

## The Role of the Organ Procurement Organization (DSO) in Coordinating Organ Donation in Germany and the Organ Donation Initiative Plan

### SUMMARY

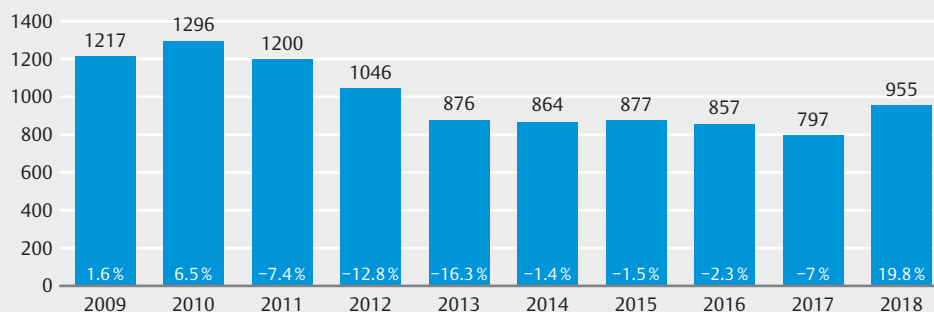
Organ donation in Germany started to decline in 2010 and dropped to a 20-year low of 797 organ donors in 2017. The rate of 9.7 organ donors per million population is far below donor rates in other European countries. The Deutsche Stiftung Organtransplantation (DSO, German Organ Procurement Organization) has been concerned about this development for many years and, in cooperation with German donor hospitals, has conducted extensive analyses to identify possible causes. While the causes are multifarious, the DSO sees the improvement of the identification and referral of potential

organ donors in hospitals as a key factor in enhancing organ donation rates. This is also necessary to comply with the wishes of individuals who have chosen to become organ donors after death. In order to improve the low organ donor rate in Germany, the DSO is asking for a general public discussion of the issue and for joint efforts by all stakeholders from professional medical societies to patient-support networks as well as political decision makers. A collaborative effort is necessary to achieve a turnaround in organ donation and help more patients waiting for a life-saving organ transplant.

The Deutsche Stiftung Organtransplantation (DSO, German Organ Procurement Organization), based in Frankfurt/Main, is the statutory organ procurement organization for organs donated after death in Germany. In this capacity, the DSO provides comprehensive support to the roughly 1250 donor hospitals regarding all aspects of organ donation. Once a potential donor has been identified and brain death has been determined, the DSO offers expertise to the local staff and/or the transplant coordinators in the donor hospital and coordinates all steps of the organ donation process. The services offered by the DSO include talking to the donor's family, supporting the intensive care management of the donor to maintain organ function, and the careful evaluation of the donor to prevent transmission of diseases such as infections or tumours from the donor to the recipients. The DSO is also responsible for coordinating organ recovery and transport of the organs to the transplant centres. All these services aim at guaranteeing a well-organized and transparent organ

donation process, supporting the donor family, reducing the burden for the donor hospital, and increasing the quality and safety of the donor organs for the recipients.

Organ donation in Germany declined by roughly one-third between 2010, when there were 1296 organ donors and 4205 organ transplants, and 2013, with only 876 organ donors. This decline was followed by 3 years of stagnation and another marked drop in organ donations in 2017. Encouragingly, there was a reversal of the downward trend in 2018 with an increase in post-mortem organ donors to 955, up 158 from 2017 (► Fig. 1). In 2018, Eurotransplant allocated 3113 organs donated in Germany, compared with 2594 organs in 2017. The number of organs transplanted after death was 3264 in 2018 versus 2765 in 2017. The difference between the number of organs donated and transplanted in Germany is due to organ exchange within Eurotransplant and beyond. In 2018, German donor hos-



► Fig. 1 Post-mortem organ donations in Germany (2009–2018); percentage indicates change from previous year [1].

pitals contacted the DSO about a potential donor in 2811 instances. This is a 26% increase in the volume of contacts on the previous year and marks a substantial positive trend.

Notwithstanding this promising trend, the increase in donations still falls far short of what is needed to compensate for the drop in organ donations witnessed since 2010. The chronic shortage of donors means that, despite the high quality of transplant medicine in Germany, it is not possible to provide adequate care to the more than 10 000 seriously ill patients waiting for a donor organ. The benefits of transplant medicine are thus not available to all patients in need. A dramatic consequence of the donor shortage is that in Germany three patients on average die every day while waiting for a suitable organ. This situation has not improved over the years, and each death on the waiting list means that a patient did not get the chance to live a longer and better life with a new organ. Germany's organ donation rate is very low compared with other countries. In 2016, the rate was 10.6 donors per million population (PMP), while most other European countries had donor rates at least twice as high or even up to 4 times higher. To cite just a few examples, France had 28.7 donors PMP, UK 21.5, Italy 24.7, Austria 25.2, Belgium 30.8, and Spain as many as 43.8. The United States also had a markedly higher donor rate of 30.8 [2].

