

## Cascade Supports New Fellowship Program

Attracting talented hematologists to work for comprehensive Hemophilia Treatment Centers in our region and throughout the country is of paramount importance to the bleeding disorder community. Cascade is dedicated to helping support physician's education through a Cascade Fellowship program.

Our first Fellowship awardee is Dr. Clayton Habiger of the Michigan Medicine Hemophilia Treatment Center. Colleen Joiner sat down with Dr. Habiger to learn more about him and his interest in the bleeding disorders community.

**Hello Dr. Habiger. Thank you for talking with me today and congratulations on being selected for the Fellowship program. What drew you to the area of medicine and particularly to the field of hematology?**

I have always been drawn to fields that involve science, serving my community and problem solving. Once I found that medicine involved all three, I was sold. While in medical school, I found the underlying mechanisms of bleeding and clotting fascinating. My hematology and coagulation interest was further solidified after I saw how dramatic treatments for hemophilia could be in a clinical setting.

**How did you hear about the fellowship, and what made you interested in applying?**

My research mentor mentioned that there was a fellowship through Cascade that was focused on hemophilia. Since hemophilia and coagulopathy in general is my direct career focus, it sounded like a great opportunity that I wouldn't want to miss. I was absolutely thrilled to be chosen! It's truly something special to be supported for a field that you are so passionate about.

**How do you envision your fellowship experience impacting the bleeding disorder community?**

Part of the educational program of the fellowship involves working with multiple disciplines at the bleeding disorders/hemophilia clinic. I feel that these various disciplines bring such nuance and a different perspective in approaching the same disease. I hope to integrate these different perspectives into my future practice. Additionally, I will continue to work in Dr. Shavit's coagulation lab, so I hope to contribute to the science of the field from that aspect as well.

**What are you most looking forward to in your Michigan Medicine Fellowship?**

To be able to learn from experts in the field and even work along-side them is such an honor. I am really looking forward to learning all that I can from them and relaying this to the bedside to help treat the hemophilia community.

**Now that we know a little bit about you professionally, what do you enjoy doing in your spare time?**

I really enjoy cooking and playing guitar. Since living in Michigan, I've started to do some hiking as well since there are so many trails and fun places to explore around Michigan. Me and my wife enjoy traveling with the most recent trip being to Italy. In some other personal news, my wife and I recently had our first daughter (Flora Habiger), so some of those hobbies might be on hold for a little while!

**Congratulations Clayton! It sounds like you have a lot of good things happening. Good luck with the Fellowship and your role as a new dad.**



## Dr. Roshni Kulkarni Receives Lifetime Achievement Award!

The Hemostasis and Thrombosis Research Society (HTRS), honors members of the community who have made a lasting and extraordinary contribution to research, education, mentorship, or clinical care in hemostasis or thrombosis. Dr. Roshni Kulkarni, from the Michigan State University Hemophilia Treatment Center, was this year's distinguished recipient. She was presented this award at the 2023 HTRS Scientific Symposia in Orlando, Florida on March 11. Congratulations Dr. Kulkarni! This is a well-deserved honor.

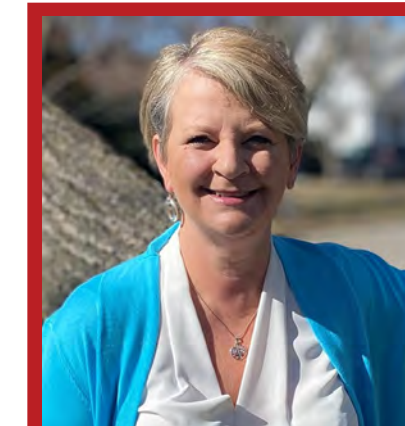


## Cascade... A Trusted Partner in Your Circle of Care

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Colleen Joiner, LMSW, CCM  
Clinical Care, Education & Outreach Manager

Dear Readers,

I often stop and think about the extraordinary families I'm fortunate enough to know in the bleeding disorders community. I regularly hear family stories of celebration as well as stories of life's difficult moments. And I'm always impressed at the ways people learn to not only "get through" those moments but to also grow through their adversities.

In this issue, we hear from one wonderful family; how they came together for support when it mattered and how they leaned on their faith to get through each day. We hear about an extraordinary little boy who will

hopefully look back on his first year of life and marvel at his own resilience.

