

# Directed Altruistic Donation – Where do we draw the line?



**Chair:** Dr Antonia Cronin  
*Consultant Nephrologist, Guy's Hospital London*

**"Directed donation dilemmas:  
a transplant surgeon's perspective"**

Frank Dor  
*Head of Transplantation, consultant transplant and general  
surgeon, Hammersmith Hospital.*

**"Practising pragmatism with altruistic donation:  
opportunities, challenges, and solutions"**

Lisa Burnapp  
*Lead Nurse - Living Donation, NHS Blood & Transplant and Consultant  
Nurse, Guy's and St. Thomas' NHS Foundation Trust.*

**This is a Chiesi sponsored symposium. Please note the views expressed  
by the speakers do not necessarily represent those of Chiesi.**



# Directed altruistic donation dilemmas: *a transplant surgeon's perspective*



**Frank JMF Dor, MD PhD FEBS(Hon) FRCS**

Consultant Transplant Surgeon, Head of Transplantation,

Imperial College Renal and Transplant Centre, London, UK @frank\_dor

# Directed altruistic live donation

## What is it?

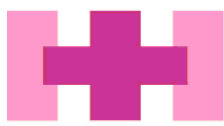
- The HTA framework describes a spectrum of relationships that constitute directed altruism and defines **two categories**:
  1. **Genetic relationship and no established emotional relationship** (e.g. Donors living overseas who have not seen their potential recipient for many years; relative with whom there has been no contact previously)
  2. **No pre-existing relationship between donor and recipient** prior to the identification of the recipient's need for a transplant (i.e. contact through social networking or media campaigns e.g. facebook, bespoke websites, local newspapers).



# Directed altruistic live donation

What is it NOT:

- Anonymous donation to a person who is not genetically related nor emotionally related (non-directed altruistic donation, unspecified donation)



# Advantages Live Kidney Donation

## Elective surgery

### Advantages for recipient:

- pre-emptive Tx: prevent dialysis
- alternative programs: ABOi, paired exchange, unspecified
- selected donors -> good quality kidneys
- short cold ischemia -> superior graft function
- "impossible transplants"

## Economic advantages

# 7th Kidney Transplant



Photo with permission





# Live donor kidney transplantation

- Preferred treatment for ESRD
- Recipients dependent on social network
  - genetically related
  - emotionally related
- Go and find a live kidney donor ...

# Altruism

Care about, or help other people, even though this brings no apparent advantage to yourself



Han Wezelaar 1964



# Altruism

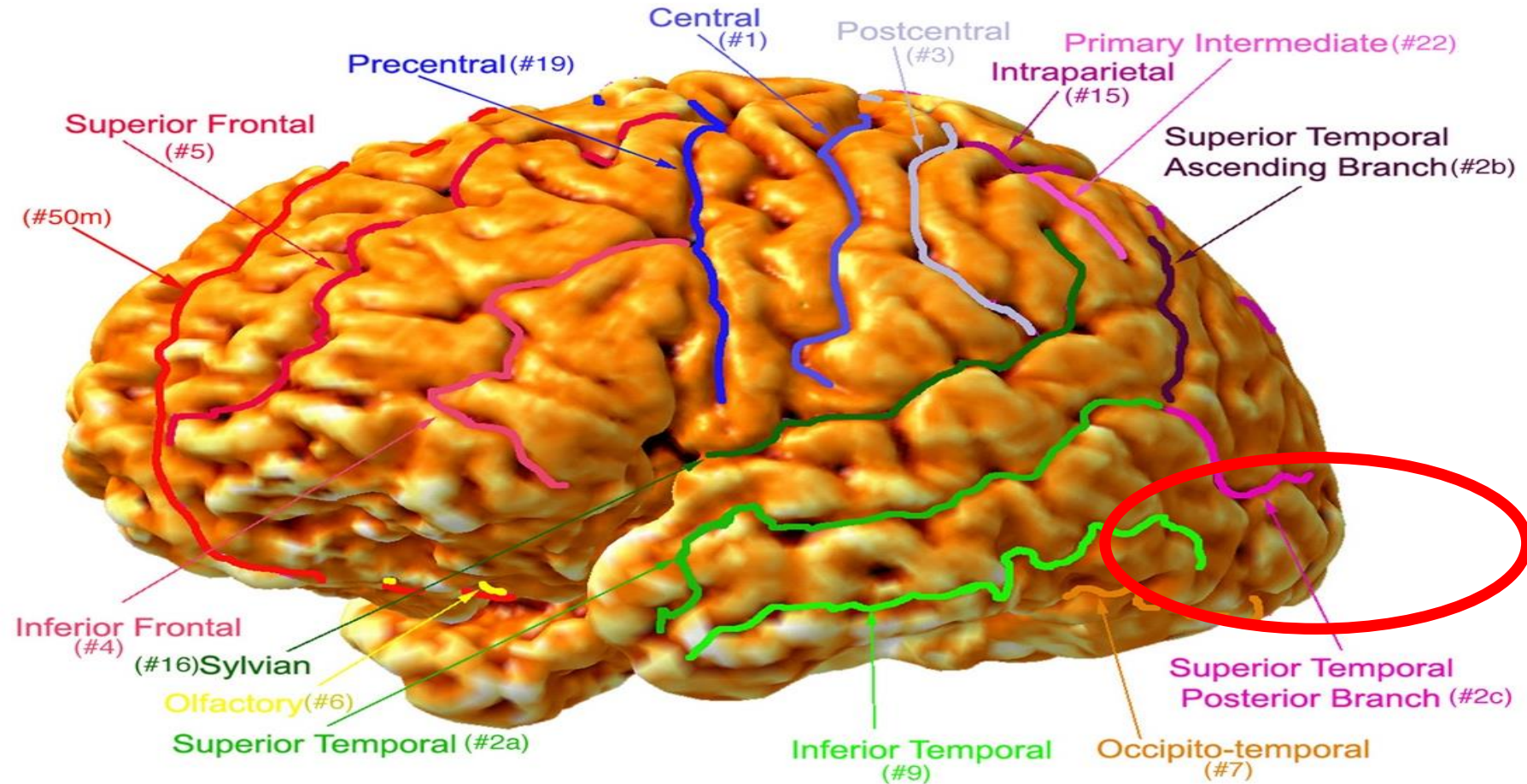
Auguste Comte 1851



“Care for well-being (fitness) of another person”

Life style of a person acting in the interest of others

# “Anatomy” of Altruism





# Altruism ?



Photo with permission

**My Mother In  
Law and I were  
happy for 20  
years.**

**Then I met her!**

# Classification Living Donation

Dor et al. Transplantation. 2011 May 15;91(9):935-8

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**TABLE 1.** New ELPAT classification for living organ donation

**Specified donation**

Direct donation

When a person donates directly to his or her intended recipient

Donation to genetically and emotionally related recipient (e.g., to one's child, parent, or sibling)

Donation to genetically unrelated but emotionally related recipient (e.g., to one's spouse, friend, or acquaintance)

Donation to genetically related but emotionally unrelated recipient (e.g., to an estranged child, parent, or sibling)

Donation to genetically and emotionally unrelated recipient, but the recipient (or the group to which he/she should belong) is specified (e.g., to persons younger than 18 yr or a specific person in need of a transplantation, who was interviewed by the media)

Indirect donation

When a person donates indirectly to his or her intended recipient

Donation to a specified recipient through an exchange program

**Unspecified donation**

Donation to an anonymous and unspecified recipient (e.g., donation to the waiting list or to the recipient of an exchange couple in the case of domino-paired exchange)

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ELPAT, Ethical, Legal, and Psychosocial Aspects of Transplantation.

# Public Solicitation of Organs from Living Donors



# I need a Kidney Now! אני זקוק לכלייה עכשיו!

## I Need a Kidney Donation Now!

### 744 Responses to "I Need a Kidney Donation Now!"

[« Older Comments](#)

**Ktm Hussain says:**

May 14, 2013 at 7:02 am



Anyone not needed to call to my number given above messages started with ktm hussain says, for kidney or kidney related purpose.

