir y elevar) y comuníquese con su centro de tratamiento de trastornos hemorrágicos (HTC).

Deje de jugar o hacer ejercicio si le duele un músculo o una articulación. Las lesiones tardan en sanar, así que hable con el equipo de su centro de tratamiento sobre cuánto tiempo debe esperar después de un sangrado para hacer ejercicio. Puede ejercitar otras partes de su cuerpo mientras la articulación o el músculo lesionado se cura.

EL TIEMPO FRENTE A LA PANTALLA NO ES SOLO TIEMPO DE INACTIVIDAD

Claro, mirar televisión o jugar videojuegos es divertido, pero también lo es andar en bicicleta, nadar, jugar al frisbee o incluso pasear a su perro. Mantenerse físicamente activo puede ayudar a reducir la cantidad de hemorragias. La próxima vez que descargues una canción, ¡levántate y baila! ¿Te gustan los videojuegos? ¡Prueba un videojuego controlado por movimiento para que puedas moverte!

Tomado de Pasos para vivir de NBDF <https://stepsforliving.hemophilia.org/next-step-kids/maintaining-a-healthy-body-kids/physical-activity-kids#take-precautions>



SHARED DECISION-MAKING

Shared decision making (SDM), the concept by which patients and healthcare providers work closely together to arrive at personalized treatment-related decisions, can have significant positive impacts for individuals with hemophilia. It fosters a reciprocal and collegial provider-patient dynamic in which both parties arrive at key decisions only after open, two-way discussions about patient/caregiver goals, values, and desires.

As a relatively new approach to care, it sheds the one-size-fits-all method associated with a more paternalistic model whereby patients and caregivers – the latter when the patient is a child or otherwise not able to make decisions – function in a mostly passive role, deferring to their providers on decisions about their care. Instead, SDM embraces the patient-as-partner style, which cultivates a truly reciprocal relationship.

Taken from <https://www.hemophilia.org/news/learn-more-about-shared-decision-making-in-hemophilia>. Read more at <https://www.hemophilia.org/news/new-paper-explores-shared-decision-making-in-hemophilia>.

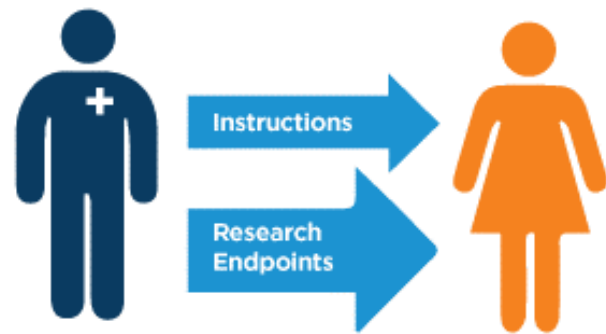
TOMA DE DECISIONES COMPARTIDA

La toma de decisiones compartida (SDM), el concepto mediante el cual los pacientes y los proveedores de atención médica trabajan en estrecha colaboración para llegar a decisiones personalizadas relacionadas con el tratamiento, puede tener importantes impactos positivos para las personas con hemofilia. Fomenta una dinámica recíproca y colegiada entre proveedor y paciente en la que ambas partes llegan a decisiones clave sólo después de discusiones abiertas y bidireccionales sobre las metas, valores y deseos del paciente/cuidador.

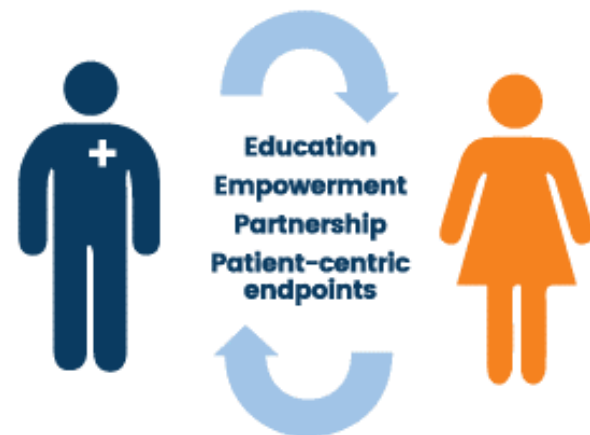
Como enfoque relativamente nuevo de la atención, abandona el método único asociado con un modelo más paternalista según el cual los pacientes y los cuidadores (estos últimos cuando el paciente es un niño o no es capaz de tomar decisiones) funcionan de manera mayoritariamente papel pasivo, dejando en manos de sus proveedores las decisiones sobre su atención. En cambio, SDM adopta el estilo del paciente como socio, que cultiva una relación verdaderamente recíproca.

