

## BECAUSE YOU MATTER TO US.



## Together, Even When Apart.

Connection has always been important for members of the bleeding disorders community. Many local chapters host events several times a month while national organizations have annual meetings where hundreds of consumers gather to learn and engage. These face-to-face interactions are the lifeblood of what keeps us together as a community.

Since the COVID-19 pandemic began earlier this year, much of that has changed. We've had to reinvent what connection means in light of a world where hugs, handshakes, and even fist-bumps are discouraged. Many virtual meetings have emerged including hangouts, educational presentations, and support groups. As the outlook changes each day and uncertainty persists, we are all working towards a new normal. That's why we want you to

know we are here for you, as your specialty pharmacy to help you in any way we can. Simply call 1-800-291-1089 during business hours and 24/7 for emergencies.

In this issue you'll learn how we stay safe during COVID-19, meet our new team member and scholarship award winners, and read patient and provider experiences with telemedicine.

Happy Reading!

—Jessica Steed, Editor



## UPCOMING EVENTS

Due to COVID-19, in-person chapter events have largely been cancelled or moved to a virtual platform. Check with your local chapter or Brothers Healthcare's Facebook or Instagram accounts for updates.

Please consider registering for these free educational national conferences offered online.

National Hemophilia Foundation Annual Bleeding Disorders Conference  
[www.Hemophilia.org](http://www.Hemophilia.org) August 1-8, 2020

Hemophilia Federation of America Annual Symposium  
[www.Hemophiliafed.org](http://www.Hemophiliafed.org) August 24-29, 2020

Familia de Sangre (en Español)  
[www.familiadesangre.org](http://www.familiadesangre.org) September 18-19, 2020

For more info, contact your local chapter or [info@brothershealthcare.com](mailto:info@brothershealthcare.com)



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# WELCOMES HUGO HELM!



## HUGO HELM JOINS THE BROTHERS HEALTHCARE TEAM.

Hugo joins us from Herndon Pharmacy where he's been an working in the bleeding disorders

community for 5 years. As a person with hemophilia, Hugo appreciates his connections in the community. He says, "I like the companionship, that we don't have to walk with this disease by ourselves." Hugo lives on a ranch in Sanger, CA with his wife Ruth. In his free time, Hugo plays video games and enjoys the outdoors, especially surfing, snowboarding, and skateboarding. Joining Brothers Healthcare as a Specialty Pharmacy Patient Care Manager is an exciting opportunity for Hugo who continues to support his patients while getting to know his new team.

Welcome, Hugo! 

# ENSURING PATIENT SAFETY DURING COVID-19

By Angela Castagneto, Pharm.D.  
Clinical Pharmacy Services Manager

While you already might be aware of the measures needed to keep our family and loved ones safe, you may wonder what Brothers Healthcare is doing to keep our patients and employees safe. As many states loosen or lift the stay-at-home restrictions, we continue to practice the CDC/EPA guidance for cleaning and sanitizing to ensure the safety of our staff and our patients. The safety and well-being of our patients and staff is paramount for us at Brothers Healthcare. We have worked tirelessly to procure PPE (personal protective equipment) and disinfecting supplies. When hand sanitizer was not available, we were able to purchase the supplies to make our own hand sanitizer.

**What steps is Brothers Healthcare taking to ensure patient safety during the pandemic?**



- Our staff has their temperature and any symptoms checked every day before their shift starts.

See "Patient Safety" Continued on Page 4

# BROTHERS HEALTHCARE SCHOLARSHIP AWARD RECIPIENTS 2020

In January, Brothers Healthcare announced our second annual scholarship award program to support the higher educational pursuits of bleeding disorders community members. We received more than 50 applications for two scholarship awards of \$1000 each.

Many remarkable applicants demonstrated academic excellence, personal growth, and commitment to the bleeding disorders community. Although many deserving students applied, we selected two notable students to receive this year's scholarship award.


**Please join us in congratulating Grace and Nathan.**



**Grace Miller** is from Howard City, Michigan and is currently attending Ferris State University in order to pursue an associate's degree in Diagnostic Medical Sonography and obtain a bachelor's degree in

Healthcare Systems Administration. Grace is very passionate about having a career in the medical field and is very excited to continue her journey. She says, "Most of all, I would like to thank the Brothers Healthcare Scholarship program for their generosity and kindness."