**john says:**

May 31, 2013 at 1:38 am



want to sale my kidney. I'm 35 years old, weight 70 K.G. blood group is O+(O

Anyone who needs a kidney donation can post their contact information here free of charge in the hope that someone will contact them to provide assistance. Please write your name, email, phone number and city and country where you live. Once you have received your kidney, email [admin@ineedakidneynow.org](mailto:admin@ineedakidneynow.org) with both your first and last names and we will remove your post. Receiving money for a kidney is currently illegal. We will not post any request that asks for financial payment.

Good Luck!



Photo with permission

Photos with permission





# Dealing With Public Solicitation of Organs From Living Donors—An ELPAT View

Mihaela Frunza,<sup>1</sup> Kristof Van Assche,<sup>2</sup> Annette Lennerling,<sup>3,4</sup> Sigrid Sterckx,<sup>2</sup> Franco Citterio,<sup>5</sup> Nizam Mamode,<sup>6</sup> Willij C. Zuidema,<sup>7</sup> Lisa Burnapp,<sup>6,8</sup> Willem Weimar,<sup>7</sup> and Frank J.M.F. Dor<sup>9</sup>

Although transplant professionals have initially been reluctant to perform transplants after public solicitation of organs from living donors, nowadays these transplants are increasingly being performed and reported. After clarifying the existing terminology, we elaborate an operational definition of public solicitation that is consistent with the Ethical, Legal, and Psychosocial Aspects of Transplantation classification for living organ donation. Our aim is to critically assess this phenomenon, from a legal, moral, and practical perspective, and to offer some recommendations. From a legal point of view, we analyze the current situation in the Europe and the United States. From a moral perspective, we evaluate the various arguments used in the literature, both in favor and against. Finally, we offer a set of recommendations aimed at maximizing the organ donor pool while safeguarding the interests of potential living donors.

*(Transplantation 2015;00: 00–00)*





# Context



- Legal context:

solicitation of an organ is prohibited only if it involves financial inducement or comparable advantages (US, EU) or coercion

- Practice:

liberal (North America)

conservative (Europe)



# Terminology



- Public solicitation could target both **deceased** donation and **living** donation
  - focus on living
- Public solicitation could involve **monetary gain** or **altruism**
  - focus on altruism



# Terminology



Gradient scale of "how public" the solicitation is:

- one's community (sport, church, school)
- traditional media
- specially designed websites
- social media





# How public is public?



Relatedness	
Appeal to family, spouse, friends, acquaintances.	<ul style="list-style-type: none"><li>- Genetically Related</li><li>- Emotionally Related</li></ul>
Appeal to church community, sports club, former school colleagues, intranet at work	<ul style="list-style-type: none"><li>- Emotionally Related?</li></ul>
Appeal via media (facebook, billboards, advertisements, blogs etc).	<ul style="list-style-type: none"><li>- Genetically Related?</li><li>- Emotionally Related?</li><li>- <b>Not</b> Related?</li></ul>

1. Dew MA, Boneysteele G, DiMartini AF. Unrelated Donors. In: Steel J, editor. *Living Donor Advocacy*: Springer New York; 2014. p. 149-67.

2. Frunza M, Van Assche K, Lennerling A, Sterckx S, Citterio F, Mamode N, et al. *Dealing With Public Solicitation of Organs From Living Donors-An ELPAT View*. *Transplantation*. 2015;00: 00-00

iPad 19:28 49%

nl-nl.facebook.com

Help Raymond aan een nier | Facebook

facebook

E-mail of telefoon  
Laat mij aangemeld blijven

Wachtwoord  
Wachtwoord vergeten?



**Help Raymond aan een nier**  
Community

Tijdslijn Info Foto's Vind-ik-leuks Video's

PERSONEN >

716 vind-ik-leuks

INFO >

Noodoproep: donor nier gezocht

FOTO'S >

BERICHTEN OP PAGINA >

**Help Raymond aan een nier** heeft de status van Marieke Hanse gedeeld.  
27 mei

Het is zover, we gaan ons geestelijk voorbereiden op de meest spannende dag ooit...

Volgende week vrijdag wordt Ray opgenomen in EMC om hem in 11 dagen voor te bereiden -->17 juni transplantatie--> klaar voor de sprong in het diepe — met Raymond Copier.

Vind ik leuk · Reageren · Delen 14

**Help Raymond aan een nier** 18 april

Een paar maanden dachten we dat Sjors Los onze donor was. Toch blijkt Ray zijn bloed nooit te kunnen passen met die van Sjors --> nu geen donor meer, wel een matti voor 't leven... lees het artikel in het AD

via internet is met meer nodig

Donor die zich aanmeldde via Raymond

Algemeen Dagblad

18 april 2014

Donor die zich aanmeldde via Raymond

09:06

**AD Algemeen Dagblad**

Vrouw Raymond Copier doet oproep op Facebook

**Donornier laatste hoop**



ROTTERDAM - Ruim zestig keer werd Raymond Copier (40) geopereerd als gevolg van een ziekte die zijn nieren verwoestte. Een nieuw medicijn biedt kans op volledig herstel, maar daarvoor heeft hij eerst dringend een nier nodig.

De grap is snel gemaakt: „Ik ben Feyenoordsupporter in hart en binnenkort hopelijk ook in nieren,” zegt Raymond Copier. Een beetje zelfspot en relativiseringsvermogen zijn geen overbodige luxe want de Rotterdamse voetballiefhebber leeft tussen hoop en vrees.

In de positieve variant gloort een gezonde toekomst met een donornier en een medicijn dat zijn ziekte een kopje kleiner maakt. „Ik wil nog genieten van mijn lieve vrouw en kinderen,” zegt hij.

**Nierdialyse**  
Maar op sommige momenten kijkt Copier de dood in de ogen. Ik krijg al 22

12/11/2013

5 nov 2013





# Directed altruistic living donation: what is wrong with the beauty contest?

Greg Moorlock

Moorlock G. *J Med Ethics* 2015;**41**:875–879. doi:10.1136/medethics-2014-102230