Tomado de <https://www.hemophilia.org/news/learn-more-about-shared-decision-making-in-hemophilia>. Lea más en <https://www.hemophilia.org/news/new-paper-explores-shared-decision-making-in-hemophilia>.

Traditional uni-directional research-centered view



New bi-directional patient-centered view



WOMEN'S AND GIRLS' RETREAT: ME, MYSELF, AND MENTAL HEALTH

The Women's and Girls' Retreat July 21-23 aimed to celebrate the incredible journeys and inspiring stories of women affected by bleeding disorders. From patients to caregivers to advocates, the retreat provided a platform for women to share their experiences, exchange knowledge, and strengthen their network of support. BDAI hosted an array of speakers that promoted thought-provoking discussions intended to empower women with knowledge, encouragement, and a profound sense of community.

RETIRO PARA MUJERES Y NIÑAS: YO Y LA SALUD MENTAL

El Retiro para Mujeres y Niñas del 21 al 23 de julio tuvo como objetivo celebrar los increíbles viajes y las inspiradoras historias de mujeres afectadas por trastornos de la coagulación. Desde pacientes hasta cuidadores y defensores, el retiro brindó una plataforma para que las mujeres compartieran sus experiencias, intercambiaran conocimientos y fortalecieran su red de apoyo. BDAI recibió una serie de oradores que promovieron debates estimulantes destinados a empoderar a las mujeres con conocimiento, aliento y un profundo sentido de comunidad.



FIRST AND ONLY FDA-APPROVED GENE THERAPY FOR HEMOPHILIA B

STEP INTO A WORLD OF ELEVATED FACTOR IX LEVELS THAT LAST FOR YEARS

A one-time infusion delivers greater bleed protection*

HEMGENIX[®]
etranacogene dezaparovec-drlb

*In the clinical trial, annualized bleed rate (ABR) for all bleeds decreased from an average of 4.1 for patients on prophylaxis (prophy) during the lead-in period to 1.9 (54% reduction) in months 7-18 after treatment.

IMPORTANT SAFETY INFORMATION
HEMGENIX[®], etranacogene dezaparovec-drlb, is a one-time gene therapy for the treatment of adults with hemophilia B who:

- Currently use Factor IX prophylaxis therapy, or
- Have current or historical life-threatening bleeding, or
- Have repeated, serious spontaneous bleeding episodes.

HEMGENIX is administered as a single intravenous infusion and can be administered only once.

Please see full important safety information on page 13 and full prescribing information, attached.

David
Factor IX level of 37% at 2 years

Patient portrayal; HEMGENIX not intended for women.

CSL Behring

CONTACT YOUR HEMOPHILIA TREATMENT CENTER FOR MORE INFORMATION OR <https://www.hemgenix.com>

UPCOMING EVENTS / PRÓXIMOS EVENTOS



UNITE WALK

September 30, 8:30 am-12:00 pm
Brookfield Woods, Brookfield
uniteforbleedingdisorders.org



HISPANIC HERITAGE DINNER

October 14
<https://tinyurl.com/BDAISpanish2023>



ANNUAL WINE AUCTION AND DINNER

October 20, 7:30-10:00 pm
Columbia Yacht Club, Chicago



CONSUMER INSURANCE CONFERENCE

November 11



END-OF-YEAR WINTER PARTY

December 2, 10:00 am-1:00 pm
Holiday Inn, Countryside



210 South DesPlaines St.
Chicago, IL 60661-5500

Non-Profit Org.
U.S. Postage
PAID
Chicago, IL
Permit No. 216

UPCOMING EVENTS

UNITE Walk

September 30, 8:30 am-12:00 pm
Brookfield Woods, Brookfield

Hispanic Heritage Dinner

October 14

Annual Wine Auction and Dinner

October 20, 7:30-10:00 pm
Columbia Yacht Club, Chicago

Consumer Insurance Conference

November 11

End-of-Year Winter Party

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Holiday Inn, Countryside

CONTACT US!

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