

OPEN LETTER

End German aberration in organ donation policy Catastrophic results after 3 years of new legislation

Dear Federal Minister of Health Prof. Dr. Karl Lauterbach, Ladies and Gentlemen Ministers of Health of the Federal States, Ladies and Gentlemen members of parliament,

According to Article 2 of the German Constitution, everyone has the right to life. This obviously does not apply to patients on the waiting list for organ donation. Three years after German Parliament voted to reform the organ donation law, we are mourning another 3,000 deaths that could have been saved by organ donation. Instead of the hoped-for doubling of organ donation numbers, we are experiencing a worse crash than ever before. In one of the richest countries in the world, it is not possible to provide adequate medical care for the patients concerned. The German misguided path in organ donation policy has finally reached a dead end. We demand a radical reversal with the following measures:

1. Presumed consent (Opt-out-system)

In 2020, many experts warned against a disguised "business as usual" in the form of the so called "Entscheidungsregelung" (informed consent/ opt-in system) - they were not heard. The population and the supporters of all democratic parties, the majority of whom are in favor of a so called "Widerspruchsregelung" (opt-out system/ presumed consent), were ignored. An opt-out system is cost-effective, strengthens patient autonomy and relieves the burden on relatives. In 29 of 35 European countries, it is already in place or being introduced.¹ What is new is that "Bündnis 90/Die Grünen" (a German political party being part of the German government) voted at their federal party conference in October 2022 to finally introduce the opt-out system in Germany as well.² Regarding the catastrophic situation, the German Foundation for Organ Transplantation (DSO) is in favor of it, as is the Bundesverband Niere e.V.³ The opt-out system is also endorsed by the National Ethics Council.⁴ Germany "imports" hundreds of organs/year from Eurotransplant partner countries; the opt-out system applies in all of these countries.⁵

2. Reform of organizational structures and processes in organ donation.

The central problems of the German healthcare system also affect organ and tissue donation. From the point of view of transplantation officers, staff shortages in nursing and among physicians as well as a lack of capacity in intensive care beds are at the top of the list of causes of grievances.⁶ These deficits are so serious that the possibility of organ donation is not always clarified, an unfavorable prognosis leads to premature limitation of therapy, and the improved remuneration for organ donation does not take effect. The identification of potential donors with the help of digital tools (i.e. the DETECT program) must become part of routine care.

3. Organ donation after circulatory death.

In Germany, organ donation is only possible after brain death. In most other European countries, Donation after Circulatory Death (DCD) is also possible, which has led to more organ donations there.^{6,7} This results in a paradoxical situation: organs from people who have died due to cardiovascular failure must not be provided to German waiting patients by Eurotransplant. DCD is already in force in 17 European countries and is planned to be introduced in 8 countries - why not in Germany?⁶

4. Crossover and chain living donation

Crossover and chain living organ donation must also finally be established in Germany, as in neighboring European countries. If a living organ donation between persons who are allowed to donate organs is out of the question for medical reasons, it should be made possible to bring such a donor-recipient pair together with suitable pairs and to perform living organ donations crossover and chain.

5. Altruistic organ donation

Living organ donation of a kidney in Germany is restricted to a narrowly defined family or friend recipient group. In an altruistic donation, it would be possible for a person to voluntarily donate a kidney to an unknown person without payment.

Showing political will

Germany lacks a culture of organ donation. In view of the very high willingness of the population to donate organs, we expect our politicians to take a stand.⁸ Those who speak of ethics and at the same time stand idly by while three patients on the waiting list die every day are not acting ethically. Politicians must take a stand by legislating the behavior desired by the broad majority of the population and by all experts for the benefit of all by implementing the above points 1-5. In addition to these demands, people who have donated organs post-mortem should be better appreciated, for example, by having the state cover the funeral costs.

Finally implement the worldwide known and proven concepts for success!

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Warteliste e.V.



Heim Dialyse Patienten e.V.



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Dialysepatienten und
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Hilfsgemeinschaft
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HLTX e.V.
Verein für Herz-Lungen-
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IG Niere Rhein-Ahr-Eifel e.V.



Initiative Menschen auf der
Warteliste bei Eurotransplant



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Junge Nierenkranke
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Leben spenden e.V.



Landesverband
Niere Bayern e.V.



