How could such a thin sleeve mean the difference between life and death?

When a dangerous dilation of her aorta was discovered, science journalist *Gemma Venhuizen* knew she was facing open heart surgery. The alternative was an unconventional approach developed by a remarkable British engineer who wanted to wrap the aorta like a bulging hose-pipe.

"What a lovely green," I said, looking at the walls of the operating theatre. "And everyone is so kind."

In late November 2023 I spent several hours under anesthetic, for a heart operation in Amsterdam University Medical Center that would possibly save my life. The PEARS procedure is an innovative technique to support the aorta that at the time had been performed on under 1000 patients worldwide – I was patient no. 935.

As a science journalist I found it fascinating, as a patient terrifying. What was the science behind the surgery? When I lay on the operating table, high on the fumes of the adhesive used to fix to my head the electrodes measuring brain activity, the choice had been made. But my search for answers had only just begun.

I counted the spotlights in the surgical lamp above the operating table: 30.

And then I was gone.

Heart murmur

Six years ago, I was due to sail on a research vessel across the Indian Ocean for an article in the NRC, the Dutch daily newspaper where I work. Before the trip, I had to undergo a seafarer medical fitness examination. The doctor noticed a heart murmur. Cardiological tests revealed that I had been born with a bicuspid aortic valve: a defect in the valve that allows blood to flow from the heart to the aorta, the great artery that pumps liters of oxygenated blood per minute around the body. My heart valve did not resemble the Mercedes Benz logo, composed of three equal 'leaflets', but of two half-moons with an opening between them. As a result, a small amount of blood was flowing backwards at each beat, making my heart work much harder.

This is not so unusual. One in a hundred people has a bicuspid aortic valve; it is one of the commonest congenital heart defects. But in a few cases the defect is accompanied by a dilated aorta: an aneurysm. A diameter of up to 4 cm at the point where the aorta begins is considered 'normal'. The aorta first ascends from the heart to the aortic arch, where arteries branch off in various directions, and then descends into the abdomen. In women, the aorta is narrower than in men and during a lifetime it enlarges somewhat as a result of the constant inflow of blood.

But the aorta may not dilate too much. That can lead to dissection, where a tear in the internal wall of the artery causes blood to leak between the layers of the wall, cutting off blood flow to organs, or even to an aortic rupture, where all the layers tear and you can bleed out within minutes.

It appeared that my ascending aorta, where it leaves the heart, had a cross-sectional diameter of 4.5 cm. Over a centimeter wider than you would expect in a woman in her thirties, but still a centimeter less than the limit at which intervention is required. Only in the event of a sudden dilation or a family history of connective tissue disorders is that limit reduced to 4.5 or 5 cm.

"One day, when I've retired, I might have to have surgery," was my response whenever the subject came up. For the moment, my heart defect was no more than a curiosity. All I had to do was have an ultrasound scan once a year.

A ticking bomb

Last year, on a scorching day in late June, I went through the usual routine of undressing. Dress and bra off, just my panties and sandals still in place. The sonographer warned me that the gel might feel cold. I made a feeble joke: "Oh lovely and cold, after the heat outside." Just small talk, like every year. Afterwards I got a cup of watery chocolate milk from the machine and waited for the cardiologist to tell me the results. "Everything's stable," she would say, "Nothing to worry about."

The floor of the cardiologist's office was covered with blue marmoleum. The cardiologist was as friendly as ever, asking about my work and my wish to have children. I waited for the reassuring words, but they didn't come. The scans had shown an increase of 4 mm. That rapid, sudden dilation presented a palpable risk: at 4.9 cm my aorta had in an instant become a ticking time bomb.

Before I had time to digest this information, we were talking about surgery options. The Bentall procedure, for example, where part of the aorta is replaced with a man-made tube, or the valve sparing aortic root replacement (VSRR), or a new procedure called PEARS – "a sort of compression sock around the aorta." She spoke of heart-lung machines and the risk of dying, about the dangers involved in pregnancy and about cutting through my breastbone. About a CT scan using contrast dye that would make me feel as if I needed to pee my pants. About months of rehabilitation.

