HACA Teams with Theater for ‘Roz and Ray’

Theater J in DC will be presenting the play “Roz and Ray” from April 3-29, a gripping medical drama about the effect of the AIDS crisis on the hemophilia community in the 1980s. Dr. Roz Kagan offers a new miracle drug to save Ray Leon’s hemophiliac twins. But miracles aren’t always what they appear to be, and life on the cutting edge of biomedicine means moral ambiguity and impossible choices.

HACA will be hosting a reception for the Sunday, April 22, matinee performance, which will be followed by a panel discussion featuring longtime HACA member Linda Price and pediatric hematologist Dr. Naomi Luban of Children’s National. The reception begins at 12:30 p.m., with the play to follow at 2:00 p.m. Click here to register.

There are a limited number of tickets for the April 22 reception and performance. Thank you to Matrix Health for sponsoring this event.

If you can’t attend that day, use the coupon code HACA15 for 15 percent off your ticket.

HACA’s annual Family Education Day is coming up soon. We have a great lineup of speakers and activities for this year’s event, which will take place Saturday, March 12, from 9:30 a.m.-3:00 p.m. at the Ernst Cultural Center at Northern Virginia Community College in Annandale, VA.

This year’s event will include two tracks of education: one featuring topics of interest to parents, and the other for adults with a bleeding disorder and their family members.

Highlights include:

- “ABC, Easy as I-2-3, Simple as 504, IEP: The Basics of School Advocacy” – This program from HFA guides parents and caregivers on how to best advocate for their child with a bleeding disorder in the school setting. This presentation includes

Continued on page 11

Mission Statement
HACA’s mission is to support advocacy, education, and awareness efforts that build and sustain community among all people impacted by bleeding disorders.

Hemophilia Association of the Capital Area
8136 Old Keene Mill Road, Suite A312
Springfield, VA 22152
Phone 703-352-7641, Fax 540-427-6589
E-mail: admin@HACAtakes.org • www.HACAtakes.org

CFC #42259
Scholarship Application Available

Applications are now available for the George and Linda Price Scholarship program. This scholarship program is offered to both members with a bleeding disorder and their siblings or parents. Two $3,000 scholarships are awarded each year. The funding can be used for tuition at any accredited non-profit college, university, vocational or technical school in the United States. More details are available within the application, which can be found here. Deadline is May 15.

Registration Open for Camp

HACA is partnering again in 2018 with the Virginia Hemophilia Foundation for Camp Youngblood at Camp Holiday Trails in Charlottesville, VA.

Summer camp will take place July 8-13. Camp gives kids with bleeding disorders and their siblings a week of fun and learning with others that are faced with similar challenges and life experiences. There is a $25 registration fee per child, and deadline to register is April 30.

Space is limited, go to www.campholidaytrails.org and click on the “Apply To Camp” button on the top right corner of the page and scroll down to select Camp Youngblood from the list. If you’re new to camp, click on the guides at the center of the page to learn more, then set up an account.

Women’s Group Gathering

The women’s group will be gathering on Saturday, April 21, at Cherry Hill Farm in Falls Church, VA. The event will feature a program about the farm; a delicious tea; and a Blood Sisterhood rap session. The event begins at 1:00 p.m. Space is limited, so register today.

Thank You, Volunteers!

During March, HACA participated in the NBC4 Health and Fitness Expo at the Washington Convention Center in DC. Thank you to our volunteers: Ishaan Babbar, Emmitt Jackson, Edmund Leong, Andrea Parson, Veronica Scott, Matthew Stone and Terry Stone. We appreciate you taking time out of your weekend to lend a hand.

This year’s event, held March 10-11, was the 25th anniversary of the expo, which featured a variety of vendors and activities.

Ishaan Babbar was one of the many volunteers that helped at the NBC4 Health and Fitness Expo in March.
Save the Date!

HACA FALL FESTIVAL AND WALK

Saturday, September 29, 2018 Lake Accotink Park Springfield, VA

THIS YEAR’S EVENT WILL INCLUDE:

Games and activities
Walk along scenic Lake Accotink (or run or bike)
Easy access from the Beltway and plenty of free parking
A picnic following the walk

MORE DETAILS TO COME SOON!
Get Educated at Annual Event
Continued from page 1 (cover)

an overview of IEPs, 504s and health care plans utilized in schools.

