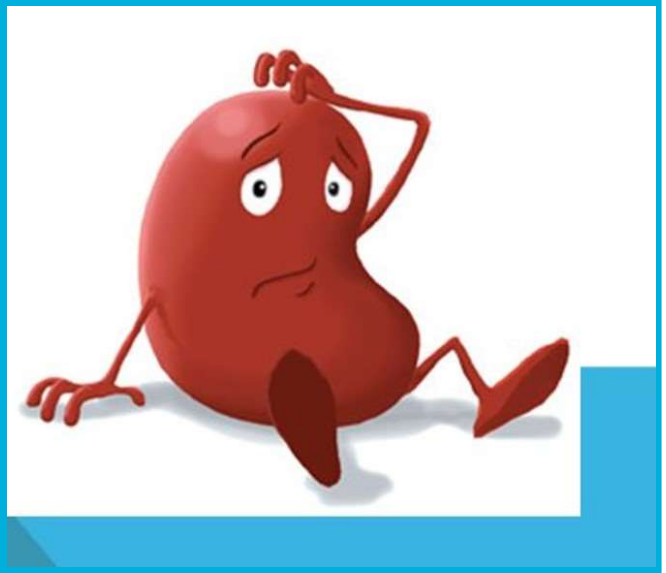
# Ethical dimension in pre-transplant counseling and decision-making

## Case Study - J
## child with short life expectancy



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- Story of J – Case study
- Ethical questions
- ‘Nijmegen Method of Ethical Case Deliberation’

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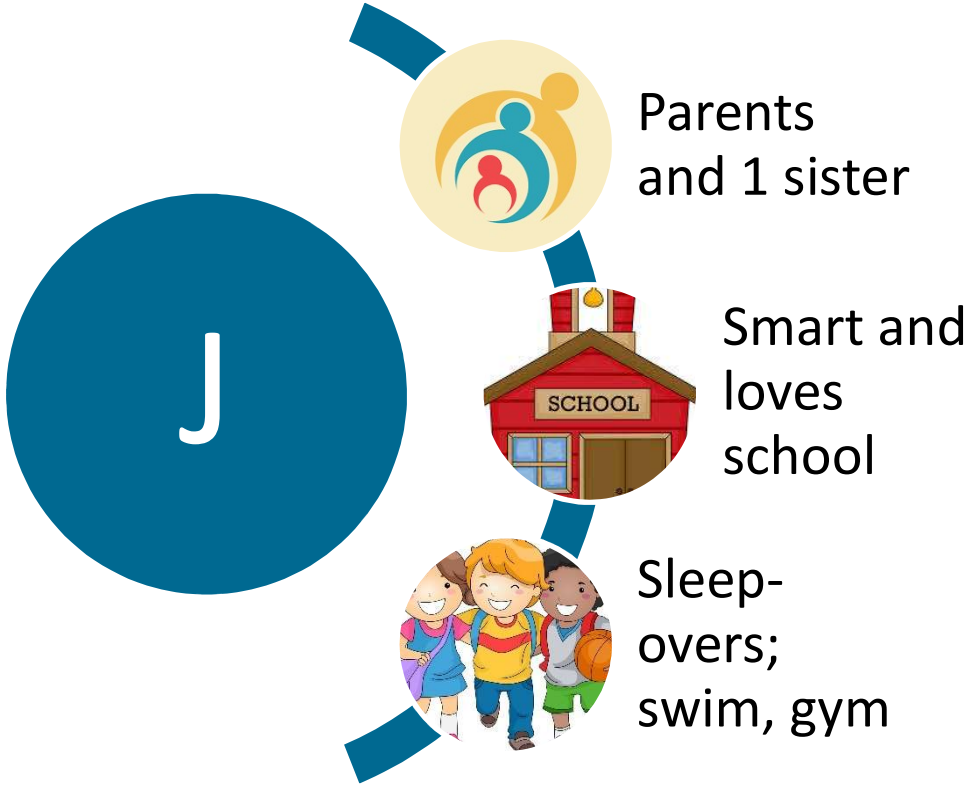
# Introduction of J – 6 years old