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KfH Kuratorium für Dialyse und
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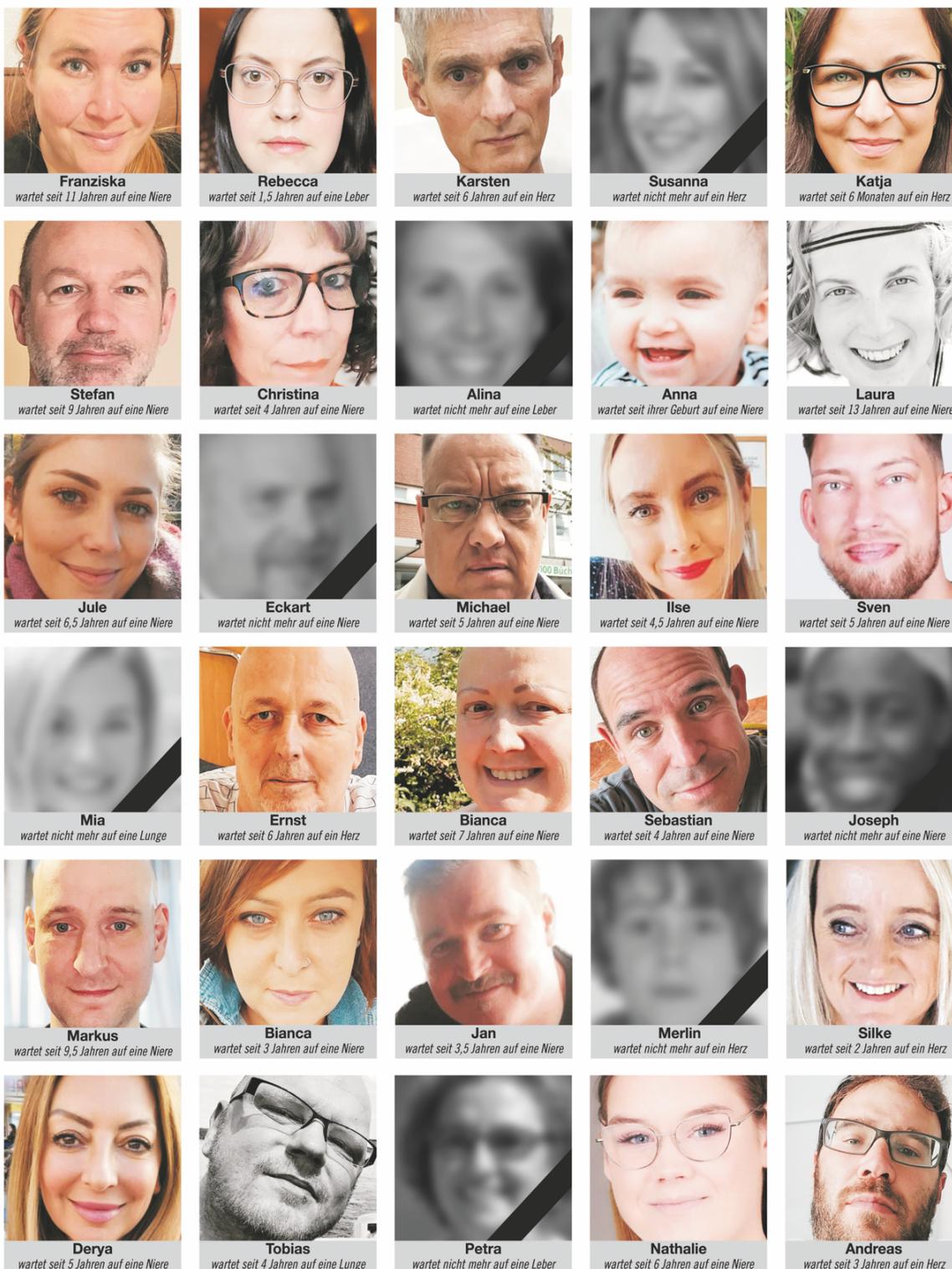
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³https://dso.de/SiteCollectionDocuments/Pressemeldungen%20PDFs%20und%20Anh%C3%A4nge/DSO%20Kongress%202022/PM_PK_DSO-Jahreskongress_2022_final.pdf (retrieved on November, 29th, 2022)

⁴https://www.ethikrat.org/fileadmin/Publikationen/Stellungnahmen/Archiv/Stellungnahme_Organmangel.pdf

⁵ <https://www.eurotransplant.org> (retrieved on November, 29th, 2022)

⁶ DSO-Kongress 2022; Bericht des Vorstandes (board's report), November, 3rd, 2022: <https://www.dso.de/DSO-Kongress/Pages/R%C3%BCckblick.aspx>

⁷ de Jonge et al. [Organ donation after circulatory death]. Nervenarzt. 2016 Feb;87(2):150-6

⁸https://www.bzga.de/fileadmin/user_upload/PDF/pressemitteilungen/daten_und_fakten/BZGA_Infolblatt_Studie_Organspende_2022_final.pdf

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