• “Disclosing Your Child’s Bleeding Disorder” – Presented by NHF, this workshop will help you make decisions around disclosure and gain comfort around discussing your child’s bleeding disorder with others.

• Managing Transitions – Chris Guelcher of Children’s National Medical Center will moderate a panel that will discuss transition in the hemophilia community.

• “It’s Not Too Late to Save Your Joints” – Whether you have never had a joint bleed or have had more than you would like to count, it isn’t too late to learn more ways to prevent future joint damage. In this session presented by NHF, you will learn small steps for incorporating safe physical activity in your routine and identifying and addressing a joint bleed when it takes place.

• “Understanding Medicare and Protecting it for Tomorrow” – A representative from the AARP will provide information about Medicare and the information you need to understand the benefits available. The presentation will also explore proposed changes that could reduce benefits.

• “Show Me Where It Hurts: Pain, Anxiety and Depression” – Mental health and physical health are closely related. This presentation by NHF will discuss how pain, anxiety and depression can be intertwined. We will explore coping strategies, ways to work with a healthcare team, and lifestyle approaches that can improve well-being and put us back on track to enjoying life and loved ones.

Renowned artist, instructor and HACA member Chinedu Felix Osuchukwu will lead an art program called “Express Yourself.” Growing up with hemophilia, he turned to art as therapeutic way to express his feelings about having a bleeding disorder. During the workshop – which will feature a session for kids ages 7-11 in the morning and a session for the teens in the afternoon – participants will create a print and a painting, then follow up with a writing exercise about the project. Felix will offer suggestions and answer questions during the presentation.

There will be two other programs for the teens as well in the morning: “Advocacy is All Around Us,” led by HFA, and “Getting Real: Being a Teen or Young Adult with Hemophilia,” presented by Pfizer.

Kids ages 7-11 will also participate in the “Creative Kids Writing Workshop” in the afternoon, presented by Diplomat.

Most of our industry partners will be represented at the event. Take time to speak with the home healthcare and pharmaceutical company representatives. Their exhibit fees make this event possible. Pick up your Passport to Health when you check in, have it stamped by all the exhibitors, and turn in your card at the end of the day for a chance to win a gift card.

The cost of parking is included in the event, and there is an ample parking lot. The closest Metro station to the campus is the Vienna station, which is about five miles away. If needed, transportation costs can be reimbursed through the patient assistance fund. Hold on to your receipt and contact the HACA office at director@hacacares.org to request reimbursement.

A catered lunch and snack breaks will be provided as well, and there will be coffee and light refreshments when you arrive in the morning.

Register here for Family Education Day.
“Spring at the Mansion” is the theme of HACA’s annual spring fundraiser, which will take place Sunday, May 6, from 4-7 p.m.

The event takes place at the Stone Mansion, 3900 Stoneybrooke Drive, Alexandria, VA.

The highlight of the day will be the silent auction and drawings. We will have a large variety of new items at this year’s event, including:

- 2 travel vouchers for Spirit Airlines
- Ski package for Liberty Mountain
- Potomac Nationals tickets
- Winery and brewery tours and tastings
- Tickets for Roer’s Zoofari in Vienna, VA

There will also be gift baskets to bid on as well.

Tickets for the event are $40 per person or $75 per couple, which includes tickets for two glasses of wine and heavy hors d’oeuvres. There will also be other beverages such as water and soda on hand. Click here to purchase tickets.

There will also be music by iliandi, who are returning for a third year! Thanks, Spencer and Iliana, for volunteering your time and talent.

The Stone Mansion is owned by Fairfax County Parks and Recreation, and the original structure was built in 1780 by Walter Brooke, a commodore of the Revolutionary War Navy of Virginia, friend of George Washington and first cousin to George Mason. Brooke originally called the house “Retirement,” but it’s now known as Stone Mansion. A major renovation in the 1940s enlarged and modernized the house, added two wings, a stone facade, and an elegant two-story colonnaded front porch.

Please support HACA by purchasing tickets to attend and bidding on some of the items. This is one of only two major fundraisers that the chapter does annually, and the money raised is used to support chapter programs such as summer camp, support groups, scholarships and patient assistance.

