

# Family donation with a young child

## What do the families need?



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**Radboudumc**

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# Background

Family donation with a young child

**Major life event** for parents and family

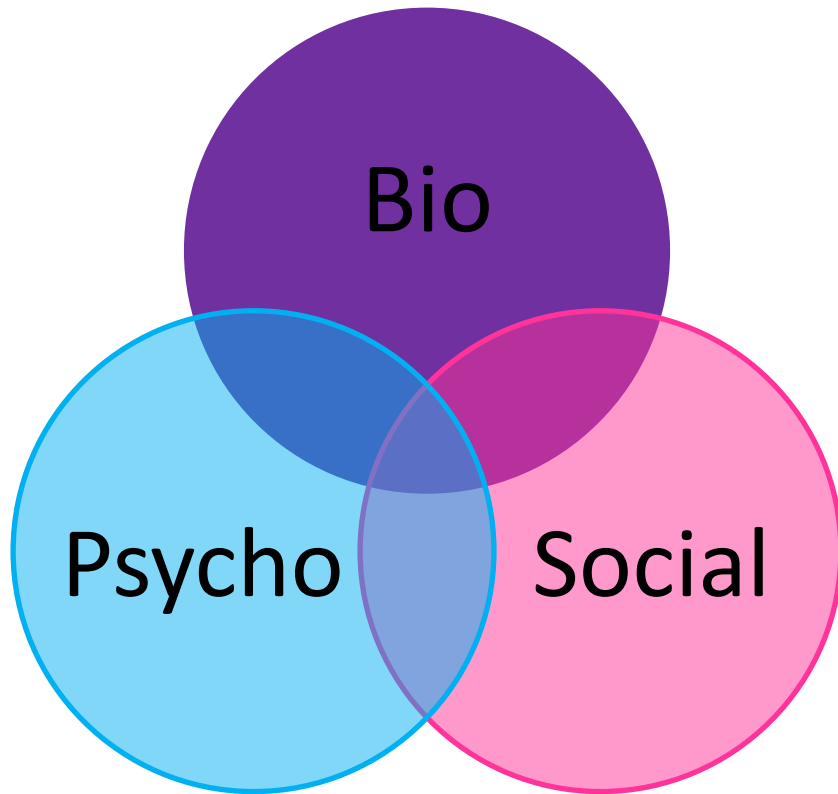
**Early childhood** development issues

**Extra care** of a small child with kidney disease



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# Family issues and dynamics



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# **Radboudumc - Kleine Kint**

