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FROM THE EDITOR

We want to take a minute to share our gratitude for an incredible 2021 year!



Brothers Healthcare has been thriving and growing throughout one of the most challenging economic and social seasons in history. We recognize that we have come out strong through the fortitude, flexibility, loyalty, enthusiasm, and dedication of our Brothers team, patients, and partners. **THANK YOU** for riding the 2021 waves with us and proving that we are **BONDED BY BLOOD.** 

Stay healthy and safe,
—Kelle Carthey, RN, Editor

It's not Goodbye,

It's See You Soon



One of the most challenging tasks in life is to say goodbye to someone. Of course, that includes many forms of goodbye; some are more permanent than others. We all have perhaps heard the expression, "it's not goodbye but see you later." I think that is more relevant to what I am discussing here. We love, value, and cherish many

persons within the Brothers Healthcare organization. As a part of the management team, I like to call our team here my work family. Even though retirement is a happy occasion when a family member moves on, you mourn that loss. This is an absolute certainty in saying goodbye to **Patti Nieves-Chapman**, a Specialty Pharmacy Account Manager in our sales staff.

Patti is, without a doubt, very passionate about her work and the people she serves. If you are a Bleeding Disorder patient in the Northern California area and have had the opportunity to meet Patti, you know exactly what I mean. Patti has always gone

the extra mile in all aspects of her work in the community. She is known for her ability to advocate alongside a patient, roll up her sleeves as a volunteer, or be a gentle and wise soul to offer support. Patti is continually working to ensure our patients and others receive what they need when they need it. She is the type of person you want in your corner, standing next to you, no matter the circumstance.

Patti has been an active and vital part of the Bleeding Disorders community for nearly thirty years. She's held various positions in the industry side of the community and

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WINTER 2022

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NATIONAL WOMEN'S HISTORY MONTH

If we've learned anything over the past two years, it's how healthcare workers are heroes. The COVID-19 pandemic showed us the importance of the selfless acts of healthcare workers everywhere. That's why, in honor of Women's History Month, we wanted to shine the spotlight on woman trailblazers in medicine.

DR. ELIZABETH BLACKWELL (1821 - 1910)

Elizabeth Blackwell, who was born in the United Kingdom, became the first woman to earn a medical degree in the United States.

One of Blackwell's friends inspired her to become a physician—she told Blackwell how embarrassing it was to see male doctors. So, Blackwell set out to change that.

Sadly, many medical schools rejected her because of her gender. In fact, when the Geneva Medical College finally accepted Blackwell's application in 1847, the student body called it "an administrative practical joke."

Despite all of the adversity and opposition Blackwell faced, she graduated first in her class in 1849. She had a successful career as a surgeon, and when an injury left her unable to perform surgery anymore, she continued to blaze the trail for women in medicine by setting up a private practice. Years later, Blackwell started a women's medical school and founded two clinics for poor women and children.



DR. REBECCA LEE CRUMPLER (1831 - 1895)

Despite facing gender and racial prejudices, **Rebecca Lee Crumpler** became the first African-American female in the United States to earn a medical degree.

As a child, Crumpler watched her aunt take care of sick people in the community, which sparked her curiosity about a career in medicine.

This curiosity led to her working as a nurse in Charlestown, Massachusetts, in 1852. The doctors she worked with were so impressed with Crumpler that they recommended her to

the New England Female Medical College.

Despite mistreatment from some professors at medical school because of her race, Crumpler graduated in 1864 and started a medical practice for poor women and children in Boston.

In 1883, she published her *Book of Medical Discourses*, where she shared medical advice for women and children—one of the first medical publications by a Black person in history.

DR. MARGARET CHUNG (1889-1959)