If you have something you’d like to donate for the auction, please contact Stephanie at admin@hacacares.org.
HACA Well-Represented at Washington Days

Washington Days, NHF’s annual advocacy event on Capitol Hill, brought about 500 people to DC March 7-9.

HACA was well-represented again this year, with more than 30 members in attendance, representing Virginia and Maryland. The overall Virginia group, including members of the Virginia Hemophilia Foundation, had more than 40 people and was the largest state in attendance.

Concerns about the future of healthcare motivated participation again this year.

Jennifer and Evan Blaisdell and their son, Simon, of Maryland, were first-time participants.

“We are happy to report that everyone we spoke to express a lot of support for our community,” Jennifer said in an email. “Our group included two energetic mini-advocates who really helped show our representatives the faces of the bleeding disorders community and the importance of our ‘asks’ regarding health care policy and funding. As the mom of one of those boys, I appreciate the opportunity of Washington Days to show my son what democracy looks like and teach him the importance in taking part and sharing his voice. We were all very proud to help fill the halls of Capitol Hill with red ties!”

This year participants asked their lawmakers to support policies that protect the bleeding disorders community:

- Support federal standards for public and private insurance so that patient protections and access to insurance is maintained. For private plans, this means maintaining current pre-existing condition policies, the ban on lifetime and annual limits, and federal standards for Essential Health Benefits. For Medicaid, this means maintaining the Medicaid expansion and opposing state waivers that could threaten meaningful coverage.

- Support federal hemophilia programs at CDC and HRSA that ensure access to care for people with bleeding disorders. The HRSA Maternal and Child Health Bureau Hemophilia Program provides funding to hemophilia treatment centers and allows participation in the 340B program, which supports comprehensive care. CDC Division of Blood Disorders supports critical surveillance and prevention activities.


The event also included social media training, information on the Red Tie Campaign and advocacy training on Wednesday. Participants also had state advocacy training on Friday.

Thanks to the National Hemophilia Foundation for providing another great advocacy event!
HACA Well-Represented at Washington Days

Continued from previous page
In late February, I had the opportunity to participate in advocacy with Rare Disease Legislative Advocates, a collaborative organization designed to support the advocacy of all rare disease patients and organizations.

Besides my work with HACA, I’m also part of the rare disease community personally, as the mother of a 20-year-old with a rare congenital anomaly of the bladder and the aunt of an 8-year-old with a rare metabolic disorder called tyrosinemia type 1. It was my sister’s desire to get involved with advocacy that led me to sign up for RDLA’s events.

Rare Disease Week featured five days’ worth of activities, including a legislative conference and advocacy training, visits with lawmakers, a rare disease congressional caucus briefing and tours and programs at NIH.

I attended the daylong legislative conference at the Ronald Reagan Building in DC on February 26. The event offered advocacy training sessions for first-timers, as well as “deep dive” topics for more experienced advocates. We also had the chance to meet the other participants from our district that would be making visits with us. There were nine of us in my District 11 group, and we were led by Ron Bartek, the president of Friedrich’s Ataxia Research Alliance. I met several people: parents advocating on behalf of their children living with a rare disorder, as well as spouses.

The congressional meetings took place on February 27, and our group met with representatives from the offices of Sens. Mark Warner and Tim Kaine, and Rep. Gerry Connolly.

The “asks” we discussed were:

- Support for the OPEN Act (Orphan Product Extensions Now, Accelerating Cures and Treatments), HR 1223, S 1509 – This bill would create a six-month exclusivity extension for companies that repurpose existing therapies for a rare disease indication.

- Support for Advancing Access to Precision Medicine Act, HR 5062 – This bill would direct the Department of Health and Human Services to enter into an agreement with the National Academy of Medicine to develop recommendations on how the federal government may reduce barriers to the utilization of genetic and genomic testing. The bill would also let states apply for an exception to the federal medical assistance percentage rate to provide whole genome sequencing clinical services for certain children on Medicaid who have an unresolved disease that is suspected to have a genetic cause.

- Joining the Rare Disease Congressional Caucus – The caucus was established in 2010, and now encompasses both the House and Senate. This bipartisan group provides a vital platform for discussing pressing policy issues and giving rare disease patients a voice in DC.

- Funding for National Institutes of Health – This was not one of the official “asks,” but our group also talked about how important the NIH was for people looking for a diagnosis that are living with a rare disorder.

