

# WE ARE GRATEFUL TO PLASMA DONORS

HOW IS  
YOUR DAY?

## KAREN, LIVING WITH ALPHA-1 ANTITRYPSIN DEFICIENCY

I am Karen, and I am 46 years old and an elite disabled athlete. Because of my plasma therapy, I can participate in sports, run a nonprofit that works globally to socialize and mobilize people with lung disease, and spread information to the public about lung disease, and Alpha-1 in particular.

My plasma therapy has given me part of my life back. I have slowly but surely over the past six years rehabilitated to a life in sports, and today I am the first athlete under oxygen therapy with certification from the World Anti-Doping Agency for the use of oxygen therapy in competition. I also do obstacle course racing (OCR), and I was the first athlete under oxygen therapy to participate in the OCR world championships. My life in sport is far from over, my goals are high, and I am thrilled to pave the path for those who come after me.

I am a powerlifter in the Norwegian non-disabled federation and a disabled strongman in the elite class with several world records under my belt. Because of my therapy, I can continue my quest to

change the Paralympic criteria — I want children with cystic fibrosis, for instance, to be allowed to have a Paralympic dream (everyone with lung disease is currently excluded from parasport).

I am forever grateful that I won in the “postcode lottery” and got my diagnosis in a country that offers treatment. This is also why I work hard for others to get access to treatment. Before my plasma therapy was set in, I fought for my life for over two years — years that were mostly spent in hospitals and rehabilitation. When I came out on the other end, I had moved. Shortly after that I got my diagnosis, and all the pieces of the big puzzle with my lungs were laid. Though the path back to life was long, already after the first infusion, I felt something had changed in my body. Over the next years, I rehabilitated from not being able to walk and talk to a life in sports.

My life is truly grand. I enjoy it to the fullest, and I am grateful for every single good day I get. The plasma therapy is giving me a second chance in life. To live with Alpha-1 and lung disease can be hard and challenging, but with access to therapy, I can live a full life. ●

## JOHN, LIVING WITH HEREDITARY ANGIOEDEMA

I am a 32-year-old patient living with Hereditary Angioedema (HAE). I am happy to say I am living with this condition, rather than just suffering with this condition, thanks to C1-esterase inhibitor plasma therapy. Before having access to the therapy, my life was dominated by emergency room visits and many late nights spent on the bathroom floor. HAE patients carry a 30 percent mortality rate when untreated. For me,

that meant every night when I went to bed there was a chance I might suffer laryngeal swelling in my sleep and not wake up.

Thanks to access I have to treatment that is a fear that I no longer have to live with. I am now able to work, travel with my family, and enjoy many aspects of life that I once thought to be out of reach as a chronically ill patient. Watching the tremendous improvement in many HAE-affected family members has given me hope for the future — not only for me but for all my family. ●