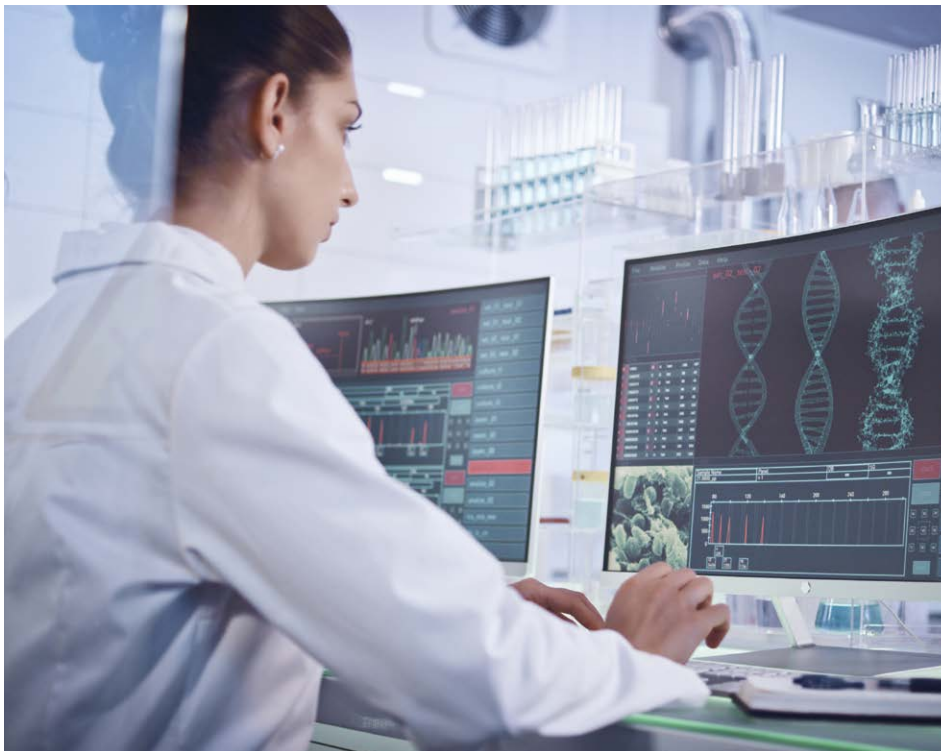
Margaret Chung graduated from the University of Southern California Medical School in 1916. She became the first American-born Chinese woman physician in the United States.

A devout Christian, Chung applied to be a medical missionary but was rejected because of her race. However, she was determined to work as a physician, and after completing residency, she moved to L.A. and became a well-known surgeon to the stars.

She used her connections with celebrities and politicians to lobby for the formation of the U.S. Naval Women's Reserve (WAVES), an organization she wasn't allowed to join herself because of her age, race, and suspected LGBTQ+ identity.



WE WANT TO SHINE THE SPOTLIGHT ON THESE WOMEN TRAILBLAZERS IN MEDICINE.



DR. BERTHA BOURONCLE PERENY (1919 - 2013)

Peruvian-born hematologist **Bertha Pereny** was the first person to identify hairy cell leukemia. She also became the first full-time female professor in the state of Ohio, after moving to the United States upon completing medical school in Peru.

Pereny and two colleagues developed a drug to treat hairy cell leukemia in the late 1980s. She also helped found the James Cancer Hospital, which opened in 1990 at Ohio State University.

DR. ANTONIA NOVELLO (1944 -)

Born in Puerto Rico, **Antonia Novello** earned a master's degree in public health from Johns Hopkins University.

In the early 1980s, Novello advised legislators on health matters, including tobacco-related diseases. She became the first Hispanic U.S. Surgeon General with her 1990 appointment by President George Bush, who was extremely impressed with her knowledge.

During her time as Surgeon General, Novello worked to improve minority health care and raise awareness about smoking-related health problems, drug abuse, and AIDS.

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Breaking Free Through Self-Care!

“Self-care is a critical component of living a high-quality life while managing a lifelong chronic condition...”

In August 2020, the World Federation Of Hemophilia (WFH) published new guidelines for managing bleeding disorders.¹ Reading down the long table of contents, you find the expected medical topics like coagulation therapies and clotting factors. Look closely, though, and you find topics like “patient self-management and empowerment,” “fitness and physical activity,” and “self-management at home.” Learning self-care is just as important as medical care.

Self-care is a critical component of living a high-quality life while managing a lifelong chronic condition, like a bleeding disorder. Ashley Judd, who lives with a chronic condition, summed it up well when she

said, “Self-care isn’t selfish. It’s self-esteem.” How you feel extends beyond physical health to include emotional and spiritual health. People with bleeding disorders or any chronic condition must learn to care about themselves throughout a lifetime to enjoy family, friends, work, and recreational activities. In doing so, they also help the caregivers who love them avoid burnout.

Self-Care Is an Intentional Lifelong Learning Journey

What does self-care mean, exactly? The definition quoted by the U.S. National Institutes of Health says it all. Self-man-

agement is “the ability of the individual, in conjunction with family, community, and health-care professionals, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions.”² However, self-care is more than keeping doctor appointments, taking medications, and avoiding injury. It is a lifestyle reflecting a personal decision to live the best life possible in all aspects—physically, psychologically, emotionally, and spiritually.

Ideally, younger children with a chronic condition are taught early that self-care is important, helping them understand that they need not fear living with their condition. This teaching prepares them to enter the teenage years with the right mindset.