# Challenges?







# Challenges?

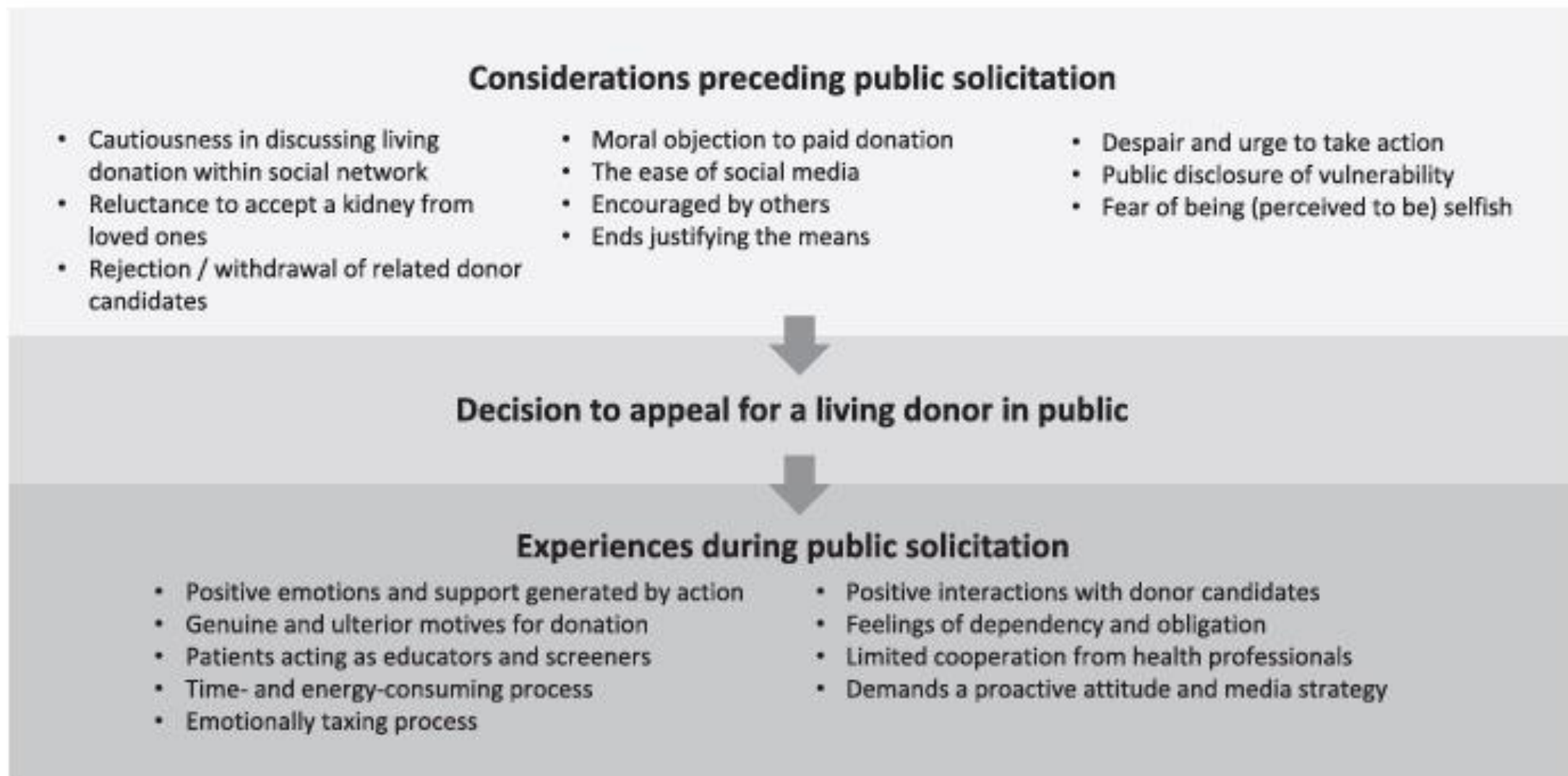




ORIGINAL ARTICLE

# **“What if this is my chance to save my life?” A semistructured interview study on the motives and experiences of end-stage renal disease patients who engaged in public solicitation of a living kidney donor**

Mathilde C. Pronk<sup>1</sup> , Dorthe Slaats<sup>1</sup>, Willij C. Zuidema<sup>1</sup>, Medard T. Hilhorst<sup>2</sup>, Frank J. M. F. Dor<sup>3,4</sup>, Michiel Betjes<sup>1</sup>, Willem Weimar<sup>1</sup>, Jacqueline van de Wetering<sup>1</sup> & Emma K. Massey<sup>1</sup> 



**Figure 1** Factors influencing the decision of patients with end-stage renal disease to engage in public solicitation and their experiences with public solicitation.

# Conclusions

## Public Solicitation:

- Decision to engage in PS was mainly driven by a lack of organs from other living and deceased donors, and a need for action in a hopeless situation.
- PS was experienced as an emotionally and logistically taxing process.
- Expectations unrealistic; many disappointments
- Need for improved education and support for patients with ESRD considering and undertaking PS.



American Journal of  
Transplantation

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ASTS  
American Society of Transplant Surgeons

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Personal Viewpoint

# Beyond the Billboard: The Facebook-Based Application, Donor, and Its Guided Approach to Facilitating Living Organ Donation

K. A. Bramstedt [✉](#), A. M. Cameron

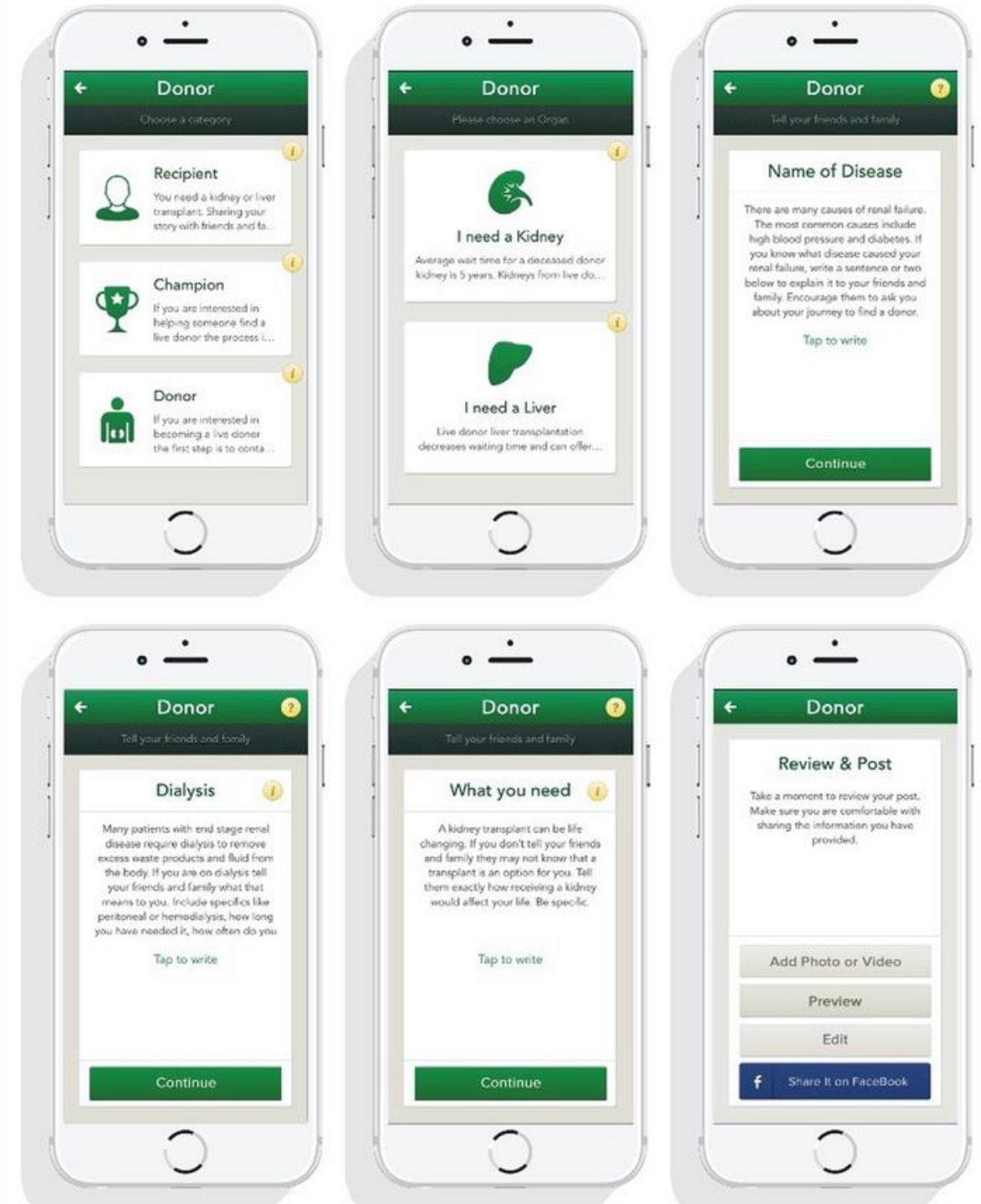
First published: 7 September 2016 [Full publication history](#)

DOI: [10.1111/ajt.14004](https://doi.org/10.1111/ajt.14004) [View/save citation](#)



# Smartphone App

# Standardised format for Public solicitation



# A Smartphone App for Increasing Live Organ Donation

When searching for a living donor candidates don't know **who to ask** and **what to say**



We developed **an app** that helps candidates share their need for a live donor through Facebook



Those who used the app were **6X** more likely to have a potential live donor come forward





# Dealing With Public Solicitation of Organs From Living Donors—An ELPAT View

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*(Transplantation 2015;00: 00–00)*