My biggest takeaway from this event was that the bleeding disorders community is very fortunate to have two organizations working tirelessly on their behalf through advocacy efforts in DC. I hope that some of these families will be fortunate enough one day to have a group like HFA or NHF looking out for them.
HACA and Children’s National partner throughout the year on a variety of events. In February, there were two such programs: an infusion class and a couples’ workshop. Both are organized and staffed by the hemophilia treatment center, while HACA covers expenses such as food and space rental.

An infusion class took place on February 20 at the Northern Virginia clinic in Falls Church. After a pizza dinner and viewing of the infusion video, participants worked with several nurses to practice infusions on dummy arms. They also had the opportunity to watch a young man self-infuse. Jack Prophett, a high school junior, and his dad, Chris, attended and shared their story about his journey to learning. He infused himself in front of the participants while talking about how he plays basketball for his high school and lives an active life.

Funding for the infusion clinics are provided by Bioverativ, CSL Behring and Shire. The next clinic will take place June 14.

The couples’ workshop, the follow-up to a carrier conference held in 2017, included education and support for couples whose current or future family is or may be affected by hemophilia. There were four couples at the workshop, which featured an overview of hemophilia and bleeding disorders led by nurse practitioner Chris Guelcher; an update on current and future therapies presented by Dr. Michael Guerrera; the genetics of hemophilia presented by genetic counselor Rhonda Schonberg; and the psychosocial effects of living with hemophilia led by social worker Marissa Zanno.

Thank you to the Hemophilia Alliance for providing the funding that was used for the workshop.
HACA Teams with Theater for ‘Roz and Ray’
Continued from page 1 (cover)

purchase online or by phone for another performance. Go to https://theaterj.org/ for more information or to purchase tickets for other dates.

Theater J will take donations for HACA’s summer camp program after each performance. We are thrilled to be partnering with Theater J for this special event!

The play, written by Karen Hartman, has already been staged in Seattle, Chicago and San Diego to rave reviews.

The theater is in the Edlavitch Jewish Community Center, 1529 Sixteenth Street, NW, Washington, DC. To get to the theater, you can take the Red Line to Dupont Circle, using the Q Street exit.

There are also parking opportunities available:
- Colonial Parking lot at 1616 P Street NW (between 16th and 17th Streets) and 1515 15th Street NW (between 14th and 15th Streets, entrance on P Street opposite Whole Foods), just two blocks from the Edlavitch DCJCC.
- The center has partnered with Parking Panda to allow guests to purchase guaranteed parking near the community center. Once purchased, parking is 100 percent guaranteed, even if the location otherwise fills up. Parking availability is limited, so it is strongly recommended that you purchase your parking in advance if driving. First-time users can use code DCJCC10 at checkout for an additional 10 percent off your reservation.

Dr. Michael Guerrera of Children’s led a session on current therapies at the workshop.

Nurse Chris Guelcher talked about the basics of hemophilia at the couples workshop.

Learning to infuse can be a challenge.
The Families of Young Children group met on Saturday, March 10, and Children's National social worker Marissa Zanno presented a program on “Hitting a Homerun at Your Clinic Visit.”

The program, a part of the HFA Families series, offered information on preparing for a clinic visit, such as reviewing the past year and preparing questions to bring along. The program discussed what to expect the day of the visit (there may be a wait, so bring some snacks!), with tips on how to take charge of the conversation as well.

Participants were grateful to have Marissa on hand to ask HTC-specific questions.

Thank you to HFA for providing us with this session, and Families program funders Novo Nordisk, Bayer, Genentech, Accredo and CVS Specialty.
HACA is partnering with the Wingmen Foundation for its Inspiring Shots Golf Clinic, a free multi-week local golf clinic for people with bleeding disorders and/or their caregivers that begin in May.

The sessions will take place May 19, June 2 and June 16 from 10:00 a.m.-noon, and June 23 from 3:00-5:00 p.m. There will be a celebration dinner sometime in July. Last year pro golfer Perry Parker was the special guest at our dinner.

Last year’s session was quite a success, with two participants traveling to Arizona in November to participate in a championship game. They tied for second place, which netted the chapter a $500 donation from the foundation.

If you are looking to learn how to play golf or would like some tips from a pro on how you can improve your stroke, this clinic may be for you. Attendees will receive eight hours of instruction in a clinic setting with a golf pro and others from the HACA community. Golf clubs will be provided if needed.

