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FROM THE EDITOR

Change is upon us!

We are excited to announce changes to the Brothers Healthcare newsletter. Our beautiful redesign is coupled with a new name, *Infusing Life*, which is fitting for a fresh start to the new year.

“Learn how Brothers Healthcare puts patients first...”

Infusing Life brings to mind both our focus on infusion therapies and our commitment to the whole-person approach to healthcare. With each infusion of life-changing therapies, each phone call, and each warm smile, we honor you and your family.

A few other changes you'll find in *Infusing Life*, is a Clinical Corner article for healthcare professionals in the bleeding disorders community. These articles are written by experts for experts. We are also proud to

feature messages from our manufacturer sponsors, to highlight products and services relevant to you.

This issue will help you decode your prescription label, understand more about joint health, and visualize the clotting process. You'll also get an advocacy update and learn how Brothers Healthcare puts patients first. 🐾

Happy Reading!
—Jessica Steed, Editor



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.

(800) 291-1089

info@brothershealthcare.com

SCHOLARSHIP INFORMATION



The third annual **Brothers Healthcare scholarship award program** applications will open January 15, 2021. Please note there are changes to criteria this year.

Our committee will select two students with bleeding disorders, a male and a female, to receive a \$1000 scholarship award. **Applications and details are available on our website: [Brothershealthcare.com/scholarship-application](https://www.brothershealthcare.com/scholarship-application).**

For questions email: info@brothershealthcare.com



FOUNDERS' FORWARD

As we transition to a new year, growth continues to be a theme for Brothers Healthcare. Last year, we added fantastic new team members, educational programs, payer contracts, and even a new arm of our business: Brothers Pharmacy. These elements expand our scope but also bring us back to our core mission: unmatched patient care. We are grateful for the hard-working team we have built and the patients who trust us with their care.

Wishing you a 2021 filled with gratitude and growth!

Scott Carthey and Kevin Shaughnessy

Presidents and Co-founders



JOINT HEALTH OVER TIME



Clinical Corner is a new feature in *Infusing Life* and is targeted at healthcare professionals in the bleeding disorders space. Each issue will cover a specific topic detailed by an expert in the community. It is our hope that healthcare providers will use this information in their practice to benefit their bleeding disorders patients. In this, our first article, please enjoy an interview with physical therapist Heidi Purrington by Jessica Steed discussing the findings of the Joint Outcome Continuation Study (JOS-C)¹ and other aspects of joint health.

“Education is a key component to prevent progressive joint damage.”

*Heidi Purrington
PT, DPT, PCS, CBIS
Heidi has been a physical therapist at the Hemophilia and Thrombosis Center at Phoenix Children's Hospital since 2004. She received her Doctor of Physical Therapy from the University of Minnesota. She is a board-certified pediatric specialist and certified brain injury specialist. Heidi served as the Mountain States Regional representative for the National Hemophilia Foundation Physical Therapy Working group from 2010 – 2014. She enjoys working with children and adults in the treatment center to assist with recovery from injury or surgery*

and with improving overall health and participation in desired daily and recreational activities.

Steed: Thank you for sharing this study and talking about the findings. It's my understanding that the original Joint Outcome Study (JOS)² was pivotal in making prophylaxis a standard of care for severe hemophilia patients in the US. This extension study follows many of the patients to examine changes to their joints over time. As a PT, what was the biggest takeaway for you?

Purrington: The main takeaway for me is that even with current treatment recommendations and

treatment throughout childhood, we are still seeing increased joint damage and restrictions in activities in people with bleeding disorders. Also, once there is damage to the joint structures, that joint damage is more likely to progress. Another recent study³ examined MRI findings of joint damage and the likelihood that a person with severe hemophilia will have more bleeding and progressive damage of that joint over a 5-year period.

Another interesting part of this study showed that kids participating in sports and activities did not have significantly increased incidence of joint injury. This has been seen in other studies as well.

S: Were there any surprises for you in this study?

P: No, I don't think so. It was nice to see that the participants generally rated their overall quality of life as good. That's important.

Also, it is interesting to see that the PT exam scores correlated well with the MRI scores at least for later stages. This has not been shown to be true for early joint damage. We know that MRIs are a more precise way to examine joint structures, but they are not practical to monitor joint health and we must rely on physical exam findings to help us identify early problems in the clinic.

Many centers are using musculoskeletal ultrasound (MSKUS) in addition to PT exams to better monitor joint and muscle health and recovery from bleeds. It can help us determine how to proceed after a bleed to help prevent damage later. It has also been used as a good educational tool.

S: What elements of the study are the key takeaways for busy clinicians?

P: It shows we are likely to still see joint damage over time, so we must consider what else are we going to do to prevent damage and especially progression of joint damage to the point where there is chronic pain, loss of motion and difficulty with activities. As PTs, we recommend safe participation in sports, PRICE (or POLICE) for bleeds, full recovery of joint and muscles and progressive return to sports/activity. It seems education is a key component to prevent progressive joint damage and there are many great handouts and videos available. However, education and resources do not always help the patient. As clinicians, we need to figure out what is important for each patient and support them as they make choices in their health. We may also see improved long-term joint health with new treatments and the use of MSKUS to provide monitoring and education.