I stared blankly at the text on my paper cup: *Plastic in product. Product bevat plastic. Plastik i produktet. Plaisteach sa táirge. Tuotteessa on muovia.*

The cardiologist continued to speak, but I was no longer registering what she said. Cut open. Plastic tube. Peeing your pants. Rehabilitation. The marmoleum turned into a blue haze.

Polar opposites

I had always seen myself as someone who would respond rationally to illness and adversity, someone who would surrender themselves to the science, confident that things would turn out fine. In reality, science journalist Gemma and heart patient Gemma proved to be polar opposites. During the day I buried my head in the sand. Denial made everything seem further away. "I might not have the surgery at all," I said in a fit of adolescent irritability to my partner. "I just don't feel like doing this."

At night in bed I spent hours reading medical articles. I read that there were two sorts of dissection: type A in the ascending aorta and type B in the descending aorta, on its way down from the aortic arch. If you suffer an aneurysm in the descending aorta, it is sometimes possible to reinforce the artery by fitting a stent inside the aorta that is inserted through the

groin (TEVAR procedure). But 'my' aneurysm was in the ascending aorta, making heart surgery involving cutting through the breast bone inevitable.

Every year several hundred aorta dissections occur in the Netherlands. The vast majority are due to ageing: the older a person is, the more fragile their blood vessels are. In a few cases, a congenital heart defect is responsible.

I read about the Bentall procedure, developed in 1968 by surgeons Hugh Bentall and Antony de Bono, in which part of the aorta is replaced and a mechanical valve replaces the aortic valve. During the operation you are connected to a heart-lung machine. This means you are not breathing for yourself and have no heartbeat. Following surgery, you have to take anticoagulant medication for the rest of your life. The risk of dying during the operation is low, but not negligible. "Only 5.5%," I read in one of the publications. Over 1 in 20. Figures that, as a journalist, I could easily qualify ('That study is over 20 years old!", "The percentages in Amsterdam UMC are much lower!") suddenly became far too concrete to me as a heart patient.

The VSRR, the Valve Sparing Root Replacement, is a variant on the Bentall procedure and for around twenty years has been the gold standard for aorta surgery in the Netherlands. Patients no longer have to take anticoagulants but do have to be placed on a heart-lung machine during the operation.

Specialists wait as long as possible before performing the Bentall procedure or a VSRR. "Think of it like a set of scales," explained a friend who is a doctor. "On the right you have the risk of dying because of a dissection or rupture, and on the left, the risk of dying because of the surgery. Only when the right side of the scale weighs heavier is an operation advisable."

Searching for 'PEARS procedure' produced far fewer research results than the other two types of surgery. I clicked eagerly on an article entitled *Systematic review of Pears and Health* – which turned out to be a study of the health benefits of pear consumption.

Just a plumbing problem

In the articles that did actually discuss the procedure, the same co-author constantly reappeared: a man named Tal Golesworthy. On YouTube I found a Ted Talk he had given in 2012 entitled *How I repaired my own heart*. Golesworthy was a tall, lean, balding and bespectacled Brit with Marfan syndrome: a congenital connective tissue disorder in which the aorta may become particularly weak.

Before the Bentall procedure was invented, many Marfan patients died young when their aorta ruptured. In 1999, when he was 43, Tal Golesworthy learned that his aorta was so enlarged that he was facing the same fate – unless he had surgery. But he didn't want such an invasive procedure, especially if he had to take strong anticoagulant medication for the rest of his life. So he wondered if there was an alternative. Much of Golesworthy's engineering work was concerned with pipelines. As he says in the video, he thought to himself: "This is just a plumbing problem. If your hose-pipe bulges a little, you just wrap some tape around the outside." Why wouldn't you be able to do that to the aorta?

