

BONDED BY BLOOD | BROTHERSHEALTHCARE.COM | SECOND QUARTER 2019

#### BECAUSE YOU MATTER TO US.



At Brothers Healthcare, you are part of our family. Like a caring family, we are here to support you not just by delivering your specialty medications, but by connecting with you as we work together to achieve your goals.

Maybe you've heard the buzz about new and upcoming therapies in the bleeding disorders community. We see technology advancing treatment for bleeding disorders and the potential benefits may be life-changing. However, let's remember the importance of care and education surrounding treatment. Having the right treatment is one piece of the healthcare puzzle. But, it's also important for your specialty pharmacy to deeply understand how chronic conditions affect your life and your family. This includes maintaining strong relationships, continuing education, and working toward independence in all areas.

We hope you enjoy this issue of our quarterly newsletter as we discuss what makes a specialty pharmacy great, revisit the benefits of essential oils, and hear from remarkable community members about their successes.

-Jessica Steed, Editor

2 GETTING THE MOST OUT OF YOUR PHARMACY

3 COMMUNITY CORNER

#### **UPCOMING EVENTS**

HFA Annual Symposium San Diego, CA April 4 - 7, 2019
AHA Salsa Challenge fundraiser Mesa, AZ April 14, 2019
LAHF Family Day in the Park Alexandria, LA April 14, 2019
NV NHF Golf Gets in Your Blood Las Vegas, NV April 15, 2019
World Hemophilia Day April 17, 2019
HFNC Unite for Bleeding Disorders Walk Oakland, CA May 5, 2019
HCC Legislative Day, Sacramento, CA May 8, 2019
LAHF Capitol Days Baton Rouge, LA May 9, 2019
HFSC Family Info Day Knott's Berry Farm, CA May 11, 2019
HASDC Family Education Day San Diego, CA May 18, 2019
LAHF Camp Globeclotters Baton Rouge, LA May 26 - 30, 2019
Hope for Hemophilia Spring Education Weekend New Orleans, LA May 31, 2019
Hope for Hemophilia Gala New Orleans, LA June 1, 2019
HFSC Family Retreat Running Springs, CA June 7 - 9, 2019
Koko Ohano Family Camp Oahu, HI June 7, 2019
HFNC Camp Hemotion Oakhurst, CA June 16 - 22, 2019
For more info, contact your local chapter

4 ESSENTIAL OILS

# ARE YOU GETTING THE MOST OUT OF YOUR SPECIALTY PHARMACY?

By Jessica Steed

When you get an occasional prescription, you can fill it at the corner pharmacy or the supermarket while you shop for groceries. But, did you know you may also have pharmacy choice for specialty medications?

Selecting the right specialty pharmacy is an important decision because they are the core of your healthcare team. It can be tricky to know which options are available to you. Perhaps pharmacy A is recommended by your doctor or you hear about pharmacy B from a friend. How will you choose?

Keep in mind, the National Hemophilia Foundation recommends HTCs "Allow patients choice of product, supplier and the delivery of health care services. This requires HTCs to provide complete information on its pharmacy services and inform



patients that other pharmacy provider options are available." You can feel confident about your right to choose where you get your medication, just like any other Rx.

At Brothers Healthcare, we care about you like family and we hope you'll choose

us for all your specialty pharmacy needs. So, think about your current specialty pharmacy and ask yourself—

#### Does My Specialty Pharmacy...

- Connect me with a caring team member who helps me understand my condition, treatment, and calls monthly to check in, take my order, and learn about my needs?
- Provide a social worker on staff to answer my psychosocial questions and connect me with applicable community resources?
- Include a director of nursing who

#### **LESSON IN SELF-ADVOCACY**

By Breanna Hubbard



Recently, I went to my hematologist to ask for treatment for my bleeding disorder. Up until then, my doctor had prescribed hormonal birth control

to manage my bleeding, but it wasn't working. I experienced pretty much constant bleeding. In fact, my most recent menstrual cycle had lasted two months. I was exhausted and couldn't fully participate in activities I loved, like working out or practicing mixed martial arts, MMA.

When I told my doctor about these problems, he offered to put me on an additional form of hormonal birth control. Instead, I asked for a prescription for factor

replacement therapy for von Willebrand's disease. The reason I felt so confident asking for treatment was because I went into my appointment armed with information. I knew there were medications available which were indicated treating bleeds in patients like me, with VWD. I also knew the basics of clotting which made me think that replacing the factor protein which wasn't working in my blood would lead to less bleeding.

Also, my specialty pharmacy rep was crucial in helping prepare me talk to my doctor with confidence. I knew what I wanted, that other patients were treating and having good results, so I was able to directly address his concerns. Even then, it wasn't an easy process. After two months of discussion, including getting additional information requested by my doctor, we arrived at a treatment plan. I'm grateful to be able to treat with VWD

factor for the first three days of my menstrual cycle as well as treat for any other spontaneous bleeding.

Treating with factor replacement therapy is working well for me so far. I can do so much more now that I'm not constantly bleeding! I wish I had access to this treatment when I was younger. By nature, I'm an athletic person but I was discouraged from joining team sports because I would let my team down when my bleeding episodes caused me to miss practices and games.

Having a reliable treatment to help my blood clot without the side effects of hormonal birth control has been a game-changer for me. It makes me realize that normal blood clotting is not a luxury, it's a necessity to live my best life. I'd recommend self-advocacy to other patients who are struggling with bleeding and not getting the treatment they need and deserve.

personally trains and coordinates my in-home nursing care to customize my treatment and education?

