

The European Day for Organ Donation and Transplantation

Held in a different country every year since 1996, the European Organ Donation Day (EODD) has been organised by the Council of Europe to help raise public awareness on the need for organ donation and to promote the principle of voluntary and non-remunerated donation.

Essential points

Organ, tissues and cells transplantation is one of the great medical success stories of modern times and is the only life-saving treatment for end-stage organ failure in many conditions.

Key figures from the annual European-wide survey on transplantation¹ show the terrible situation of thousands of European citizens who suffer in silence:

- in 2015, more than **143 000 patients** in Council of Europe member states were on waiting lists (WL), representing an increase of 5% (compared to the previous year);
- the same year, while 39 343 patients were transplanted, 47 613 were added onto a waiting list – equivalent to **5 new patients added to a waiting list every hour** across Europe;
- more patients on WLs, combined with the chronic lack of organs, tissues and cells available, also meant that more patients died while waiting for a transplant (in 2015, 6702 people, +7%); **an average of 18 people on waiting lists die every day** across Europe;
- overall family refusal remains high: out of 12 730 families asked to donate the organs of their deceased next of kin in 2015, on average 40% refused. One reason for this is the fact that families are not always aware of the wishes of their deceased loved ones.

In fact, these figures probably do not represent the true scale of patient needs. The epidemics of diabetes and arterial hypertension and the general ageing trend of the population in Europe have resulted in increased needs, so that many more people could benefit from organ transplantation than the number presently receiving this kind of therapy.

This situation is not new and is regularly monitored by the Council of Europe using data collected annually across its member states.

With the view to improving this situation, the EODD has been held:

- to encourage debate, provide information and sensitise the public on organ, tissue

¹Newsletter Transplant 2016, published September 2016.

and cell donation and transplantation so that each person can decide for themselves;

- to establish trust among the general public towards responsible, ethical and non-commercial donation and transplantation;
- to honour and thank all organ donors and their families and to thank transplantation professionals throughout Europe whose hard work helps to save lives and to improve the quality of life of many people; and
- to raise awareness among governments of the need to support and allocate sufficient resources to organ donation programmes at national level.

The EODD event in 2017

The theme of this year's event is **"share a common goal: to bring back hope to the patients on waiting lists all over Europe"**.

The event will be hosted by Switzerland and Swisstransplant, the Swiss National Foundation for Organ Donation and Transplantation, on 9th September 2017 in Bern (more information on the event can be found here: www.eodd2017.ch). The new awareness campaign recently launched by Swisstransplant can be seen here: www.vivre-partager.ch.

Communication and Organ Donation Campaigns in member states

As the organising institution of the EODD, the Council of Europe's EDQM has created materials and visuals for the international campaign and developed a social media campaign comprising a newly designed webpage [HERE](#), and a [Facebook page](#). There are facts, figures, real stories/testimonies and experiences about transplantation to provide Europeans with relevant and exhaustive information. A thunderclap challenge completes the campaign to reach out to as many Europeans as possible.

Initiatives and contact persons in member states are detailed in Annex 1.

The status of donations and transplantation in Europe

Key figures are illustrated in this [infographic](#). The complete set of data per country is published in [Newsletter Transplant](#).

National consent systems for organ donation

Details of the two main types of consent systems are described in Annex 2.

Questions concerning Organ, Tissue and Cell donation

Is there a minimum and a maximum age to become a donor?

Anybody could potentially become an organ or tissue donor, regardless of their age. At the

time of death, any potential donor's organs and/or tissues are evaluated to determine their suitability for donation. Individuals in their 80s and 90s have successfully donated organs including liver and kidneys to save the lives of others.

What do religions say?

The major religions support the idea of organ donation.

- **Catholicism**
“Organ donation after death is a noble and meritorious act and is to be encouraged as an expression of generous solidarity.” *Pope Francis, Bishop of Rome*
- **Buddhism**
“Giving is the greatest of Buddhist virtues. The Buddha in a previous life gave his body to a starving tigress who could not feed her cubs. There are many such Jātakas Tales, some in which he even gave his eyes to someone who wanted them. What loss do I suffer to give an unwanted organ after my death to give another person life?”
Dr Desmond Biddulph, Chairman of The Buddhist Society, UK
- **Hinduism**
“Organ donation is consistent with Hindu beliefs as it can help to save the life of others.” *The Late Mr Om Parkash Sharma MBE, President, National Council of Hindu Temples, UK*
- **Islam**
“If you happened to be ill and in need of a transplant, you certainly would wish that someone would help you by providing the needed organ.” *Sheikh Dr MA Zaki Badawi, Principal, Muslim College, London, UK*
- **Judaism**
“One who saves a single life – it is as if he has saved an entire world” *Pirke D’Rav Eliezer, Chapter 48*
- **Sikhism**
“The Sikh religion teaches that life continues after death in the soul, and not the physical body. The last act of giving and helping others through organ donation is both consistent with and in the spirit of Sikh teachings.” *Lord Singh of Wimbledon CBE, Director of the Network of Sikh Organisations, UK (endorsed by Sikh Authorities in Amritsar, Punjab)*

Why is donation anonymous?