In a nursing guide for the National Hemophilia Foundation (NHF), Jocelyn Bessette Gorlin discusses the importance of understanding what children comprehend at each age, so caregivers can use the right healthcare education tools and hold productive conversations to establish a belief in self-care. She acknowledges that educating a child early helps them learn the skills needed to succeed as they grow older and their health needs change. In one NHF study she mentioned, researchers found that only one-third of adolescents with a chronic illness had developed a good understanding of their condition.³ This

crucial high level of education has a ways to go.

The journal *Haemophilia* also highlights other factors in self-care. In a survey of caregivers and the people they cared for, many of the overarching themes concerned treatments because medical care must be regular and fit within school and work schedules. Treatments can also cause anxiety, stress, and physical trauma. The survey likewise found a connection with social stigma and adverse effects on personal relationships, and some adults put their careers on hold because of the difficulty in managing treatment schedules. Yet, even the researchers were

“Self-care isn’t selfish. It’s self-esteem. How you feel extends beyond physical health to include emotional and spiritual health.”

surprised to learn of the social stigma and anxiety associated with a chronic condition. The conclusion was that conversations about chronic conditions should go beyond medical care to discuss the impact on quality of life, lifestyle choices, and psychological conditions. All of these factors together impact the ability of patients and caregivers to self-care over a lifetime.⁴



those who live with and interact with the person, especially caregivers. According to the National Association of Caregivers (NAC), more than one in five Americans (53 million people) are caregivers, 61 percent juggle work and caregiving, and 36 percent consider their situation highly stressful.⁶ It follows that the decision to self-manage directly impacts the caregiver and the person with the medical condition.

Caregivers assist people with chronic conditions in so many ways. Depending on the age of the person living with a chronic condition, a caregiver may help them with home treatments, doctor appointments, and episodes of bleeds or other symptoms like joint pain. In addition, the caregiver must learn to manage the constant psychological and emotional stress, similar to the person with the chronic condition. Besides the physical and mental strain, it is difficult to see a loved one coping with a lifelong chronic condition because there is only so much even a caregiver can do.

When the caregiver sees the person with a bleeding disorder, or any chronic condition, grow as a person, learn self-care, and develop self-esteem, they receive a boost as well. Caregiv-

As you can see, self-care is a lifelong learning journey. Starting self-care education at an early age sets a person up for successful lifestyle management into adolescence and adulthood, becoming a way of thinking as much as a way of living. As Psychology Today discusses, the only things a person can control in life are thoughts, feelings, and behaviors. Control requires the use of the brain’s intentional system, so-called because it requires an intentional effort to turn on and is the reasoning, mindful self.⁵

A self-care lifestyle needs the intentional system or conscious processing of thoughts because thoughts lead to feelings and then behaviors.

Caregivers Are Impacted, Too

One of the often-overlooked facts of chronic conditions is how they affect more than the person with the condition. A chronic condition also affects



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THE POWER OF

// PODCASTS ARE AMAZING EDUCATIONAL TOOLS, ALLOWING THOUSANDS OF INDUSTRIES TO SHARE INSIDER TIPS AND ADVICE."

We live in the era of accessible information. One increasingly popular way to get information and continue learning—no matter your age—is through podcasts. You’ve likely heard your co-workers, kids, and maybe even your grandkids talk about podcasts lately, and you might have asked yourself ‘what’s the big deal with podcasts, anyway?’ In this email, we’ll go over everything you need to know about podcasts, and why you should start listening.

PODCASTS

WHAT IS A PODCAST?

Podcasts are audio programs, similar to talk radio, that are available directly through your mobile device. To find podcasts, you can simply enter the type of podcast you're looking for on Google. For example, "podcast about hematology treatments." You can also go directly to the Podcasts app on your smartphone and use the search feature there to find your podcast. There are no limits on podcasts, from length to topic, there's a podcast for everything and for everyone.

BENEFITS OF PODCASTS

So, what's so great about podcasts? Check out these benefits:

- **Listen anywhere, anytime** – Podcasts allow you to listen, learn, and understand on your own schedule. If you start a podcast while dropping the kids off at school, you can pause it for a morning meeting and pick back up where you left off on your afternoon walk — or, let's be more realistic, weeks later when you finally have some peace and quiet!
- **Find new community** – As we mentioned, there's a podcast for everyone. Podcast hosts are typically very active on

// THERE'S A COMMUNITY WAITING FOR YOU TO TAP INTO AND CONNECT WITH."

social media and share the social media handles of their guests as well. This allows you to find a whole new community of people in similar situations as you. A simple podcast listen can link you to the host's resourceful Instagram page and even Facebook support groups. Whether you're a hematologist or a patient or family member of someone with a bleeding disorder, there's a community waiting for you to tap into and connect with.