When we experience life's challenges, we often reflect on how we made it through. Perhaps it was the overwhelming support we received from friends and family. Or maybe we recognize how we are changed by what's happened and how we are stronger for what we've endured. It's in these moments that we learn about ourselves and the people around us. It's in these moments that we appreciate not only the happy times, but also the challenging times that have helped us become who we are today.

## Cascade Hemophilia Consortium Mission

To enhance the system of care for people with bleeding disorders and related complications, by assuring the lowest possible price for the full range of treatments, HIV and hepatitis related therapies and other medications available to treat their disease; to provide access to these medications for those without insurance or inadequate insurance coverage; to support the comprehensive hemophilia treatment centers in treating and educating consumers and their families so they may become knowledgeable and proactive in managing their own care; to fund research.

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# A Portrait of Family Resilience: Nyair and Nicole Stanfield

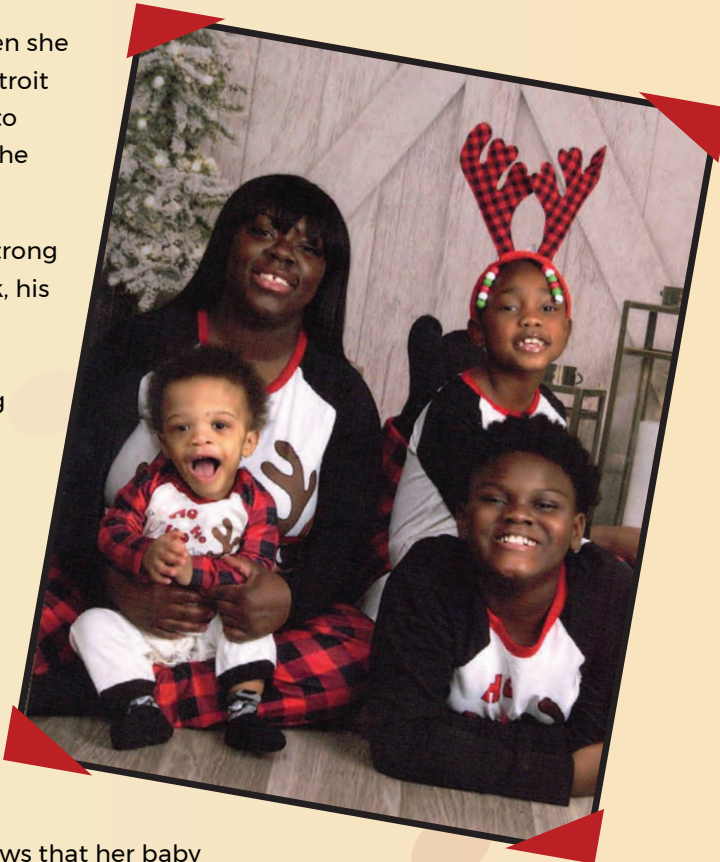
In September of 2021, Nicole Stanfield was 33 weeks pregnant when she tested positive for COVID. Her obstetrician at Hutzel Hospital in Detroit felt that in the best interest of her baby, they perform a C-Section to bring her third child into the world. Nicole and her family adored the new baby boy, Nyair, who was born with COVID as well.

Nyair spent his first 3 weeks of life in the NIC-U at Hutzel and the strong baby recovered from the virus. However, during a routine heel stick, his physician's noticed prolonged bleeding and it was discovered that Nyair also had severe hemophilia A. Nicole and her family were surprised by the diagnosis. There was no known history of bleeding disorders in the family which meant that there was a lot to learn.

The hospital prescribed factor as needed, and Nyair went home to his loving family. Four months later, Nyair experienced his first minor bleed and Nicole took him to the Children's Hospital of Michigan's emergency room for treatment. It was then that the medical staff noticed his breathing was unusually rapid; he was having difficulty catching his breath and was admitted to the hospital immediately.

After several diagnostic tests, an ECHO test revealed that Nyair had an enlarged heart. Two weeks later, the doctors diagnosed him with dilated cardiomyopathy. Nicole received the terrifying news that her baby would require a heart transplant. If they didn't find him an available heart, he would not live past his first year. The close family were shocked and afraid as they began the long search of a new heart.

The search took seven months. During that time, Nyair developed an inhibitor to his factor product which was successfully treated. His HTC hematologist worked diligently with the transplant team to ensure Nyair's bleeding remained under control. All along, he was a happy boy, laughing, eating well and playing in his crib at the hospital. Nicole stayed with him throughout the entire seven months. She had two other children at home aged 6 and 11, and took time to take them to the park or out to eat while her mom cared for them full-time. Nicole's focus was on getting Nyair the transplant he needed and bringing him home.



