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## Life after death

### The Flemish non-profit Navado brings relatives of organ donors together in times of grief



On 28 February, 2000, the Van Kempen family experienced its darkest day: Eight-year-old Kelly fell down the stairs while playing with her two sisters. Kelly's mother, Lia, drove straight to the hospital, where doctors told her that Kelly was already dead.

Immediately after giving her the terrible news, the doctors asked Lia and her husband, Erick, if they would allow Kelly's organs to be donated. "We knew we couldn't do anything more for Kelly and that by allowing organ donation we could maybe give

other children a chance to survive," says Lia Van Kempen now, 12 years after she lost her daughter. "So we immediately gave our permission. After that, the doctors told us about the donation procedure, but because we were still overcome by sadness, that information didn't get through to us."

#### Strength and support

A couple of weeks later, when Kelly's parents were slowly trying to come to terms with what had happened, they found the business card of Walter van Donink, the transplant co-ordinator at the hospital where their daughter had died.

"We met him several times, and he explained all the details of the complicated organ donation procedure," says Van Kempen. "We asked if there was some kind of self-help group for people like us; parents whose child had passed away and who had allowed the organs to be donated. Flanders has thousands of associations for all sorts of things, but at that time there wasn't one that dealt with the needs of relatives of deceased organ donors. So we started to talk to other doctors, and with another afflicted family, in August 2004, we founded Navado."

Navado stands for *NAbestaanden VAN DONoren*, Dutch for "relatives of donors", and has 370 families as members. "We mainly bring together people who have lost a loved one and, immediately after their death, gave permission for organ donation," explains Van Kempen, who lives in Antwerp."

Most of our members are parents who lost a child in an accident." She also points out that relatives often have many questions about what has happened to the organs, who the recipients are and how problematic the need for organ donors is.

"We can bring our members into contact with a transplant co-ordinator, and we share our stories with each other. Every year, we publish a little magazine that tells the stories not only of deceased donors, but also of recipients of an organ and their specific transplant case. And we interview doctors and transplant co-ordinators. Finally, every year in October, we organise a big social event, our Relatives Day, to which all our members and organ recipients are invited."

#### Grateful strangers

While Navado members are given help to find out more about organ donation, they will never get to know the patient who received an organ from their child or relative. European law doesn't allow relatives of the donor to meet the recipient – for several good reasons, one of which is avoiding a sense of guilt on the part of the recipient towards the donor's family.

However, the law does allow relatives and recipients to correspond via letter. Van Kempen explains: "Information about the identity of the donors and recipients is kept strictly inside the transplant hospitals (*who are part of the Eurotransplant network, in which the Benelux, Germany, Austria, Slovenia, Hungary and Croatia work together to exchange organs*).

"So as a relative of a donor, we can write to our hospital, and they will send the letter on to the recipient of Kelly's organs. We have done that several times, and they have written back saying that they are very grateful to us. But we can't ask them to tell us personal things in their letters, not even their nationality, because every personal details are strictly confidential. "The only thing we know is that, thanks to Kelly's organs, four children and one adult survived. However, now these children are adults, and I keep dreaming that some day, they will come round to say hello."

[www.navado.be](http://www.navado.be)

### **Make your wishes known**

Until recently, Flemings had to sign an official document in their town hall if they wanted to donate their organs in case of untimely death. But thanks to Facebook, that procedure has become much easier now. Since September, with one mouse click on their Facebook profile, people can publish their willingness to become an organ donor.

However, in practice, when you die you are always regarded as a possible donor in Flemish clinics – unless your relatives object. But having signed an official statement or having an organ donor's profile on Facebook can help persuade relatives to allow organ donation.

Senne Starckx

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