

# ALTRUISTIC KIDNEY DONATION

*South Africa, 28th SATS & SATiBA  
September 2019*

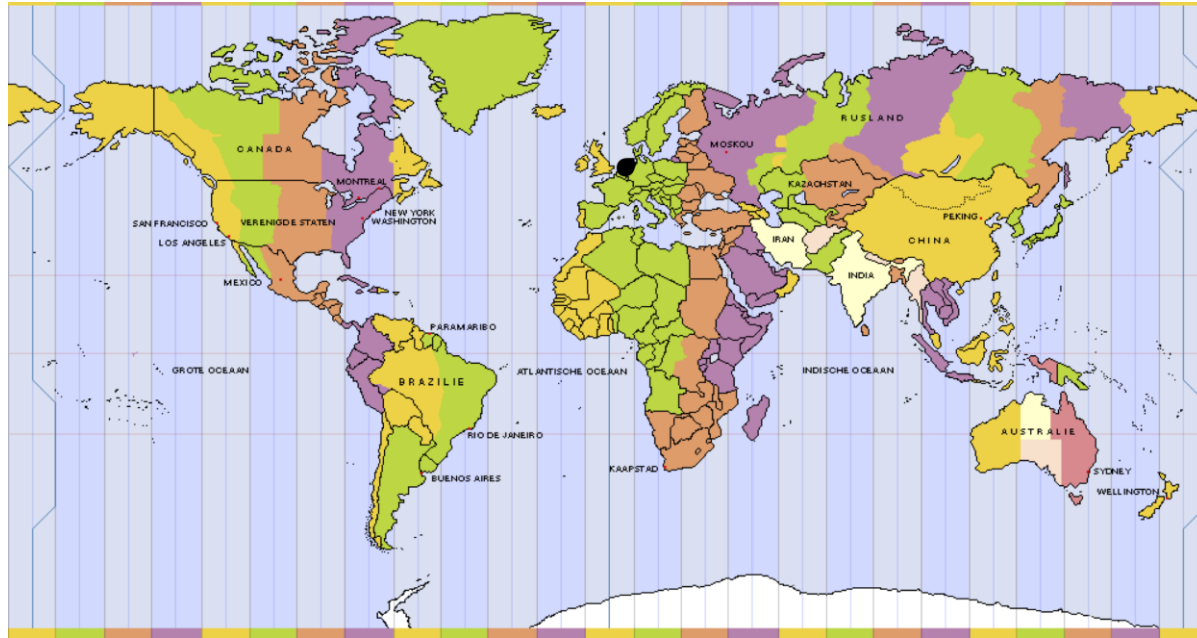
*Willij Zuidema*



**Erasmus MC**  
University Medical Center Rotterdam



# The Netherlands



# South Africa and The Netherlands



121.912 km

55.000.000 inhabitants

11 languages

Football, cricket rugby and boxing

Desert, sub-tropical

Elephant, lion, rhino, hippopotamus, leopard



41.526 km

17.000.000 inhabitants

2 languages

Football, skating, cycling and swimming

Moderate maritime climate

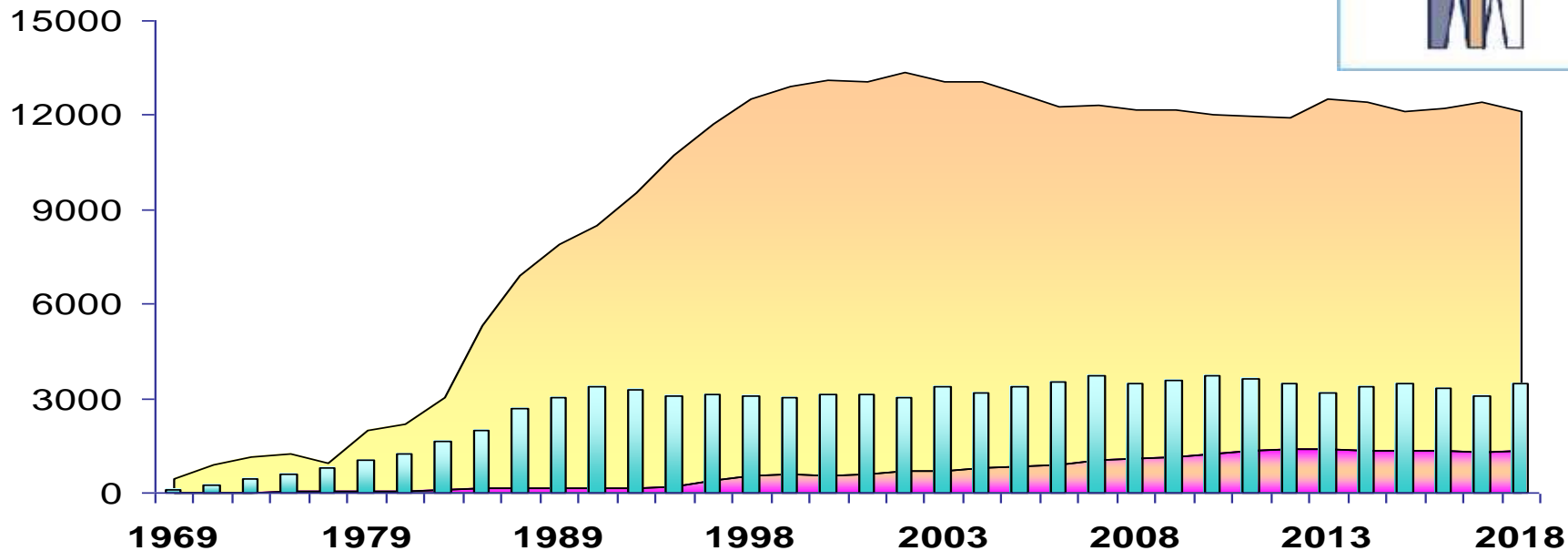
Cow

# SCOPE OF THE EUROPEAN PROBLEM

120.000	On dialysis
65.000	Waiting for a transplant
25.000	Transplanted per year
3-5 years	Wait time
5.500	Die on wait list per year
??	Removed from wait list
??	Not even on wait list



# EUROTRANSPLANT KIDNEY WAITLIST



# EUROTRANSPLANT KIDNEY WAITLIST 2018



Waitlist: 11.105 → 10.791

Inflow: 5.999

Outflow: 6.313

Outflow:  $3.480 + 1.326 = 4.806$  transplants  
1.507 dead/delisted/NT (24%)

# DUTCH KIDNEY WAITLIST 2018



Waitlist: 673 → 741

Inflow: 1.521

Outflow: 1.433

Outflow: 512+532 = 1.044 transplants  
389 dead/delisted/NT (27%)

