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Brothers HEALTHCARE NEWSLETTER

BONDED BY BLOOD | BROTHERSHEALTHCARE.COM | FOURTH QUARTER 2018

YOU MATTER TO US.

At Brothers Healthcare, we care about you as a whole person, as part of our family. That's why we feature personal reflections on living with a chronic condition, like a bleeding disorder, or having a child with one.

Also in this issue, you will find ways to improve your health by discovering new phone apps and spending more time in nature. Remember to take a moment each day to breathe deeply, connect with someone you love and express gratitude.

Happy reading, —*Jessica Steed, Editor*

UPCOMING EVENTS

HFNC 60th Anniversary Luncheon Silicon Valley, CA Oct. 7, 2018

HFSC Long Beach Marathon Long Beach, CA Oct. 7, 2018

HFSC Golf and Tennis Tournament La Canada, CA Oct. 8, 2018

NHF Annual Conference Orlando, FL Oct. 11-14, 2018

HASDC Unite for Bleeding Disorders Walk Mission Valley Oct. 28, 2018

LHF 20th Annual Huey Wilson Open LaPlace, LA Nov. 2, 2018

HFSC Unite for Bleeding Disorders Walk Los Angeles, CA Nov. 3, 2018

HOPE for Hemophilia Annual Meeting New Orleans, LA Nov. 9-10, 2018

HFNC Family Education Day Oakland, CA Nov. 11, 2018

HEMOPHILIA & FEELING LIKE an OUTCAST

By Adrian Flores

As a 36-year-old man who happens to have hemophilia, I am grateful for many things; access to safe and effective treatment, the ability to live a full life, and my connection to the bleeding disorders community. That connection helped me through difficult parts of my youth where I carried the label of “outcast.” Despite this, my journey has made me stronger and I hope my story will benefit others because I know I have the support of our wonderful community behind me.

Since medical treatment has improved much in past few decades, I’m hopeful families today won’t deal with traumatic experiences like those in my childhood. However, it’s worth considering that today’s children with bleeding disorders may still feel different from their peers.

When I was a child, my parents and doctors helped me learn the importance of injury prevention, joint health, regular doctor visits and taking my medication. But hemophilia affects more than just my body, it affects my mind, my feelings, and my sense of self. Often, when I was young, I compared myself to my peers and wondered, *Am I different? Am I flawed? Is there something wrong with me?* I didn’t have the words then, but I felt isolated. As a child in the 1980’s, I peered over my window sill and watched my friends rough-house while I was in bed with a bad bleed. Some nights I sat in the ER with pain so overwhelming I would hallucinate as I tried to change my reality. My parents would smile, stroke my hair, and tell me that I’d feel better soon, but they didn’t believe it any more than I did.

Growing older and reaching school age increased my sense of isolation. I remember being bullied when I arrived on campus in a wheelchair or on crutches. Other children were mocking, calling me “faker” because while I was playing the day before, I was unable to walk the next day. I felt like an outcast. At lunch I would sit on “the hill,” a grassy spot with a single tree for misbehaving students. But, my only crime was being “the bleeder” whom recess aides were afraid to let play.

When my parents learned of my isolation I felt at school, it broke their hearts and motivated them to action. They soon became

LFH Annual Meeting
Baton Rouge, LA
Nov. 30 - Dec. 1, 2018

NHF Annual Family Conference
Henderson, NV Dec. 1, 2018

CCHF Holiday Party
Carmichael, CA Dec. 1, 2018

HFSC Snowflake Festival
Santa Ana, CA Dec. 8, 2018

HASDC Factor Frost
Mission Valley, CA
Dec. 15, 2018

For more info, contact your local chapter or info@brothershealthcare.com

SMARTPHONE

It’s clear that smartphones help us in nearly every part of life- connecting with family, friends and colleagues, planning and scheduling, research, and playing games involved with our local Hemophilia Foundation chapter. There, we found resources for children like me. *Children like me;* the idea was strange yet comforting. I really enjoyed bleeding disorders summer camp. There was no “hill” where I would feel left out. There were only children being children with varying levels of physical ability. Help replaced teasing as young bleeders made sure those in wheelchairs were pushed to the next adventure and not pushed aside. Summer camp was where I learned I was a special part of something bigger, something that I would later come to know as the bleeding disorders community. It was where I began to take on, and welcome, the responsibility for my health care.

