

30 years of Swiss Organ Living-Donor Health Registry (SOL-DHR)



SOL-DHR

Schweizer Lebendspender-Gesundheitsregister

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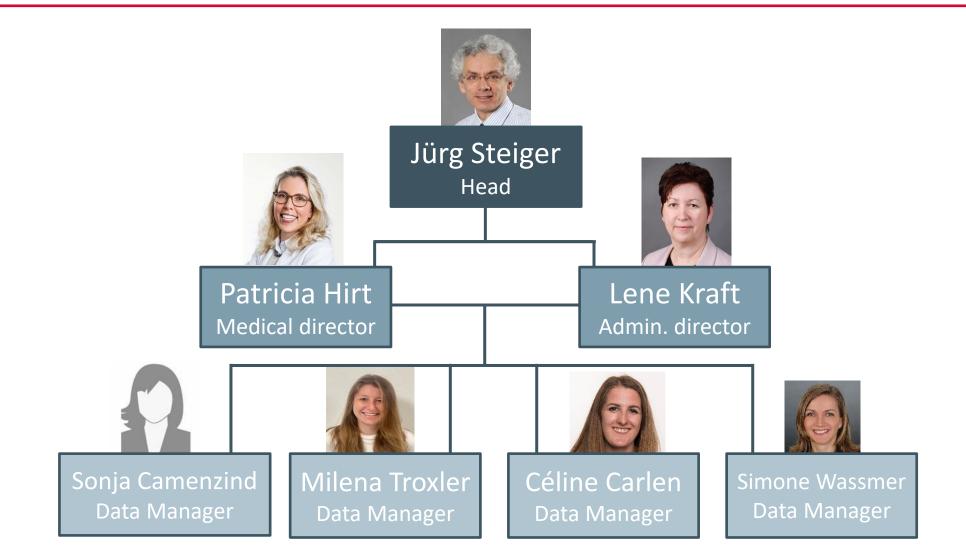
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SOL-DHR – Organization chart





www.sol-dhr.ch



Das Register Leben nach Organspende Wissenschaftliche Aspekte SNO Stiftung Home Herzlich willkommen auf der Webseite des Schweizer Lebendspender-Gesundheitsregisters SOL-DHR (Swiss Organ Living-Donor Health Registry) Die Webseite richtet sich an Organiebendspenderinnen und Organiebendspender, an Ärzte und Fachpersonal im Gesundheitswesen sowie an alle, welche sich für die Lebendspende interessieren. Sie finden auf dieser Webseite viele Informationen zur Organlebendspende in der Schweiz sowie statistische Auswertungen und Fakten wie auch nützliche Links zu anderen Webseiten. Für Ärzte und Transplantationszentren Für Organlebendspender

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- SOL-DHR (Swiss Organ Living
 - Donor Health Registry)
 - Founded 1993 by Prof. G. Thiel, *1934; † 2012
 - SNO (Swiss foundation for the aftercare of living organ donors) since 2009
 - > Head of SOL-DHR since 2010: Prof. J. Steiger
 - Reorganisation since 1.1.2021







SOL-DHR - Overwiev

- Prospective and continuous registration of all living kidney donors of the 6 Swiss transplant centers since 1993 and, also of living liver donors since 2008
- Living donor follow-up was declared as a mandatory legal service for transplant centers in Switzerland in 07/2007
- Federal mandate officially handed over to SOL-DHR/SNO in 11/2017 (FOPH supervises SOL-DHR)



SOL-DHR – Aims and follow-up

The Living Donor Health Registry has three main objectives

- > I. Early detection of possible problems after donation
- ➤ II. Notification of donors and treating physicians/general practitioners in case of health problems
- > III. Analysis of risks after living donation

Follow-up

- > 1, 3, 5, 7, 10 years after donation and then every 2 years for life-long
- > SF-8 questionnaires sent before donation, 1 year after donation and then every 5 years and, also the so-called "Social Status" questionnaire