National legislations in Europe ensure that the donor and recipient remain mutually anonymous. Not only does this avoid the creation of an emotionally difficult relationship between the donor's family and the recipient, but it allows the donor's family to grieve and

the recipient living with the donated organ or tissue to begin healing in private, both physically and psychologically.

Many families of donors find it comforting to be told by the transplant team which organs have been removed from their loved one and about the outcomes of the transplants.

Recipients often like to hear which country their donated organ came from.

Why is it so important for families to talk about organ donation?

Because once a patient has been declared dead, healthcare professionals only have a few hours in which to bring up the delicate subject of organ donation with the family and the subject can come as a total surprise to them.

France's story: France's eldest son, Pascal (19) was run over on his way home from school and went into a coma from which he never recovered.

"After a few hours, the consultant and his staff came to tell us that Pascal wasn't going to survive. We were devastated. We just couldn't believe it. But the staff was great, so supportive and kind, talking us through it until we eventually understood what was happening to us. Then they very gently brought up the subject of donation..... "Donate his organs"! I never thought I would hear that question. Of course I knew organ donation existed: I had seen programmes on the TV, but we'd never talked about it at home. I mean, why would we? We never thought it would happen to us!

It was the sort of thing that you see in American films, not something that concerned us..."

France's words remind us of just how important it is to break the silence around organ donation and talk about it before it is too late. Most families may not be fully aware of the wishes of their deceased loved ones, because the issue of organ donation was never discussed and death came unexpectedly.

How do families that say "yes" to organ donation in such distressing circumstances feel about their decision?

Families that give permission for their deceased relative's organs to be removed later see their gesture as worthwhile and generous, or find it comforting to think that, somewhere, some part of their loved one lives on.

They don't regret having said "yes". They understand that their sacrifice means the gift of life for someone else and this was a way of extracting some good out of a tragedy.

France eventually said "yes" because of her son's own generous nature. She says:

"I needed to know that he lived on somewhere. I got back in touch with the staff at the hospital, especially the chaplain whose messages were such a help at the time. He told me that, yes, Pascal's organs had gone to several people! Yes, they were alive! Yes, they were all well! His answers brought me such comfort".

The mother of B., a three year-old boy:

"I was suffering so much that I didn't want other mothers to suffer too. If I had refused, my

little boy would have died "for nothing"..., instead, by donating his organs, he saved five lives. For example, I know that somewhere in Germany there is a little girl who received his heart! If he knew that, he'd be happy, because he really loved little girls."

The role of the European Committee on Organ Transplantation

In the field of health, the Council of Europe coordinates inter-governmental co-operation, involving experts from European states and contributions by other international organisations such as the World Health Organization and the European Union.

The Council of Europe's European Committee on Organ Transplantation (CD-P-TO) is the steering committee in charge of organ transplantation activities. It actively promotes:

- the non-commercialisation of organ, tissue and cell donation;
- the fight against trafficking;
- and the development of ethical, quality and safety standards in the field of organ, tissue and cell donation and human application.

Its activities include the collection of international data and monitoring of practices in Europe, the transfer of knowledge and expertise between organisations and experts through training and networking and the elaboration of reports, surveys and recommendations.

It supervises the activities of a number of individual projects, as well as the *ad hoc* Working Groups on the "Guide to the Quality and Safety of Organs for Transplantation" and the "Guide to the Quality and Safety of Tissues and Cells for Human Application". These Guides have become standard references in Europe and beyond, providing quality, safety and ethical guidance for professionals in the field² – a major achievement of the Council of Europe.

The Committee also creates legal and guidance instruments, as well as laymen brochures aimed at familiarising the general population with various topics of interest. The most recent ones are *Exercise your way to better post-transplant health* (July 2016) and *Umbilical cord blood banking. A guide for parents* (2nd edition, 2016).

The outcomes of this work are disseminated to the member states in order to stimulate evolution of national legislation.

More information concerning Council of Europe reference texts available in Annex 3.