- Employ expert pharmacists, including one who is also a nutritionist to answer my questions about how medications and food work in my body?
- Have all staff on call 24/7 to meet my urgent needs?
- Work closely with my doctors, pharmaceutical manufacturers and payers to keep my costs to a minimum while providing excellent medical care?
- Focus on my unique needs and goals to maintain or achieve independence?
- Offer educational scholarships available to students with bleeding disorders and their family members?
- Provide educational presentations for schools, daycare and extended family?
- Help me find the best way to track my treatments and bleeds to provide

my medical team with accurate information?

 Offer bleeding disorders education for managing anxiety, depression, and bullying?

 Support local bleeding disorders events and programs?

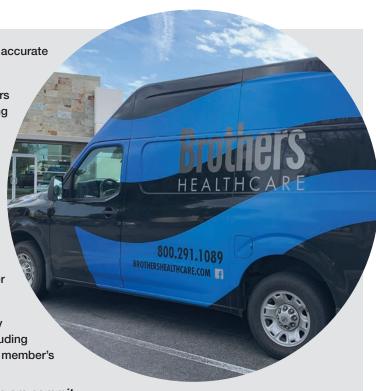
 Include staff who truly understand living with a bleeding disorder as a patient or caregiver?

 Deliver my meds to my preferred location including work, school or family member's home?

At Brothers Healthcare, we are committed to using our expertise to make your life easier. That's because life is busy and dynamic, and managing a bleeding disorder can often be complicated. Brothers Healthcare will help you manage your bleeding disorder so you can focus on enjoying life!

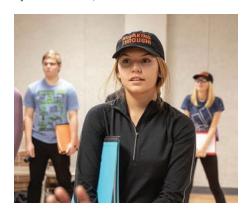
If you're interested in choosing Brothers Healthcare, talk to your rep, email: info@brothershealthcare.com or give us a call at 800-291-1089.

<sup>1</sup> https://www.hemophilia.org/sites/default/files/document/files/NHF-Position-Statement-Regarding-Hemophilia-Treatment-Center-Participation-in-the-340B-Drug-Discount-Program.pdf



### **COMMUNITY CORNER**

By Veronica Diaz, LCSW



In November 2018, Destini had once in a lifetime experience. She was honored to be one of twenty-five teens chosen to travel to New York City to participate in the Hemophilia, the Musical and Breaking Through! Musical Theatre Intensive, a three-day theatre and arts workshop for the bleeding disorders community, produced by Believe Limited and sponsored

by BioMarin pharmaceuticals. The program concluded with a six-song musical, performed by the participants, depicting the challenges of living with a bleeding disorder on the New World Stages in New York City. Destini described her experience as the most amazing and humbling experience of her life. Destini shared that acting and singing in plays "gives me an opportunity to express myself and not be defined as someone with a bleeding disorder." The highlight of her experience was seeing her name in bright colors on the jumbotron on Broadway. Destini walked away from the experience with wonderful memories and lifelong friendships.

Back at home in California, she is currently rehearsing five days a week for her performance in a high school musical, Once on This Island. In the fall, she will attend the school of her dreams, Cali-



fornia State University, Fullerton double majoring in music theatre and forensic psychology. We wish her the best in her endeavors and look forward to watching her accomplish her dreams.

## ESSENTIAL OILS — A TESTIMONIAL

By Nicole Chavez BSN RN, Young Living Essential Oils Instagram: @mrs.nico.chavo Email: Nicole.jayawellness@gmail.com



When I was a young girl, my family grew mint in our backyard. On warm summer days, I would yank a piece of mint off the bush and chew on it throughout the

day. The cool and refreshing taste was a treat, both fulfilling and remarkable because it grew from the earth. At the end of each summer, my family vacation at Yosemite National Park. Driving in, all six of us would roll the windows down while my father blasted "In the Air Tonight" by Phil Collins and we savored that first breath of pinefilled air. Experiencing nature in its purest form was simply beautiful.

Fast forward many years when a friend introduced my husband and me to Young Living Essential Oils. We both teach yoga and used them in our classes for their lovely fragrances. She mentioned that they are "therapeutic grade" with healing properties and high purity. Because I worked as a registered nurse for ten years, I began researching essential oils' benefits and how to use them regularly in our life.

Essential oils are plant concentrates: "the blood of the plant." They are derived from plants through steam distillation or cold pressing from the rind (for citrus oils). Therapeutic grade essential oils can be used

aromatically (breathed in), topically (on the skin), or internally (Vitality line is labeled for dietary consumption). The goal of essential oils is to bring the body back into balance.



The benefits of therapeutic grade essential oils are countless-varying from strong antibacterial qualities to promoting mental clarity and awareness. Lemon essential oil can act as both a detoxifier for the body and an antiseptic in non-toxic cleaning products! It's also a "powerhouse" immune boost when used alongside oregano, clove, cinnamon bark, rosemary, and eucalyptus. Copaiba has natural anti-inflammatory properties and when used with wintergreen and clove, can relieve sore muscles and pain. Both eucalyptus and peppermint aid respiration (like clearing your sinuses)! Also, peppermint is highly regarded for assisting with digestion.

Beyond benefits to the physical body, essential oils have been used for emotional and spiritual purposes as well. Lavender calms the mind and frankincense has been recorded in ancient Hebrew times to deepen spiritual connection. Patchouli, Geranium, Bergamot and Ylang Ylang uplift the mood and have been linked to improving depressive states and decreasing anxiety levels.

Essential oils are nature's gift to nurture the body, mind and spirit. When I smell or taste peppermint or pine essential oils, I am taken back to childhood memories with nature. As I use oils to nurture myself and my children, I am reminded of how supportive nature is, if we allow it to be. Essential oils can provide stability, bringing our body and mind into balance.

\*These statements have not been evaluated by the Food & Drug Administration. These products are not intended to diagnose, treat, cure or prevent any disease. Only ingest oils labeled as Vitality oils.

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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