SOL-DHR – Facts and figures

Living kidney donors

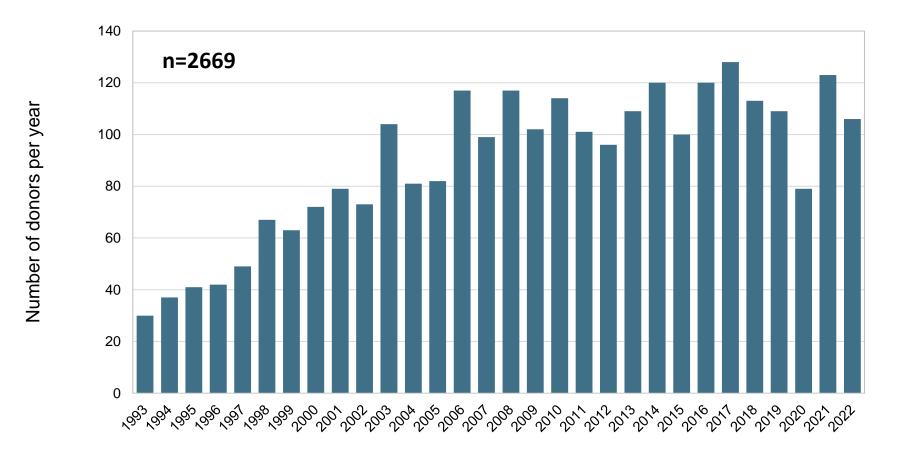
- > N= 2671 (as of 25/01/2023); n=4 donated abroad
- > N= 106 donated in 2022

