PSYCHOSOCIAL AND SOCIOLABORAL PROTECTION OF LIVING DONORS

Webinar 27th February

Program For the promotion of sociAl protection of lIving donoRs

FAIR



EKPF
EUROPEAN KIDNEY PATIENTS' FEDERATION
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Uniting for Kidney Health:
Empowering Lives, Enhancing Futures

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SPEAKERS:



DR. BEATRIZ DOMÍNGUEZ-GIL

Beatriz Domínguez-Gil is a nephrologist and currently the General Director at the Spanish Transplant Organization (ONT). She presented about the overall situation of living donor kidney transplantation in Europe.

DANIEL GALLEGO



Daniel Gallego is the President of the EKPF and the Spanish Kidney Patients Federation. As a dialysis patient since 1995, he brings firsthand experience to his advocacy work. He presented the Legislative initiative to improve the social protection of living donors in Spain.



DR. IGNACIO REVUELTA

Dr. Ignacio Revuelta specialized in nephrology, organ transplantation, research, and obtained the title of transplant expert from the European Society for Organ Transplantation (ESOT). He spoke about the Psychosocial monitoring and satisfaction of living donors.

LISA BURNAPP



Lisa Burnapp is a consultant nurse and associate medical director- living donation and transplantation, NHS Blood and Transplant. She presented about the Psychoscial protection of living donors in the UK.

SPEAKERS:



GERBEN VAN DEN BOSCH

Gerben van den Bosch is a medical Social worker at Radboud University with a lot of experience with the care for living donors especially the psycho social aspects. He presented about the Dutch situation and new initiatives in the Netherlands.

YVES SALQUE



Yves Salque, a living donor and dedicated volunteer at Renaloo, a French Patients Association, brought valuable firsthand experience to the table. He spoke about the current situation and initiatives in France.



GREGORY MOORLOCK

Gregory Moorlock is an Associate Professor at Warwick Medical School and is the chair of the ELPAT Living Organ Donation Working Group of the European Society for Organ Transplantation (ESOT). In this webinar, he served as moderator during our debate.



OVERALL SITUATION IN EUROPE

Speaker: Beatriz Domínguez-Gil, ONT General Director.

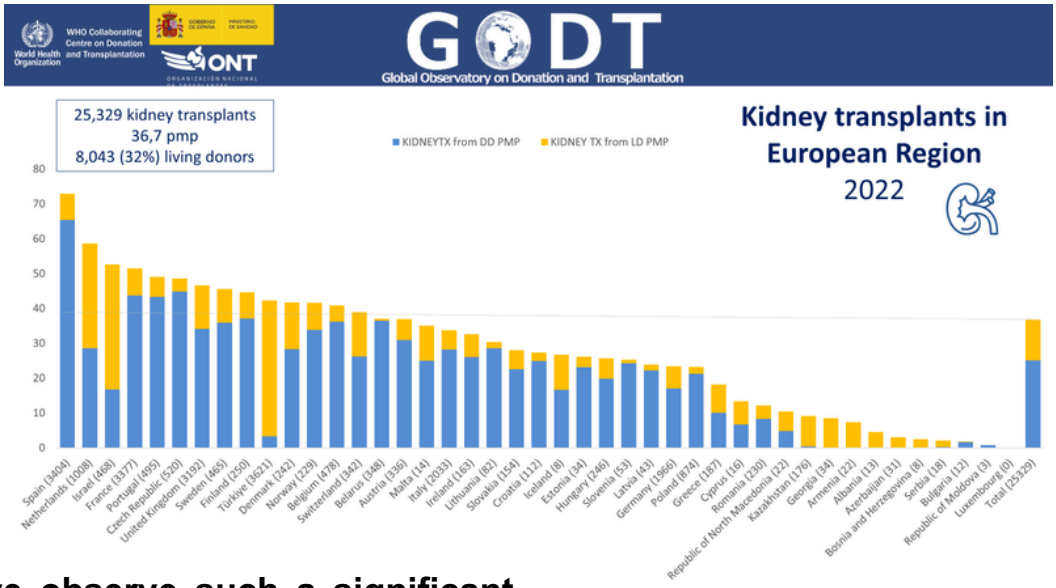
The most common organ transplant is the kidney, comprising almost double the number of all other transplants combined (Figure 1).