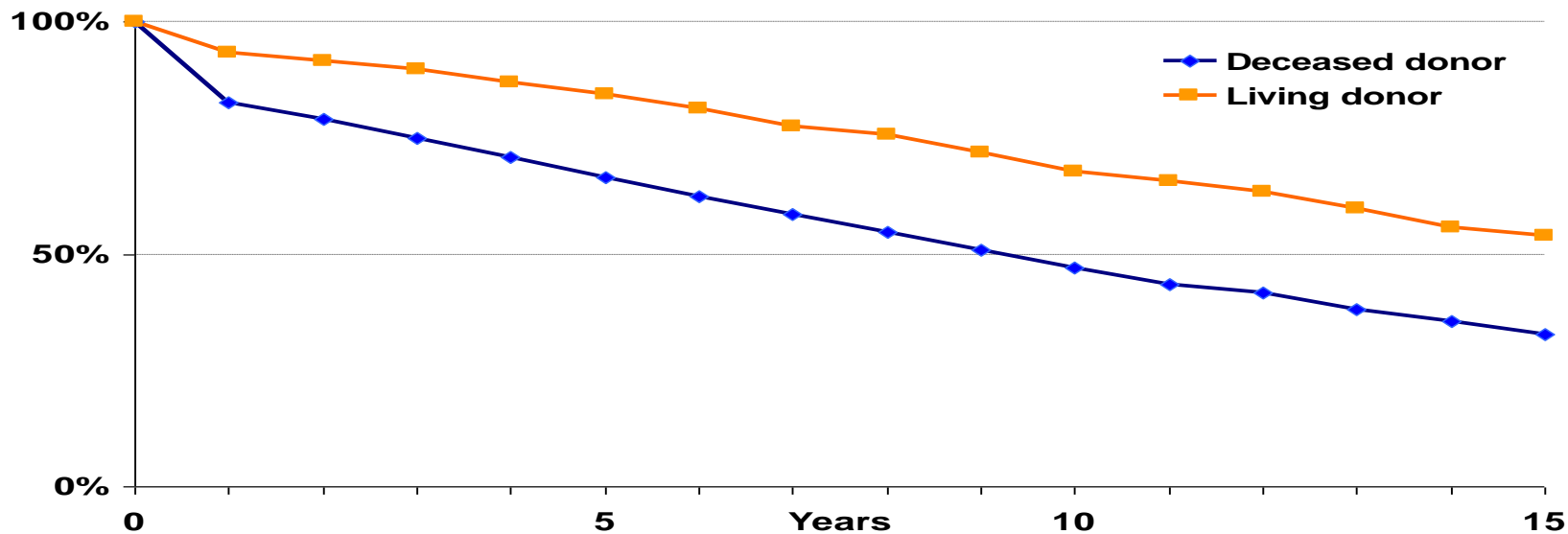


# INCREASE THE DONOR POOL

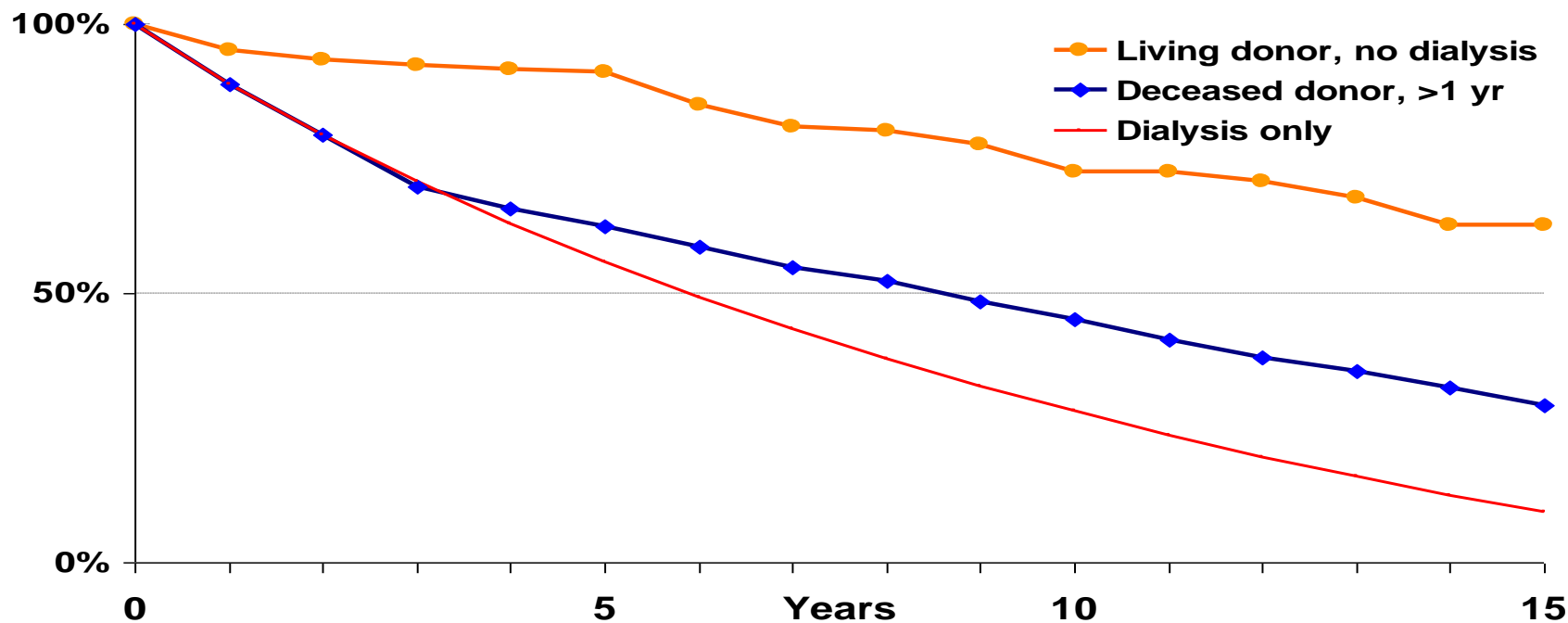
- Expand deceased donor criteria
- Opt out legal system
- Active promotion of living donation