The clinic will take place at Westfields Golf Course, 13940 Balmoral Greens Ave., Clifton, VA.

The Inspiring Shots Golf Clinic is sponsored by CSL Behring in conjunction with pro golfer Perry Parker, who is on the board of the Wingmen Foundation.

Wingmen Foundation’s Inspiring Shots Golf Clinic’s primary focus is the collaboration of golf fundamentals with life lessons that can translate into the development and shaping of life skills and discipline. The program concentrates on golf education, fitness, and improving one’s own quality of life with a chronic condition.

On the last day of the clinic, two attendees will be chosen to participate in the CSL Behring Junior National Championship (JNC) in Arizona during September. Airfare, hotel and ground transportation will be paid by the Wingmen Foundation.

If chosen to attend the JNC, participants will tee off in the Perry Parker Open two-person best ball competition in hopes of winning money for their local chapter. Participants will also assist Perry Parker in mentoring and teaching the educational golf components at the JNC.

There is a maximum of 12 participants, so space is limited. If you are interested, email Don Regan at dregan@wingmenfoundation.org to sign up.
For too many people with a bleeding disorder, pain isn’t well-managed. The landmark Haemophilia Experiences, Results and Opportunities (HERO) international study, supported by Novo Nordisk and completed in 2014, found that 89% of people surveyed had experienced pain that interfered with their daily lives in the previous four weeks. Further, more than half of those in the HERO study indicated they were in “constant pain.”

A growing body of research shows promising results for a range of nondrug, mind-body pain management therapies such as mindfulness and music therapy. Used as complements to mainstays of bleeding disorders management — clotting factor for joint bleeds, physical therapy and carefully chosen pain relievers — these strategies “allow people with bleeding disorders to enjoy meaningful, satisfying, full lives and relationships instead of living in a cycle of pain, fear of pain and pain medication side effects,” says Georgia Panopoulos, PhD, LP, a clinical psychologist in Minneapolis who specializes in pain management.

Ready to give one of these techniques a try? Consult your care team before beginning any new pain management therapy.

**Mindfulness**

Mindfulness is the act of being focused on the present moment, while acknowledging thoughts and feelings. This type of focus can “let you notice pain without having negative reactions to it,” says Christi Humphrey, LCSW, a social worker with Hemophilia of Georgia who teaches mindfulness-based stress-reduction techniques.

**Try it:** Sit or lie down in a comfortable, quiet place. Breathe normally as you notice how your body is feeling, scanning from head to toes. Then focus on your breath—the inhalation and exhalation—for five or 10 minutes. If you become distracted, just refocus on the breath.

**Music therapy**

“Actively listening to music occupies your whole brain, leaving little room for pain signals to reach the brain,” explains music therapist Tim Ringgold, MT-BC, director of Sonic Divinity Music Therapy Services in Orange, California.

**Try it:** Pay attention as you listen to your favorite music. Listen silently or sing along out loud, savoring the melodies, harmonies, rhythms and sound textures. Enjoying a piece of music boosts levels of feel-good brain chemicals such as dopamine, prolactin and oxytocin and reduces the level of the stress hormone cortisol—blunting feelings of pain.

**Endorphin-boosting fun**

Any activity you truly enjoy can increase your level of endorphins, another feel-good brain chemical that helps block pain signals.

**Try it:** Anything goes. When Panopoulos asked people with bleeding disorders what they did for fun during a pain flare, the list included massage, aromatherapy, being outdoors, laughing, playing with bubbles and baking.
Tai chi

The postures and gentle, flowing movements of the ancient Chinese martial art are coordinated with mental focus and a consciousness of the breath. Benefits of tai chi include flexibility, strength, balance, relaxation and mindfulness.

Try it: Tai chi instructor Rick Starks offers classes for people with bleeding disorders on Facebook at TaijiFit/Tai Chi for the Bleeding Disorders Community. He also leads an instructional video as part of NHF’s Make Your Move series on the Steps for Living website.

Thanks to Our Donors, Sponsors and Granters

The Hemophilia Association of the Capital Area gratefully acknowledges our donors who have given so generously. Below are donations received from January 1-February 28, 2018. We have made every effort to ensure all donations are listed.