He designed an 'exostent': the opposite of an ordinary stent (endostent) which is placed inside a narrowed blood vessel. Golesworthy's invention simply reinforced the outside wall of the

aorta, while the artery itself remained intact. This makes connection to a heart-lung machine and anticoagulant therapy unnecessary.

London surgeons Tom Treasure and John Pepper joined him in developing his invention. On 24 May 2004 John Pepper performed the operation on Tal Golesworthy. The first Personalised External Aortic Root Support was born.

Medical revolution

On the one hand, I was skeptical. Although Tal Golesworthy was still alive 20 years on from his operation, science had taught me to distrust 'n=1': you can't draw conclusions on the basis of one patient. And even though the number of patients had now risen to nearly 1000 and the surgery had also been performed on heart patients with a different connective tissue disorder or congenital heart defect, most of them had only been walking around with their 'aortic sleeve' for a couple of years. In 2018 there were two hundred, the rest followed in the six years since then. What if serious complications emerged over time? What if, in practice, the PEARS procedure shortened my life rather than extended it? How could I say yes to a procedure about which so little was as yet known?

At the same time, I was filled with a sense of adventure. I was fascinated by the PEARS procedure. New developments were precisely what interested me in my work as a journalist, as did scientists who dared to stray off the beaten track. This was my opportunity to become part of a revolution. A medical achievement that in the best-case scenario would ensure that I could grow old with a safely wrapped aorta, no medication and no complications.

Doctor Dave

For the remainder of the summer I visited Amsterdam UMC every few weeks. For a CT scan that showed the dilation in detail, and for a follow-up appointment with the cardiologist, together with my parents, to talk through the options available. Less than five minutes after we sat down, my mother was in tears and from sheer embarrassment I moved into journalist mode. I made notes, as if I was conducting an interview.

One name kept recurring during the conversation: Dave Koolbergen. "He can answer all your questions." She offered to schedule an appointment with him, so that I could make a considered choice.

That freedom of choice made me both anxious and relieved at the same time. On the one hand, I wanted to trust blindly in the science and longed for confirmation from the doctors: what would *they* recommend? On the other, I was happy to be part of the decision-making process regarding my own future: I wasn't a passive guinea pig.

There are around one hundred cardiothoracic surgeons in the Netherlands, but only one of them can perform the PEARS procedure. That is Dr. Dave Koolbergen, or as I soon came to call him (in my mind), Doctor Dave. I regarded the fact that his initials were also D.R. as a favorable omen. (Don't be so superstitious, said my rational self). In one of my sleepless nights I watched a presentation Koolbergen gave for CAHAL, the Amsterdam-Leiden Centre for Congenital Heart Defects. He works as a surgeon in both Amsterdam UMC and Leiden University Medical Center. During the presentation, Koolbergen – silver-grey hair, black shirt, well-trimmed beard – spoke calmly and deliberately. An experienced heart surgeon who

was sure of his facts, who believed in this procedure and – very important – had performed it dozens of times.

He summed up the advantages of the PEARS procedure clearly and precisely: by wrapping the aorta you could not only prevent future dilation, but also *reduce* the current diameter by several millimeters. And with a bit of luck that would also decrease any leakage from the aortic valve. In addition, the procedure would reduce the stress on the aorta wall and strengthen the entire wall through the growth of new connective tissue around the sleeve. An autopsy performed on a PEARS patient who died from unconnected causes revealed that new connective tissue and a network of new blood vessels had formed around the sleeve, making the aorta stronger than had been foreseen.

A fine-meshed white sleeve

A few days before my appointment with him I sent Koolbergen a whole laundry list of questions. Later on, I saw that an assistant had forwarded the email to him, adding "Good luck!" and a winking emoji. Deep shame. I had suddenly become the stereotypical demanding, interfering patient.

Dr. Dave was somewhat shorter than I had imagined. But his handshake was firm and he strode confidently ahead of me. I wasn't bold enough to tell him that I already referred to him as 'Doctor Dave', or to ask what the initial R. stood for. I politely used the formal 'you' when actually I wanted to be more informal – someone who in the near future would cut me open already seemed so familiar. He did the same.