## What Does it Mean to Be Resilient?

Resilience is the ability to bounce back when faced with adversity. Being resilient doesn't mean that you won't experience stress or pain, or that you need to just "get over it." It means actively working through your emotions, so you are not only able to cope, but grow from each stressful event. Resilience is closely linked to happiness and allows you to find pleasure and meaning even through hardship.

Resilience is not a fixed state. You may be more resilient at different times in your life than others.

Can we nurture our ability to become more resilient? It's interesting that people who are most resilient have similar characteristics. And the good news is that resilience is something everyone can learn. It just takes time and practice.

*Stanfield story continued...*

One day, Nyair wasn't his usual bubbly self. He was clearly getting sick. Two days later the family received miraculous news - a heart was available. Nicole was beyond thankful and relieved when the transplant team, in consult with the HTC, immediately performed the surgery. Nyair, at 11 months old, was strong and he recovered well. After one additional month in the hospital, he was able to come home to his family.

In one short year, Nyair and his family experienced COVID, a hemophilia diagnosis, the onset of an inhibitor, and a heart transplant. He is still as happy as ever, running all over the house and laughing and playing with his brother and sister. This amazing little boy and his family are resilient.

### How did Nicole find the strength to get through such an emotional year?

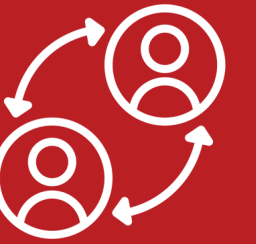
Nicole credits her strong faith in God as the main reason she was able to make it through such a scary time. She said that Nyair was never alone. Gospel music played in his room and family were always there to support him and each other every day.

Nicole focused solely on Nyair overcoming this challenge and returning home. She wouldn't accept any other outcome. She had her faith in God and the full support of her family. She was determined that Nyair would make it well beyond his first birthday.



## Connection

Connecting with Others - Resilience isn't about putting up with something difficult, being stoic or figuring it out on your own. In fact, being able to reach out to others for support is a key part of resiliency. Fortunately, several options are available to help you to connect with others who share your same struggles. Reach out to others to lighten your load, perhaps through support groups or counseling, camp programs for your kids, or bleeding disorders conferences throughout the year. If those don't appeal to you, having at least one support person, whether a family member or friend, can make a difference.



### Coping

Taking Care of Yourself - Focus on what you can control and do your best to let go of those things you cannot. As is often said, the only thing you can control is how you respond to a life situation. Take a moment to slow down and breathe when you are feeling most stressed and, if possible, briefly step out of the "fray" of life. Go outside for a walk or exercise to your ability to relieve built up emotions.

## Competence

Becoming an "Expert" in Your Own Care - Remember when you or your first child were first diagnosed? If you are like many people in the community, treatments and infusions may have seemed foreign. Once you learned about your bleeding disorder, how to recognize a bleed, and how to treat it, you felt more confident and competent. Your child will become more resilient too as he or she takes on more responsibility for their care and develops a belief in his or her own abilities.

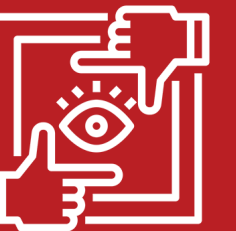


### Confidence

With Competence, Comes Confidence - This is particularly true for children who are learning to treat, and to understand their disorder, their medication, and eventually insurance. The more they understand, the more confident they become. According to one study, people who are competent and confident have lower levels of depression, anxiety, and emotional incapacitation. Focus on your strengths and remind yourself of the obstacles you have overcome.

## Reframing

Finding a New Normal - From the time of any diagnosis, you are adjusting to a new normal. Many parents have said those words after their child is first diagnosed. After several target joint bleeds some older folks are forced to find a new normal as well. Adjusting your point of view with each change is a way to move forward with a positive outlook.



### Learning

Learn from experience - Think of how you've coped with hardships in the past. Consider the skills and strategies that helped you through difficult times. You might even write about past experiences in a journal to help you identify positive and negative behavior patterns - and guide your future behavior.

## Faith

Believing in a higher power - Regardless of religious denomination or spirituality, faith can give a strong foundation when life becomes overwhelming. For many people, believing in a higher power gives the comfort of not being alone and hope through life's difficult moments.



*Resilience: Build skills to endure hardship - Mayo Clinic*

