

Dear friends overseas....

It took me some time to write this e-mail, but I have to inform you all that my dearest Anneke passed away on December the 11th.

Most of you knew that last spring we had to make a tough decision in Miami, Florida. Anneke's heart condition had been declining over the last year (and the years before that) so we came to the point where the risk of losing Anneke during the mission of sailing Bodyguard back to The Netherlands was simply too high. Especially in light of some promising news from our cardiologist in The Netherlands, offering screening for a heart-transplantation. When we started cruising back in 2010, heart transplantation had not been an option for Anneke due to all her medical treatments since 1993.

So we made the decision not to ruin her chance on a third life and arranged transportation for Bodyguard on a Cargo ship and booked ourselves a regular flight to Amsterdam. A month later, on May 23th, we loaded Bodyguard onboard HHL Lagos. We were really worried for Anneke's flight to Amsterdam because her strength was weakening. We were very lucky to find a nice couple near Port Everglades where Anneke could escape the heat and did her utmost to strengthen up the week before the flight. And she did. We crossed our fingers, were lucky to have three seats for maximum rest, and survived the flight.

After some hurdles Anneke got her screening for heart transplantation. After a hospitalisation of 17 days in the Rotterdam Erasmus Medical Centre her whole body including all her organs were checked. So far no obstacles were found... so we thought. August the 28th we heard the official outcome: a NO-GO on transplantation AND a NO-GO on a temporary solution called "Left Ventricular Assist Device" (LVAD). Based on the total amount of radiation given during Anneke's treatment back in 1993 the heart surgeons voted against both operations. That left us empty-handed. No light at the end of the tunnel. Nothing to aim at. Nothing to focus. This could not be the outcome of the decision we took in Miami to pull the plug on our cruising life.

We were lucky our cardiologist was also very disappointed by the opinion of his surgeon-team. He made some arrangements and got us a second opinion on the other Academic heart transplantation centre in The Netherlands, the "UMC-Utrecht". October 9th we had our first talk with the UMC-Utrecht's cardiologist and surgeon. We found out that they knew more of Anneke's medical and social background than available to them in her medical status. Clearly some 'networking' was done in her favor. A week later we got a green light for the placement of a LVAD primarily focused as end-therapy, but transplantation in due time was still a possibility. This was very good news! Again a light to aim at. Something to focus on. And they wanted to act quickly as Anneke's heart condition was declining.

For the healthy people among us some explanation of the LVAD, a mechanical pump, small enough to implant. This pump assists the main blood circulation on the left (output-pressure side) of the heart. The heart's right, collecting side, needs to perform this task in a normal way and regulates the circulation. But the total load on the heart will be reduced by the pump and the blood flow greatly improved. An external controller and two batteries are the outside-the-body components and will become vital for Anneke. This was a mental hurdle for Anneke: no more swimming and a negative on sailing. After some discussion the doctors compromised on conditional sailing.

November 5th we got the call: tomorrow, Friday, we were expected for hospitalisation and the start of pre-OK treatment with the operation on Monday 9th. This was what we were waiting for! Anneke was treated with a strong heart dopamine Friday and over the weekend. And she was reacting great on this medication. Sunday evening in the hospital we were preparing for the big day to come: a riskful but promising operation. But when I was helping Anneke brushing her teeth her surgeon came in the room: they had to cancel Anneke's operation in favor of a more urgent patient. Oops, that's a mental change. Instead of the operation next day, most likely a trip back home!

They had to reschedule the operation and the most experienced surgeon had two weeks of training outside Europe. So this could take another three weeks before the new operation. Anneke was boosted with dopamine, but needed to be lowered gently before she could be sent home. Next morning - the original day of the operation - Anneke got out of her bed and fell due to a black-out on low blood pressure. She was out for a few seconds. So she thought. Long story short. The fall initiated a muscle injury in her hip region. This created a bleeding, pressure on her nerves and a lot of pain. A heavy morphine treatment was needed to get through the days. Just before the weekend Anneke got home with extra medication. But shortly after the weekend we went back to the hospital for some extra tests. A stronger doze of morphine was needed to handle the pain. This was a lot of extra stress on her already weak heart condition. But she managed to hold on and just before the weekend Anneke was released again. With great determination Anneke got out of the wheelchair and a could get rid of her crutches. In order to mobilize as quick as possible Anneke did daily swim training with me and other friends. Starting with only one length in the swimming pool she regained her (limited) strength and was able to do twenty turns, almost with no pain after two weeks. Anneke was ready again and just in time. We got a new call: hospitalisation on Monday December 7th, with operation Wednesday the 9th. When we arrived in the hospital again that Monday, everybody was surprised how Anneke was doing. Walking easily and looking great. And very positive about the operation to come. Loaded with positive energy.