Somewhere in the hour that followed I came to believe in the PEARS procedure. It wasn't that he downplayed the risks or presented rose-tinted future scenarios. It was simply the patience with which he answered my questions. No, another operation to replace my heart valve at some point could not be excluded with any certainty, and no, there was no guarantee that I would make it to the age of 90. But to date, of the well over 900 patients operated on worldwide, only two had died shortly after the operation.

He considered the risk of dilation reoccurring somewhere else in the aorta to be zero. The sleeve would not damage my aorta and would not lead to microplastics escaping into my bloodstream. It was made of a polyester material, like many medical prostheses.

According to Koolbergen, the fact that no other Dutch surgeon had as yet ventured to perform the procedure was bound up with the conservative nature of the medical profession. "To be able to do it, you have to have performed a lot of operations, so that you can respond quickly if something goes wrong or if you have to change course. The only problem is that most surgeons with considerable experience become fairly hidebound."

And the health insurers were not yet convinced. For that reason, my PEARS procedure would be covered by the university research budget of Amsterdam UMC's Heart Center.

One risk of the PEARS procedure was related to the point where the aorta begins. "There's a very small margin of fibrous tissue near the aortic valve, which prevents you wrapping it properly at that spot," he said. "In VSRR patients this tissue is stitched for extra support but in the case of PEARS patients we just have to keep a close eye on the area. We do that anyway by having patients come back every year for a scan." To date, he added, no PEARS patient had suffered a torn aorta after the surgery.

At the end of our appointment Koolbergen pulled out an elongated piece of plastic: a 3D printed aorta. Around it was a fine-meshed white sleeve that reminded me of the reusable plastic nets you get in supermarkets for your fruit and vegetables. "This is the PEARS," he said, indicating the sleeve. He showed me the incisions where the coronary arteries would pass through and the longitudinal seem along which the sleeve would be sewn up. On the basis of a CT scan they would make a 3D model of my aorta and then the sleeve would be made to measure in England. The material felt soft. It was an absurd idea that such a thin material could mean the difference between life and death.

The prevention paradox

Because I felt so fit, I had difficulty grasping the fact that I needed surgery. I ran five kilometers three times a week and I worked five days a week. For weeks after the operation I would be scarcely able to walk and according to the occupational health physician, it would be at least six months before I could go back to full-time work.

Besides, suppose it went wrong? What if I was the one patient who happened to die as a result of the surgery? Precisely because I was so aware of my freedom of choice, it felt as though I had to weigh up every single possibility.

Rationally speaking, I knew the operation was necessary, that my aorta could tear. But that scenario felt so abstract that it did not seem to be about me. And after the surgery, the prevention paradox would inevitably arise: my aorta would not tear but I would never know if it would have happened otherwise and so whether the operation had been necessary in the first place.

Mid-September, shortly after my appointment with Dr. Dave, I gave the go-ahead for the PEARS procedure. It was still nerve-wracking to be part of a 'medical revolution', I would still have preferred to have read great piles of medical literature about patients who had easily reached the age of a hundred thanks to PEARS. But slowly and gradually I gained the courage to relinquish control.

"Maybe it's like laser eye surgery," said a friend. "In the beginning almost no-one dared to have it done."

My CT scan was sent to the UK. It would take around six weeks for the sleeve to be ready. The operation itself would be at least two hours shorter than a Bentall or VSRR procedure. I would be under anesthesia for a total of four hours, and that period would include the cutting and stitching.

In the weeks that followed I saw in every Mercedes Benz logo the tricuspid aortic valve and in every shopping cart a PEARS mesh sleeve. During the day I threw myself into my work, at night I listened to 'Scar Tissue' by the Red Hot Chili Peppers. The words of a friend resonated in my head: "I won't be able to stand it if you die." I asked a photographer friend to take pictures of my unblemished décolletage.

