

What is Resilience?

Resilience is the ability to bounce back or roll with the punches when faced with adversity. Being resilient doesn't mean that you won't experience stress or pain. It means 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.

Increasing Your Own Resilience

We all know someone who handles adversity with grace and calm. You might even be able to roll with the punches some times better than others. But how does that happen? It is interesting that people who are most resilient have similar characteristics. And the good news is that resilience is something everyone can learn.

1 Connection

Connecting With Others – Know that you are not alone with your bleeding disorder. 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, camp programs for your kids, or bleeding disorder conferences throughout the year. If those don't appeal to you, having at least one support, whether family member or friend, can make a difference.

2 Coping

Taking Care of Yourself – Focus on what you can control, and learn to let go of those things you cannot. As is often said, you can only control 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.

3 Competence

Becoming an "Expert" in Your Own Care – Remember when you were first diagnosed? If you are like many people in the community, treatments and infusions were foreign to you, and you may have initially felt intimidated or afraid. Once you learned about your bleeding disorder, how to recognize a bleed, and how to infuse, you felt more confident and competent. Learning is a process, and with each nugget of knowledge, with each infusion, you become more resilient. 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.

4 Confidence

With Competence, Comes Confidence – This is particularly true for children who are learning to infuse, 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 what you have overcome.

5 Reframing

Finding a New Normal – From the time of diagnosis, you are required to find a new normal. HTC social workers have said those words to many parents 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 is a way to move forward with a positive outlook.



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

Cascade Hemophilia Consortium

Cascade Social Worker, Colleen Joiner



Colleen

Dear Readers,
Living with a chronic illness, such as a bleeding disorder, can be challenging and overwhelming. Coping with spontaneous bleeds, heavy menstrual periods, factor delivery, scheduling time for treatments and clinic visits is stressful. In fact, research has found that stress associated with a chronic illness can effect your immune system and, in some cases, can be detrimental to your overall health. The best way to manage stress is to actually learn and, dare I say, even grow from adversity. In other words, one can learn to become more resilient. I am in awe of how many resilient people we have in the bleeding disorder community; those who consciously make efforts to improve their mood, change their viewpoint, or take control of their health in order to live a more satisfying life. I hope you find inspiration in the personal stories in this newsletter. I know I have.



Cascade Hemophilia Consortium
Launches New Website
www.CascadeHC.org

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Claude Moore

Claude Moore's quiet and friendly demeanor is one of the first things you notice about him. When you begin talking with him about his bleeding disorder, you also realize his strength.

Claude has severe Hemophilia A with inhibitors. He started life with a serious head bleed, and he developed an inhibitor when he was just 6 months old. Claude has lived with severe bleeding his entire life. "Pain is an old friend for me", he says with a half-smile. His inhibitor required daily infusions along with almost daily trips to the hospital, not allowing him to attend school regularly. Immune tolerance treatments worked well for him for short periods of time, but would inevitably fail.

As a teenager, Claude developed an uncontrolled bleed in his right arm. The result was compartment syndrome, a condition in which hematoma swelling resulted in insufficient blood supply, destroying the tissue, blood vessels and nerves. He required a skin graft and now sports a 12-inch scar running up the underside of his forearm and a railroad track of scars above.

When Claude walks, it's clear he lives with severe arthropathy. A radionuclide synovectomy briefly relieved his left elbow pain, but the bone protrudes as he moves his arm.

Claude worked hard on his education and career, getting an Airframe and Powerplant certification despite his inhibitor and subsequent surgeries. He now works at Detroit Metropolitan Airport, maintaining passenger planes.

Claude recently started treating with a new product. It does not help his arthritis pain but it definitely helped control his bleeding. With his first baby on the way, he hopes his daughter and her children will benefit from all the new and future treatments.

Why is Claude So Resilient?

Claude admits that there are days he feels down and even angry at times. When asked what has gotten him through those down days, he replies that he intentionally changes his perception of his situation.

"It's just good to breathe. To get up in the morning. I almost died on several occasions, but I think to myself that 'everything I'm going through is going to end.' Problems will resolve themselves. They usually do," advises Claude.

He also attributes his resilience to his Grandmother, Patricia. She was the main support in his life, taking him to appointments and hospital visits. She was there for him through broken bones, daily treatments and what Claude describes as, "bleeding on top of bleeding". Claude knows that changing his perspective was key, and also having her support made all the difference.



Claude Moore, age 25

Cascade Mission Statement

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.

Living and Thriving: Portraits of Resilience

Kim Allen

Kim Allen is usually a very social guy. He loves to attend events with friends within the bleeding disorder community, as well as get-togethers with old friends. But recently he has had to decline all social invitations due to health issues.