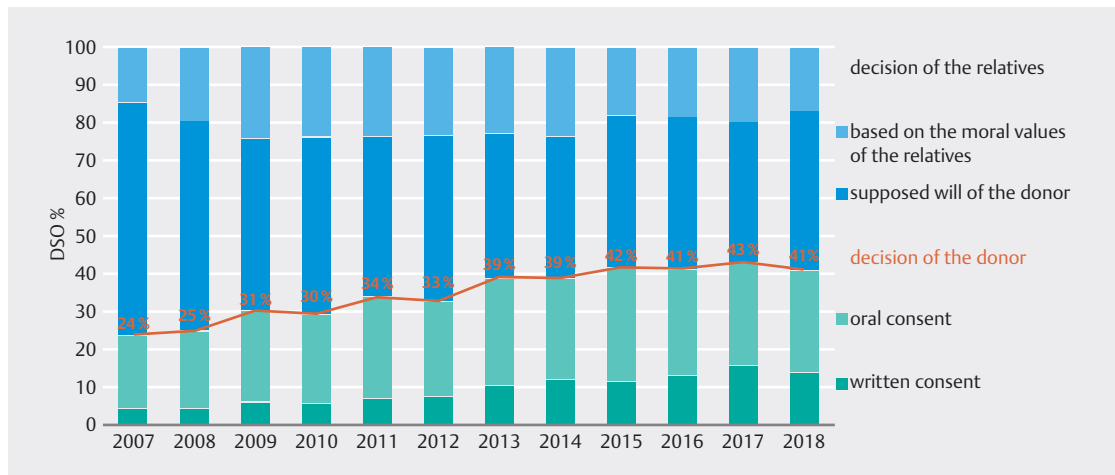
## Reasons for the shortage of donor organs

The decline in organ donations in Germany is often attributed to data manipulation and irregularities in some German transplant centres: it emerged in 2012 that some physicians falsified their patients' health details in an attempt to move them up the waiting list for donor organs at Eurotransplant, the central organ allocation organization for eight European countries. However, more recent investigations suggest that the deplorably low number of organ donations and transplantations in Germany cannot be explained by this scandal alone [3, 4]. Both the results of surveys conducted by the Bundeszentrale für gesundheitliche Aufklärung (BZgA, Federal Centre for Health Education) and DSO data on consent to organ donation in cases of reported potential organ donors suggest that support for organ donation in general continues to be high. This is also apparent from the fact that the proportion of Germans who report having an organ donor card increased from 17% in 2008 to 36% in 2018 [5]. Analysis of organ donations over recent years indicates a relatively stable consent rate in the range of 70%. In the same period, there was a continuous increase in donors who had given prospective

written or oral consent to organ donation during their lifetime (► Fig. 2).

A closer look into the data provided by the donor hospitals indicates that failure to identify and report all potential organ donors to the DSO is a major underlying cause of the low organ donor rate in Germany. This failure may in turn point to both structural and organizational deficits. In-depth analyses of patients who died with brain damage suggest that certain strategies of end-of-life care may on occasion contribute to problems in identifying and reporting potential donors and complying with the deceased's preferences regarding organ donation. These analyses identified a number of cases with clear evidence of an irreversible loss of brain function (brain death) in which the patient's family was not approached about an organ donation. In other cases, organ donation was not considered before treatment was limited and changed to purely palliative end-of-life care. We may thus assume that simply being aware of when a terminally ill patient might be eligible for organ donation before discontinuing end-of-life treatment could markedly enhance organ donation. This conclusion emerges both from a study of investigators from Schleswig-Holstein University Hospital [6] and from the DSO's retrospective evaluation of all deaths of patients with primary or secondary brain damage conducted in all donor hospitals in the DSO-region East (Saxony, Saxony-Anhalt, Thuringia) [7].

The first study [6] included more than 100 million cases (patients) to identify those with serious brain damage and showed that both identification and reporting of potential donors decreased from 2010 to 2015. The results also clearly indicate that hospitals differ markedly in organ donation activities, and that the number of organ donations performed per hospital differs considerably even from one German university hospital to the next. The investigators conclude that there is a considerable potential for increasing organ donation by supporting donor hospitals politically and helping them implement the organizational structures necessary for organ donation (► page 4). This conclusion is supported by the results of the analysis conducted in the DSO-region East [7]. We can only speculate why hospitals fail to identify and report all potential organ donors. One possible reason is that physicians and nurses working in intensive care units (ICUs) face a mounting workload. Over the last decade, there has been a marked increase in the number of cases treated in ICUs while, at the same time, hospitals have reduced their staff and the number of intensive care beds. Overall, brain death is rare in any hospital, and special knowledge is required to make the diagnosis and provide adequate donor care before organs are recovered for transplantation [8, 9]. Besides the heavy workload of ICU staff,



► **Fig. 2** Breakdown of types of consent to organ donation in Germany (eligible donors reported to the DSO; 2007–2018).

there is increasing economic pressure on hospitals that might also discourage organ donation activities. The reimbursement a hospital receives for an organ donation may not fully cover its actual costs. Currently, the average donor age is rather high at 56 years. These donors tend to have more co-morbidities, making organ recovery more time-consuming. This also means that more extensive testing is required for protection of the recipients. Unclear or ambiguous living wills might be another obstacle to organ donation. Sometimes such wills rule out certain types of treatment (e. g. ventilator therapy) while at the same time it is stated, for example on a donor card, that the patient wishes to be an organ donor after death if possible.