## **Nathan Mermilliod**

excels academically and enjoys many extracurricular activities like acting, baseball, swimming, altar serving, and singing in the parish choir. Nathan's favorite school subject is science and he hopes to study biology in college. Nathan puts all of his effort into advocacy for his bleeding disorder, Hemophilia B. He has been spreading awareness in his school and community through public speaking for over 12 years. In high school, Nathan participated in honors courses, the varsity swim team, and the theatre guild. 





# PERSPECTIVES ON TELEMEDICINE

By Jessica Steed

One possible silver lining of the COVID-19 pandemic is increased opportunities for telemedicine. A subset of telehealth, telemedicine is an electronic clinical visit (e-visit) with a medical provider. Thus, patients who must otherwise travel for their appointments can now have a virtual visit. This visit can be on a computer's webcam, a video call or a phone call. In April, National Hemophilia Foundation hosted a webinar discussing telemedicine. You can view it online.\*

Although the technology has been available for decades, many people are new to telemedicine but have adapted quickly to this way interacting in the healthcare system. Of course, since each person is unique, we've asked a few patients with bleeding disorders and providers about their experiences with telemedicine.

## PATIENTS

**Asher**, age 14, sees his physical therapist (PT) for an ankle injury. Just like his in-person visits, on his Zoom e-visits, Asher and his PT discuss Asher's exercise regimen and pain levels. However, when it's time to test his strength and flexibility by pulling and pushing gently on his feet, Asher's mom helps out as instructed by the PT.

Telemedicine has even given Asher more options for exercise. "Now that it's hot outside, my best way to exercise is in my backyard pool. It's also easier on my joints because it's lower impact. I put my tablet on the side of the pool so I can see and hear the instructions then I do the exercises as my PT guides me."

**Raul**, a young adult, sees his hematologist regularly to manage his inhibitor. "Because my doctor is older, he was sent home to work remotely when the shelter-in-place order (in CA) began." Raul's appointments have been by phone ever since then, visiting 3-4 times, more than he would have seen him in person.

Additionally, Raul explains, "I've talked to him a lot, actually. We had a scare with a family member who had been exposed to COVID-19. My doctor helped us access resources for COVID-19 testing. When I talked to my doctor, he was calm, precise and explained things to me saying, 'Let me know when you hear the results and give me a call if your family needs anything.' I



really appreciated his support."

Raul discussed the quality of his e-visits, "When I had visits in person he was sometimes distracted and occupied because he's more experienced and other doctors were seeking consultations. He's just a busy doctor. But when we're on the phone for visits, he's much more calm, relaxed, asking questions, attentive, detail-oriented, asking about my whole person. Not just cutting to chase and asking about a bleed. Also, when I'm at home I also feel more relaxed and I don't have to set aside an entire day for a visit to the clinic which usually takes 4-5 hours."

The downside for Raul is that phone calls don't have a video element. He said, "When I have pain in my knee, he can't see it and it's hard to describe. I have a visit coming up with him and I've been thinking about how to describe the issue for a week! I even looked at an anatomy chart, so I can better describe it but I would prefer him to see my knee."

**Steve**, who is retired, has many experiences with telemedicine. "Before the pandemic, [my wife and I] had 7-8 doctor's visits a month. Now, [because of e-visits] our only physical visit since early March was to the dentist. I hope telemedicine can be expanded. It would be neat for people with hemophilia in rural areas to have telemedicine so they have better access to good healthcare and specialty healthcare.

"The benefits are increased safety, less traffic, no parking issues, and you can get ready ahead of time. It's stressful when

someone doesn't feel good to get up, get dressed, remember everything (sunglasses, purse, insurance cards, etc). It's nice to be at home without the stress.

"Before our appointment starts, we can check our weight and blood pressure at home. Then we write down our questions for the provider. If the doctor asks questions about what medications we are taking, our medications are all right there. Our dermatologist even offers telemedicine as a type of screening. We call and describe the issue, send a photo. She looks at the photo then decides if we need to go in.

"A few drawbacks are that different providers have different tech systems and some are complicated. For example, I struggled to get a copy of our insurance card uploaded to one site. Also, some doctors still like to see the patient in person. It's a sea change in how medicine is practiced. I'd like to see more of it. Perhaps NHF, HFA or local chapters can provide assistance to community members who do not have computers or internet access so they can take advantage of telemedicine."