# ALIVE WITH FUNCTIONING KIDNEY



# PRE-EMPTIVE TRANSPLANTATION



# INCREASE THE LIVING DONOR POOL

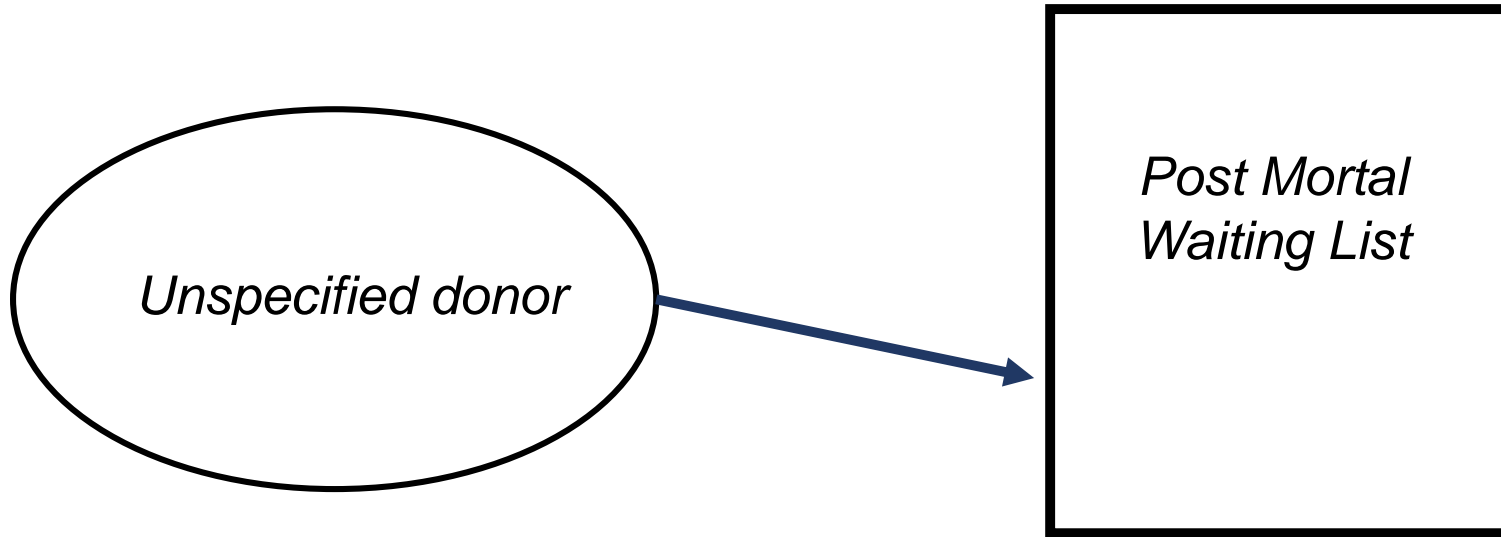
## ALTERNATIVE PROGRAMS

- Genetically related
- Genetically unrelated
- Kidney exchange
- **Unspecified donation**
- Domino-paired chains
- ABOi, HLAi, desensitization

