In Loving Memory of André en Milan (43&14 - vEDS – Netherlands)

June 16th, 2000 was a day filled with love and joy for André and Roelien. They said “I do”, and in 2003 their love was blessed with the arrival of their beautiful son, Milan. Even though André’s health was fragile, they embraced life wholeheartedly.

André and Milan were inseparable, bound by their profound love for rear-engine automobiles. While both shared this fervent passion, their allegiances diverged: André championed the robust Skoda, whereas Milan's heart belonged to the prestigious Ferrari. They had an incredibly beautiful time together as a family during their holiday in the Czech Republic.

But then fate struck. André’s physical struggles caused him deep frustration, because all he ever wanted was to take care of his family. Roelien found him in the shower, and there was nothing more she could do. He had suffered a brain hemorrhage and an abdominal rupture. André passed away as a result of Vascular Ehlers-Danlos Syndrome (vEDS)—an unbearably cruel condition. He had survived earlier life-threatening moments, but this battle could not be won.

Genetic testing was already underway, as André’s brother and mother had also lost their lives to the same condition. Even so, receiving the news that their son Milan carried the same gene mutation was heartbreaking.

As unbearable as that news was, and while grieving a husband and father, Roelien and Milan found a way to move forward. They continued taking little trips—although the return to the Czech Republic had to wait, because Milan insisted he first needed his driver’s license for that. Milan excelled in school, returning home with outstanding results. In 2017, with a heart full of love Roelien surprised Milan with a trip to a car show. There, one of his dearest dreams came true: a ride in his absolute favorite sports car, a Ferrari. Supported by his mother, he grew into a caring, thoughtful young man.

I first met Roelien in August 2017. My daughter had been admitted to the hospital for tests. Milan, however, had been rushed in urgently—this time not for tests, but straight to the pediatric ICU due to complications from vEDS. In such moments, words fall short. Everyone knows how fragile the situation is. Yet even through our chats, I felt the strength of this remarkable woman. And when I heard how Milan was fighting, I saw him as an example to us all—a true warrior.

When my daughter was discharged, we brought a card and a balloon for Milan, hoping it would bring a smile. It felt like so little. The helplessness I felt as an outsider—how must it feel for a mother?

Milan had always said he would reach 53 years old. But with Vascular Ehlers-Danlos, the unexpected can strike in an instant. Suddenly everything changed. After first being stabilized in a regional hospital, he was transferred to a children's hospital, where investigations revealed a tear in the main artery near the connection to the small intestine.

There is still so little known about Vascular Ehlers-Danlos Syndrome—a condition that deserves far more recognition, research, and urgency. Too often, families must spell the condition to medical staff, who then must look it up online. Time that vEDS patients do not have.

Still, Milan refused to be defeated. He fought with everything he had—his battle to stay with his mother was one that many adults could not have endured. His fight became a source of strength for countless others. When I face something difficult, I think of Milan.

For over three months, this incredible young man battled with real highs and lows. His mother never left his side, giving him strength and love every step of the way. Even during those months, Milan still dreamed, still found ways to celebrate life. One of the hospital's child-life specialists managed to arrange something truly special for Milan. A Ferrari was brought to the hospital so he could admire it and hear its engine one more time from his hospital bed. It feels impossible to believe that André wasn't there, watching over them, lifting them up.

It had become heartbreakingly clear that Milan's vEDS was far more aggressive than André's. His body could no longer function — yet his heart kept beating, strong and full of love.

Despite all the love, strength, and courage, Milan eventually had to surrender to an unfair fight. Yet still today, when I read Roelien's messages, I feel the presence and power of both Milan and André—still beside her, just in a place we cannot touch.

Roelien continues forward, celebrating life as much as she can—for her husband and for her son. Milan's story stays with me, and it must never be forgotten. Nor the story of the family who fought this battle with love, courage, and dignity.

May we reach a world where researchers finally see Vascular Ehlers-Danlos Syndrome as a condition worthy of urgent study—where better treatments, awareness, and hope exist.

My call for this will never fade—**in Milan's name**.