S: As far as patients starting or maintaining PT, does this



study inform your recommendations for physical therapy for your patients?

P: I think it is important that physical therapy is part of the multidisciplinary care provided to reduce potential joint damage. Physical therapy may involve a phone call, a single clinic visit or ongoing physical therapy services. If a child or teen is developing a problem joint, we'll need to determine if they need bracing or orthotics. Do they need to improve strength, flexibility, balance, and/or coordination? Do we need to re-evaluate what activities they are participating in and how we can help them participate without causing more damage or bleeding? The recent use of telehealth has allowed for improved communication and follow up after a bleed.

S: Does this study line up with your experience of working with patients with bleeding

disorders who have joint damage?

P: What I see from this study and my experience, is that while we continue to see incidents of joint damage in children and adolescents with bleeding disorders, there are still much fewer people than in previous generations who will have long term consequences of severe joint damage as a result of their bleeding disorder. Compared to previous generations our kids and young adults are able to participate in a wider range of activities and many have never had a bleed. Of course, this is not at 100% with no bleeds yet which is what we want. With all of the new therapies becoming more available and ongoing support for general health, I like to think of the possibilities that people with bleeding disorders will have better rates of participation in physical activities/sports and decreased incidence of injury

“Many centers are using musculoskeletal ultrasound in addition to PT exams to better monitor joint and muscle health and recovery from bleeds.”

and long-term joint damage than the general population.

S: Heidi, this has been very insightful. Thank you for your time.

P: You're welcome. Thank you for the opportunity to discuss an area I am passionate about. 🌊

References:

1. Warren, B. B., Thornhill, D., Stein, J., Fadell, M., Ingram, J. D., Funk, S., Norton, K. L., Lane, H. D., Bennett, C. M., Dunn, A., Recht, M., Shapiro, A., & Manco-Johnson, M. J. (2020). Young adult outcomes of childhood prophylaxis for severe hemophilia A: results of the Joint Outcome Continuation Study. *Blood Adv* (2020) 4 (11): 2451-2459. <https://doi.org/10.1182/bloodadvances.2019001311>
2. Manco-Johnson MJ, Abshire TC, Shapiro AD, et al. Prophylaxis versus episodic treatment to prevent joint disease in boys with severe hemophilia. *N Engl J Med*. 2007; 357(6):535-544.
3. Foppen W, van der Schaaf IC, Beek FJA, Mali W, Fischer K. MRI predicts 5-year joint bleeding and development of arthropathy on radiographs in hemophilia. *Blood Adv* 2020; 4:113-121. doi: 10.1182/bloodadvances.2019001238

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COVER STORY

FACTOR 101

PART 1:

DECODING THE

LABEL



By Eslam Omar, RPH, MPH Pharmacist

Many patients who have bleeding disorders use clotting factor concentrate (factor) to treat or prevent bleeding. Often, when patients receive a factor prescription (Rx) delivery from our pharmacy, they notice

the Rx label has many numbers and directions. Sometimes, these numbers are confusing, for example there is a factor range (Nuwiq 4104-5016 IU) on the box, as well as the actual factor units, and finally the Rx factor units prescribed. So, what do all these numbers mean and how can we interpret them? Let's examine an example prescription label step-by-step.

READING YOUR FACTOR RX LABEL

With each factor Rx dose, you will get pharmacy label that explains the content and directions. If you get your factor Rx from Brothers Healthcare, the Rx label will look like this.

FACTOR RX LABEL KEY

■ **Nuwiq:** Factor product brand name. The manufacturer is Octapharma.

■ **Dispensed Dose 4339U** is the exact number of international units (IU), or units (U) for short, available in this box of Nuwiq. In this example, this is also the patient's dose.

■ **Qty: 2** means there are 2 boxes of Nuwiq in this order. Always check that the quantity matches the number of doses you received.

■ **Lot#: M849B13292** is the lot number the manufacturer assigns to each batch they produce. The lot number is also

found on the manufacturer box and the factor vials. Lot numbers are important because if there is a recall on a product it is identified by batch and patients who have received this product are notified by the pharmacy.

■ **Exp: 11/30/2020** is the expiration date. Always check that date before you infuse factor. It is best to rotate factor by expiration date the same way you would with your groceries. You would use a milk carton expiring sooner before opening one with a later expiration date.