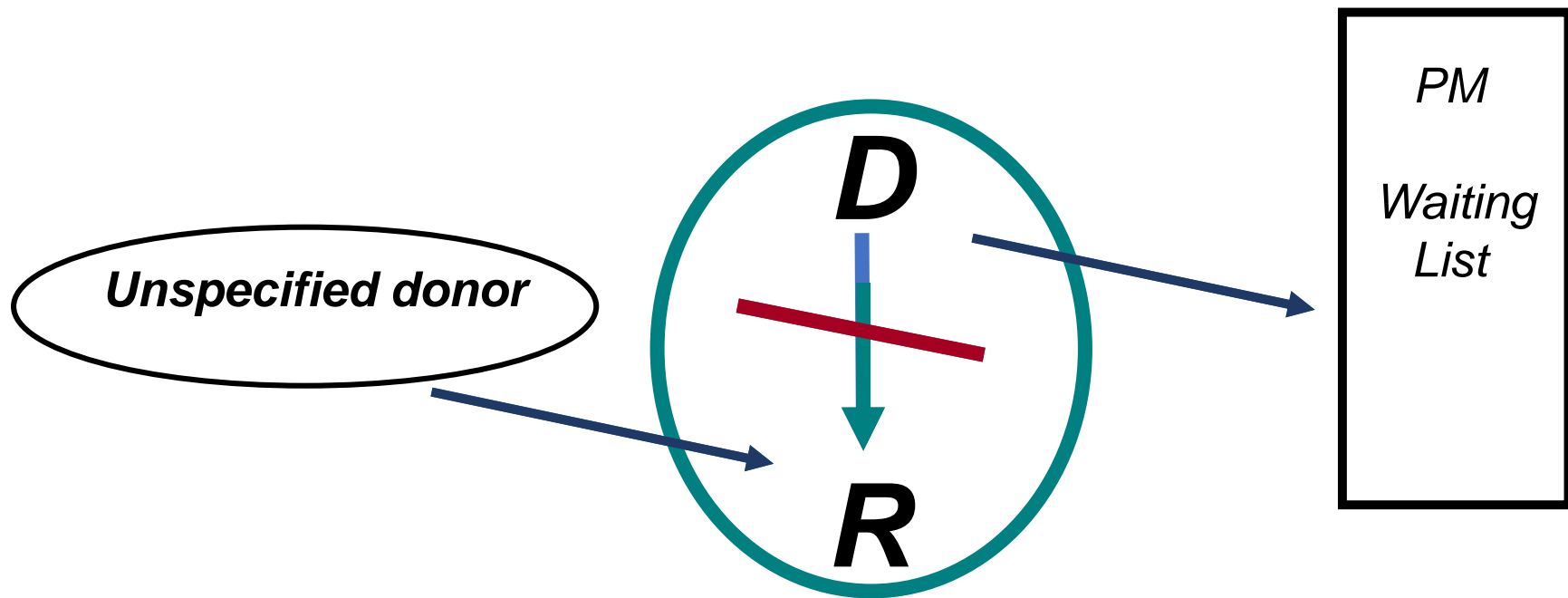




# DIRECT TO WAITLIST RECIPIENT



# DOMINO-PAIRED TRANSPLANTS



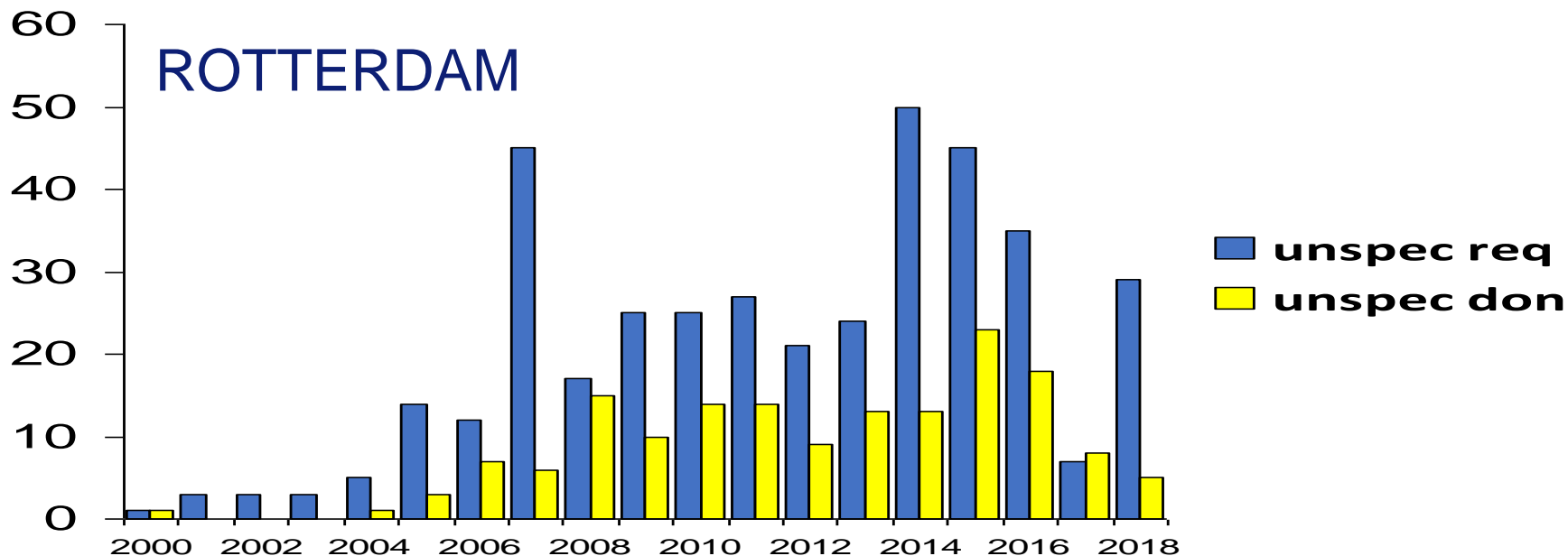
# SMALL CITY IN BIG CITY



Erasmus MC Rotterdam



# RESULTS





# UNSPECIFIED DONATION ROTTERDAM (2000-2018)

REQUEST	SCREENING	ACCEPTED	DONATED
390			
	258		
		172	
			160

# DONOR CHARACTERISTICS

	Unspecified
N	160
Male/Female	76/84
Age of donor	58 (21-89)

# RESULTS

PERFORMED	N	Total TXP
Doublet	76	152
Triplet	12	36
Quartet	4	16
<b>TOTAL</b>	<b>92</b>	<b>204</b>
1-1	68	68
<b>TOTAL</b>	<b>160</b>	<b>272</b>

# MOTIVATION

Way of life, blood donor, voluntary work

Kidney disease in their environment

Stories in the media about organ shortage

Serious illness in their environment

Prefer to give by life

Bereavement and give new life

Moral duty

Religion

Give something back to the medical staff as gratefulness

# MENTAL HEALTH AMONG UNSPECIFIED LIVING KIDNEY DONORS AFTER DONATION

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# AIM

1. To investigate the mental health after anonymous kidney donation (quantitative)
2. To investigate the experience of anonymous donation (qualitative)
  - anonymity
  - impact on life, physical and mental health
    - attribution of problems to donation

# RESEARCH QUESTIONS (quantitative)

- How many donors reported positive psychological well-being after donation?
- How many donors reported psychological symptoms after donation?
- How many donors received a psychiatric diagnosis after donation?
  - Which diagnoses are reported?
  - Did this develop before or after donation?
  - Does the donor attribute psychological problems to donation?