Mirror image

The evening before my surgery Dr. Dave visited me in my hospital room. With a magic marker he drew a vertical line down my breastbone. "So that we know where to cut tomorrow. Once you lie down, it's harder to find the exact middle." Before I went to sleep, I

stared at the black line in the bathroom mirror. Tomorrow my image in the mirror would change forever.

The morning before the operation I spent pacing the wing. I put on a hospital gown and a white, netlike thing that was supposed to represent panties. Then I was wheeled in a hospital bed to the surgery department.

"What is your favorite color" asked the anesthetist just before we entered the operating theater.

"Green," I replied.

"Then it's your lucky day," he laughed.

I have only fragmented memories of the days after the operation. The nurse who held my hand in the middle of the night when I wasn't getting enough oxygen. The feeling that I had bubble wrap in my windpipe – a collapsed lung, requiring the immediate insertion of a drain in my chest. Dr. Dave, who dropped by to ask me how I was on the eve of St. Nicholas (a feast day on which Dutch children receive gifts) having just performed the PEARS procedure on a nine-year-old girl.

"At last – a man who mended my heart rather than broke it," I said.

The beat of my heart

At my request, Dr. Dave had filmed the operation. My skin was yellow with iodine, my chest held open by a sturdy metal clamp. Usually, I couldn't stand looking at images of surgery but now I stared transfixed at my own beating heart.

"It's working," I muttered in a morphine haze. "It's still working."

The disadvantage was that I also *felt* my heart beating. I even heard it, in quiet moments. While I was recovering from the surgery in my parents' house I thought the neighbors were playing really loud bass music. It took me a while to realize that the beat came from my own body. Some nights, the incessant pounding kept me awake for hours. It felt as though I was always afraid of something, without knowing what that 'something' was.

At Christmas I burst into tears when my father carved the rolled roast. The tight net around the meat reminded me of the sleeve in my own body. I wanted to cut it open, pull it out and give my aorta the room to move again, unrestrained.

But the PEARS implant would fuse with my connective tissue: removing the exostent would involve irreparable damage to my aorta. From now on, I was the rolled roast.

Anyone recovering from heart surgery encounters both mental and physical problems. In the months after their operation, patients may react extremely emotionally and various studies have shown that six out of ten experience symptoms of depression.

Before the surgery I had mainly worried about my physical recovery. It was only during rehabilitation that I realized that mental recovery was as least as complicated. After six weeks the wheelchair was no longer necessary but it was still hard to form coherent sentences. After four months I cautiously started running at the rehabilitation center, but my short-term

memory was still a disaster. And I would suddenly burst into tears or want to smash everything around me to bits.

The honeymoon period was over.

A Facebook invitation

I tried to find out if health insurers were gradually adopting a more positive attitude to the method. Their reply was: "We follow the advice of the medical associations." But the Dutch Association for Thoracic Surgery has not been asked for its advice. In May 2023 the Association sent a letter to the National Care Institute – which has oversight of the healthcare market – to express their support for full coverage of the PEARS procedure. The letter states that "in the opinion of the experts consulted", the safety and effectiveness of the procedure "in the medium-term" have been sufficiently demonstrated. As yet, nothing has been done with that recommendation.

Some of the spokespersons referred me to the National Care Institute, which advises the government on basic health insurance. They told me that precisely this kind of specialist medical care had to be assessed by the insurers themselves. "To date, we have received no request to advise on this new technique." No-one I spoke to had heard of PEARS.

In the week before Easter I got an invitation on Facebook for a closed group: *The Most Exclusive Club On the Planet*. Accessible only to PEARS patients. The invitation came from Tal Golesworthy.

Initially, I hesitated. I could think of a hundred things that were more exclusive than being a PEARS patient. I wasn't looking for solidarity through shared suffering. But in the end, my curiosity won out over my resistance. And anyway, I was now a member of the PEARS club, whether I liked it or not.

Scrolling through the messages, all I saw was enthusiastic stories from patients who were immensely grateful to Tal Golesworthy for giving them back their future. "Welcome Gemma!" they wrote. I didn't reply.

