In Loving Memory of Daphne (23 - hEDS - Netherlands)

Creating a space to honor those who have lost their lives to the consequences of Ehlers-Danlos Syndrome does not come from nothing. In our community, we lose far too many beautiful souls to this condition. There are two people who are always in my thoughts—two people who continue to motivate me to keep fighting for better care.

Daphne is one of them.

I met Daphne at a patient conference—a young woman who radiated joy, strength, and spirit, even while fighting a fierce battle with her body. Her mother reflected that same light, even though I knew how heavy the reality was that she carried. One look at each other was often enough to tell a whole story — a silent understanding that words didn’t need to fill.

It was an honor to stay in touch with her, and I also came to know her sister. Such a beautiful, warm, and incredibly loving family. People often ask who I look up to, or who I am a fan of, and my answer is always different from most. People like Daphne and her family are my heroes — true examples of strength, compassion, and resilience.

Daphne devoted herself not only to raising awareness and supporting foundations, but, above all, to being there for fellow patients. Throughout everything, I never once heard her complain, never a bitter word — even though her fight was overwhelming. She would regularly send me messages asking how my children were doing, and whenever I asked how she was, she always responded with positivity and grace.

Sadly, Daphne suffered from severe gastrointestinal failure, a complication all too common in Ehlers-Danlos Syndrome. She relied on TPN to survive, and when the hospital failed to act quickly and effectively enough, a bloodstream infection took hold. In the end, modern medicine could not save her.

Daphne will never be forgotten.

Her story will continue to be told, and her spirit lives on through the work of so many who were touched by her life.

Her kindness, her courage, and the light she shared remain an inspiration — a reminder of why we must keep fighting for better understanding, better care, and better outcomes for everyone living with EDS.