Further information:

www.coe.int/organ-donation and [@EDQMCouncilofEurope](http://www.eodd2017.ch)

² The EDQM publications are available here: <https://www.edqm.eu/freepub>

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Initiatives and Contact Persons in Member States (Annex 1)

Estonia: Contact: peeter.dmitriev@kliinikum.ee

Finland: Contact: heikki.makisalo@hus.fi

France: Promotional campaigns are planned for October (living donation). Contact: fabienne.tong@biomedecine.fr

Greece: Contact: hellenictransplantorg@gmail.com

Germany: Contact: birgit.blome@dso.de

Iceland: 2017 communication initiatives aimed at educating the public, including articles in news media and magazines and an educational film (*Annað líf* [A new life]) as well as maintaining a high level of media attention with a significant contribution from families of young individuals who have donated their organs. Electronic registry for organ donation at the Directorate of Health, which was launched 2 years ago. Contact: jorlaug@landlaeknir.is

Ireland: Some media campaigns are planned around this EODD Event. The ODTI team also provides study days and nationwide education and awareness sessions on donation in hospitals and colleges. Annual report each year. Press & media submissions - interviews. Contact: odti@hse.ie

Italy: Contact: daniela.storani@iss.it

Latvia: Different promotional campaigns are made for media, patients and medical workers but without definite times and dates. Contact: liga.grudule@stradini.lv

Poland: Poltransplant promotes organ donation year-round during congresses and during sport and cultural events when Poltransplant is involved.

Contact: jczerwinski@poltransplant.pl

Republic of Moldova: Official Celebration in Chisinau, 14th October 2017. Promotion of transplantation in mass media (combating stereotypes on organ trafficking), organisation of advertising in action (flash mobs) and provision of information points.

Contact: tatiana.timbalari@gmail.com

Slovenia: Celebration in the context of the Ljubljana Film Festival LIFFE (November).

Contact: Danica.avsec@slovenija-transplant.si

Sweden: Contact: helena.strom@socialstyrelsen.se

Switzerland: Official host of the international event on the 9th of September.

Contact: katrin.uhlmann@swisstransplant.org

The Netherlands: Annual national “week of the donor” organised on the 9th October. During this week the ministry of Health advertises on national radio and television to raise the awareness of the Dutch people on the importance of registering their choice about donorship in the national registry. Contact: j.reiger@transplantatiestichting.nl

National consent systems for organ donation (Annex 2)

Member states of the Council of Europe have put in place two main consent systems to donate organs after death:

an opt-in or informed consent system under which donors are required explicitly to give their consent for organ donation. However, even if the system theoretically requires express consent from the donor, it allows the donation with the consent of the next of kin when no express consent from the deceased donor has been given during their life time. A certain number of member states have an opt-in system in place (e. g. Cyprus, Denmark, Germany, Ireland, Lithuania, Netherlands and Romania);

- an opt-out or presumed consent system, in which consent to donation is presumed where no objection to donation has been registered by an individual during their lifetime or is known to the donor's family. The vast majority of European countries have chosen this approach (e.g. Austria, Belgium, Croatia, France and Spain).

In practice, variations exist within both systems, and the family still plays a prominent role in the decision.

As legislation can change it is recommended to contact the national authorities in charge of these questions to confirm the current applicable consent systems in a selected country.

Council of Europe reference texts on transplantation (Annex 3)

- The [Convention against Trafficking in Human Organs](#) and its [Explanatory Report](#), which opened for signature on 25 March 2015 in Santiago de Compostela, identifies distinct activities that constitute “trafficking in human organs”. The central concept is “the illicit removal of organs”, which consists of removal without the free, informed, and specific consent of a living donor; removal from a deceased donor other than as authorised under domestic law; removal when a living donor (or a third party) has been offered or received a financial gain or comparable advantage; or removal from a deceased donor when a third party has been offered or received a financial gain or comparable advantage.
- The [Convention on action against trafficking in human beings](#) and its [Explanatory Report](#) (European Treaty Series, No. 197), which opened for signature in Warsaw on 16 May 2005 and entered into force on 1 February 2008, addresses the trafficking of human beings, including for the purpose of organ removal.
- [Additional Protocol to the Convention on Human Rights and Biomedicine Concerning Transplantation of Organs and Tissues of Human Origin](#) (European Treaty Series #186), which opened for signature on 24 January 2002 in Strasbourg and entered into force on 1 May 2006, aims at protecting the dignity and identity of everyone and to guarantee, without discrimination, respect for his or her integrity and other rights and fundamental freedoms with regard to transplantation of organs and tissues of human origin.
- [Oviedo Convention: Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine](#) (European Treaty Series #164), signed on 4 April 1997 and entered into force on 1 December 1999, is the first legally binding international text designed to preserve human dignity, rights and freedoms through a series of principles and prohibitions against the misuse of biological and medical advances.
- [Convention for the Protection of Human Rights and Fundamental Freedoms](#) (European Treaty Series #005), drafted in 1950 by the Council of Europe and entered into force on 3 September 1953, is an international treaty aiming at protecting human rights and fundamental freedoms in Europe. It.