# Recommendations - I

1. PS likely to remain in countries that allow genetically/emotionally unrelated LD KTx
2. Review LD screening procedures to deal responsibly with donor offers from PS: LD coordinators to take into account the specific risks and practicalities (possibly excess calls, possibly problematic motivations, etc.)
3. transparency, accountability, and comprehensive oversight



# Recommendations - II

4. Not to condemn patients who engage in PS as often desperate
5. Our responsibilities:
  - Optimize national organ donation laws to maximize the deceased and living donor potential;
  - remove misconceptions and disincentives for live donors to step forward.
  - Paired kidney exchange and domino-paired kidney exchange should be instated.
  - Better information should be provided to our patients (e.g., home based education), to health care professionals, and the general public about the advantages of live donor kidney transplantation.
  - Specific attention to potential of unspecified / non-directed altruistic donation (part of exchange schemes)



# Recommendations - II

6. Deal with public solicitation and respect solicited donors as regular specified live donors, despite practicalities / challenges
7. Patient education / expectation management when considering PS
8. Develop national guidelines / framework  
[BTS Guidelines Directed Altruistic Donation](#)



Imperial College  
Renal & Transplant  
Centre

**Thanks for your  
attention!** [Frank.Dor@nhs.net](mailto:Frank.Dor@nhs.net) @frank\_dor



# Practising Pragmatism with Altruistic Donation: opportunities, challenges and solutions

Lisa Burnapp  
Consultant Nurse  
Lead Nurse –Living Donation  
NHS Blood and Transplant



1960s



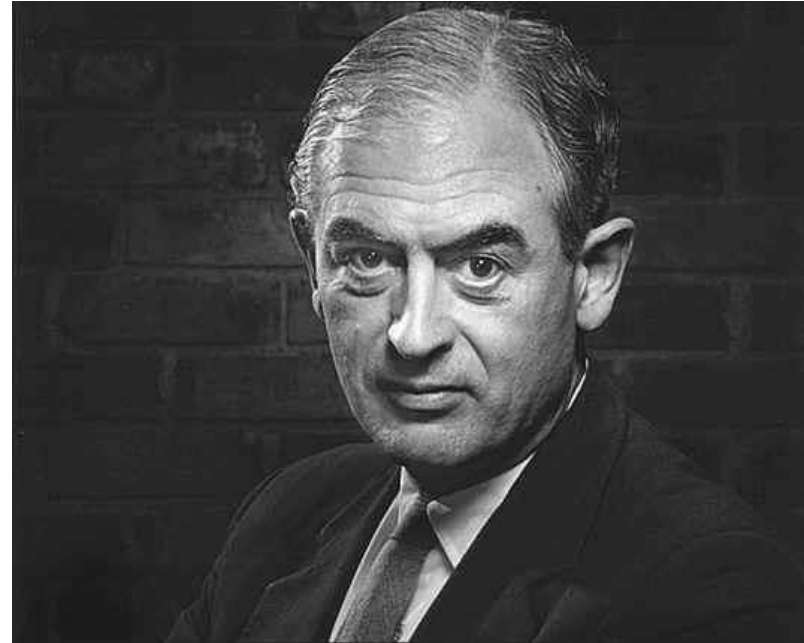
The Voice of Transplantation in the UK

“Is kidney transplantation ethical for patients with kidney failure?”

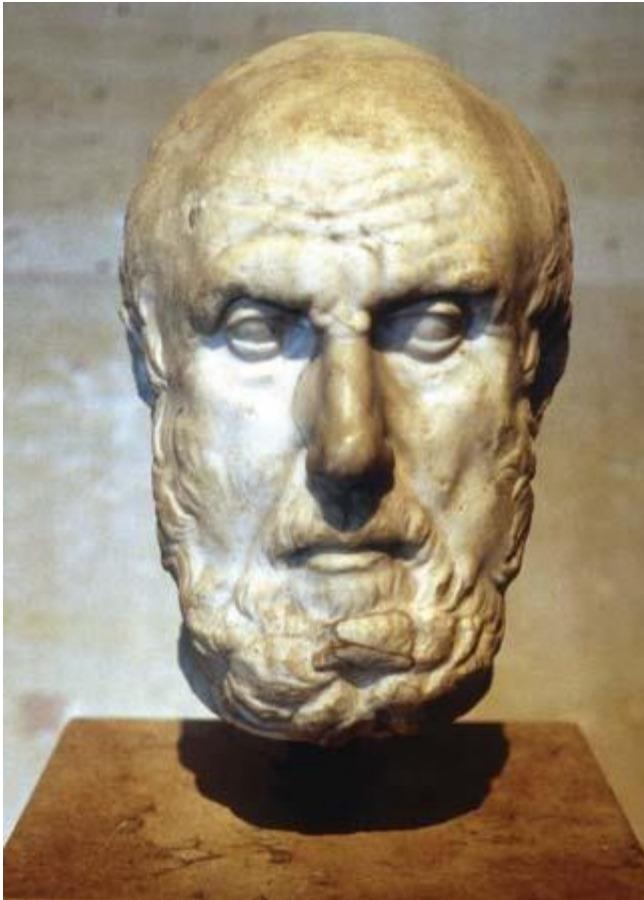
# 1960s

“That’s very simple.  
People would rather  
live than die.”

Sir Peter Medawar



*Dr. Clyde F. Barker, Philadelphia, on ‘Health-Related Quality of Life After Different Types of Solid Organ Transplantation’,  
C. Wright Pinson et al, Annals of Surgery, Vol. 232, no4, 597-607, October 2000.*



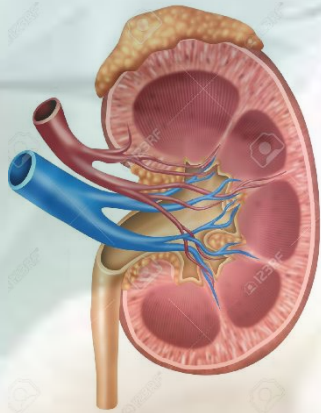
*“First do no harm.”*

*Hippocratic Oath*

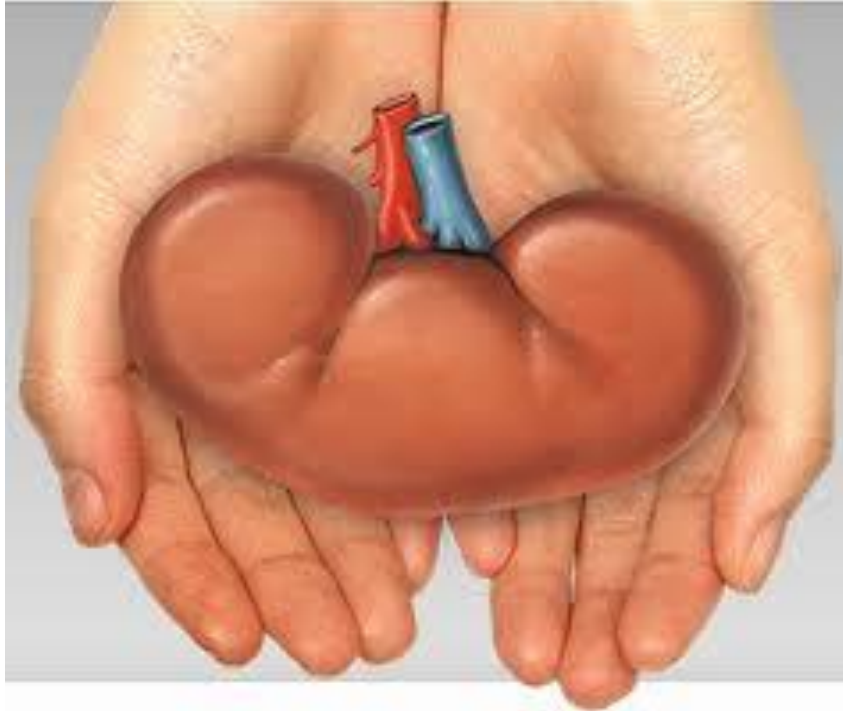


**99%**  
**of things**  
**you worry**  
**about never**  
**happen.**

Are we right to worry?