**Kidney transplant for children under 3 years of age**

**Started in 2012**

**Donor kidney placed in stomach cavity**

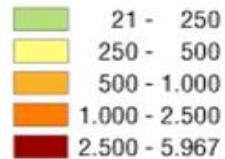
**Waiting list shorter donor kidney**

**Improving quality of life**

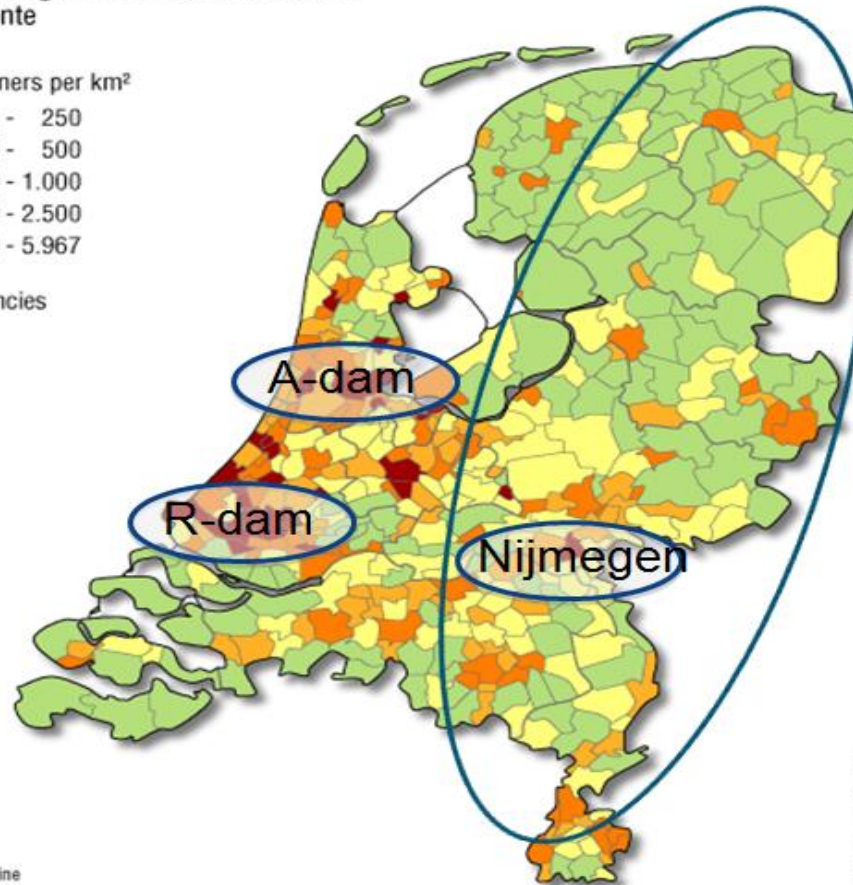
# Pediatric kidney centers

Bevolkingsdichtheid 2010  
per gemeente

Aantal inwoners per km<sup>2</sup>



— provincies



Bron: CBS Statline

www.zorgatlas.nl

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# Psychosocial services

- Pre-screening meeting with parents
- Counseling, advice, information, referrals
- Post-transplant assessment and services



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# Research questions

What are the specific issues and needs these families are addressing **before** and **after** the kidney transplant?

How can we improve **psycho-social services** to better meet the **needs** of these families?



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# Methods

## Procedure

All families transplanted from 2012 - 2016 with Kleine Kint

Families invited by mail in March 2016, with followup telephone call

Preference interview by telephone or home visit

Interview questions and case reviews





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# Methods

## Content

### Case/chart review:

Initial family assessments and treatment plan; followup

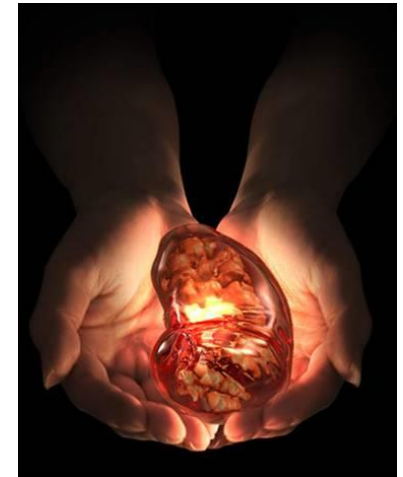
### Qualitative interview:

- Before and after transplant
- Questions: Issues, Needs, Evaluation

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# Interview questions

1. Which **issues** were the family dealing with?
  2. What were the family's **needs**?
  3. Which **support** was given?
  4. What was **helpful** and what did you **miss**?
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# Results

Alle of the Transplants were succesful, although in the beginning, there were several children with more complications and longer ICU admissions. These are some pictures of the 11 children (before and just after) who have received a succesful kidney transplant through the Kleine Kint transplant program.

- All of the families decided to participate in the interview.
- 9 families were interviewed by telephone.
- 2 families were interviewed in their own home.
- In 8 cases the mother was interviewed. In two cases, both parents were interviewed together and in one family, the father was interviewed.

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# Results - demographics

Child and Treatment						
Age of Child at transplant		Living Donor			Treatment path	
Mean	Range	Father	Mother	Other	HD/PD	Preemptive
2,7 years	20 mo to 4.1 years	4	6	1 uncle	4	7

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# Results - demographics

Family Circumstances							
Marital Status		Employment status			Number of Siblings		
Married	Single/ divorced	Both	One	None	2+	1	0
9	2	4	4	3	3	7	1

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# Family circumstances

**Single mother** with history of depression

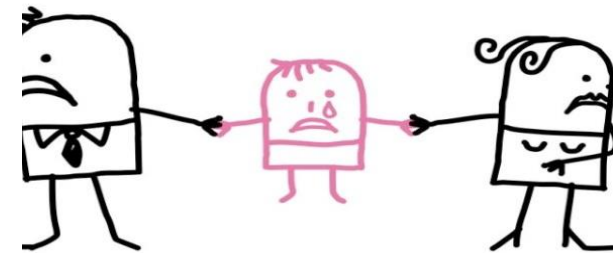
Family with recent **divorce**

Families with recent **job loss**

**Siblings** with special needs

One child with healthy twin

**Travel distance** to hospital 187 km



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# Results – services provided

