

Author: **Audrė Srėbaliėnė**

National nominee for **Lithuania**

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Blood sister

Spouse? Haematologist? Psychologist? Donor? Which is most important for someone who's just found out they have blood cancer?

Not that the patient has a choice: all are important. But without a donor – ideally a relative – there's no hope of survival. Rita Subačiūtė, 25, was aware of this when she became one of Lithuania's six bone-marrow donors. So far she is the only woman in Lithuania to have donated to an unrelated blood-cancer patient, and given them a chance of recovery. But worldwide, she is one of the 12 million registered bone-marrow donors willing to offer a helping hand.

Rita was about to head home after a day at the office. She was just arranging some papers on her desk when her mobile phone rang.

"Hello, Rita", said a woman's voice that Rita didn't recognise. "About a year ago, you signed up to the register of non-relative bone-marrow donors, do you remember? We really need your help. You haven't changed your mind, have you?"

Had she changed her mind? As a doctor's daughter, Rita knew that a cancer patient's fate would depend on her answer – yes or no.

Rita didn't need any time to think it over. With a single phone call, haematologist Dr Rita Kviliūtė had changed the course of this exceptionally generous young woman's life.

That same night – 3 August 2007 – she found herself in the haematology, oncology and transfusion centre of the Vilnius University Hospital's Santariškės Clinic (VULSK). Blood samples were taken and despatched to Poland for urgent tests to determine precise immunological blood markers.

An instant decision

Donating bone marrow is unusual in one respect: a donor can save a patient's life without losing their own. All it takes is resolve.

Rita would find it hard to single out any one reason for taking the decision she did. But one of the main reasons she signed up to the register of donors a couple of years back was the desire to help others.

"My parents never turn their back on someone in distress. I try to live according to the same principle", Rita says.

One day, as she was surfing the Internet, Rita came across the "Be good" campaign. Hoping she'd be able to help a patient some day – regardless of where they lived or what nationality they had – she went straight to Santariškės, the Vilnius University Hospital blood centre.

All it took was a questionnaire, an agreement to register and a few millilitres of blood from a vein, to enable some important immunological markers to be identified. The information was all sent off to the national and global bone marrow registry for non-sibling donors. Then last year, some one else's disease chose her – as a suitable blood sister for a patient she'd never met.

Priceless experience

Rita's blood samples were sent off to Poland and that was followed by weeks of painful silence – painful not so much for Rita as for the patient, a man in a critical condition. The disease – acute blood cancer – was particularly aggressive. But the patient already knew that they'd found someone and that there was a chance he might be saved.

"When the results finally came back from the Polish laboratory, I could hardly contain my joy: I was a suitable bone marrow donor, though not an ideal one. Not all, but 9 out of 10 of my immunological blood markers matched the patient's, so the doctors asked me to prepare gradually for the procedure", says Rita, recalling last year's events.

Rita had a choice: the haematopoietic stem cells could be collected from her blood or direct from the bone marrow itself.

She knew the second option was simpler for the donor. Everything is done with the donor unconscious under general anaesthetic. In the operating room, a few hundred millilitres of blood are taken from the pelvic bones containing stem cells.

But Rita was curious. She wanted to be properly involved in the procedure, so she went for the first option: cell collection from the blood stream (peripheral circulation).

Five days prior to the procedure, Rita had to inject a special medicine into her abdomen twice a day. The medicine caused haematopoietic stem cells to be ejected from the bone marrow into her peripheral blood.

"During the preparation for the procedure, I was constantly thinking about the sick man. How does he feel? What's he doing? What's he thinking about? I knew he was being prepared for the transplant and had to take very strong medicines. I knew it was a tough treatment to take. The only consolation was the thought that I might be able to help", says Rita.

On 19 September last year, when Rita went to the VUL SK haematology, oncology and transfusion centre, the first thing she had to do was just make herself comfortable in an armchair, in preparation for the aphaeresis procedure.

A needle was inserted into a vein in each arm. The flow of blood started – from one arm, through the "smart" aphaeresis machine, which extracted the stem cells and returned all the remaining blood components to her other arm. Rita's task wasn't hard: she just had to lie still for five hours.

"Many people are afraid of needles and the pain they imagine goes with them, but I can assure you there's no pain during procedure for collecting haematopoietic stem cells. I mean, do people feel pain when they have a blood sample taken? Just a slight prick", Rita says.