Health concerns are not a new concept for Kim. Born with severe hemophilia A in 1954, Kim suffered a stroke as an infant, which paralyzed his left side. As a boy, Kim did not have the benefit of the synthetic treatments that kids do today. After many years of spontaneous bleeds he developed severe and progressive joint damage.

In fact, the plasma-derived products he received were tainted with HIV and Hepatitis C. Kim was diagnosed with both in 1988 at 34 years old. He remembers the fear people had of HIV during that time. Once, while visiting a friend who owned a restaurant, he was hurt to see that his dishes were thrown away after he ate. That, and the fact that he lost so many friends to the disease, has shaped Kim.

Because Kim is generally very positive, it's hard to imagine what he has been through physically and emotionally. His wife, Lynn, states that "Kim always has hope. He is the most hopeful person I know."



Kim Allen, age 62, with wife Lynn

His outlook certainly was tested last year when after several hospitalizations he was diagnosed with pericarditis, and underwent open heart surgery to remove excessive tissue. The idea of open-heart surgery in general is worrisome, but with his other conditions it was frightening. He could not have done it without the support of Lynn.

Why is Kim So Resilient?

Kim's best lesson came from his mother when he was a boy. Kim was frequently hospitalized for bleeds and on one occasion was complaining about his situation. His mom, showing it could be worse, took him to see kids with polio who lived in iron lungs. Kim remembers that day as an epiphany. He realized that someone is always in a more difficult situation. To this day, he uses that lesson to reframe his perspective to this day.

His most recent surgery reminded him to take time to heal. He decided to take care of himself, to turn down all of the social invitations, and to have more quiet time for one year so that he can fully recover. Sometimes being resilient means slowing down.

Throughout the years, Kim has had many friends be there for him. Even at an early age, his 30 schoolmates gave him support.

Of course, having the support of his wife Lynn has been invaluable as she has been with him every step of the way. Lynn aptly stated that, "The guys who have been through so much, have such a will to live." Kim's outlook on life is certainly something to learn from.

Malysa And Conner Harris

Malysa Hadland grew up with an almost innate knowledge of hemophilia. Her brother had hemophilia and she was very familiar with bleeds and infusions. Told that her brother's bleeding disorder was caused by a mutated gene, Malysa was surprised when her son Conner was also born with severe hemophilia. She admittedly felt anxious about his future. When Conner was 7 months old, Malysa noticed that a knee bleed would not stop with the usual treatment and was, in fact, uncontrollable. After contacting the treatment center and going through testing, he was diagnosed with an inhibitor.

Because of the inhibitor, Conner was required to infuse two times every day. Monthly shipments of factor grew to over 120 boxes. These and countless supplies filled up Malysa's pantry and scheduling countless appointments filled her time. Conner spent his early years in a wheelchair much of the time, due to repetitive bleeds in his ankle, and was unable to participate in many activities.

At age 5, Conner was granted a "wish" trip for a Disney Cruise. During the cruise, he suffered a rare infection in his port. Two teeth were also infected. Severely ill and unable to enjoy the trip, he was immediately admitted to the hospital on his return. The infection was under control, but Conner barely remembered his special week away.

Last year, on his 6th port, Conner developed a very rare clot in the same area he had the previous infection. He was hospitalized for four weeks as medical teams worked to reduce the clot. Connor's heart-rate was dangerously high and Malysa rarely left the hospital during that difficult time.

Fortunately, life is better today. Conner recently started treating with a new product that only requires one infusion per week. And he no longer requires a port because he received his "Butterfly Award" at camp this past summer and now infuses on his own. Malysa is thrilled for her son...and to have her pantry back!

How Have Malysa and Conner Learned to be More Resilient?

Malysa says that through each event in Connor's life, they learned to accept what became their "new normal". At times this meant more work, planning and emotional energy. For Malysa, "You just adapt, and you keep your head up. Things do get better."

Malysa sees her family as her "saving grace" and her mom is her "backbone". She had Conner at a young age, and the support of her family, her friends and her employer is invaluable. Reaching out to other families in the bleeding disorder community and attending camp and support events have also been important for them both.

According to Malysa, Conner "fits in now". He runs, climbs stairs, and rides a bike. He is also in competitive swimming. This year the family went to Mackinaw Island and they didn't even take the wheelchair. "Our normal at one time was seeing Conner limp. At times it was scary to see the future, and now the future looks so bright."

Conner hardly seems phased by his experiences, frankly, because it's what he has always known. While in the hospital, he says he actually enjoyed his stay. He got to "play X-box and even made a new friend." This shows how mom, Malysa, has carried the burden. But through it all, they have both learned to adapt and to look at the positive in order to build their resiliency and be prepared for the future, whatever it may bring.



Conner Harris, age 9, with mom Malysa