Kidney	Liver	Heart	Lung	Pancreas	S. bowel
102 090	37 436	8 988	6 784	2 026	170

Global Observatory on Donation and Transplantation

Estimations regarding global activity. In 2022, there were 102,090 kidney transplants worldwide, with 39% originating from live donors. This figure is likely an underestimation of the true reality.

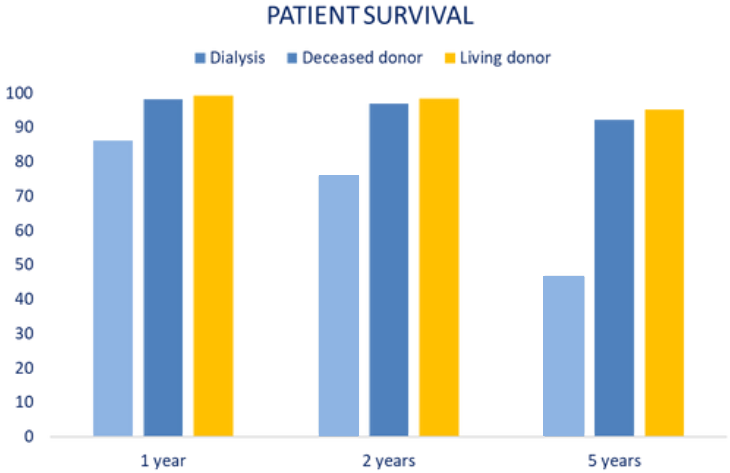
The situation in Europe shows more than 25,000 kidney transplants, approximately 8,000 of which were from living donors. Data varies significantly across countries. In countries with lower rates of kidney transplantation, live donors predominate. Of the living kidney donors, 53% are female, and 16% are unrelated to the recipients.



Why do we observe such a significant development of live kidney transplantation worldwide, especially in Europe?

Firstly, there is a pressing need, with 1,100 patients on the waiting list throughout the year. Live kidney donors make a vital contribution to meeting this demand.

Additionally, live kidney transplantation offers the best outcomes for recipients, including improved patient survival rates and enhanced quality of life. Kidney transplantation is associated with better survival, quality of life, and cost-effectiveness compared to dialysis.



OVERALL SITUATION IN EUROPE

Fundamental to this development is the **protection and care of donors**. This encompasses not only medical issues but also the psychosocial and work well-being of individuals. The World Health Assembly adopted **Resolution 63.22 in May 2010**, urging member states to maximize deceased donation and protect the health and welfare of living donors through appropriate health care services and long-term follow-up.

The Council of Europe stipulates that organ or tissue removal from a living person for transplantation must be solely for the therapeutic benefit of the recipient, in the absence of suitable material from a deceased person and no alternative therapeutic method of comparable effectiveness. Initially stringent, the Council of Europe has become more flexible over time, **emphasizing the autonomy and decision-making of potential living donors**.

A high-level meeting during the Spanish presidency of the EU in Santander, held just a few months ago, resulted in several recommendations to decision-making bodies and governments. It emphasized that governments should progress towards transplantation sufficiency by expanding both deceased donation and living donation programs, ensuring informed consent and optimal care for living donors.

The EU has invested significantly in promoting the care and welfare of live organ donors. Numerous projects funded by the EU have had a significant impact on the development of registries and outcomes for transplant recipients and donors at both member state and pan-European levels.

While there have been many initiatives by international organizations, more needs to be done to ensure comprehensive protection for individuals who generously provide organs, offering others the opportunity for a better life.

Highlighted key points include:

- Central to this progress is ensuring the safeguarding and support of donors.
- Resolution 63.22 was endorsed by the World Health Assembly in May 2010.
- A high-level gathering during the Spanish presidency of the EU in 2024 in Santander underscored various recommendations.
- The EU has made substantial investments in advocating for the well-being of living organ donors.
- Further efforts are necessary to guarantee comprehensive protection for organ donors.