Living liver donors

- > N= 67 (as of 25/01/2023)
- > N= 3 donated in 2022

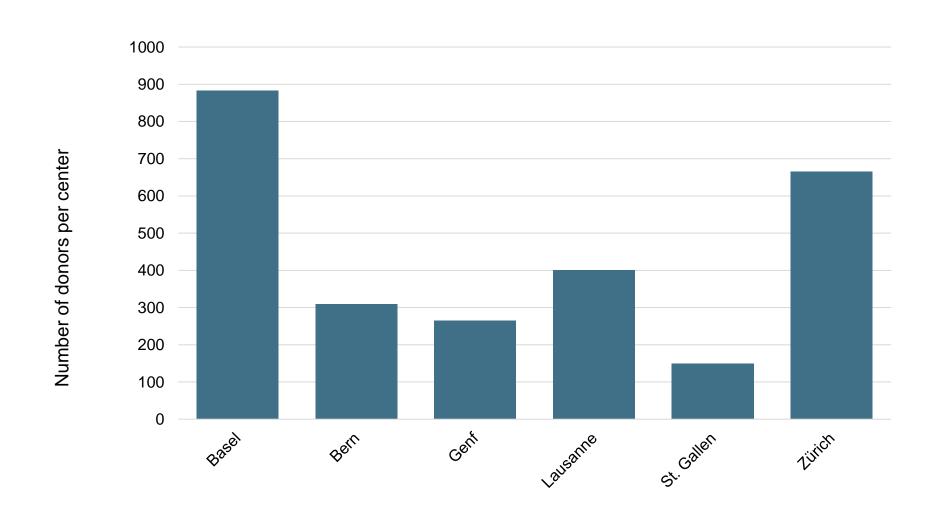


Entry of living kidney donors over time



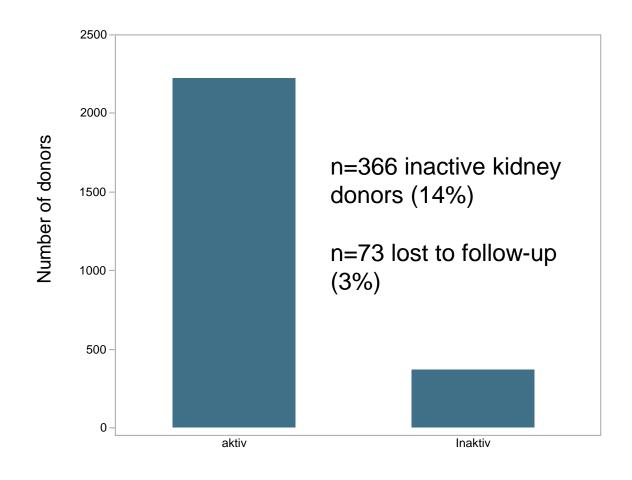


Living kidney donors per center



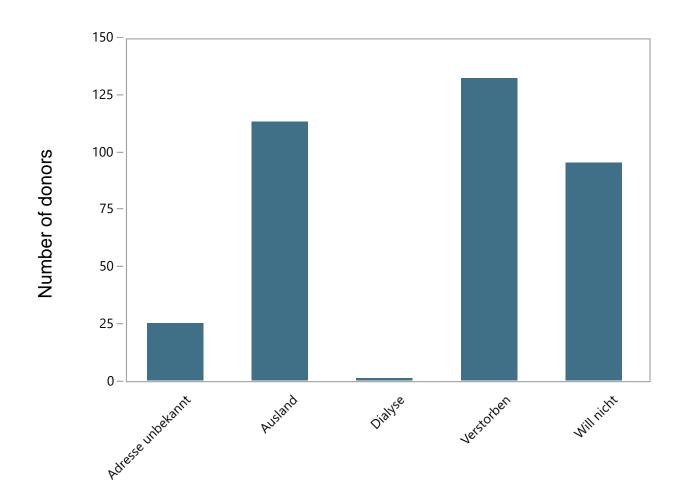


Inactive kideny donors / lost to follow-up



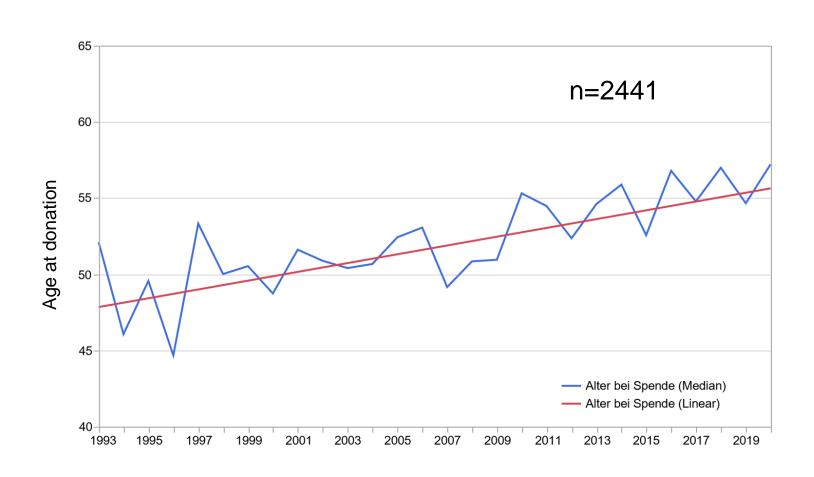


Reasons for inactivation





SOL-DHR – Age at the time of LKD

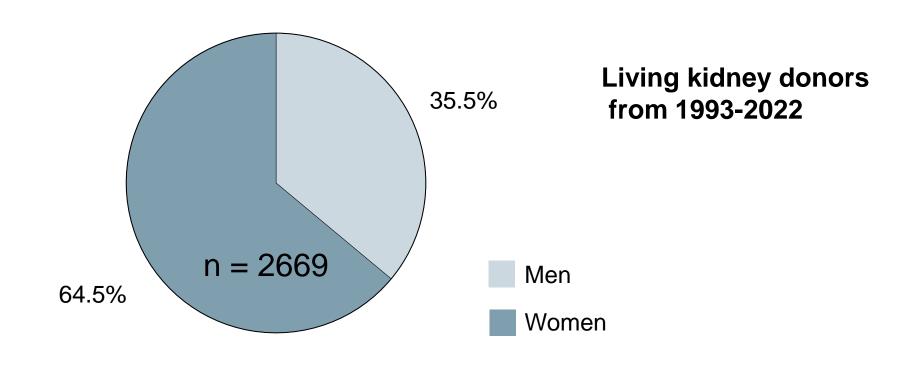


The median age among living kidney donors at donation is 53 years old

The median age among living liver donors at donation is 37 years old

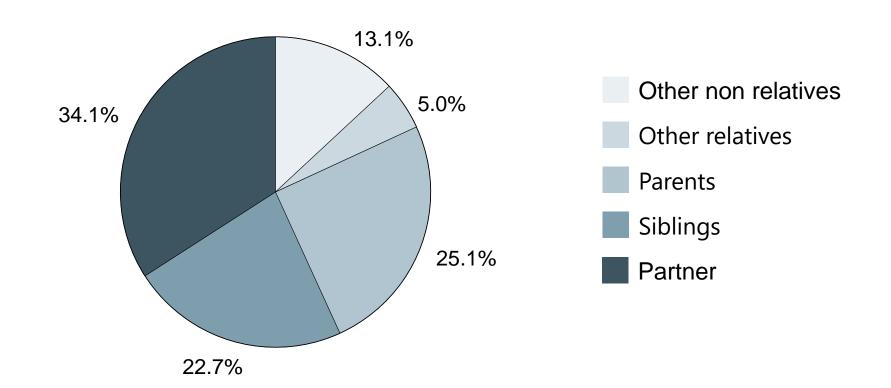


SOL-DHR – Gender distribution





SOL-DHR – Relationship with recipient





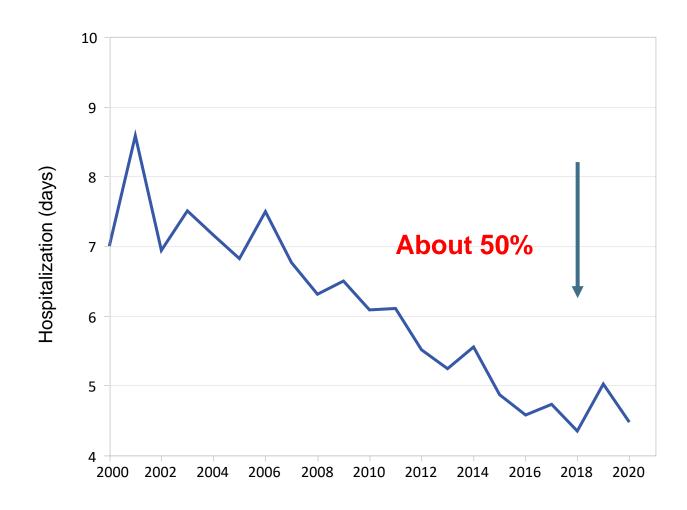
SOL-DHR – Early complications

- Prospective recording of early complications since 1998 by filling out a questionnaire by the transplant centers