While the aphaeresis machine was filtering her blood – pumping it round a bit like a coffee percolator – Rita was trying to guess what her future blood brother might be thinking. Is he worrying? Maybe. And she was anxious to give him *enough* stem cells, otherwise all the effort to save this dying man might be in vain. Rita could only really stop being concerned about it once the procedure had come to an end, the needles had been removed from her veins and the doctors had confirmed everything was all right.

With both arms still numb, she dialled her mother's number to let her know "mission accomplished", explaining that the donated bone marrow now had be transplanted into the patient within 72 hours.

"I knew the real fight for survival would only start once my stem cells were circulating in his blood. I knew the months right after the transplant would be especially hard", says Rita. "I spent those long months waiting too – waiting for news of his condition. Not a day went by when I didn't wonder how my blood brother was doing. Thankfully, the updates I got from the doctors were always positive: a steady recovery."

Indescribably happy

Rita Subačiūtė still doesn't know her blood brother. But Dr Kviliūtė keeps her informed of how he's getting on. A friendship has grown up between the two women, based on a shared desire to help another person.

Rita knows only that her blood brother lives on the other side of the country, that he is alive and living with his family. And he is making a rapid recovery. She also knows that, once all the crises are over, they will meet.

And for now she does what anyone with a modicum of responsibility and compassion would do: she talks to young friends and colleagues she knows well, and encourages them to what they haven't yet dared to: sign up to the bone-marrow donors' register.

Rita reckons we all have a built in self-preservation instinct that we're not in control of. Even when we hear a cry for help, we think first of all about ourselves – about our own health. We worry that even a routine medical procedure could cause harm.

"I've noticed that many people want to help others, but they're paralysed by groundless fears", says Rita. "But it may be that, in someone's hour of need, when they come face to face with death, we happen to be the one who's around and it's up to us whether we snuff out the flame of hope, or make it burn more brightly."

Another perspective...

"Very bad blood-test results. They're taking me into hospital right now." When Virginija Januškevičienė heard her husband say this, she almost dropped the phone. She headed straight out to the Kaunas Medical University haematology clinic.

In just a short moment, her eyes have filled with tears. "What are you supposed to think, faced with a cancer diagnosis? There's just one thought in your mind: this is it – the end. So we hugged each other and stood crying", Virginija sighs. Who knows

how long they would have gone on crying if it hadn't been for a man passing by the hospital corridor. He had battled leukaemia and won.

He started to explain how it is treated, what new techniques there are and what kind of help was available.

"Even today, I can picture his face", Virginija says, as her baby son Gerdas wriggles about on her lap, "As he went on speaking, we both calmed down. I can't tell you how much it helped. And now it's our turn to help others."

Gvidas Januškevičius, 29, was working as a sales analyst for "Topocentras" when he was diagnosed with acute leukaemia on 15 July 2007. Leukaemia means that the bone marrow stops producing regular healthy blood cells and starts producing cancer cells. Without the right treatment, leukaemia can progress very fast.

Three weeks after Gvidas got his diagnosis, his son was born. Four hours later in another hospital, his chemotherapy started, along with the search for a bone marrow donor.

"The patient's path from illness to recovery is quite long: months rather than weeks. If a donor can't be found, we can't perform a transplant", explains Dr Laimonas Giskevicius, head of Vilnius University Hospital's Santariškės Clinic (the VUL SK). "Without a donor, there's no chance. Chemotherapy can extend a person's life, but only for a certain length of time."

Gvidas had a transplant on 25 October. He still doesn't know who gave him his new lease of life. And probably the donor knows only that the patient they saved can now enjoy being a father.

Blood cancer: truth covered

When a doctor gives the fatal diagnosis "blood cancer", the patient's mind is immediately taken over by single thought: "I'm going to die". And, with fear of death, the descent into abyss begins. Only the prospect of being saved by a bone-marrow transplant restores the desire to live once more.

In this interview, Marija Turlinskienė, a psychologist at the VUHSC haematology, oncology and transfusion centre, talks about ways of looking at the disease, anxiety and the exhausting therapy:

Blood cancer is a disease which that forces you out of your own home and into hospital – for a long stay. How do you cope, not just with the disease, but also this kind of change in your life?