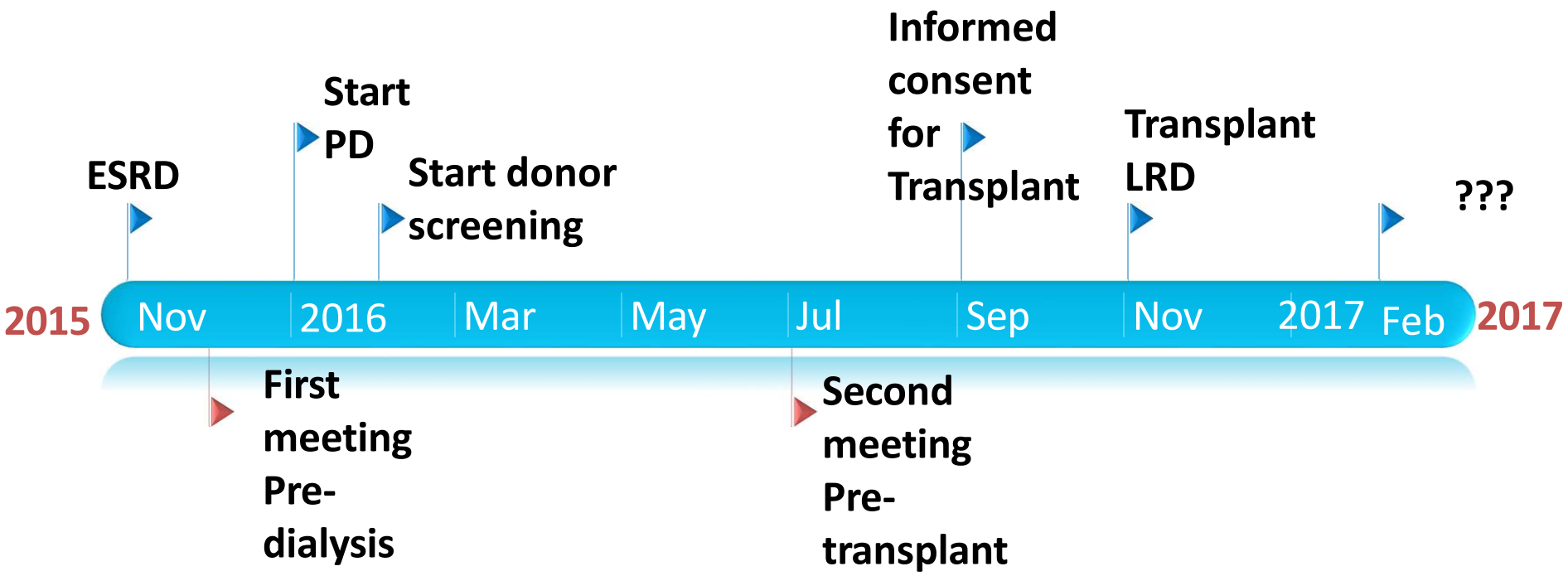
**Schimke**
**Immuno**
**Osseous**
**dysplasia**

short stature
ESRD
T cell deficiency

Life expectancy
childhood to early
adolescence



# Story of J - Timeline



# Informed consent

**Father/donor –**

Would like to donate, even if J would die shortly after the operation. Wants to offer all chances for best QOL.

**J/recipient –**

doesn't like PD; wants transplant to be able to swim and sleepover.

**Mother –**

supports decision 100%, with LRD, even if there are complications.
Trusts what the specialist thinks is best.


**Team –**

continuing Dialysis is large risk of infections. Tx also risks. Mild IS after tx.
Supports the wish of parents and child.

# What is right?


? What is the shortest life expectancy acceptable to transplant with a living donor?

? Is it acceptable to subject the parent/donor to the risk of surgery when expected outcomes for the child/recipient are poor?

? Can shared decision-making also be a burden for parents?

# Nijmegen Method of Ethical Case Deliberation

1. What is the moral problem?
2. Inventory and interpretation of facts
   - Medical, care, psychosocial, organisational/legal
3. Assessment of normative ethics
   - Well-being, autonomy, responsibility
4. Review of the problem
   - Arguments, decision, evaluation

# Nijmegen Method of Ethical Case Deliberation

Colleague and family perspective

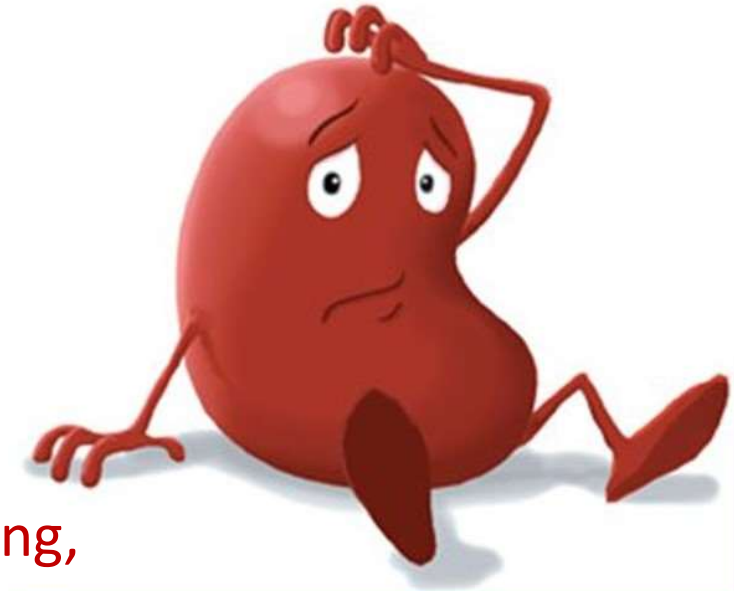

Pause for reflection


Suspended judgement

# Conclusions and discussion

## What can be learned?

- **Ethical dimension is important**
- **Relational autonomy**
- **Start early in the process**
- **Create room to interpret values and perspectives.**



In real life there is no clear right or wrong, but a messy lived experience.