- Severity of complications classified according to the Clavien classification (5 severity levels)
- For the period 1998-2020, a total of 2204 questionnaires were evaluated, in total there are 12.5% of living kidney donors with complications

Complication rate Clavien ≥ 3 = 2% within the registry



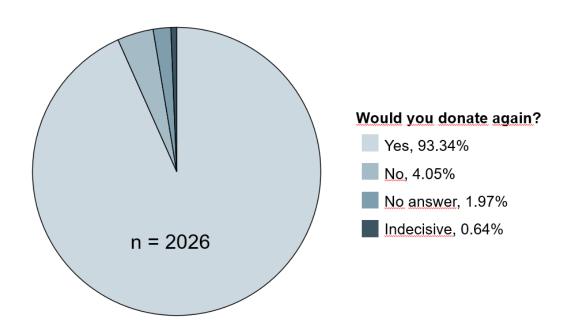
Hospitalization duration 2000 - 2020 (days)



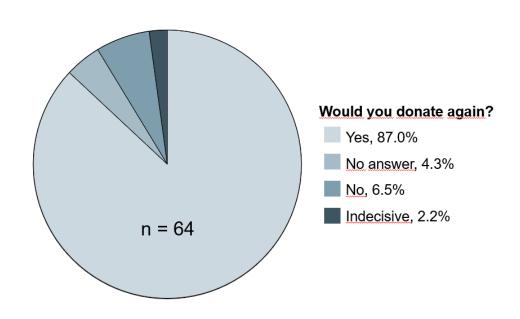


SOL-DHR – Decision to donate

Kidney donors



Liver donors



Regardless of age and gender

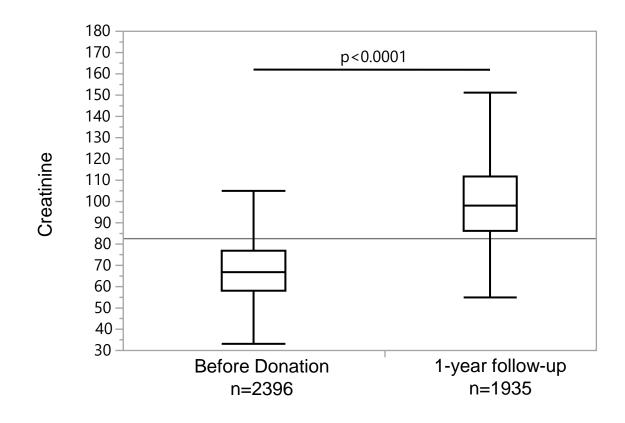


Sol-DHR - Decision to donate

- >90% of living kidney donors and nearly 90% of living liver donors do not regret their decision to donate even after years
- There are two main reasons for saying "no":
 - > Problems occurred with the organ recipient, transplantation was not successful
 - > Donor suffers from pain or problems (when quality of life is significantly reduced)