# Coercion or Reward



# The Beauty Contest



This isn't the way it should be done.....

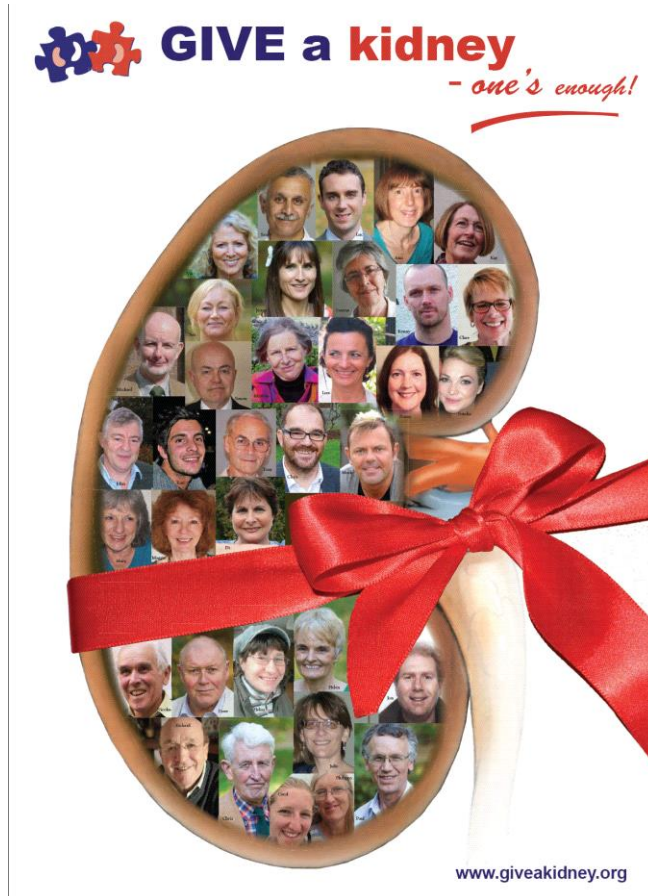


# VOLUNTEER



There is value in  
anonymity.

# Morally Acceptable



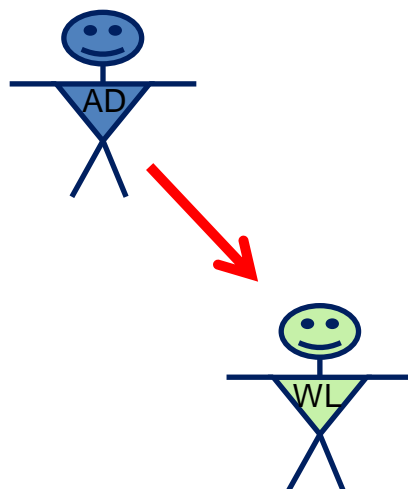
*“A charity that aims to raise awareness of non-directed (also known as altruistic) living kidney donation”*

[www.giveakidney.org](http://www.giveakidney.org)