I read that Exstent, the company responsible for producing all PEARS sleeves (the 'ExoVasc®', according to the website) was set up and is run by Golesworthy. The inventor, patient and engineer had become a businessman. I was confused. Did I still think his Ted Talk was so genuine now I knew that he was trying to sell his invention on the market? As a patient, could he be unbiased when it came to possible drawbacks? Did I have a medical innovation in my body or a lucrative gadget?

In the week before my period I was suddenly awakened every night by my pounding heart. It seemed worse than usual. One night, I grabbed the blood pressure monitor: 167/94, far too high. I remembered what the cardiologist had said, that women can retain extra fluid just before their period and that can raise their blood pressure. I tried some relaxation techniques: I listened to the voice on my meditation app that told me to focus on my breathing, but the more I focused, the louder the pounding became. I felt desperate, furious with everyone who could just sleep peacefully.

I wanted to get to know Golesworthy, the man I had a connection with, willingly or not. I wanted to hear what his driving force was, how he could possibly have submitted to a completely unproven operation.

On Good Friday I had a video call with Golesworthy. Within five minutes I had learned that you pronounce Tal as Tel ("Short for Taliesin, a famous poet in Welsh mythology."), that he was blind in his left eye after an ice splinter injury when he was seven, that he had a motorbike accident when he was 41 and that he caught Legionnaire's disease when he was 44.

Here spoke no slick businessman but an impassioned scientist. "I prefer truth to propaganda," he said. I continued with my critical questions – how much he was earning from his invention, what the weak spots were in the design – but the patient in me had lost all her skepticism.

Golesworthy said that being the first PEARS patient, 20 years ago, had been terrifying. "They actually had someone else in mind, but at the last minute, the patient was not ready for the operation. So I became the guinea pig."

He said he sometimes felt desperately tired of peddling his invention. That he simply wanted to give patients the choice he had had and that he felt powerless in the face of doctors who described him, condescendingly, as 'that plumber'. That he cried when patient no. 36 died, and that he and his wife Teresa had chosen to remain childless. "I wouldn't want anyone to live with the uncertainty that comes with Marfan syndrome."

To compensate, he celebrates his birthday twice a year: once on 10 December and once on 24 May, the day in 2004 he became the first PEARS patient in the world. Sometimes he celebrates with the surgeons who operated on him, sometimes with patients: "The PEARS community is my family."

Patient no. 1000

"No. 935," he said, when he looked me up in his Excel list with patients. On the day we spoke, it showed 999 PEARS operations: 702 men and 297 women. "No. 1000 is being operated on as we speak." The youngest patient on the list was three years old, the oldest 80. Of all these patients, 132 had a bicuspid aortic valve, like me, and most of them had Marfan syndrome. "If you add all the patients together, you end up with over 3,300 patient-years of information. But there are still doctors who call it an experiment."

He went on to talk about his career as an engineer, and his research into flue gas filters. "If I hadn't had bloody Marfan, I'd probably still be working with those filters."

It was his father, also a Marfan patient, who had persuaded him in 1992 to have his aorta measured. It was growing steadily, reaching a diameter of 5 cm by 2000, the year in which Golesworthy approached surgeon Tom Treasure. He said to Treasure, "You face the same problems as an engineer, but you're not engineers."

In the eyes of an engineer, it's all about the stress on the aorta wall. They see the aorta as just an air chamber, an airtight compartment that transforms the pulsing bloodstream from the heart into a more regular flow. "As the pressure on the wall grows, or as the diameter of the artery increases and the wall becomes thinner, the faster you approach the ultimate breaking point. So what do you need to do? Maintain blood pressure, reduce the diameter and reinforce the wall. PEARS helps with the last two objectives."

Different acoustics

In our two hour conversation, Golesworthy shared a lot of information. He told me that identical twins can have very different aortas – two 16-year old twin brothers had both

undergone PEARS surgery. He explained that the sleeves ('ExoVascs', he specified) are produced by selective laser sintering, a technique by which powder is converted into a textile graft – a perfect model of the aorta. The fabric is made from the same polymer (polyethylene terephthalate) as standard vascular prostheses. However, it is knitted instead of woven and has a higher porosity.