## Initial meeting with Social Worker

all parents, 6 months to 1 ½ year before ntx  
with/without Child Psychologist

## Counseling/advice/support –

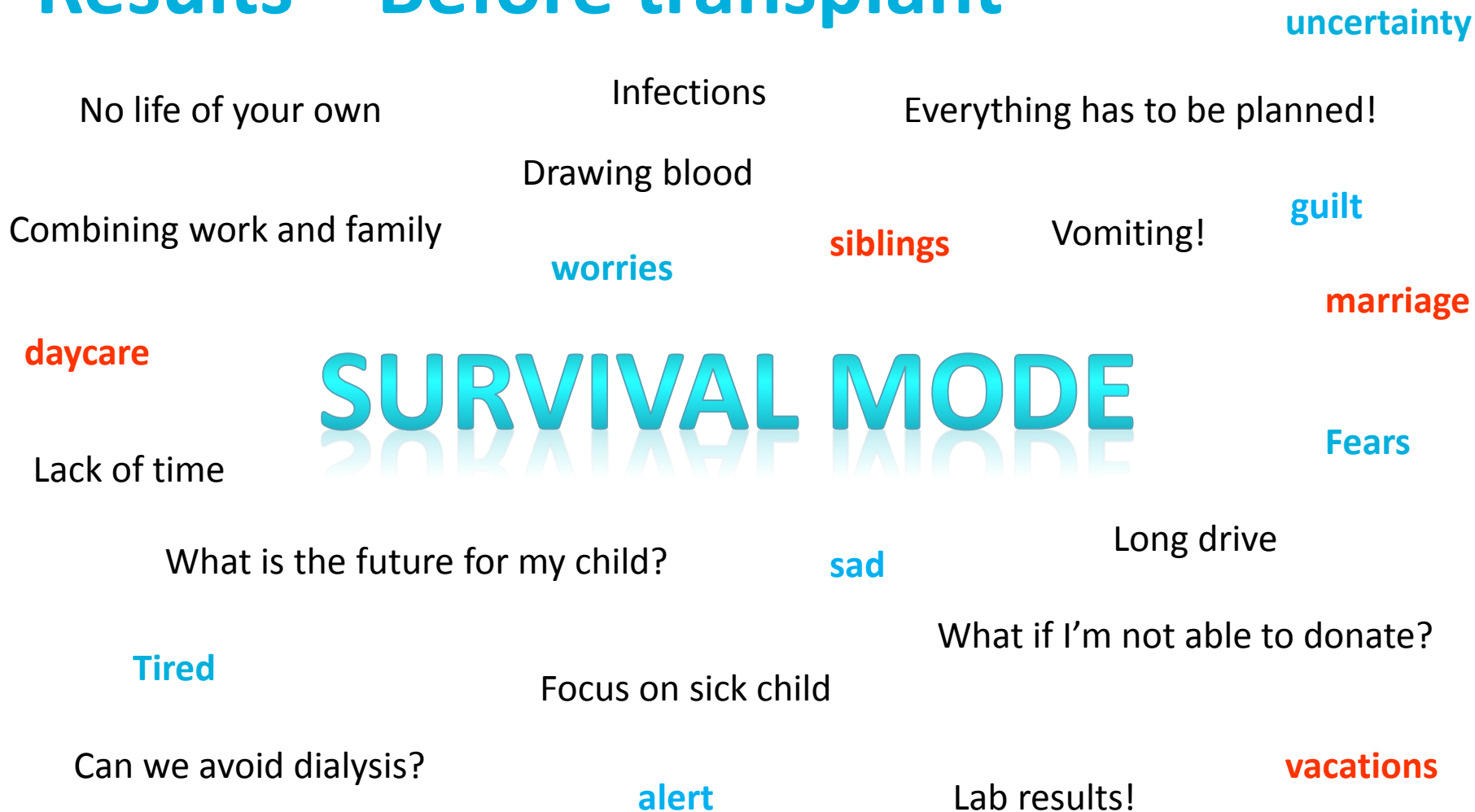
3 families on HD/PD,  
mostly just before admission  
at request of parents

## Post transplant followup and services

4 families  
at request of team or parents

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# Results – Before transplant





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# Results – After transplant



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# Results - Needs

- Too little **followup** after initial assessment
- Missed contact at **regular intervals**
- Missed **psychosocial support** for child and family after the transplant
- **Information** and **knowing what to expect**
- Wasn't aware of which **psychosocial support is available**



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# Conclusion

- **Information!**
- Need for structure in psychosocial support.
- Families have need for **practical support** and advice, as well as **advocacy** around different social and parenting issues.
- Parents appreciate **emotional support** during the process up to transplant and in the period after transplant –  
**But don't always ask for it!**

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# Implications for care

## Psychosocial care better inbedded in treatment plan

More counseling about **psychosocial impact** on child/parents/family

**Initiate SW contact** with family at **regular intervals** after donor screening; poor lab results; when date for transplant is set

Attention for **child development and school** after transplant

Folder with information about **psychosocial team**

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# Thank you for your attention