To view the complete presentation, please follow this link:



SPAIN- LEGISLATIVE INITIATIVE

Speaker: Daniel Gallego, EKPF and ALCER president

Living donation in Spain is regulated by Law 30/1979, which was created by Professor Carlos Mª Romeo Casabona, the first president of ALCER (Spanish Kidney Patients' Federation). Interestingly, Professor Casabona, who was undergoing hemodialysis at the time, later received a kidney transplant under his own law. The criteria for obtaining an organ from a living donor includes:

- **being of legal age,**
- **without financial consideration,**
- **possessing full mental capacity,**
- **intending the donation for a specific person,**
- **providing informed, express, free, and conscious consent.**

The proposed changes emphasize the need to protect the psychosocial and health aspects of the donor. They aim to **ensure that living donations minimize physical, psychological, and social risks for both the donor and the recipient,** preserving trust in the healthcare system, as outlined in Directive 2010/53/EU of the European Parliament and the Council dated July 7, 2010. The Spanish Royal Decree 1723/2012 of December 28th ensures that the living donor is not financially burdened by the act of donation.

The new proposal seeks to address the process of temporary incapacity during the preparatory actions for donation, which may involve medical and bureaucratic procedures requiring absence from work for a full or partial workday. This proposal implies several changes:

- Previous social security contributions will eliminate the need for a prior contribution period.
- Sick leave will be covered from the day of hospital admission until medical discharge following the procedure.
- Coverage will extend to the period before the procedure, encompassing days when the donor cannot provide their services due to medical preparation for surgery.
- Paid leave will be provided for essential briefings and to conduct reports, examinations, and tests necessary for the donation process.

Regarding legislative modifications, steps have been taken to advance the proposal:

- Presentation in the Senate in 2014, initiating a request for a regulatory project.
- Leadership from the Spanish Transplant Organization.
- In 2021, the draft law was completed, with the Ministry of Health assuming responsibility and leadership.
- Parliamentary proceedings commenced in 2023, involving registration, publication, and debate in the Spanish Parliament. However, the process was halted due to parliamentary elections called by the president.
- In 2024, the process resumed, with all proceedings being reinstated.

SPAIN- PSYCOSOCIAL MONITORING AND SATISFACTION OF LIVING DONORS

Speaker: Ignacio Revuelta, Nephrologist at University Clinical Hospital of Barcelona, Spain

IIn the examination of various facets of living organ donation, the significance of psychosocial aspects sometimes gets overlooked. To address this, several years ago, the creation of a living donor observatory was initiated, uniting a diverse community to undertake projects focused on understanding the impact of psychosocial aspects of living donation. Throughout the year, several projects were conducted aimed at refining the evaluation of these aspects, emphasizing the importance of comprehensive follow-up for living donors, not only within the EU but also in Africa, where significant work is needed in this area.

Supported by EU funding, a conference was convened to explore best practices in living donation, with a focus on safety, quality, and transparency. In working group 3, recommendations for kidney living donor follow-up practices were specifically assessed

Conclusion: the necessity of short-term psychosocial follow-up and recommended long-term follow-up for donors and recipients experiencing high levels of medical or psychological stress



Among the projects, a recent study published in 2020 aimed to identify psychosocial risk factors for living donors across different European countries. Using various instruments, including assessments of quality of life, mental health, coping strategies, personality traits, and socioeconomic status, a prospective follow-up involving 60 donors was conducted, evaluating them both before and after donation. The analysis revealed several variables, with unexpected differences between pre- and post-donation states. A factorial analysis was carried out, where there were 11 items indicating discrepancies between donors' expectations and their actual experiences, 4 items related to the perception of donation interference in daily activities, and 5 items measuring pain and physical discomfort. The discrepancies between donors' expectations and their actual experiences emerged as the main component of satisfaction.

SPAIN- PSYCOSOCIAL MONITORING AND SATISFACTION OF LIVING DONORS

Donor satisfaction

- FACTORIAL ANALYSIS.
  - **Factor 1:** 11 items that assess the discrepancies between donors' expectations about the donation and their actual experience.
  - **Factor 2:** 4 items on the perception of the interference of the donation in their daily activities both pre and post-donation.
  - **Factor 3:** 5 items that measure pain and physical discomfort, including the perception of being completely recovered at hospital discharge and the degree of discomfort of tests and studies to be a donor.