I asked how he felt about being showered with praise by patients. He shrugged. "I'm no hero. I didn't start this process to save people, I did it to save myself." He's not interested in financial gain, he says. "If I wanted to become rich, I'd have been better off stopping the project."

I had read on *The Most Exclusive Club's* page on Facebook that, following surgery, some PEARS patients got an infection in the pericardium, the sac that surrounds the heart. "That's a risk in any heart operation," emphasized Golesworthy. Others had experienced the loud pounding I had felt. One of them, operated on four years ago, wrote that he still felt every heartbeat, mostly when sitting still and when his blood pressure was raised.

Golesworthy admitted that it was indeed not ideal that the aorta could no longer expand in synchrony with the heart rhythm due to the tight sleeve around it. The diameter of a 'normal' aorta increases by 10% with every heartbeat, but the PEARS sleeve reduces its flexibility. "The acoustics change because part of the aorta is more rigid, but the same applies to the Bentall and VSRR procedures." And yes, the ExoVasc was relatively expensive at around €10,000. On the other hand, the surgery was quite short and the risk of reoperation or infection was much smaller. His own operation had cost under €1 million, everything included. "Peanuts, in my opinion."

Giving one or two away every year

In 2015 Golesworthy won a Patient Innovation Award for the PEARS technique. He wasn't the first to come up with the idea of wrapping a dilated aorta rather than ruthlessly replacing it, but earlier attempts had failed due to lack of flexibility. (Or lack of strength – in 1948, the abdominal aortic aneurysm of Albert Einstein was wrapped in cellophane. It lasted seven years, but eventually it gave way and the aneurysm ruptured.)

Until 2017, Exstent was in fact a one-man business and Golesworthy did everything himself, from analysing the CT scans and making 3D models to producing the ExoVascs. Now it employs 12 people. "We make over two hundred a year, I can't do that alone." He still flies all over the world to promote his product at cardiology conferences and is always present when the PEARS procedure is being performed in a hospital for the first time. "Actually, I'd like to be doing something different now. I'm 67 – I'd like to have the time to learn bass guitar, go swimming and hunt deer. But I feel compelled to keep publicizing the PEARS procedure."

Golesworthy referred repeatedly to the difficulty of convincing doctors and insurers. At present, the PEARS procedure is performed in over 40 hospitals worldwide, from the UK and Belgium to Brazil and Australia. It is not carried out in the US because it hasn't been approved by the Food and Drug Administration. The question of who pays depends on the country involved: in the UK the National Health System covers the costs, in principle, while

in Brazil patients themselves pay for the ExoVasc. Every year, Golesworthy and his colleagues give one or two away to patients who really cannot find the money.

Patients inquire about the procedure

Golesworthy's story sounded convincing. But why was PEARS surgery still so rarely performed? And why did no-one want to pay for it?

The various Dutch hospitals I approached after the interview were cautious in their responses: they were following developments with interest but preferred to wait a little longer. Utrecht University Medical Center, for example, saw the PEARS procedure as "an innovative technique that could be very beneficial for patients," but "wished to see the long-term outcomes and additional evidence-based information."

Only the Radboud University Medical Center was now convinced. Aortic surgeon Guillaume Geuzebroek called me back and spoke enthusiastically about his team that "was all set" to be the second hospital in the Netherlands to perform the operation. "You have early adopters and you have the extremely prudent types. I belong to the second group. No operation is without risk, and with the PEARS procedure you're of course leaving a sick aorta in place instead of removing it. In theory, the coronary arteries can easily be damaged during surgery or a type A dissection can still occur within the sleeve, though to date that has never happened. And after a thousand successful operations worldwide, you see that the international surgical community is beginning to be persuaded." More and more patients were inquiring about the procedure. "In the beginning I referred them to Dave Koolbergen. But since then I have trained with him."