- **Learn unique topics straight from leading experts** – What other method allows you to have 24/7 access to top experts when you need it? Podcasts are amazing educational tools, allowing people from thousands of industries to share insider tips and advice.

Ready to start reaping the benefits of podcasting? Try listening to these top podcasts from leaders in the bleeding disorders community today!

1. **BloodLine Podcast**, by *BloodStream Media*

This is a patient-centered podcast which seeks to explore the stories of individuals living with a bleeding disorder.

2. **B's in a Pod**, by *Pfizer Hemophilia*

This podcast explores issue relevant to people living with Hemophilia B.


3. **Utah Hemophilia Foundation Education Podcast**, by *the Utah Hemophilia Foundation*

This podcast presents helpful programs that pertain to self-sufficiency in the lives of bleeding disorder patients.

4. **Hemophilia**, by *Aremu David*

This is a fictional presentation of the lives of bleeding disorder patients.

5. **Forgotten Factor**, by *Shellye Horowitz*

This podcast deals with lesser known issues in the bleeding disorders community, including the diagnosis and treatment of women. 



The advertisement features a collage of images representing diverse individuals and community support. On the left, the Brothers Healthcare logo is displayed with the text "Brothers HEALTHCARE" in a bold, sans-serif font. The collage includes a smiling young man, a woman holding a puzzle piece, a smiling young woman, a young boy with glasses and a red tie, a man pointing, a couple embracing, a smiling woman, hands clasped together, and a smiling man with glasses. The text "IT'S ALL ABOUT YOU!" is prominently displayed in large, white, bold letters on the right side of the collage.

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DR. LINDA LAUBENSTEIN (1947 - 1992)

Linda Laubenstein was an American hematologist and early HIV/AIDS researcher. In fact, Laubenstein was one of the first doctors in the U.S. to recognize the appearance of the AIDS epidemic.

While Laubenstein was working at a private practice in New York City, she observed a sudden spike in the number of Kaposi's sarcoma cases in young gay men with immune deficiencies. Kaposi's sarcoma, a rare form of cancer, went on to be identified as an AIDS-defining illness.

In 1983, Laubenstein co-founded the Kaposi's Sarcoma Research Fund and arranged the first national medical conference on AIDS at NYU. She was also an outspoken AIDS activist and often criticized the U.S. government for what she called a "reluctance to combat the AIDS epidemic."

DR. KIZZMEKIA CORBETT (1986 -)

Dr. Kizzmekia Corbett is a viral immunologist born and raised in North Carolina. She is best known for her efforts in developing the COVID-19 vaccine. After working at the Vaccine Research Center (VCR), National Institute of Allergy and Infectious Diseases, and the National Institutes of Health, Corbett became a professor at Harvard's Radcliffe Institute and assistant professor of immunology and infectious diseases at Harvard T.H. Chan School of Public Health.


After her appointment to the Vaccine Research Center in 2014, she became the scientific lead of the VCR's coronavirus team. The team's efforts focused on propelling novel coronavirus vaccines, including a vaccine for protection against the SARS-CoV-2 coronavirus.

At the onset of the coronavirus pandemic in 2019, Corbett started working on a vaccine to protect people. She recognized that the virus had similar characteristics to severe acute respiratory syndrome (SARS) coronavirus and used that knowledge to tackle COVID-19.

Corbett and her team partnered with Moderna to manufacture and test the COVID-19



vaccine. Corbett has admitted that she cried when the results showed that the mRNA-1273 Moderna vaccine worked.

These women—and countless others—changed history and inspired millions of other women with their compassion, care, intelligence, and trailblazing. We are so thankful for their crusade to provide equitable care, and we can't wait to see the next class of trailblazing women in medicine. 

Continued from page 2


has always remained focused on supporting the community she loves so much. Patti was very involved as a board member for the Hemophilia Foundation of Northern California and the Hemophilia Council of California. She found her passion in helping the Spanish-speaking community, playing a crucial role in assisting this community with insurance issues, and helping families with their immigration status through various legal avenues. In addition, Patti was a strong ally, advocate, and support system for many patients and their families during the height of the Hepatitis C and HIV crisis.