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Hay demasiadas personas con trastornos hemorrágicos que no tienen un manejo del dolor adecuado. El revolucionario estudio internacional, Haemophilia Experiences, Results and Opportunities (Experiencias de Pacientes con Hemofilia: Resultados y Oportunidades) (HERO), que promovió Novo Nordisk y que se llevó a cabo en 2014, encontró que el 89% de las personas encuestadas sufría un dolor que interfería con sus actividades diarias en las últimas cuatro semanas. Además, más de la mitad de aquellos participantes del estudio HERO indicaron que presentaban “dolor constante”.

Cada vez más investigaciones muestran resultados prometedores de una variedad de terapias no farmacológicas para el manejo del dolor físico y mental, tales como la conciencia plena y la musicoterapia. Utilizadas como complementos de los tratamientos fundamentales para el manejo de los trastornos hemorrágicos - factor de coagulación para sangrados articulares, fisioterapia y analgésicos escogidos cuidadosamente - estas estrategias “permiten a las personas con trastornos hemorrágicos disfrutar de una vida y relaciones significativas, satisfactorias y plenas, en lugar de vivir en un ciclo de dolor, miedo al dolor y efectos secundarios de los medicamentos analgésicos”, dice Georgia Panopoulos, PhD, Psicóloga Licenciada (Licensed Psychologist, LP), una psicóloga clínica de Minneapolis especialista en manejo del dolor.

¿Está preparado para probar alguna de estas técnicas? Consulte con su equipo médico antes de comenzar cualquier terapia nueva para el manejo del dolor.

**Conciencia plena**

La conciencia plena es el acto de estar concentrado en el momento presente mientras se reconocen los pensamientos y sentimientos. Este tipo de concentración puede “hacer que perciba el dolor sin reaccionar de manera negativa a él”, comenta Christi Humphrey, Licenciada en Trabajo Social Clínico (Licensed Clinical Social Worker, LCSW), una trabajadora social de Hemophilia of Georgia que enseña técnicas antiestrés basadas en la conciencia plena.

**Inténtelo:** Siéntese o recuéstese en un lugar cómodo y tranquilo. Respire con normalidad y perciba cómo se siente su cuerpo, desde la cabeza hasta los dedos de los pies. Luego concéntrese en su respiración (las inhalaciones y exhalaciones) durante 5 a 10 minutos. Si se distrae, vuelva a concentrarse en la respiración.

**Musicoterapia**

“Escuchar música activamente involucra todo el cerebro lo que deja poco margen para que las señales de dolor lleguen a él”, explica el Musicoterapeuta Tim Ringgold, Musicoterapeuta Certificado (Music Therapist – Board Certified, MT-BC), Director de Servicios de Musicoterapia Sonic Divinity en Orange, California.

**Inténtelo:** Preste atención mientras escucha su música favorita. Escuche música en silencio o cante en voz alta y saboree las melodías, armonías, ritmos y texturas de los sonidos. Disfrutar una pieza musical estimula los niveles de las sustancias químicas del cerebro que producen bienestar, tales como la dopamina, la prolactina y la oxitocina, así como reduce los niveles de cortisol, la hormona del estrés, lo que desaparece las sensaciones de dolor.
**Entretenimiento estimulante de endorfinas**

Cualquier actividad que en verdad le guste hacer puede aumentar sus niveles de endorfinas, otra sustancia química del cerebro que produce bienestar y ayuda a bloquear las señales de dolor.

**Inténtelo:** Cualquier cosa vale. Cuando Panopoulos preguntó a las personas con trastornos hemorrágicos qué hacían para divertirse durante un episodio de dolor, la lista incluía masajes, aromaterapia, estar al aire libre, reír, jugar con burbujas y hornear.

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**Taichí**

Las posturas y movimientos sutiles y fluidos de este antiguo arte marcial chino están coordinados con la concentración mental y la conciencia de la respiración. Los beneficios del taichí incluyen flexibilidad, fortaleza, relajación y conciencia plena.

**Inténtelo:** El instructor de taichí, Rick Starks, ofrece clases para personas con trastornos hemorrágicos a través de Facebook en **TaijiFit/Tai Chi for the Bleeding Disorders Community.** Starks también es presentador de un video educativo como parte de la serie **Make Your Move de la NHPen** la página web de Steps for Living.

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