	All sample (n=332)	Cluster 1 (n=116)	Cluster 2 (n=170)		
	Mean (SD) / n (%)	Mean (SD) / n (%)	Mean (SD) / n (%)	t/x^2	p
Gender *(Female)*	216 (65.1%)	74 (63.8%)	113 (66.5%)	0.218	0.640
Age *(Years)*	56.43 (10.52)	54.80 (10.76)	56.91 (10.49)	-1.654	0.099
Donor-recipient relationship *(Genetically related)*	209 (63.0%)	68 (58.6%)	108 (63.5%)	0.702	0.402
Years between donation and satisfaction survey	3.85 (2.18)	3.90 (2.24)	3.80 (2.19)	0.371	0.711
SATISFACTION [illegible]					
Factor 1: Non about donati					01
Factor 2: Don activities (0 –					01
Factor 3: Pair					01
Perception of status (VAS 0- [illegible]					08
Recipient died (Yes)	16 (4.8%)	8 (6.9%)	6 (3.5%)	1.67	0.195
Feeling that hospital discharge was premature *(Yes)*	69 (20.8%)	37 (31.9%)	21 (12.3%)	16.22	<0.001
Economic losses related to donation *(Yes)*	107 (32.2%)	50 (43.1%)	46 (27.1%)	7.77	0.05
Willingness to donate again *(No)*	7 (2.1%)	6 (5.2%)	0 (0%)	8.98	**
Recommendation of living kidney donation to others *(No)*	4 (1.2%)	4 (3.5%)	0 (0%)	5.96	**

ANALYSIS OF CONGLOMERATES: donors are very satisfied with their donation process, two subgroups were identified.

Cluster 1: less satisfied 40.6%

The discrepancies between the patient's expectations and their actual experience seem to be the main component of satisfaction

Menjivar et al. Sci Rep 220

The last of the studies I am bringing today it is how is the fear of kidney failure (Torres et al. Transplant Direct 2021), comparing them to genetic relatives of patients with chronic kidney failure and the general population. Our analysis involved more than 1,332 pediatric recipients and pair exchange donors from various centers in Spain. Living donors reported less fear of kidney failure compared to other groups. However, **donors with greater fear of losing the remaining kidney report: Higher scores in neuroticism, major scores in anxiety and depression, worse quality of life. greater dissatisfaction with the donation and greater regret for having given.**

In summary, we emphasize the necessity of long-term follow-up for living donors, with a particular focus on psychosocial aspects. Understanding the impact of psychosocial risk factors on health-related quality of life is crucial. Despite generally high satisfaction levels among living donors, targeted follow-up strategies are recommended. While the fear of kidney failure may not be prevalent, stringent approaches to psychosocial support remain essential.

To view the complete presentation, please follow this link:

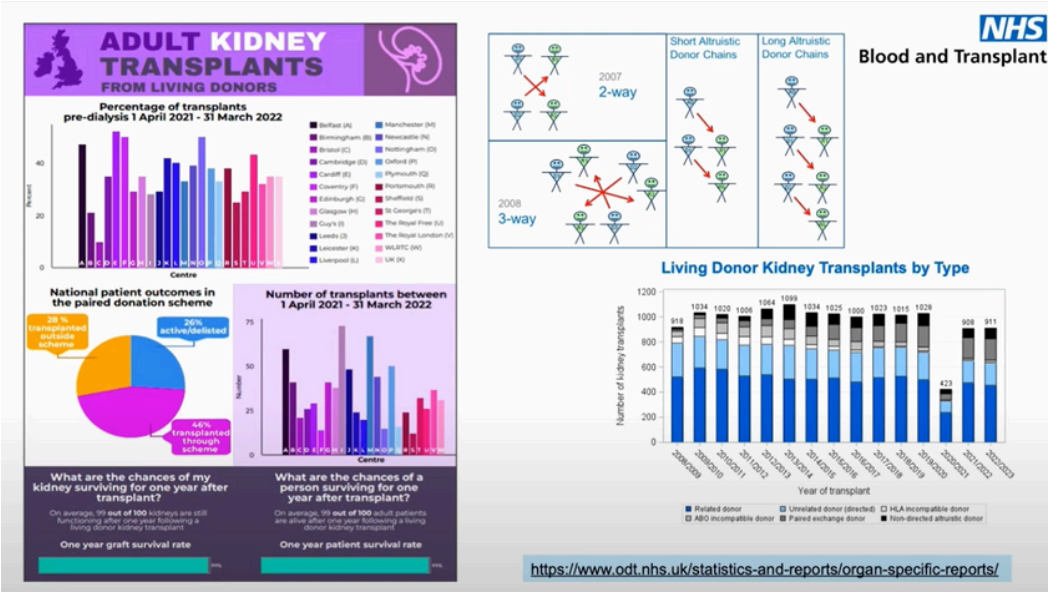


UK - PSYCHOSOCIAL PROTECTION OF LIVING DONORS

Speaker: Lisa Burnapp, consultant nurse and associate medical director NHS Blood and Transplant.

Living organ donation in the context of the UK, comprising four nations, presents a unique landscape as they not always work as one. Living donation has seen evolution within the UK and there is a lot more to do. At the heart of living donation's success are the individuals involved: **potential donors must be aware of their options, professionals must endorse its merits, and policymakers play a crucial role**. 98% of living donations in the UK pertain to kidneys, boasting excellent outcomes for recipients while positively impacting the healthcare economy.

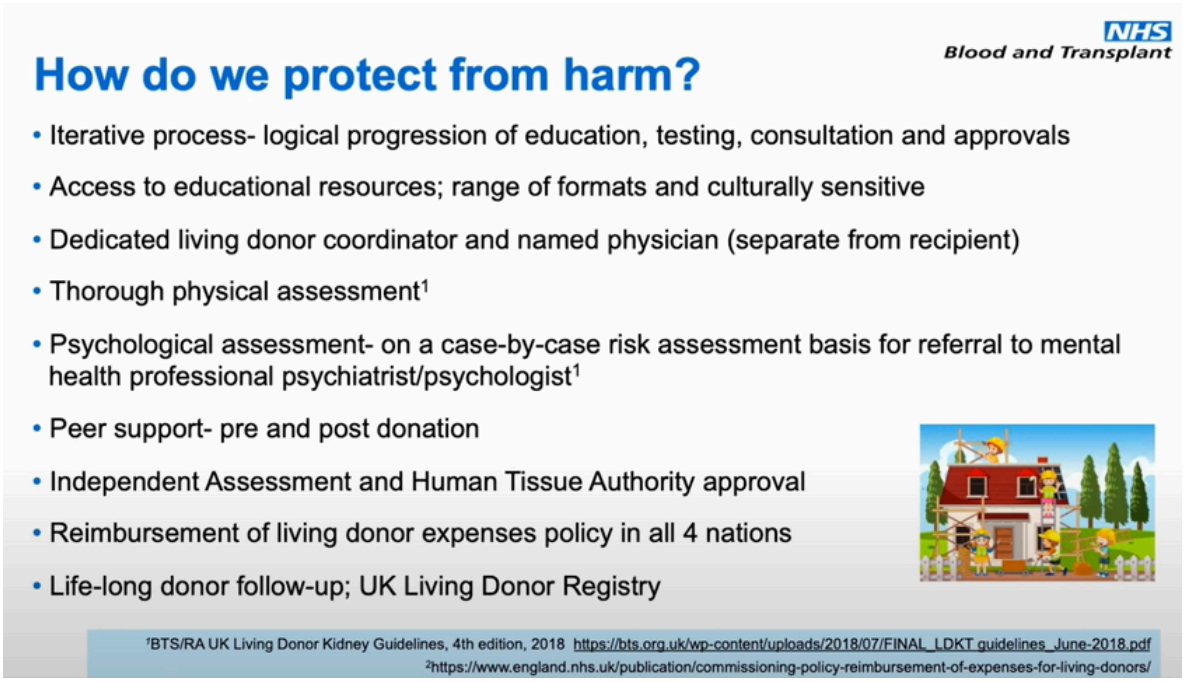
Legislation supporting living donation has progressed simultaneously across Scotland, Northern Ireland, Wales, and England. Close collaboration with human tissue authorities has been maintained to ensure the smooth functioning of living donation. Opportunities beyond relative donation, such as paired donation and kidney exchange programs, have been facilitated. Encouragingly, there has been a significant response from the general population, particularly regarding non-directed donors, contributing to the country's self-sufficiency in transplantation and diminishing the necessity for patients to seek transplantations abroad. **About 10% of donors are not directed, they are volunteers to donate a kidney to somebody on the waiting list.**