Blood cancer therapy takes a long time. It may take over a year before the patient is well enough to go home and return to work. All that time, the patient is worrying about whether a donor will be found. And if so, will the donor really be willing to go ahead? Will there be complications?

The cancer often hits young people. They lose their health, and their ability to work for quite an extended period, and their social life collapses.

After a long stay in hospital, they have to guard against infections, even simple colds, as they can have severe consequences for a body with a severely compromised

immune system.

They have to spend a lot of time at home, and find it difficult to adjust to the situation they find themselves in. They need endurance to live with the disease and to change their lifestyle after it. If they can be cared for by close relatives or friends, that is a major source of support.

What is the role of the psychologist?

Both patients, and their relatives experience many difficult moments. But patients may be worried about making relatives feel awkward and so avoid talking about the fear of death and sharing their anxiety.

Relatives do the same. They feel anxiety, but will try anything to convince the patient, "You'll make it through." And so the patient doesn't dare talk about being afraid of dying and suffering, so as not to undermine their efforts.

In that situation, it is very important to find an outsider. Someone who can listen to the patient and share inner anxieties and tensions. The psychologist's job is to hear the patient. And to equip him or her with some basic knowledge about coming to terms with the disease, reacting and coping in hospital.

Doctors don't give that information?

They do, but usually people under stress can't absorb all the information. Usually things have to be repeated several times by different people before patients understand – if they can go outside without a mask, for instance.

That's why a psychologist talks with patients about basic everyday and medical issues, such as what feelings come after chemotherapy and what can I do to help myself?

Do the relatives also need counselling from a psychologist?

Relatives may have a harder time of it than the patients themselves. Yes, the patient has to deal with disease, nausea and suffering. But the relatives see a suffering person and can't help. They put in a lot of effort by visiting, preparing meals, devising entertainment.

But the patient's primary need is for someone to be there. Even when patients are exhausted by treatment, irritable or angry or when they turn close friends away, deep down, they still want support.

It's been found that patients who are not alone recover quicker after chemotherapy and after bone marrow transplantation.

The Haematology, oncology and transfusion centre is usually caring for around 30 patients. How do you manage to see all of them?

Usually I get acquainted with every newcomer and have a chat with each of them. Later communication depends on the situation. Patients have days when they're feeling up, and others when they fall into despair.

It is always important to know the patient's reaction to the official diagnosis. One third of patients experience a severe crisis, requiring the support of a psychologist. Another third are disturbed, but support from relatives is sufficient. The remaining third manage everything themselves.

It is hard to tell what factors determine the reactions. Maybe the power of personality. Or maybe the fact that not everyone is able to master stress. Sometimes several causes in combination: a strong personality, sincere support of relatives and treatment that delivers results more easily.

No donor – no transplant

The first registry for non-sibling donors was created in 1974 in the UK. The initiative came from the mother of little boy called Anthony, who died because no donor was found.

A bone-marrow transplant is the only way to fight blood cancer.

The first sibling bone-marrow transplant was performed in Lithuania in **1999**, the first non-sibling transplant in **2000**. So far 500 transplants have been performed in the country.

The search for a donor usually begins with the patient's relatives – brothers and sisters are tested – but the chances of finding a match are not very high. Then a non-sibling donor is sought.

The search for non-sibling donors is done through the national register (2 700 entries) and the worldwide register (12m entries).

The national register is the **best bet** for finding a suitable donor, as members of the same population are closer genetically.

Over the past 3 years, Lithuania's national **register** has **grown** tenfold – **from 250 to 2700 potential donors**. 6 people have already donated stem cells to 5 Lithuanians and 2 Latvians. By chance, the bone marrow of one donor was suitable for 2 patients.

The **biggest registers are in the US (5m entries) and Germany (3m)**. Worldwide, there are some 30 000 patients in need of a non-sibling donor, and around 100 in Lithuania. A suitable donor is found for one in every three patients.

Lithuanian patients were mostly helped by the donors from Germany, but also from Poland, Italy, the UK, Cyprus and the US.

70% of potential donors in the national registry are women. But male bone marrow is more suitable for transplantation, because of immunological factors.

The aphaeresis procedure **does not harm** the health of the donor. The haematopoietic stem cells removed are usually replaced within 2 weeks.