

Testimony of a Dutch donor, with related fourfold recipient. José Rutten and André Bek. Brussel, 18 october 2011.

Goodmorning ladies and gentleman,

My name is André Bek and this is my partner José.

We are delighted to be here in Brussels to talk to you about being a donor and a recipient.

Let me tell you a little bit about myself. I started life as a baby. And when I was a little bit older, after learning to read and write, I trained as an officer in the Royal Dutch Marine Corps. Later in life I got two masters in dentistry and physiotherapy. Now I am a manager in a Sports- and Health Centre near Rotterdam.

And now ladies and gentleman, I would like to introduce you to José, my partner and my only love.

Hello everybody, my name is José. I met André on the dancefloor. That was when love kicked in. Now we are together for almost 30 years. If you want to know what I do for a job...

I work as a human resources manager for a large trading company in Rotterdam.

Together we enjoy life intensely and we love for example mountain hiking, scuba diving, fitness and salsa dancing.

Yes, salsa dancing, so maybe it´s a powerfull statement if a donor and a fourfold recipient say nothing and just dance for you on stage for fifteen minutes.

But that´s not what brought us to Brussels.

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Over a period of twenty years, one of us received a kidney from his or her brother, father, mother and partner. He or she had the great misfortune the original disease returned in the first three donor organs. That makes André or me, according to professor Weimar at the Erasmus MC in Rotterdam, an unique recipient in the world. Since the last transplantation everything goes very well. We have no limits and life is smiling on us.

So now we want ask you the following question.

Who of us is the fourfold recipient?

Please raise your hands if you think it's José...

Please raise your hands if you think it's André...

OK. Let's reveal the secret.

I am the recipient...

And I am his fourth donor...

Why is it, we have asked you this question?

Because what you see is much more powerfull than what you hear or think!

Look at us and see for yourself:

living donation is a great way to save someone's life!

We started this presentation a little bit light hearted.

But we are talking today about a matter of life and death.

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The need for donor organs is increasing worldwide. The lack of available organs has resulted in an increase in the number of patients on the waiting list. In the European Union alone, more than 50.000 people are waiting for organ donations. Each day, on average, a dozen people die while waiting for a transplant.

This is a terrible situation within the European Union.

With promotion of post-mortem donation, an opt-out system applicable almost throughout the European Union and optimise the allocation of organs, we can't solve the problem of the shortage of organs anymore. Growing number of senior citizens, healthier lifestyles, increasing traffic safety, increasing survival rates after strokes and heart attacks, increasing incidence of diabetes finally causing kidney failure – all these aspects together will make the lack of organs more acute in the future than it already is today.

In new European strategies to promote organ donation, the possibility of living donation deserves a powerful recommendation. We have to break the taboo.

Living donation is the ultimate gesture of love. Something everyone should know within the European Union.

That's the life saving issue why we are here today.

The European populations must be informed better about the opportunities, the medical as well as the social benefits of living donation.

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It is our hope and desire that living donation will be a fully accepted form of renal replacement therapy. A form that transcends cultural, demographic, ethical and religious differences.

For the record, we are strongly against any kind of organ tourism. All organ donations must be "altruistic, voluntary, and unpaid."

Transplantation kills dependency, but brings freedom instead.

A very special form of donation is living donation.

In that, we dare to call ourselves experts and we are here today to share our experiences with you.

My point of view as a donor is, that - with living donation - I not only healed André, but also myself. Because I also suffered. We were both victims of André's disease.

Living donation is an ultimate act of charity.

In case of living donation to a loved one, it affects the meaning of life almost literally by merging with the loved one.

Yet giving away a part of oneself is not the usual thing to do in an age of individualism. People seem to be more and more concerned with themselves and accept less and less responsibility for others. There is an "Every man for himself, God for us all" mentality.

Our hope is that we are able to help shift the focus. That love for other human beings is reconsidered as a core value. Not in words, but in deeds.

Scarcity of organs may then change into abundance. Then our deep concerns about the severe and increasing shortage of donors can

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transform into hope and expectation. We wish our story can help change the mindset.

As a donor, I had more fear for André's health, than for my own. He was seriously ill. I was healthy. I could do it, mentally and physically.

The difficulty for me was to convince André. Because it seems: giving is "easier" than receiving.

The recipient feels responsible and guilty because of the situation. The recipient doesn't want a loved one to take risks.

When André refused my offer, I was very angry. With the necessary verbal violence, I told him: "We suffer together. If I can do something about it and you refuse, you're an egoist." That finally convinced him.

Now looking back, I am very proud that I've managed to convince him. And I have endured all this, without adverse consequences.

I am often asked how I show my gratitude. But the expression of gratitude is not an issue for me. That's because all my donors have been able to make clear to me, that they have done their deed with the utmost naturalness.

They showed me a mirror, saying: "You would have done the same for us! Right?"

They experienced the return of my health as the greatest gift. Together we celebrated and celebrate life. Gratitude is not material, it's a feeling. The nonverbal expression of gratitude shows it all, for those who really care.

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Another frequently asked question is, if it was not terribly hard for my brother, father and mother to accept the disease had returned.

Of course it was a disaster for all of us, but there was no question of feelings of guilt. Then two options are left: to stick in suffering, or accepting suffering that you can't change and go on. In the second option, we are specialized. Moreover, remember that in between the transplants José and I enjoyed life.

The Dutch society in general, reacts very positively to the phenomenon of living donation. That is the case, even though the Dutch population itself, has trouble to register as post mortem donor. In the Netherlands, despite many political and social discussions, and in contrast to for example Belgium, there is still an opt-in system. Research shows the majority of the Dutch population has a positive attitude to post mortem donorship. Yet it is not reflected in the number of registrations. There's a big gap between being willing to donate, and actually donating one's organs. This reflects the prevailing indifference. We fear, this will not change as long as the Dutch system remains based on opt-in.

Living donation prevents a long period of very expensive dialysis and the endless, daunting and gruelling awaiting for the death of another human being.

Living donation also gives a better medical outcome than post mortem donation.

Living donation is even beneficial to people waiting for a post-mortem organ since it helps reduce the waiting list.

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There is a need for more openness and positive attitudes regarding living donations. We must no longer make an issue of 'cutting into a healthy body'. Renal failure is not only the patient's illness. Loved ones also suffer. A living transplant heals actually two people. That justifies the 'cutting into a healthy body'. Moreover, the techniques and knowledge are so developed, that risks are minimal. You can no longer speak of an unethical procedure. On the contrary... Is it not unethical not to help a loved one when it's possible?

I wrote a book about my experiences: *Dancing On Sand*, with the subtitle: *The Gift of Time*. My book received substantial attention from Dutch media. *Dancing On Sand* can be read as a political and critical statement. It brings attention to the very urgent need for organ donors around the world.

However, *Dancing on Sand* mostly is a book about life, it's ups and downs, and how we have experienced both.

Dancing On Sand received praising reviews and enthusiastic reactions. It is my wish to have *Dancing On Sand* considered for publication by foreign publishers, so our story will be helpful in raising not only public awareness, but also EUROPEAN UNION policy makers' awareness of the importance of 'living donation'. Moreover, our story can help other people, comfort them, educate them and give them hope.

Ultimately we are one in our desire for the wellbeing of our loved ones. When a loved one is seriously ill and he or she needs an organ: remember the following:

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The more you give, the more you receive.

We know.

We wish, that the people of the European Union come to realize this in the context of living donation.

Ladies and gentleman, thank you for listening to our story.

We hope that you can spread the message that we have tried to bring over.

Goodbye and goodluck!