## PROVIDERS

**Danielle Nance, MD** a hematologist with Banner Health says, "Patients who can manage the technology (about 7/10) love e-visits. I'm impressed with how they've been responding. As a provider, [the telemedicine platform] also gives me more control. I'll have the visit scheduled and if

*See "Telemedicine" Continued on Page 4*

### *"Patient Safety" Continued from Page 2*

- Employees wear a mask or face covering while in the pharmacy.
- If an employee has any signs of respiratory illness or fever, they do not report to work, or they immediately leave work. The pharmacy is disinfected as soon as the employee leaves.
- Our staff practice social distancing (staying at least 6 ft apart) within the pharmacy whenever possible.
- We practice hand hygiene (hand washing and hand sanitizer) frequently throughout the day and hand sanitizer is stationed throughout the pharmacy.
- Work surfaces and equipment are disinfected frequently throughout the day and after each non-pharmacy person (such as delivery personnel) exits.
- Workstations/areas/equipment/phones are not shared.
- Our drivers do a "no-contact" delivery. They will drop the package at the doorstep and call the patient to retrieve the package. Delivery tickets are packed within the shipment with a self-addressed, stamped envelope for return instead of the patient signing and giving the ticket to the driver. 🌊

### ASK US!

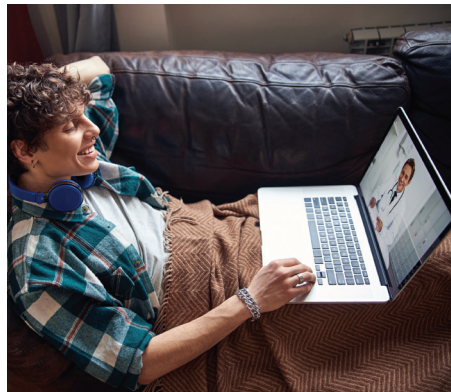
Call or email us with any questions you have about sports, life, relationships or your managing your medical condition and we will lend our expertise to help you in any possible way.

**Ph. (800) 291-1089**

**Email: [info@brothershealthcare.com](mailto:info@brothershealthcare.com)**

### *"Telemedicine" Continued from Page 3*

they log in before and I'm a little early, I can meet them early. That helps keeps me on schedule. However, your doctor might be late to their e-visit. When you schedule the visit, you can ask the staff what you should do if you need to wait. Maybe you can take a survey."



"As a provider, I prefer a virtual visit to a phone visit. I like seeing them one-on-one and being able to look at someone, it makes the experience so much better. Something about having a visual gives you a sense of their wellbeing. Often, patients can move the camera around to show me what's going on.

"Some people are surprised to see that I still wear a mask during the visit. That's because I'm in the clinic and there are several people in the room with me. My nurse is next to me, she follows up, requests labs, etc., just like a live appointment. After we create a treatment plan, it needs to be implemented and refined."

About drawbacks, she says, "Some [patients] say they didn't get the email link but sometimes they can find it if they check their spam folder. Occasionally someone won't show up on the portal, so I will give them a call and we do a phone visit."

**Heidi Purrington**, physical therapist at the Hemophilia and Thrombosis Center at Phoenix Children's Hospital says, "Telehealth has allowed me to stay connected with patients and help them continue to make progress while keeping them and their family safe during this time. I have been able to see some patients more consistently and sometimes even more times per week than before.

"It's helpful to see patients in their home environment. I suggest ways to set up their work area to decrease stress on joints/muscles, improve posture and decrease pain. When I see the adjustments they make, we problem solve what will or will not work for them in their home. I also recommend home exercises based on what is available to them. Additionally, before telemedicine, I would call patients to check on their recovery from a bleed or injury and could only make suggestions based on their verbal descriptions. Now I can see the joint or injury and watch their movement to see what they have difficulty with. Telemedicine improves our communication and my ability to assist the patient's progress with exercises and returning to full activity. I hope to continue to use telehealth in place of phone calls for follow up PT.

"A few of the difficulties of using telehealth include not being able to fully see and feel the joint or muscle as it moves and not being able to see all angles of how someone moves when they walk or do exercises. The occasional blips in technology cause some difficulty with communication and seeing things accurately. Also, for some physical therapy activities there are benefits to having the equipment that is available in the clinic." 🌊

### **Resources:**

\*<https://www.hemophilia.org/Newsroom/NHF-Community-News/Town-Hall-Webinar-Telehealth-Coping-During-COVID-19>



**BONDED BY BLOOD**