# METHODS – PARTICIPANTS & PROCEDURE

## Participants

- Anonymous donation between 2000-2016, > 18 years

## Procedure

- IRB approval
- Invited for an interview & questionnaires
- Interviews in the hospital or at home (Feb 2018 – August 2019)
- Audio recorded & transcribed





# METHODS - MEASURES

## Questionnaires

### Psychological well-being

- Dutch Mental Health Continuum short-form

### Psychological complaints

- The Symptom Checklist SCL-90

## Interview

### Psychiatric diagnosis

- Step 1. M.I.N.I. screen (*interviewer*)
- Step 2. on indication M.I.N.I. plus (*psychologist*)

# METHODS - INTERVIEW

Recorded interview with **open questions** regarding 3 moments:

Screening	}	- Experiences
Donation		- Expectancies
Follow-up		- Reaction from the social network
		- Anonymity
		- Psychopathology
		- Psychotropic medication use

# DONATION 2000-2016

Performed	N altr	Totaal Transplants
Doublet	68	136
Triplet	10	30
Quartet	3	12
<b>TOTAL</b>	<b>81</b>	<b>178</b>
1-1	66	66
<b>TOTAL</b>	<b>147</b>	<b>244</b>

# RESULTS

➤ 147 unspecified donors in study period

11 donors died not related to the donation procedure, after a median follow-up of 51 (7-164) months

➤ 136 eligible

114 consented to participate

52 male and 62 female.

The age at time interview was median 66.5 years (25-94)