It was not that we did not talk about the risks. We did talk a lot about the odds. But in Anneke's opinion it was an easy choice. She wanted to give her utmost for this chance to extend her life another five years and hopefully longer when new therapies becoming available within that timeframe. Due to the strong progression in this stage of heart failure Anneke was facing a sure end without the operation.

Anneke's first pre-operation day was going well. Her blood values within the expected figures. All green for the last important test the next, last, day before operation. This test was the GO / NO-GO for operation. It's a mapping of blood flow quantities and pressures around and inside her heart. And the values were above the safety margin. A GO for operation next day December 9th. That evening we did our preparation routine as we did for all those important medical treatments over the last 22 years. I had arranged a place nearby the hospital to stay for the last night and the days to follow during her Intensive Care period. So we agreed I would come to her room early in the morning just before the operation.

Wednesday 9th Day 0. Anneke had a reasonable good night and was really ready for the operation. We made the last preparations. Anneke did type a WhatsApp for the inner circle. I was not allowed to read before she was off for operation between the doors of the OR. I was allowed to ride her bed to those doors and we gave each other a last kiss and a thumbs up in the corridor. All in a positive way. Now I was allowed to send her prepared message. "Dear friends. 'It giet oan!' (translation: It's gonna happen). Please all thumbs up, pray, and send positive energy. Shortly I will hold you all in my 'motorhart' (translation: engine heart) Let the new life begin...."

After six hours wandering around and later in the hospital I got the call from the surgeon: "Good news, we managed to place the LVAD" It was not easy, we had some bleedings but so far so good". What a relief! But now Anneke had to become stable and free of all the supporting medication. We knew the post-operation-

phase was dangerous too. The right side of her heart has limited performance and needs to perform its task in order to make the system work.

The first hours after the operation Anneke's heart was unstable and had several runs, periods of irregular contractions. At the Intensive Care they needed to fine tune the supporting medication all the time. It got us through the evening, night and morning.

Thursday 10th Day 1. During the day things became a bit more stable. The heart rate was still high, pressures on the low side, but the heart rhythm improved. And slowly the pressures raised. It was still marginal, but Anneke had pushed herself through the critical first 24 hours. During the evening medications were gradually lowered. Anneke was holding tight and more and more on her own. A few hours after midnight Anneke's nurse and I decided this would be a good moment to get some sleep. I was offered a family room within the Intensive Care Unit. So I got to bed to strengthen up.

Friday 11th Day 2. After some hours of sleep I returned to Anneke's room. First thing I saw were drastically lowered figures. I looked at the Nurse and she confirmed what I already thought: we are going the wrong way. Again the heart rhythm was becoming less efficient and the blood flows and saturation were dropping. During the morning every possible scenario was checked and they managed to hold Anneke just above the safety margin. But only due to more and more medications. Around noon, more and more specialists gathered around Anneke's bed. They all tried to assess the situation. What was going on? An internal bleeding? An obstruction? Or a collapse of Anneke's heart condition? After some intense hours it became clear that the most likely hypothesis was a collapse of Anneke's heart condition. And we came close to an acute situation. The specialist took the decision: back to the OR and a new operation to place a supporting device for Anneke's right side. This device can only be used in a clinical situation and is intended to get Anneke out of the acute situation by relieving the overloaded heart. We both knew this plan-B was needed in some cases and has helped some patients heart's to recover from the impact of the initial surgery, after which a new operation is needed to disconnect the supporting device from the hearts-right side. But Anneke's surgeon was performing a heart transplantation on another patient. The OR schedule was immediately altered to allocate the OR next to his OR. This took some time and the situation became critical. I was told I could stay next to Anneke if I wanted and they would push me over if I was in their way. I witnessed a really motivated and professional team of Doctors, Medical Specialists and Nurses. Even a complete extra OR team came to Anneke's room, ready to start the operation there. We were signalled the OR was ready. Again they let me ride Anneke to the Operating Room, the only thing which I could be of help with. Anneke was still deeply sedated since her operation but I told her to hold on and not to let go. We had too much to go for..... We were not ready yet!

During the day, Anneke's parents, brother, my sister and a close friend of the family came in to the Intensive Care. So all united we were sending positive energy, to Anneke and could only hope she kept on the right side of a very thin line during the operation. After roughly two hours our surgeon came. Bad news. "It's becoming very difficult. New invasive bleedings due to the connection of the right-side support and in the former problem area. We won't give up yet, but be prepared for the worse". At that time we knew we needed all the luck of the world: Anneke's life was in an imminent dangerous situation. Roughly half an hour later our surgeon came back and my world collapsed. Anneke, the love of my life, my soul mate, died. Despite her iron discipline to keep herself in the best possible shape, her determination and her strong will. Anneke was a survivor. Went through unbelievable situations. Was living in extra time for many years already, purely on character. Her pugnacity was not broken, but her body was.

Dennis Bezemer and in my thought Anneke de Roo
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