When summer camp ended, my connection to the community continued. In the time that divided one summer from the next, my parents made sure to take me to various community events where I would see children like me. *We were children who had bleeding disorders. Bleeding disorders, however, did not have us.*

Over the years, I have grown with the bleeding disorders community. My days as a camper are over, but the relationships which began in those log cabins developed into life-long brother and sisterhoods. The examples of bravery I witnessed from community members have informed my role in life.

It is worth noting that my parents are proud of where I am today. The sense of helplessness and guilt that punctuated their first years as the parents of a child with a bleeding disorder has been replaced by the knowledge that they helped introduce me to the community that would forever change my life. By doing so, they inspired me to see limitations as challenges, and not barriers.

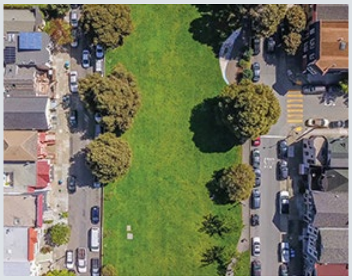
Our community is full of resources: patients, guardians, clinicians, advocates, manufacturers and specialty pharmacy providers, as well as dedicated staff and volunteers of the chapters. I’m grateful to bring a lifetime of experience with a bleeding disorder to my role at Brothers Healthcare. I am dedicated to ensuring the members of this community have access to every available resource, so they can be inspired to reach their full potential. When we realize we are each an important part of a larger whole, we will overcome obstacles, heal our sense of isolation and truly become a united community.

just to name a few. When we use our phones as tools for good, we can benefit emotionally, mentally, and physically.

Try these apps to integrate more health, mindfulness and wellness into your life(1).

1. MyFitnessPal helps you easily keep track of your food intake, so you can stick to your healthy eating goals.
2. Headspace is a meditation app to help train your mind for greater patience, awareness, and even better sleep.
3. Happify helps combat stress which is linked do serious health issues. The app includes games to foster positive thoughts and build better emotional health.
4. HealthTap is an app where you can speak face to face (or screen to screen) with a real doctor to answer your health-related questions. You may also have telemedicine benefits through your health insurance.
5. Charity Miles combines running and raising money for any of 40 global charities (funds donated fr corporate sponsors).
6. Lose It! Take a photo of your meal and this app will help you log and track your eating. You can also set weight loss goals, get recipes, and find workouts.

https://www.menshealth.com/health/g22842908/best-health-and-fitness-apps/



DO YOU SEE ME?

Empathy for a Child with a Bleeding Disorder

By Jessica Steed

Recently, my 12-year-old son told me his arm hurt and he needed a treatment for his bleeding disorder. As he put on his tourniquet and prepared his butterfly needle, he said in increasing discomfort, “It hurts, Mom. If you were inside my body, you would know how I feel.” That phrase emphasized our reality: no matter how attentive I am, I’ll never know what it’s like to have hemophilia. But, as a parent to two wonderful sons who happen to have severe hemophilia, it’s my job to try to understand.

A few years ago, our Hemophilia Treatment Center asked my sons, ages 10 and 13, and me to take separate versions of Hemo-QOL(1), a hemophilia quality of life survey. The questionnaire asks parents and children how often the child’s bleeding disorder affected various aspects of their lives. The follow questions are similar to categories in the survey and aim to determine how often these types of situations or attitudes have happened in the last month.

1. Bleeds and infusions: How often do I bleed, how painful is it, do I tell my parents right away, do I infuse independently?
2. Physical health: Do I have joint pain, difficulty walking, or other ongoing problems related to my bleeding disorder?
3. Feelings: How common are feelings of sadness, worry, loneliness, and exclusion from my peers?
4. Self-perception: Does hemophilia make me feel different than my peers? Do I have difficulty or embarrassment because of my bleeding disorder?
5. Family dynamics: Does my family treat me differently, protect me too much or does my bleeding disorder cause problems at home?
6. Support and friends: Do I have friends who I talk to about hemophilia and who look out for me? Do I feel understood or left out?
7. Sports and school: Can I participate in sports and school as much as I’d like despite my bleeding disorder?
8. Body and treatment: Do I listen to my body and take good care of it? Am I satisfied with my doctors and medication? Does my treatment and/or frequency bother me?
9. Future and relationships: Do I worry about my health and how it will affect my future relationships and potential to have a family?