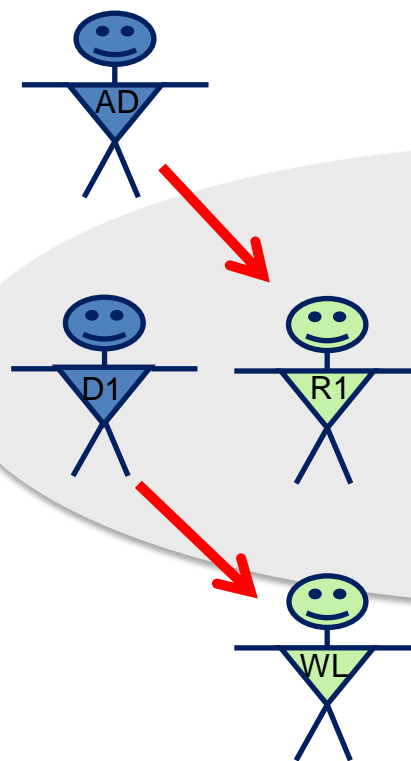


# Donation pathways

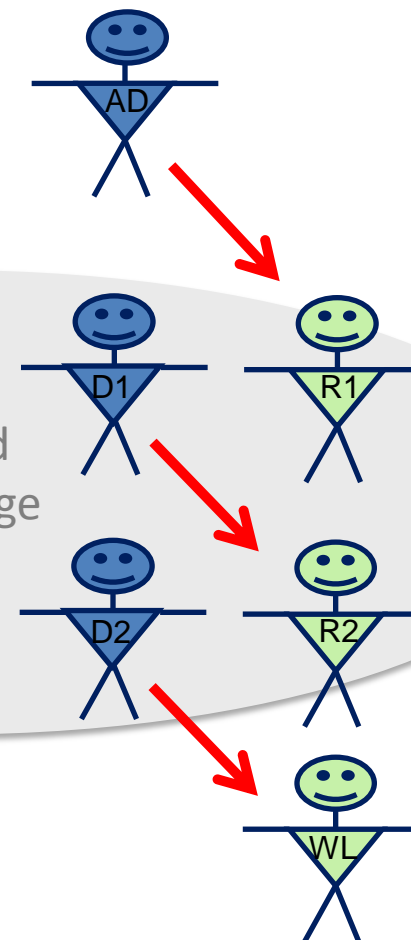
Direct to Waiting List  
2007



Short Chain  
2012



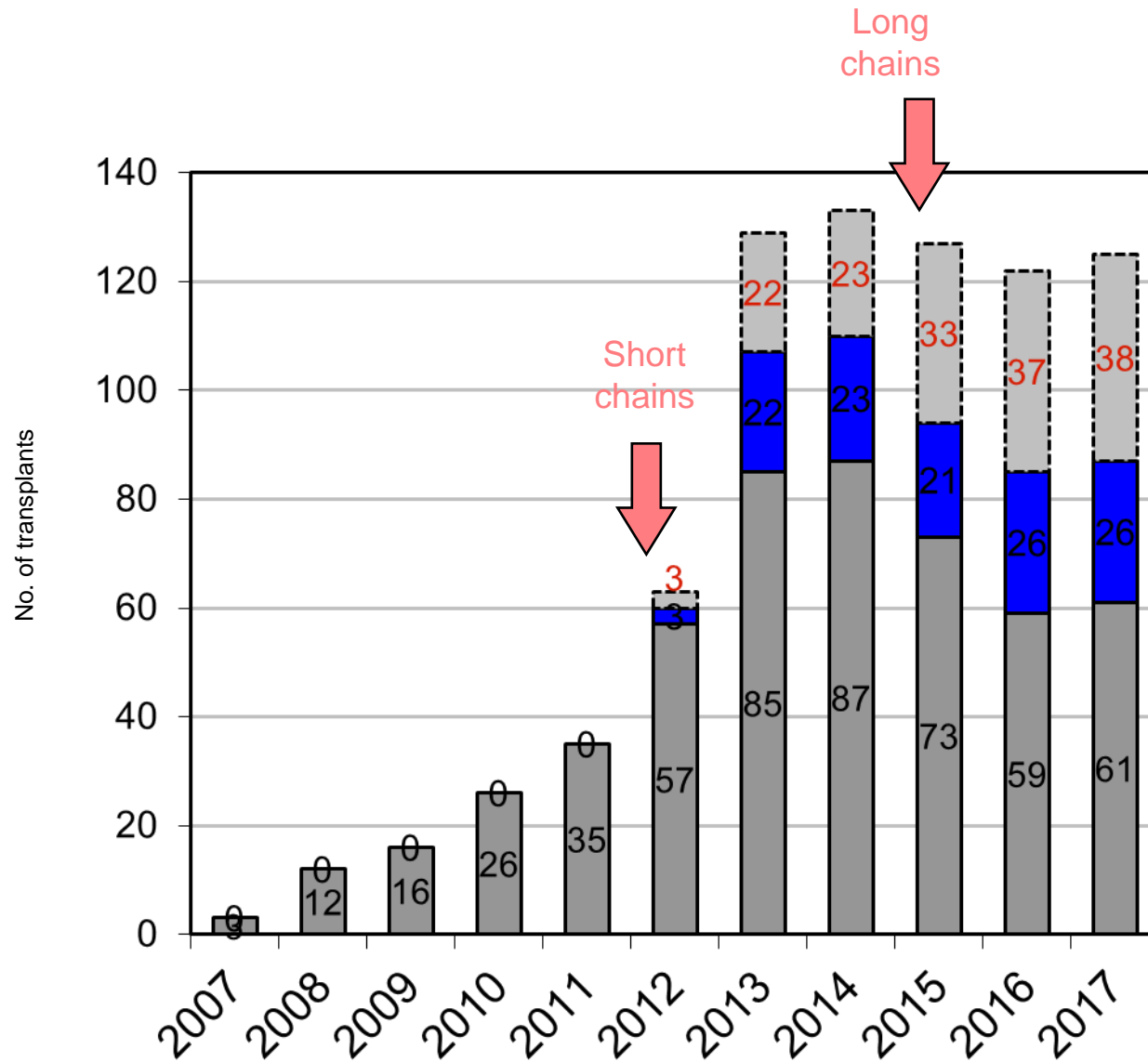
Long Chain  
2015



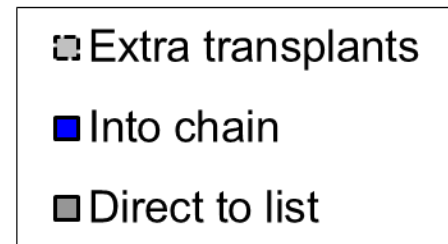
Paired  
Exchange  
pairs

Default  
pathways  
from Jan  
2018

# Altruistic Kidney Donors



Donation type

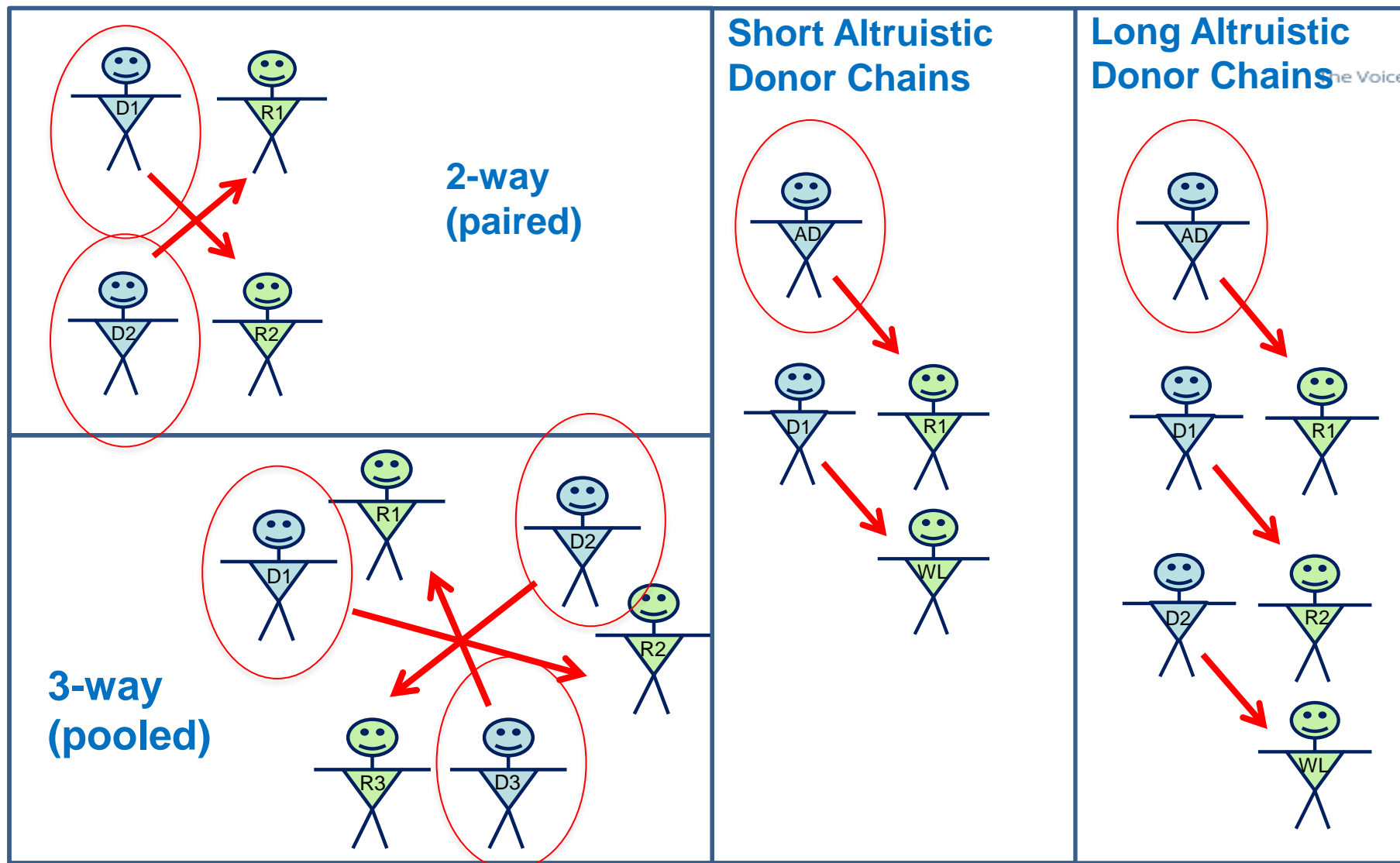


**By December 2017:**

635 Donations

791 Transplants

# UK Living Kidney Sharing Schemes\*



The Voice of Transplantation in the UK

\* Developed with University of Glasgow



# Our Fear?



BBC News - First UK live liver donation to a stranger takes place

www.bbc.co.uk/news/health-21143602

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23 January 2013 Last updated at 11:06

## First UK live liver donation to a stranger takes place

By **Smitha Mundasad**  
BBC News



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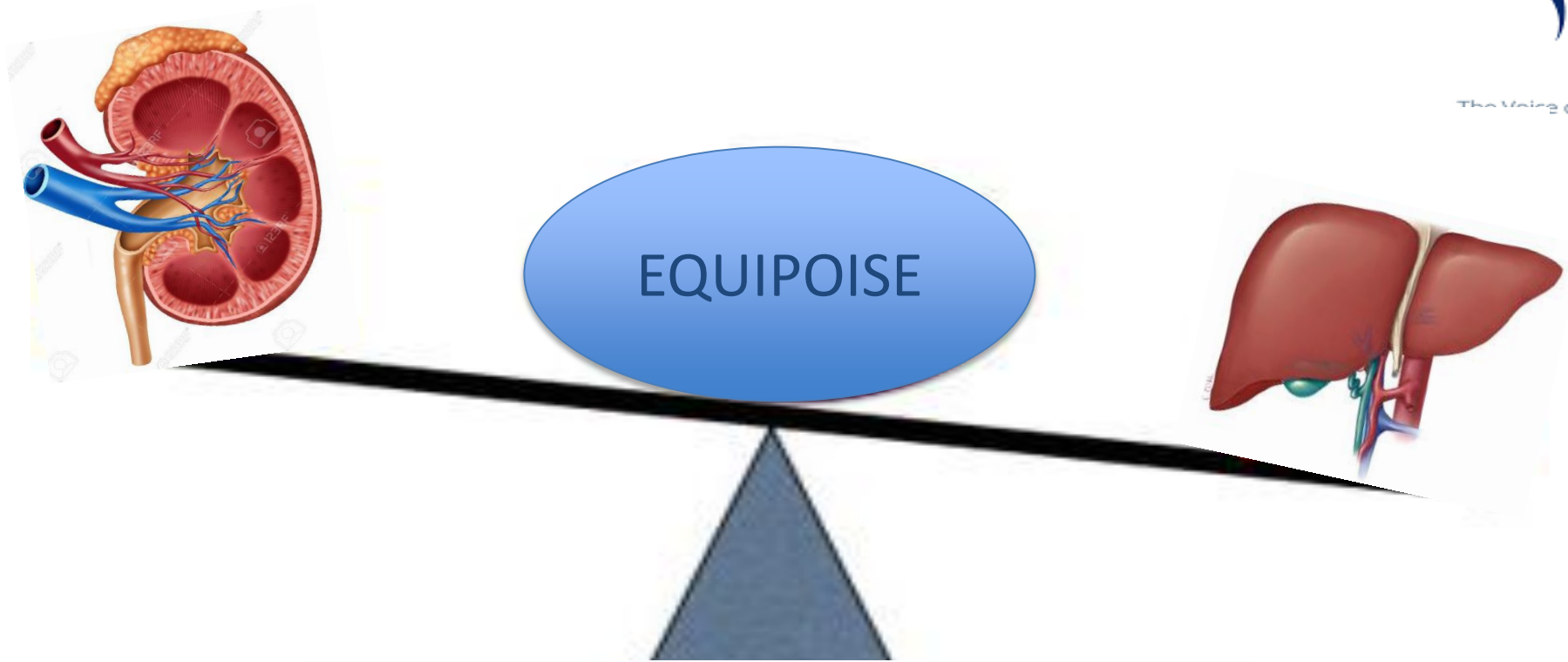
Daniel Broadhead decided to give a quarter of his liver to a stranger