## Measures to increase organ donation in Germany

In the DSO's opinion, taking a patient's consent to organ donation into account in tailoring end-of-life care could be an important factor in substantially improving the situation in Germany. Not considering this option in the medical team and not discussing it with the relatives might mean that a person's decision to donate their organs after death and help those desperately waiting for a transplant is ignored. Raising awareness among hospital staff and establishing organ donation as a routine part of end-of-life care can thus help improve donor rates. To this end, in-hospital transplant coordinators are the DSO's most important partners in its endeavours to achieve better organ donor rates in Germany. These local coordinators have a crucial role in the organ donation process: they are the link between the donor hospital and the organ procurement organization. Their central tasks are to ensure that hospitals comply with their duty to report

potential organ donors to the organ procurement organization and to establish a workflow for optimizing organ donation. As well as this, they raise awareness about organ donation by regularly educating physicians and nurses in the hospital (► [page 16](#)). A graduated reimbursement system for organ donations aimed at adequately covering the hospital's actual use of resources, for example when a donor requires extended evaluation or additional tests for optimal donor characterization, is another important factor supporting full use of the organ donation potential in Germany because it will ensure that hospitals suffer no financial losses from performing organ donations.

## Amendment to the German Transplant Act

In autumn 2018, the German Federal Ministry of Health introduced an amendment to the Transplant Act (TPG) which became effective in April 2019. The aim of the changes is to improve organ donation structures in donor hospitals, to ensure adequate reimbursement, and to strengthen the responsibilities of those involved in organ donation. The amendment specifies the previously more general policies for the nomination of in-house transplant coordinators and their exemption from regular duty based on the number of ICU beds in the hospital (0.1 position per each 10 ICU beds). The amendment requires hospitals to appoint at least one in-house coordinator for each ICU. At the same time, hospitals will be adequately reimbursed for in-house coordinators and have to account for the use of allocated funds. The new legislation will strengthen the role and competence of local transplant coordinators in donor hospitals: they must be consulted when a physician identifies a potential organ donor in the ICU. They shall be granted access to the ICU and to all patient files necessary to assess donor suitability. In-house coordinators are entitled to leave

of absence for further and advanced training to be paid for by their hospital. Besides strengthening the position of in-hospital transplant coordinators, the amendment also regulates other aspects of organ donation procedures in donor hospitals: Importantly, donor hospitals will receive adequate reimbursement. The reimbursement consists of a granular calculated component – i. e. payment for the services actually provided in the course of an organ donation – and a second element to compensate the hospital for maintaining the necessary infrastructure, organizational and personnel prerequisites to make organ donation possible. In Germany, irreversible loss of brain function (brain death) may only be determined on the basis of very strict rules of the German Medical Association (BÄK) by specially qualified physicians with expertise in conducting the tests necessary to diagnose brain death. It is planned to establish an on-call neurologic/neurosurgical consultation service throughout Germany to support mainly smaller donor hospitals in diagnosing the irreversible loss of all brain function. Under the amended law, all donor hospitals are required to establish routines and define responsibilities for the entire organ donation procedure and to lay them down in standard operational procedures. The establishment of in-hospital quality assurance programmes, including a comprehensive reporting system pertaining to organ donor identification and referral, will supplement this. The data will be made available to the responsible state authorities and the DSO. Both donor hospitals and authorities will thus have sound evidence for assessing how well the organ donor potential has actually been used.

### Joint Initiative for Enhancing Organ Donation

The DSO, with the support of the Federal Ministry of Health, takes lead responsibility in setting up an organ donation initiative plan involving all major stakeholders (list of institutions ► **Table 1, page 19**). The plan is intended to support the implementation of the new legal measures and provide the required practical instruments. The initial discussions identified three strategic areas where initial action should be taken:

1. processes before diagnosis of brain death/strategies for end-of-life care
2. processes after diagnosis of brain death/donor referral and assessment
3. promotion of society's commitment to organ donation/public relations activities

For each of these areas, work groups have been set up to develop measures and make recommendations for their stepwise implementation.

## Summary

Organ donation and transplantation are a medical success story. Over the past 50 years, around 130 000 organs have been successfully transplanted in Germany. Recipients live with a donor organ for many years, some even for decades, and gratefully celebrate the anniversaries of their transplant. For this success story to continue, it is necessary to promote a favourable attitude toward organ donation and encourage more people to become organ donors. This requires commitment and recognition by society at large and also by the many parties directly involved in organ donation and transplant medicine, especially politicians and medical professionals such as transplant experts and physicians and nurses in donor hospitals. The initiative involving all stakeholders and focusing on the improvement of organ donor identification and referral is a promising step. Clearly, the situation in other European countries shows us that it is possible to achieve a rate of more than 15 donors PMP in Germany.

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