Kevin Shaughnessy, a co-founder of Brothers Healthcare, recognizes, "Patti has assisted Brothers Healthcare to expand our footprint into Northern California." Even as an employee with a competitor organization, Patti has always been available to help. A rare quality that everyone appreciates. Her interest and heart always lie in the patients and their best outcomes. Patti is going to leave a great void in this community. Her

retirement from her role at Brothers will be felt not only within our company but across the entire bleeding disorders community. As colleague Cindy Guzman mentions, "One of Patti's favorite events that she gave her heart to was 'Hispanic Heritage' done for many years in San Jose, California. She always worked closely with everyone in bringing important information to the community. As you can see, our community will surely miss her close involvement."

As I said previously, Patti has worked in many capacities within the Bleeding disorders community; she has been at Hartwood Health, eBiocare/Millennium Health, and now at Brothers Healthcare. At each stop, she has made an impact with her clients and her co-workers, associates, and all who have had the pleasure of knowing Patti. I count myself among those fortunate enough to have been not only an associate, co-volunteer, and now a co-worker of Patti's. I have learned and positively impacted by Patti's work ethic and care for the service each patient receives. Whether those patients are hers or not, she will go out of her way to

help, and that type of person is hard to let go of.

So back at the beginning, I said that saying goodbye can be difficult. In this case, we say "see you later" to Patti Nieves-Chapman because she is retiring from a long-spanning career that we have only scratched the surface of in this article. As tough as it is to say goodbye, it is with great happiness and appreciation that I can wish Patti a very happy retirement. Patti, you have spent so much time and effort helping others, making this world and community better a better place; you truly deserve to enjoy every second of your retirement. I hope you can get that custom camping van and find the wonders out on the open road. You now get to ride off into the sunset and do all the things you may have been putting off for when "you had time." You made it; You have arrived. I wish nothing but the best for you in whatever endeavor you choose. We can all take some pages from your book in how we comport ourselves, not only in our careers but in our retirement. We look to you now and in the future for those continued lessons. 

er burnout is common, and to avoid it, the caregiver must also take time for self-care. That is only possible when the person they assist is learning self-care and eventual independence. So, the person with a chronic condition and the caregiver learn self-care together.

Never Let a Chronic Condition Define a Person

Dealing with a chronic condition and its symptoms, like chronic joint pain, may seem like a constant battle. Yet, some people see it through the eyes of acceptance and refuse to live in a bubble; they know that learning self-care is the process for living the best life. The CDC has published personal stories of people with bleeding disorders who self-care and the role of caregivers who understand the importance of independence.

One such story focused on Alden Dunlap. Alden was diagnosed at 10 months old with severe hemophilia. He thanks his parents for making it a priority to learn about his condition and the hemophilia support groups for providing support, encouragement, and help with understanding how to live life to the fullest within personal limits. Today, Alden thrives with the support of his parents, wife, and friends, and he also works. At 23 years old, Alden has wise words for others living with bleeding disorders. "I look at hemophilia and see that it's a part of me. I'm not going to work my way around it. I'm going to work with it. I'm not going to let it define me."⁷

Develop a Unique Lifestyle That Works

Adults have many options for self-care. Of course, there are recommendations to avoid injury, follow prescribed medication routines, keep doctor appointments, and learn, master and adhere to a home therapy plan.



However, if that is all a person does, their life will become restricted, and their caregiver is at risk of burnout. Self-care means proactively caring for the body, mind, and spirit, and it includes taking actions like the following.

- Connect with local, state, and online support networks to share experiences. Remember, no one is alone.
- Strive to psychologically accept the chronic condition because it is manageable in many ways and should not define a person.
- Adhere to a healthy diet and regular non-contact exercise routine because both contribute to pain management, healthy bones, muscle strength, and joint flexibility. Exercises include activities like treadmill workouts, aerobic exercises, swimming, hiking, and golf.
- Regularly take time to regroup, de-stress, and take a mental break from constant underlying worry by doing something of personal interest, like a hobby, reading, walking outdoors, or attending the theater.
- Develop an understanding of the caregiver's role as a support resource (keyword "support") rather than a sitter

or parent replacement.

- Address personal fears and the fears of loved ones by holding honest conversations about how you feel, like Max did on the *Genentech in Hemophilia* website in "Stop Running: A Letter to My Younger Self."⁸
- Attend counseling for psychological support.

Mental, emotional, and spiritual well-being is important for people with a bleeding disorder and their caregivers. Caregiving is especially difficult if the person with the bleeding disorder never assumes self-care or believes there is no hope for living a good life. In such cases, the person with a bleeding disorder or any chronic condition can become dependent rather than independent because dependency is the path of least resistance.

As the new year approaches, take time to embark on a healthier lifestyle, both mentally and physically. Not only is self-care not selfish, but it is the essence of living your best life. 🌿

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