The strategies have evolved, with dedicated efforts initially focused on living donor kidney transplantation. Looking ahead to 2030, our strategy encompasses both deceased and living donation, alongside kidney and liver donation, aiming to optimize the recipient benefits while ensuring the protection and welfare of donors.

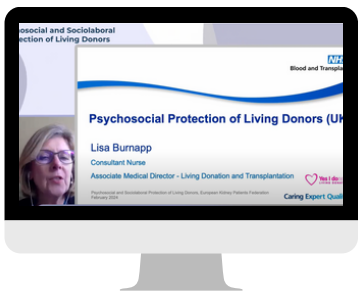
UK - PSYCHOSOCIAL PROTECTION OF LIVING DONORS

Key to the strategy is ensuring that living donation is an option accessible to all, with a paramount focus on the experience, safety, and welfare of living donors. Additionally, a recent report released in 2023, titled "Honoring the Gift of Donation: Utilizing Organs for Transplant," includes insights and considerations for living donors.



To safeguard donors, established guidelines since 2000 have been regularly updated, alongside comprehensive educational materials and resources accessible in various formats. **The donor protection framework involves an iterative process, including education, testing, consultation, approvals, physical and psychological assessments, peer support, reimbursement policies, and lifelong follow-up.**
Recognizing the importance of donor recognition, the program ensures every donor receives a silver honor, with recipients encouraged to express gratitude to their anonymous donors. Beyond legal frameworks and strategic plans, active engagement with donors, understanding their experiences, and continuous improvement efforts are integral to supporting donors effectively.
In conclusion, the success of supporting living donors hinges on a multifaceted approach, encompassing legal, clinical, and organizational dimensions, all underpinned by a commitment to partnership and patient-centered care.

To view the complete presentation, please follow this link:



DUTCH INITIATIVES IN SOCIAL PROTECTION OF LIVING KIDNEY DONORS

Speaker: Gerben Van Den Bosch, medical social worker at Radboud University

- Significant Community of Living Donors: The Netherlands boasts a substantial community of living donors, with a tradition of both non-directed and directed altruistic donations. The practice has expanded over the years, with recipients considering donors outside their immediate social circles, leading to increased instances of transplantations from living donors.
- Screening and Support System: The process of screening potential donors involves comprehensive assessments, including consultations with medical social workers and psychosocial evaluations. Health insurance covers various expenses related to the donation process, and the government provides wage loss compensation for both employed and self-employed donors. The Dutch Transplantation Foundation offers support for additional expenses, with differing terms based on employment status and the donor's country of origin.
- Navigating the Donation Process: Significant changes have been observed in the process for directed altruistic donations. Efforts have been made to create a roadmap for both recipients and donors, covering crucial topics such as preparation, decision-making, search processes, managing doubts, surgical procedures, post-operative recovery, and long-term care.

A survey involving 20 recipients and 20 donors, along with consultations with experienced professionals in this field, shed light on the dynamics of forming bonds in such situations. Creating a bond is much different if you didn't know the person before than if the donor is your relative. Expectations also play a crucial role, with some experiences resulting in tight-knit relationships while others face challenges, often stemming from mismatched expectations. Hence, emphasizing the importance of discussing and managing expectations beforehand.