Follow up time median 76.5 (24-178) months



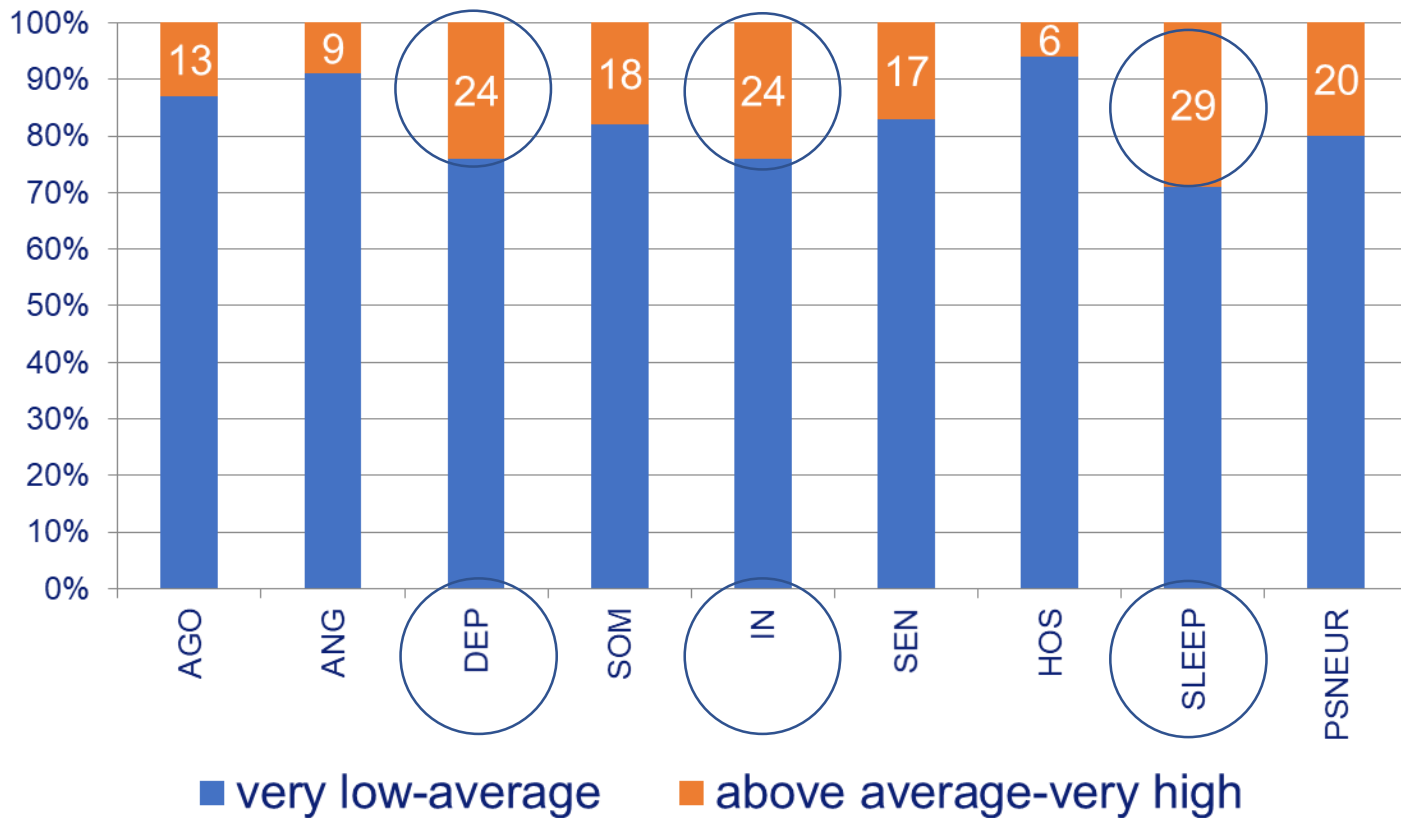
# Results – positive well-being

(Dutch) Mental Health Continuum (N=114)	Mean Unspec donors	Average score gen pop*
<b>Emotional well-being</b> <i>(positive emotions and life satisfaction)</i>	3.91	3.67*
<b>Social well-being</b> <i>(social acceptance, contribution, integration)</i>	2.73	2.33***
<b>Psychological well-being</b> <i>(personal growth, self-acceptance, autonomy)</i>	3.31	3.18
<b>Total positive well-being</b>	3.24	2.98*

\* Dutch norm scores for general population (N=1662) from Lamers et al 2011

\*  $p < .05$   
\*\*  $p < .01$   
\*\*\*  $p < .001$

# Results – psychological symptoms



# Results – psychological symptoms

Responses to specific questions of interest:

% responding *quite a lot / very much* in the past week

- Feeling lonely = 3
- Feelings of guilt = 2
- The idea that something is wrong with your mind = 2
- Thoughts about dead or dying = 7
- Thoughts about ending your life = 4

# RESULTS – MINI Screen

114 MINI Screen interviews completed

- **NO** indication for M.I.N.I. plus interview = 60 (53%)
- **YES** an indication for M.I.N.I. plus interview = 54 (47%)

└─ • **Diagnosis** from Mini PLUS = 36 (32%)



# Results – MINI Plus

36 (32%) actual diagnosis(es)

6 Risk low  
4 Risk moderate

Sub-scales	N	% Yes
Depressive disorder - present	5	4.5
Depressive disorder -past	11	10