As a parent, the survey was very helpful because it asked me to consider specific ways I could see my children’s bleeding disorder affecting them. My responses were generally positive; the boys were healthy, happy and well-adjusted. They’d been on preventative treatment (prophylaxis) since they were infants, preventing nearly all bleeds, and participate in activities with their peers.

At least that’s what I thought until I read my sons’ responses. I skimmed their answers with increasing alarm as I realized that in their eyes, hemophilia was a constant struggle. In nearly every area, their responses were more negative, sometimes dramatically so. Hemophilia was something they hated that held them back and hurt them.

How can this be?

The drastic difference between my perception and my kids’ experience

GREEN NEIGHBORHOODS: Objective Health Benefits of Nature

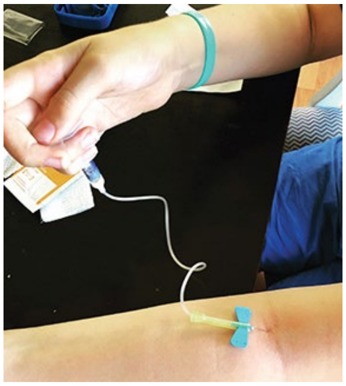
Many of us enjoy the outdoors, but did you know green spaces can actually benefit your health? One researcher, Ming Kuo(1), has studied the physical and mental health benefits of living near parks and trees. After adjusting for income and other advantages, there’s still a benefit to spending time in nature.

These studies don’t ask people subjectively how much they enjoy nature, rather, they objectively look at behaviors and health outcomes between those with and without access to green spaces(2).

For example, here are specific improvements correlated to living in green neighborhoods:

- Lower gun violence.
- Fewer prescribed medications for mental health conditions like anxiety and depression.
- Higher cognitive testing scores.
- Improved immune system functioning.

That people act, think and feel better when in nature shouldn’t surprise us. We know zoos and circuses throughout history have seen animals suffer when held in cages instead of their natural environment. Humans, too, have lived in nature for millennia and only recently began spending most of our time inside buildings. Our bodies haven’t adjusted to indoor living and can still benefit from more time spent in our natural habitat- around trees, grass and plants.



with their bleeding disorder was puzzling and upsetting. At first, I was upset my children didn't realize how lucky they were to be free from HIV, Hepatitis C, and severe joint damage like men with hemophilia born in a previous era. Advances in treatment have given me peace of mind and hope for a future with a cure for hemophilia.

However, my sons aren't comparing themselves to men with hemophilia from a generation before or to the possibility of a cure in the future. They are comparing themselves to their peers; to kids who don't have to put a needle in their veins three times a week and worry about trauma and break-through bleeds. It's this comparison that makes them feel the negative effects of their bleeding disorder. As much as I want them to be grateful for their health, I also need to acknowledge their pain and struggle.

Now what?

My children's bleeding disorder causes them challenges physically, socially, psychologically and emotionally. Here are ways I've tried to help them:
1. Listen: I continue to regularly check in and ask for details about the specific challenges they are currently facing.
2. Engage: I use these conversations to help them develop the skills to manage difficult situations. If they situation is beyond my personal expertise, I reach out to my HTC, social worker, school guidance counselor, or other child development professional.
3. Develop: I help my children access resources and discover tools available to them. For example, HFA has a series of toolkits(2) designed to address a variety of concerns.
4. Connect: I reach out to my local and national chapters to attend events for families and youth which can help my children build relationships within the bleeding disorders community.
5. Share: I use social media to find resources and stay connected with other parents.
What do you do to stay connected to your loved one with a bleeding disorder? Share your responses on our Facebook page.

http://haemoqol.de/

http://www.hemophiliafed.org/for-patient-families/resources/toolkits/

Kuo's research is a wake-up call for those of us who think it a small bonus to be in nature, but not a health necessity. Perhaps we will consider these findings when we choose between a walk in the forest or an indoor movie. Also, let's work harder to advocate so everyone has access to parks, trees, grass and other nature. For more information, check out these sources.

https://www.npr.org/2018/09/10/ 646413667/our-better-nature-how-the-great-outdoors-can-improve-your-life

https://www.nrpa.org/uploadedFiles/nrpa.org/Publications_and_Research/Research/Papers/MingKuo-Summary.PDF

Ask US!

Call or email us with any questions you have about sports, life, relationships or your managing your medical condition and we will lend our expertise to help you in any possible way.
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