Psychological Issues in Reproductive Genetics

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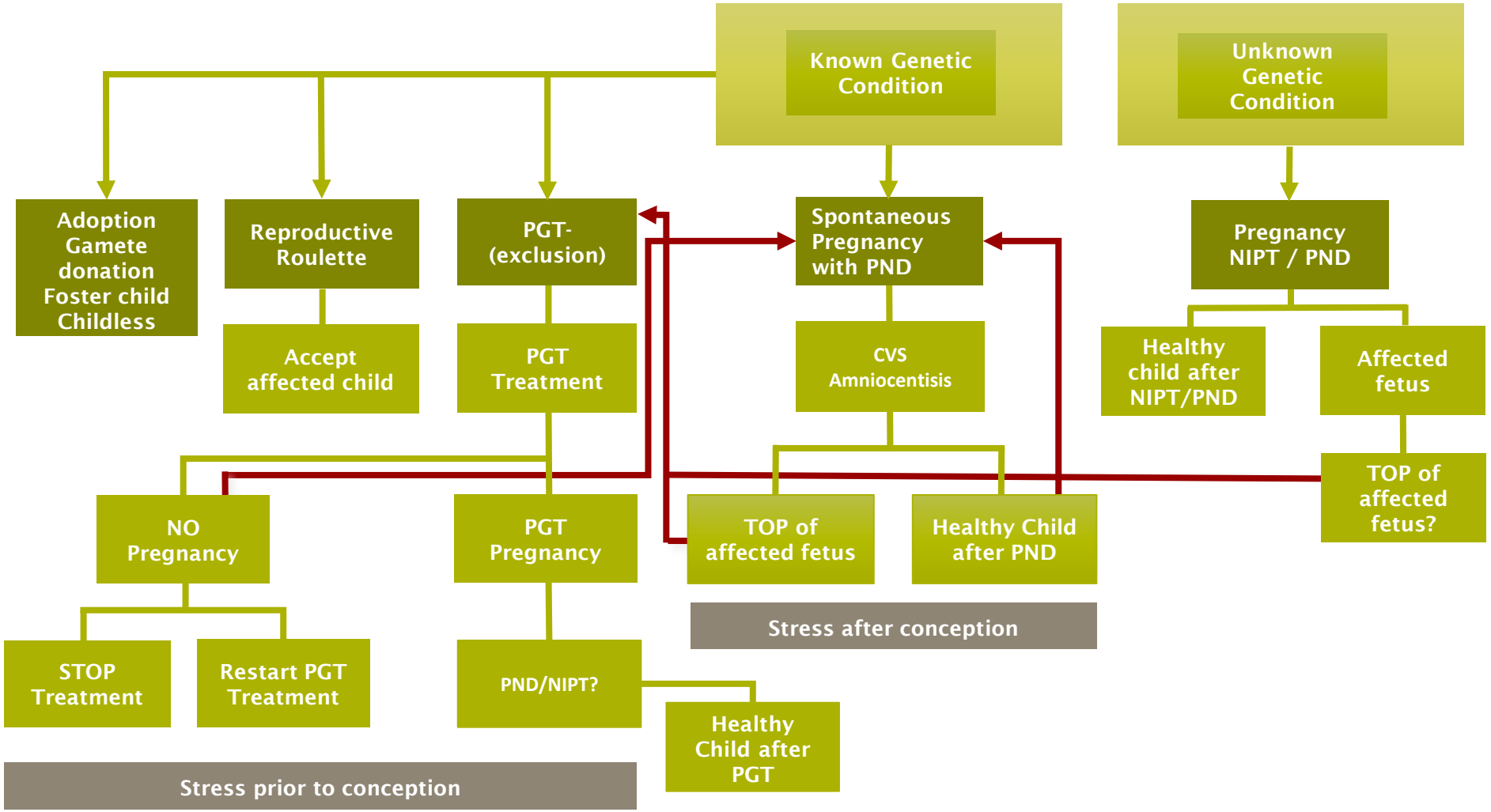
CONTENT

- **Pathways in Reproductive Genetics**
- **Psychological issues:**
  - **decision making: PGT/PND/PGT exclusion/PGT-HLA**
  - **during PGT treatment and pregnancy**
  - **After PND**
  - **And Ethical aspects**
- **Conclusions**

PSYCHOLOGICAL ISSUES WITHIN THE REPRODUCTIVE PATHWAYS



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IDENTIFYING THE PSYCHOLOGICAL ISSUES

- at preconception level given a GC: PGT or PND or..?
- after PGT treatment failure: (dis)continue PGT?
- after bad outcome of PND: TOP or not?

