

PRESS RELEASE

Place, date

Romy lost her husband to AL amyloidosis five weeks after the birth of their daughter

“Our daughter keeps me going”

Romy, 29, lost her husband to AL amyloidosis five weeks after the birth of their daughter. AL amyloidosis is a rare disease that affects approximately 150 people each year. What began as abdominal pain ended, for the newly married couple, in a farewell they were completely unprepared for.

“It still feels very unreal,” Romy says. “It’s like a bad movie in which I was given the leading role without ever asking for it. When I lay out the facts, I can hardly believe that this has actually happened to us.” Her husband, Michel, was a sporty man who led an extremely healthy lifestyle. He worked out, practised kickboxing and followed a healthy diet to match: plenty of fruit and vegetables, protein shakes and pre-prepared meals.

While on holiday in Spain, he developed abdominal pain. They put it down to the “holiday food”. But the pain persisted after they returned home. The GP diagnosed lactose intolerance. However, despite strictly following a lactose-free diet, Michel’s symptoms continued to worsen. Tests carried out by medical specialists revealed no abnormalities. “They told us everything was normal.” Yet Michel grew sicker by the day. He lost weight, and more and more symptoms developed: nerve pain in his legs, a bloodshot eye, and swelling in his legs and abdomen.

Nine months after the first symptoms appeared, the GP arranged for an ECG. The results revealed that Michel’s heart muscle was severely thickened. The word *amyloidosis* was mentioned. At that point, Romy was six months pregnant.

A time of joy?

“The cloud hanging over us was pitch-black. I felt the greatest happiness growing inside me, but at the same time, my husband was seriously ill, and I kept thinking: ‘How are we going to get through this? And how much time do we have left together?’”

A protein deposition disease

AL amyloidosis is a rare and serious protein deposition disease in which abnormal antibodies accumulate in organs and tissues. In a healthy body, proteins are used as building blocks. In amyloidosis, proteins misfold, preventing the body from recognising them properly. As a result, they accumulate in organs and tissues, causing pain and damage. There are several different types of amyloidosis.

The most characteristic feature of AL amyloidosis is that it is a multisystem disease. Because the abnormal proteins travel through the bloodstream, they can accumulate in almost any organ or tissue, often affecting several at the same time. This results in a unique and complex combination of symptoms, which is why the disease is often recognised too late.

“All those specialists at the hospital focused on individual symptoms and organs, but it was a failing system that was causing the problems.”

By the time Michel was diagnosed, he was already so weakened that medication offered little benefit. The abnormal proteins in his heart were interfering with the heart muscle's ability to function. Nevertheless, Romy held on to hope.

“I kept hoping for a miracle. That was what I clung to; otherwise, I wouldn't have been able to cope.”

On 15 May 2025, their daughter Marly was born with Michel by her side. For a brief time, the family was together at home, until Michel suffered a cardiac arrest. The same thing happened twice more over the following week. They had to say goodbye to one another.

Why she is sharing her story

“I often found myself wondering: ‘What if we had received the diagnosis a few months earlier? Would things have turned out differently?’”

“By the time the diagnosis was made, his heart was already so severely affected that the damage could no longer be reversed. Michel had an extremely aggressive form of the disease that progressed exceptionally quickly.”

Romy hopes that sharing her story will help her come to terms with what happened and provide a lasting memory for their daughter to look back on in the future. Above all, however, she wants to raise awareness of the fact that amyloidosis is a very serious disease. More and more people are being diagnosed, yet there is still little awareness of the condition.

“I can't bring Michel back by telling our story, but I hope it can help others and raise awareness, so that the disease can be recognised sooner.”

Note to the press — not for publication

For further information or to arrange an interview, please contact Wendy Bakkenes at the Amyloidosis Foundation Netherlands (Stichting Amyloïdose Nederland) via info@amyloïdose.nl or by telephone on +31 85 050 9959.

Saturday, 26 October, is World Amyloidosis Day. On this day, the board of the Amyloidosis Foundation Netherlands is calling for greater awareness of this serious disease. Become a donor and help us fund more research.

www.amyloïdose.nl