### Top Stories

- MH370 families angered by report
- Russia relations prickly - Hammond
- Poison claims over Crufts dog death
- Murray wraps up GB Davis Cup triumph
- Boys aged 13 and 14 killed in crash

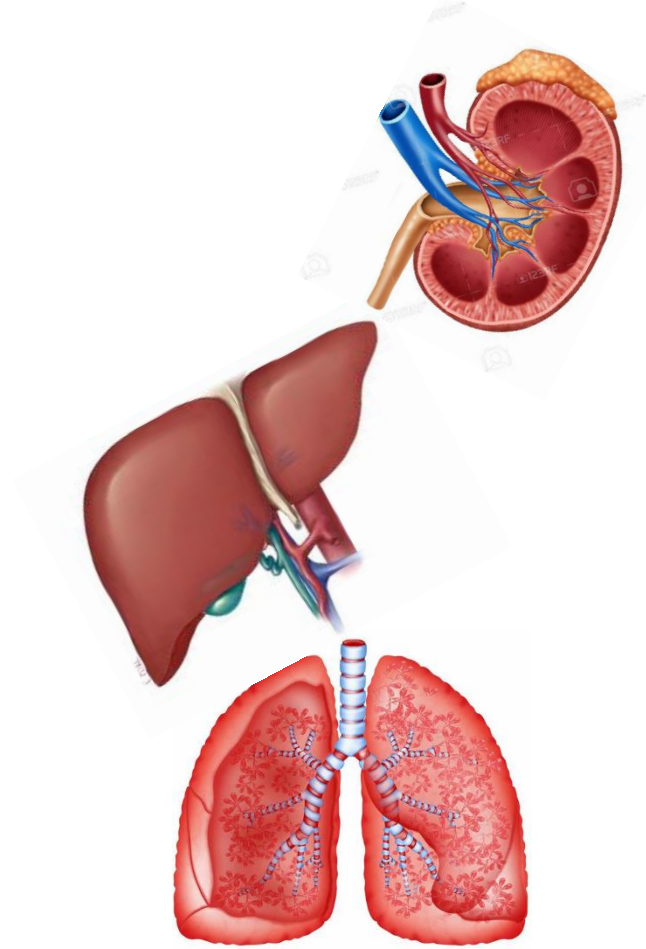
### Features

- A parent's right?**  
France refuses to be taught a lesson on smacking
- Mash and gravy**  
The strange effects of cancer on appetite
- Take me there** No, thanks
- Being hated is part of being



# Balancing the Risk

- Type of organ
- Relationship to recipient
- Motivation
- Expectations
- Clinical complexity
  - Physical
  - Psychological
- Socio-economic issues



# Our opportunity and our challenge

‘No waiting for a transplant for want of a kidney’