On Ascension Day this year I spoke to an old acquaintance in the supermarket who saw my scar and told me he had lost his brother to aortic dissection. The diameter of his brother's aorta was only one millimeter larger than mine had been. That night, for the first time, the pounding did not disturb me so much.

Open-hearted conversation

On the evening he drew the black line down my breastbone, I had asked Dr. Dave if I could interview him. About his career, about what motivated him. I had an irresistible urge to turn inside out the man who had looked into my insides. In May he invited me to come to Leiden University Medical Center, where he had just completed an operation.

At last I dared to address him with the informal 'you' and to ask what the R. in his name stood for. His full name is David Robert Koolbergen, like his father. From an early age he was 'Dave' – only his mother called him David, and only when she was angry with him.

His early ambition was to specialize in tropical medicine. "Or to be an inventor. I loved tinkering with machines. The advantage there is that no-one dies if you make the odd mistake." A few years ago he developed the Haermonics Pure, a device that ensures sufficient flushing during heart surgery. That love of innovation was something he recognized in Golesworthy when the two men met around ten years ago at a conference. He delved into PEARS and asked British colleagues if he could observe their operations. Initially, they weren't too keen but in 2018 a Dutch patient wanted to have the procedure. "And then the guys in London said they would come to the Netherlands and assist in the operation". Since then Koolbergen has performed around 130 PEARS surgeries, over 10% of the total number.

The PEARS prosthesis is relatively expensive because it is custom made. A normal tube prosthesis for valve-sparing surgery costs around €2000 rather than €10,000. "But you don't have to use a heart-lung machine and the surgery time is shorter. Patients spend less time in intensive care and go home earlier, this also reduces costs. Once more doctors are performing PEARS surgery, the insurers will come on board," he hopes. "Then it won't just be Koolbergen's hobby anymore."

After an hour and half, Dr. Dave stood up. He wanted to go to a hatha yoga lesson with his wife. As we said our goodbyes I added "Thanks for an open-hearted conversation". Only when I was sitting in the train home did I realize that it sounded like a feeble pun.

'Well done'

On 24 May this year I saw a very tall, lanky man waving at me at the busy junction at Piccadilly Circus in London. He reminded me of the Big Friendly Giant. I waved back. As I got closer, I called out "Happy birthday!"

It was the 20th anniversary of Tal Golesworthy's PEARS surgery, and I had invited myself to the celebrations. He was due to meet 12 surgeons and engineers in the exclusive Athenaeum club for a mini-symposium and lunch. He wore a blue shirt and a tie with a heart on it. Slightly embarrassed, I handed him a chocolate heart on which was written '20 years PEARS!' Read out loud, it didn't rhyme as well as in my head. Dave Koolbergen joined us for a cup of tea. He was the only non-British surgeon who had been invited.

Tal Golesworthy talked non-stop. He talked about his band, the Outboys ('Pink Floyd meets U2') and about the time his left leg twisted backwards while skiing because his joints are hypermobile.

In the beginning he was 'bloody scared' that his aorta would nevertheless fail. He still has annual tests. "But the diameter has never changed. The method works. If someone asks why I didn't do any laboratory animal research, I unbutton my shirt and say: 'Here's your animal trial data!'"

Beforehand, I was nervous about conducting the interview. But now, face to face with Golesworthy, I was happy I had persevered. Science had acquired a human face and that made it easier to have faith in it. After a cup of tea I asked Golesworthy and Koolbergen if I could take a group photo. With me nestling between my two saviors.

Later, during lunch, Golesworthy gave a speech. He recalled the meeting that had made the greatest impression on him in all those years of travelling to conferences. Over 12 years ago he met an elderly man, in his late eighties, who shuffled up to him after the presentation and shook his hand. "Well done," he said, "Well done." That man was Hugh Bentall, who in the late sixties was the first to give patients with a dilated aorta hope of a future.

A respectful silence followed. Then the server came in with the dessert: pear crumble.