■ **Nuwiq 4560 units** is the dose, which will be dispensed in one or more boxes (vials). Nuwiq

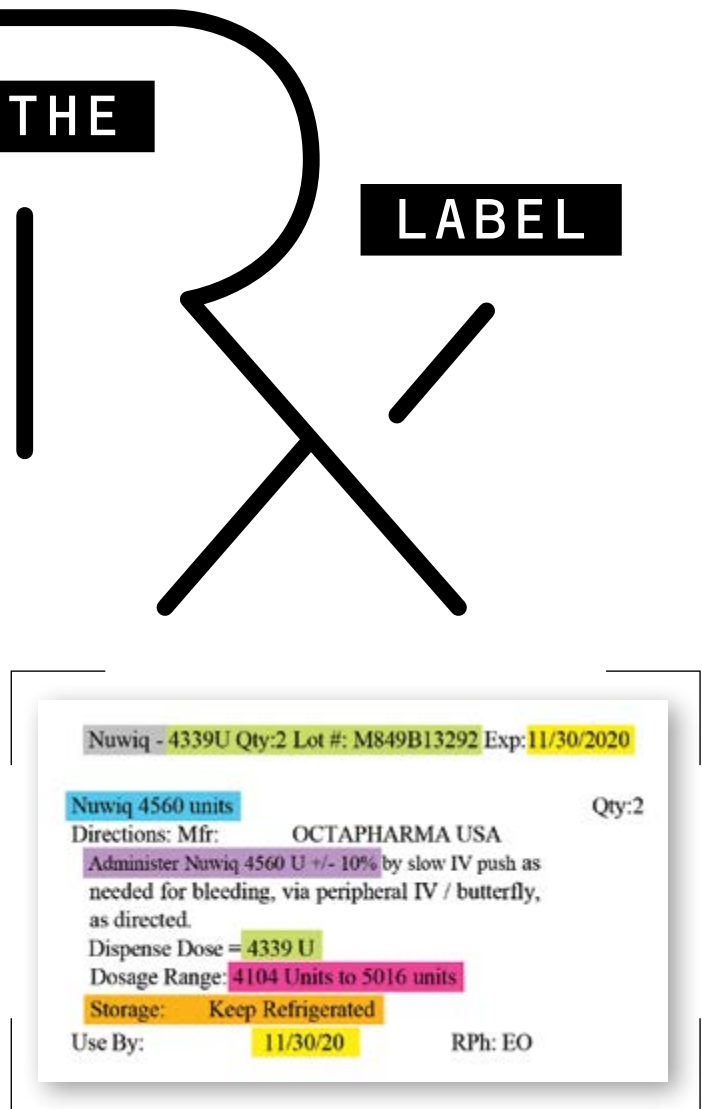
comes in these vial sizes: 250U, 500U, 1000U, 2000U, 2500U, 3000U, and 4000U.

■ **Administer Nuwiq 4560 U +/- 10% by slow IV push as needed for bleeding.** This is the dose and directions from your hematologist. Your dose is based on your weight (units per kilogram) as calculated by your doctor per manufacturer guidelines. This is why you must update your weight with each factor order. In this example, the prescription says to administer 4560 units +/-10%.

The pharmacy dispensed **4339U** which is slightly below the prescribed units, but within the range of +/-10%.

■ **Dosage Range (4104 U- 5016U)** Because factor manufacturers' products have slight variations in units per vial, factor prescriptions are usually written in range +/-5%, +/-10% and sometimes +/-15%. To meet this range with available assays, it is also common for the pharmacy to combine more than one box of factor to make 1 dose. For example, for Rx of Nuwiq 4000U +/-10%, the pharmacy can dispense **Nuwiq 1036U + Nuwiq 3177U = 4226U**. If your dose requires more than one box of factor, you will receive multiple boxes in one bag with one label as

See "Decoding" on page 8



ADVOCACY UPDATE

Excerpts FROM THE HFA'S WASHINGTON WIRE



Republican dominance in state elections creates hurdles for new Biden Administration.

Going into the 2020 election, Democrats expected a “blue wave” at the state level that would build upon their substantial gains in 2018, when they won back most of the record number of legislative seats they

had lost since 2010. However, their success in the Presidential race did not translate down-ballot where Democrats not only failed to make any state-level gains but lost at least 70 seats nationwide, including two chambers (the New Hampshire House and Senate).

The victories were critical for Republicans who preserved their ability to control the redistricting process in most states over the next decade.

Republican dominance at the state level may dramatically limit the ability of the incoming Biden Administration to pursue an agenda that includes expanding the ACA through public or Medicaid “buy in” options, expanded Marketplace

subsidies and outreach, and greater Medicare/Medicaid flexibilities for drug purchasing. While states will no longer get federal approval to narrow key protections under the ACA, they can continue to hinder state implementation or pursue alternatives like short-term health plans that could weaken the law. (Republican gains in Montana and New Hampshire may also increase attacks on existing Medicaid expansions in those states.) However, state reforms that have substantial bipartisan support such as guardrails protecting consumers from copay accumulator adjusters, balance or “surprise” billing, and step therapy should continue to progress nationwide in 2021. 🌊

“Decoding” continued from page 6 shown in the example below.



Storage: Keep Refrigerated is the general rule. Store your factor product in the fridge, preferably in its original manufacture box and sealed bag.

We will discuss more about factor storage, reconstitution, expired factor disposal, and the package insert in the next issue.

Do you have questions for our pharmacists about your factor, prescriptions or other aspects of your care? Call 1-800-291-1089 and follow the prompt to reach Beeman's Redlands Pharmacy* during business hours. For after-hours emergency calls, leave a message and a pharmacist will return your call.

*Please note: Brothers Healthcare is licensed as Beeman's Redlands Pharmacy. 🌊



BONDED BY BLOOD