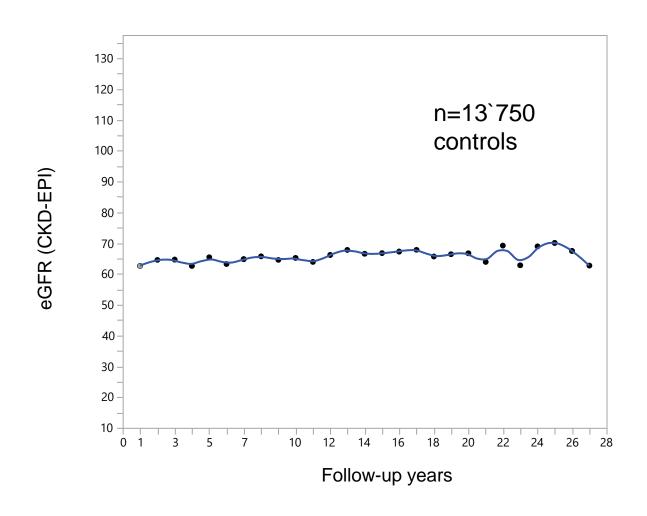


SOL-DHR – Kidney function



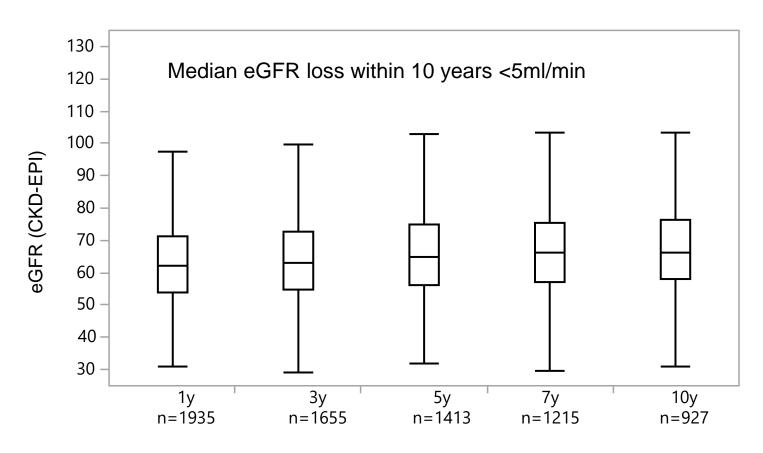


SOL-DHR – Kidney function





SOL-DHR – Kidney function



Follow-up years



SOL-DHR – How to move on

Significant growth of the registry in the last 30 years

- > Personnel resources scarce
- International position (compared to other registries, e.g., SOLKID-GNR)
- > Important issue now is also to focus on research



SOL-DHR – Research activities

EKNZ statement according to HFG Art. 51

- → 06/2021 positive vote was received for request (AO_2021-00015) → prospective positive votum
- Retrospectively no consent, but Art. 34 of the HRA allows us or justifies to use the data for scientific purposes
- Prospectively, the consent of the donors is now required for the further use of the data for scientific purposes
- According to Art. 45 of the HRA, each project must be submitted individually to the responsible EC, and data can only be further used once a positive vote has been obtained



Research activities

2 research projects in track

- Submission to EC Geneva for a single centre study (with retrospective data from SOL-DHR) with recognition of positive vote yesterday
 - "Hypertension artérielle chez le donneur vivant : impact sur le griffon"; Donor data from Geneva from 2011 to 2021 will be examined
- > Positive vote EKNZ of 12.8.2022
 - "Early complications and psycho-social outcome risks to kidney donors 12 months after donation: analysis of the Swiss Organ Living-Donor Health Registry"

Retrospective collection of research consents from all living liver donors

- Data of living liver donors are also available, please contact me!
- > n=4 missing, n=1 lost to follow up, time frame approx. 8 months, some donors were contacted 3 times, large effort for a small number of living liver donors
- Long-term complications will be analyzed as part of a doctor thesis (09/2023)



Thanks for listening



