

Dianne Hoefakker is Benne and Hille's mother. "In Hille's case, we discovered bruises shortly after he was born," she recalls. "The examination at the Academic Medical Centre (AMC) determined that it was haemophilia. At first, we thought the effects might not be that bad, but when he started to also suffer from haemarthrosis (bleeding into joint spaces), we knew something had to be done. Now the brothers are administered medication three times a week."

The Academic Medical Centre (AMC) also taught Dianne and her husband, Martijs, how to inject the clotting medicine. "Giving a shot was really hard for me," she admits. "Martijs is able to do it and he gives the kids their shots twice a week. But because of his job, he can't be there to do it that third day. The AMC referred us to the Haemophilia Home Care service. For the past 2,5 years, Hobert comes to our house every Wednesday to give Benne and Hille their shots.

"Without that option, we would be spending half a day every week taking Benne and Hille to AMC to get their shots. Not only would that take a lot of time, but it would make this disorder much more of a burden for them. This way they receive their medication at home, where it's normal. That makes them feel less 'sick'."

That does not mean that Dianne and Martijs underestimate the impact of haemophilia, but they want to try and keep things as 'normal' as possible for the boys. "We explained to their classmates at school that this was not some scary disease. One child might have to wear glasses; another has a cast on his arm; and Hille and Benne get a shot three times a week," Dianne says.

Mediq Medisource has a national network that it plans to make better use of in the near future. "If our clients are on holiday in Friesland or Limburg," Smink says, "it would be nice if they knew they can always call on us if needed. Even – and especially so – in an emergency. We know the clotting factor, always operate in conjunction with the Haemophilia Treatment Centre and have all the information at hand. That's faster than having to visit a hospital or GP wherever they are."

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Benne (2) and Hille (almost 5) have haemophilia A, a rare disorder in which the blood does not clot properly. Nurse Hobert Smink of Mediq Medisource's Haemophilia Home Care service visits Benne and Hille every week in Amstelveen to administer clotting medicine through a vein.

Benne and Hille get a shot