In light of these findings, recipients are advised to carefully consider these aspects before proceeding, with guidance from medical social workers. As part of our efforts, **we have developed a comprehensive manual for both recipients and altruistic donors, aiming to facilitate informed decision-making and successful outcomes in the donation process.**

To view the complete presentation, please follow this link:



FRANCE - PSYCHOSOCIAL PROTECTION OF LIVING DONORS

Speaker: Yves Salque, living donor and volunteer at Renaloo

"*I donated a kidney to my son nine years ago, an experience that was challenging as it didn't yield the expected outcome, leading him back to dialysis. However, five years later, my wife stepped forward and donated her kidney, making us a resilient "one-kidney-family." Now, I am proud to serve as a volunteer at Renaloo, a French association established in 2002 by Yvanie*."

What began as a blog has evolved into a forum and community, boasting 8,000 members across France. Renaloo played a pivotal role in a comprehensive study on the quality of life for living donors in 2011, surveying 500 individuals before donation, three months post-donation, and one year after the procedure.

The study uncovered profound insights: despite facing challenges such as loneliness, lack of psychological support, and post-surgical pain, an overwhelming 98% of living donors expressed willingness to undergo the process again. However, concerns lingered as 4 out of 10 donors reported not fully recovering their quality of life post-surgery, with only one-fifth returning to work within 40 days. Financial burdens were also prevalent, with 1 in 5 donors grappling with reimbursement issues and 3 in 10 experiencing financial setbacks.

Victories in the review of the 2011 bioethics law:

- Authorization of kidney donation to a friend
- Inclusion of safeguards for living donors in the French insurance code
  - Prohibition of any additional charge or disclaimer of warrantee following kidney donation to a loved one
- Guarantee of financial neutrality for living donors.
  - Still a challenge in practice.



FRANCE - PSYCHOSOCIAL PROTECTION OF LIVING DONORS

Living donation media campaigns were also initiated. Historiucally the French biomedical agency resfused to communicate on living donors transplanteion it was considered had t be secondary to deceased donnors. Thingds changed in 2011, when it was launched a cmapiagn on living donotation 2011-2014. Since 2014, the French biomedicine agency has started with living donation campaign.

Renaloo's advocacy efforts are aimed at fostering heterogeneity in living donor transplant practices nationwide. This includes advocating for the development of living donor transplant programs, allowing for altruistic undirected donations, and ensuring comprehensive protection and satisfaction for living donors. Key proposals include securing complete financial neutrality through health insurance coverage, implementing annual monitoring for living donors without time constraints, and advocating for priority access to transplant for living donors in case of kidney failure.



"As a donor, feel great, I am happy. Would I do it again? Yes, of course. Do I feel protected? Yes, I do. Even if there are still things to improve."

[To view the complete presentation, please follow this link:]



CONCLUSIONS

Global Landscape of Kidney Transplantation:

- Over 102,000 kidney transplants worldwide in 2022, with nearly 39% from live donors.
- Europe alone witnessed over 25,000 kidney transplants, with around 8,000 from living donors, addressing the growing demand for organs.
- Live kidney transplantation offers superior outcomes for recipients but requires comprehensive protection and support for donors.

Need for Comprehensive Donor Protection:

- Legal frameworks emphasize safeguarding donors' psychosocial and financial well-being.
- Critical need for financial neutrality and promoting heterogeneity in living donor transplant practices.
- Call for concerted efforts by member states, healthcare stakeholders, and international organizations to enhance donor care and ensure equitable access to transplantation globally.

Centrality of the Donor and Future Directions:

- Thorough information, dissemination and comprehensive protection for living donors are imperative.
- Efforts should focus on proper medical evaluations, psychosocial assessment, and support for donors.
- Addressing barriers to reimbursement to ensure adequate compensation and financial neutrality.
- Collaboration among member states, stakeholders, professional associations, and patient associations needed to streamline evaluation processes and enhance donor care

ACKNOWLEDGEMENTS

The EKPF extends its deepest gratitude to living donors and potential donors for their remarkable solidarity and immense generosity

You can watch the full video of the webinar in English, French, Spanish and German in EKPF's website: www.ekpf.eu

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