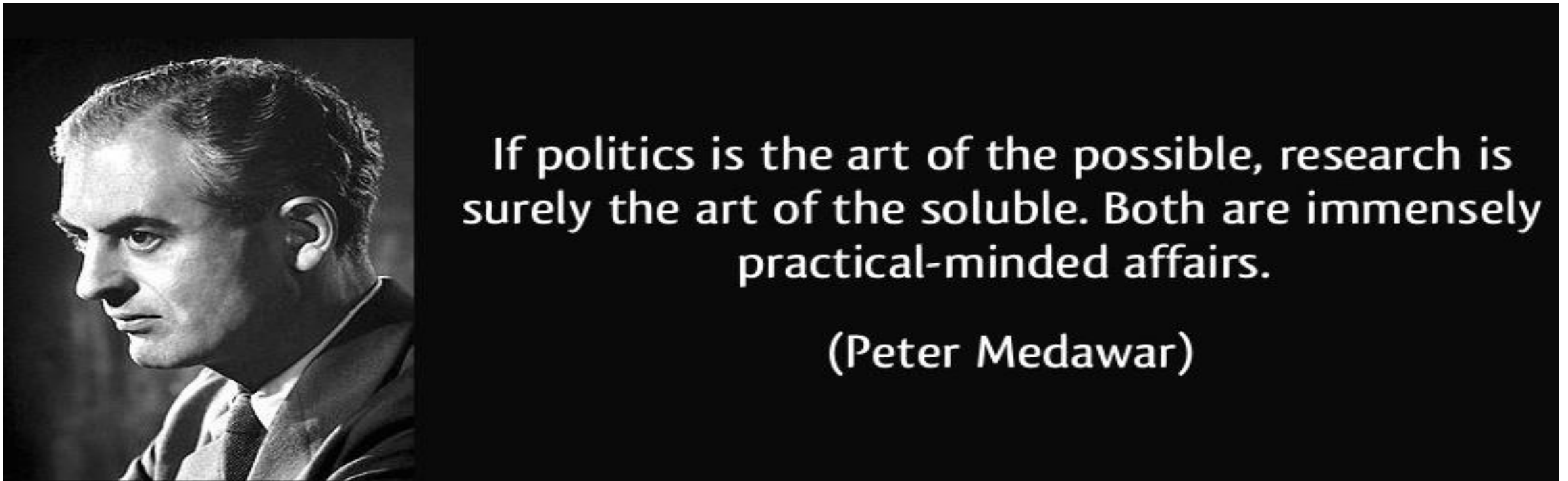




# Hearts and Minds



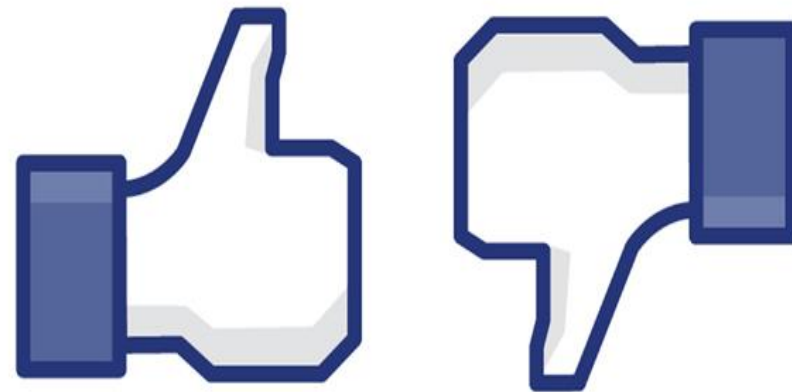
# The Art of the Possible



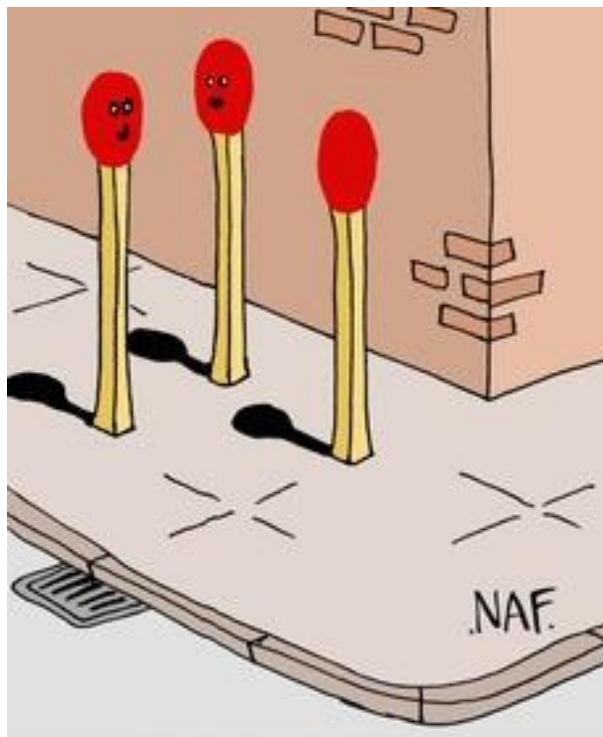
# The 'f' Factor



- Someone's story
- Personal
- Real
- Creates awareness
- Attracts people

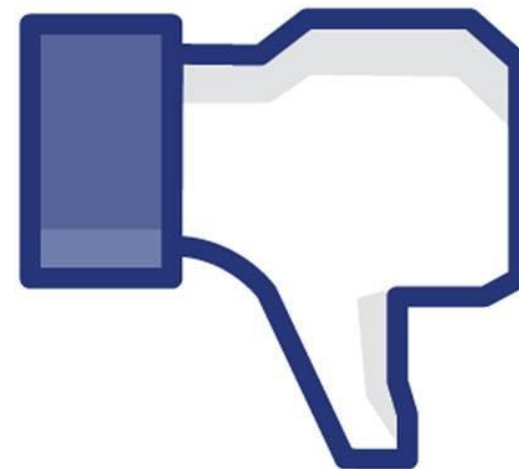


# 'Organised' Match.com?



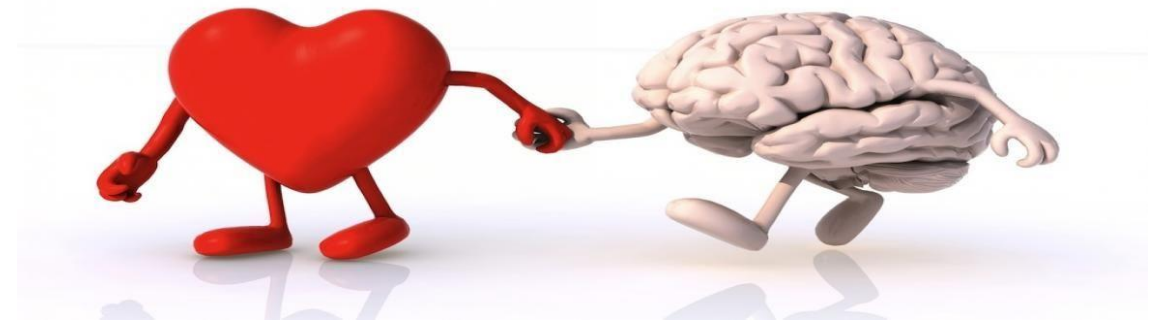
"We met on 'match.com'."

- Possible financial incentives
- Inequity of access
- 'Parallel allocation' schemes
- Global attraction
- Exploitation



# What can we do?

- Promote everyone's story
- Encourage donation for 'the greater good'
- Manage expectations
  - Recipients
  - Donors
- National guidance<sup>1</sup>
- Educational resources<sup>2,3</sup>
- Local protocols



<sup>1</sup>[https://bts.org.uk/wp-content/uploads/2016/09/16\\_BTS\\_Directed\\_Altruistic\\_2-1.pdf](https://bts.org.uk/wp-content/uploads/2016/09/16_BTS_Directed_Altruistic_2-1.pdf)

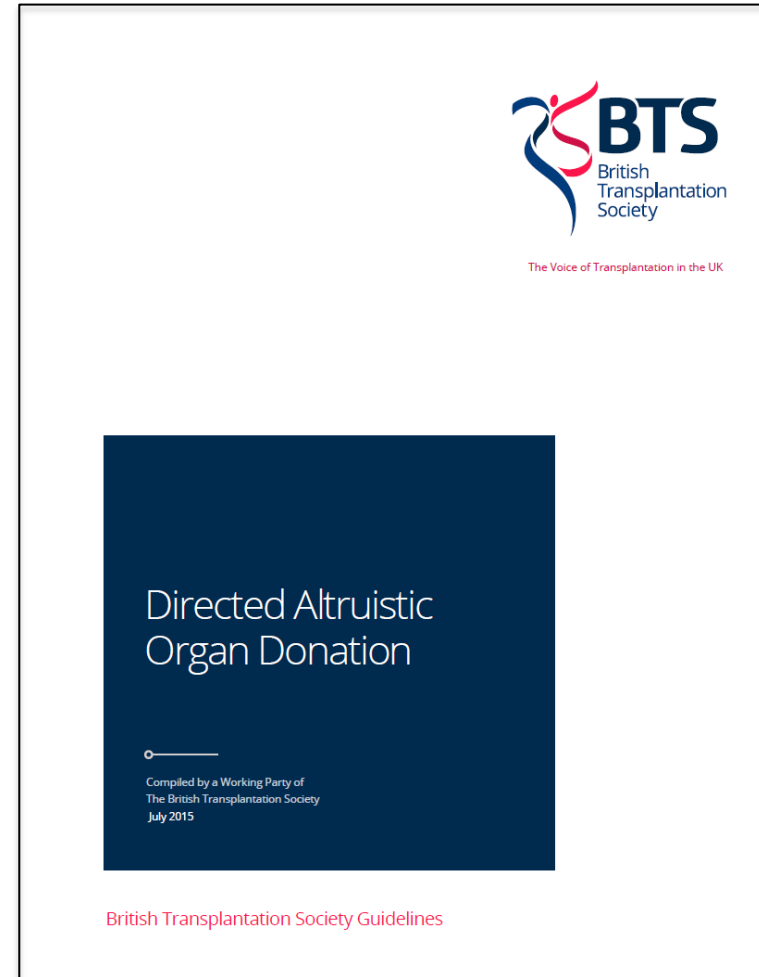
<sup>2</sup><https://www.nhsbt.nhs.uk/get-involved/promoting-donation-hub/download-digital-materials/>

<sup>3</sup><https://www.organdonation.nhs.uk/about-donation/living-donation/>

# Practical Guidance

12 recommendations

- Preferred donation options
- Individual direction only (no groups)
- Spontaneous donation offers
- Multiple donor assessment
- HTA assessment and anonymity
- No paid advertising
- No organised websites
- Ethical support



<sup>1</sup>[https://bts.org.uk/wp-content/uploads/2016/09/16\\_BTS\\_Directed\\_Altruistic\\_2-1.pdf](https://bts.org.uk/wp-content/uploads/2016/09/16_BTS_Directed_Altruistic_2-1.pdf)

# What do you actually *do*?



- What are the recipient characteristics?
- How realistic are his/her expectations?
- How many donors are there?
- How did they find out about the recipient?
- How much do they know/understand?
- What are their expectations?
- Set limits:
  - E.g. How many donors and criteria for acceptance
- Are any donors willing to become a NDAD?

# Thank you



“ The Voice of  
Transplantation  
in the UK ”