

Euro Living Donor ELIPSY Psychosocial Follow-Up



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The number of living donor transplantations has increased over the past years. Living donation is a process that can bring out the best in humans. However, the data concerning the Quality of Life, Psychological well being, Protection system and Registry of living donors are limited. The better knowledge of psychosocial outcome of Living Donors could be used to prevent postoperative complications in advance.

ELIPSY (European Living Donor Psychosocial Follow-up) is a leading project of six European centres examining in detail the psychosocial outcome of living donors in several transplant centres with the target to create a follow-up methodology for the psychosocial assessment and care of living donors and to make suggestions for the harmonization of these practices in the European area. The aim is the early detection of risk factors and the prevention of negative consequences for the living donors and to ensure a high quality of the living donation programs.

The ELIPSY project is co-funded from the European Union in the framework of the EU Health Programme as one of the 10th priorities of Action Plan 2009-2015.

The ELIPSY project aims

- To identify the current psychosocial assessment and follow-up practices of living kidney and liver donors among European centres.
- To assess thoroughly in a prospective study the psychosocial profile of living donors prior to donation among the participant centres and their respective psychosocial outcome one year after donation in order to identify risk and protective factors for living donors.
- To assess thoroughly in a retrospective study the psychosocial outcome of living donors among the participant transplant centres by using a variety of psychometric questionnaires and donation-related questions.
- To design a recipient follow-up methodology using the best indicators with the purpose to link recipient's outcome to the living donor's follow-up.
- To present detailed results on the quality of life, the psychosocial wellbeing and the satisfaction of the living donors during the donation process.
- To build an excellence group of experts in the field assuring a continuity in the follow-up process of living donation.





Methodology of the ELIPSY project

- **Starting point:** a survey that identified the current Living donors psychosocial assessment and follow-up practices among 65 transplant centres in 10 European countries. The results were analyzed separately for the kidney and liver donation programs.
- Development of a donation specific questionnaire and a psychosocial test battery for living donors pre- and post-donation.
- The living donors who participated in the study were from different transplant centres.

The research project had two arms:

Prospective study: in where the living donors were assessed before and one year after the donation.

Retrospective study: in where the living donors were assessed up to 5 years after donation.

Parallel data collection on the outcome of the respective recipients in both studies took place.

Results and Conclusions

- The study used the EULID registry, an on-line database developed within a project during 2007-2009 with more than 1400 living donors registered.
- The first survey showed no previous consensus in the Living donors psychosocial assessment and follow-up practices among the studied transplant centres.
- There was an unification of the most relevant psychosocial variables to be assessed and follow-up.
- The same tools will be used to evaluate the Living donors aspects Quality of life, Psychosocial wellbeing and Satisfaction with the donation process.
- Each of the centres translated the tools in their own language and adapted the methodology to their characteristics and resources.
- The prospective study linked post donation mental health and psychosocial wellbeing of living donors and their satisfaction one year after donation to their psychosocial profile before donation.
- The retrospective study identified the long term impact of living donation in terms of mental health, psychosocial wellbeing and satisfaction after donation process.
- The impact of recipient outcome in the living donor is evaluated in both studies.
- The donors assessed demonstrate to have absolute Psychosocial well-being and Quality of Life.
- All the centres who follow similar methodology are considered as excellence level centres.

Acknowledgments

The first gratitude goes to all the Living donors who participate in this study. Their participation allowed the realization of the project. A very special thanks goes out to all participants in all the stages of the project. We hope to have contributed with this project to a better care of Living donors.

Participants centres

Hospital Clínic of Barcelona – Barcelona, Spain
Hôpital Necker - Enfants Malades – Paris, France
Charité – Universitätsmedizin Berlin – Berlin, Germany
Centro Hospitalar do Porto – Porto, Portugal
Sahlgrenska University Hospital – Goteborg, Sweden
Medical Park Hospital Antalya – Antalya, Turkey