Dysthymia	10	9
Suicidality	10	9
(Hypo-) Manic episode - past	3	3
Panic disorder - present	1	1
Panic disorder - past	3	3
Agoraphobia - present	3	3
Agoraphobia - past	1	1
Social phobia	1	1

Sub-scales	N	% Yes
Obsessive Compulsive Disorder	0	0
Post-traumatic Stress Disorder	14	11
Alcohol abuse - present	1	1
Alcohol abuse - past	3	3
Substance abuse - past	1	1
Psychotic Disorder - NOS	1	1
Bulimia nervosa - past	1	1
Generalized Anxiety Disorder	7	6
ADHD	6	5
Adaptation disorder	2	2

# RESULTS - TREATMENT

N=114	BEFORE DONATION	AFTER DONATION
Psychological/psychiatric treatment	45 (40%)	17 (15%)
Admission psychiatric clinic	19 (17%)	1 (1%)
Psychotropic medication	38 (33%)	31 (27%)

# FIRST IMPRESSION

## EXPERIENCES AND EXPECTANCIES

- 5 donors were guilty of serious crimes before donation
- A number of donors reported incest or sexual abuse before the donation
- One donor had planned euthanasia and cancelled this after the donation



# CONCLUSION

- **High willingness** to participate (84%)
- Psychological **symptoms** and psychiatric **diagnosis** comparable with prevalence in general population / norm scores
- There is an underreporting before donation of psychiatric diagnosis and criminality
- Psychological **well-being** generally appears high
- **No psychological harm**, potentially benefits, even among those with a psychiatric diagnosis before donation

**Thank you**  
**Any questions ?**