➢ **Decision making processes**

- prior, during, after PGT treatment/pregnancy
- during pregnancy of a fetus at risk
- during and post TOP process

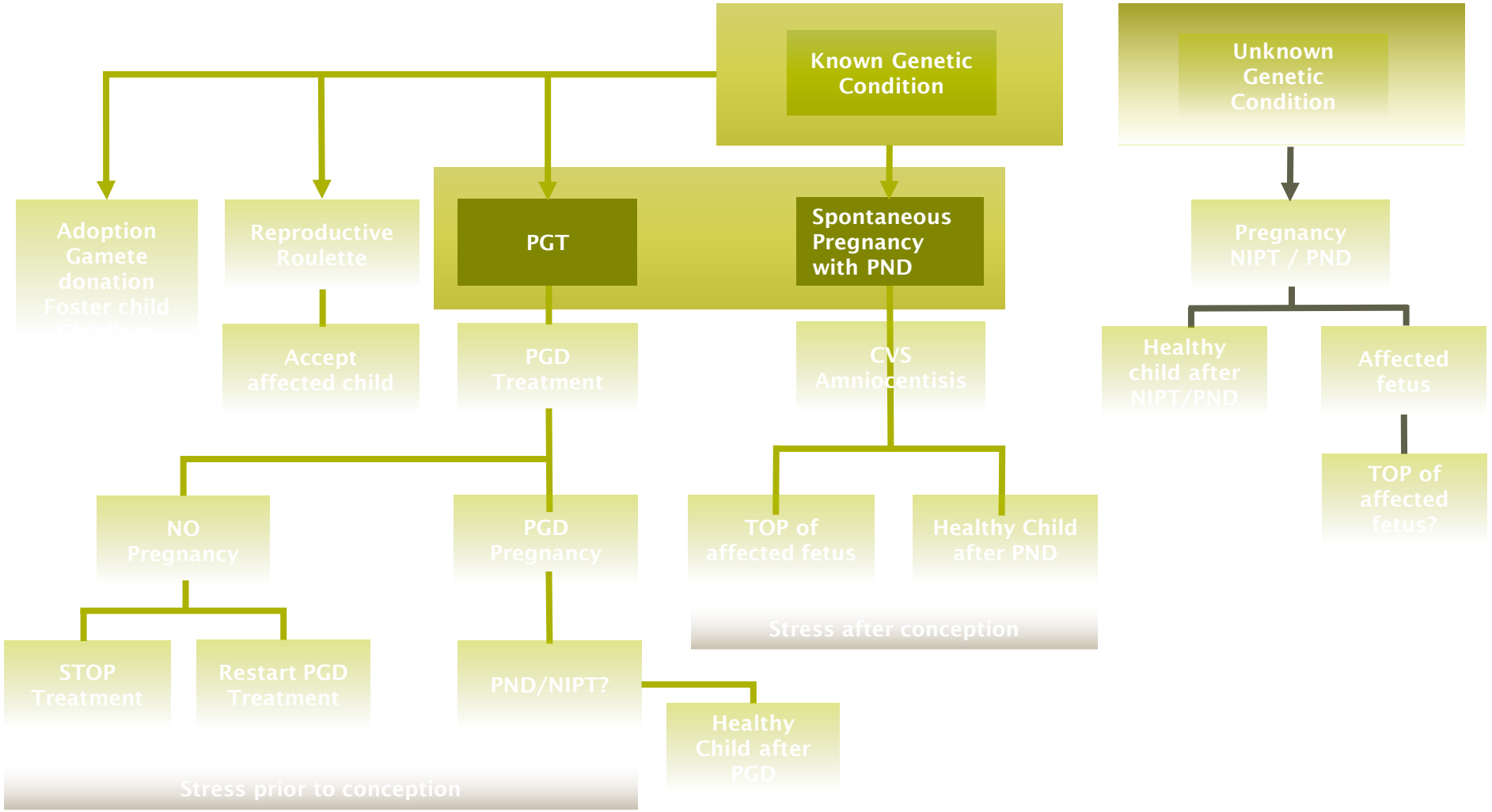
➢ **Psychological distress** (trauma, grief,..)

- after childbirth

➢ **Concerns about Child development**

PSYCHOLOGICAL ISSUES

DECISION MAKING: PRECONCEPTUAL LEVEL



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DECISION MAKING PROCESSES: PRECONCEPTUAL LEVEL

Why opt for PGT over PND and vice versa?

PGT

- To prevent/avoid trauma of TOP after PND
- Having a history of TOP (van Rij et al., 2011)
- Having fertility problems
- If the FEMALE partner prefers this over PND. Hence, the female partner decides (van Rij et al., 2011)
- Sex of the carrier, mode of inheritance and clinical impact of the disorder = less important in choice for PGT than history of TOP and living affected child (van Rij et al., 2011)
- To establish ongoing pregnancy after recurrent miscarriages due to chromosomal translocations (De Krom et al., 2015)

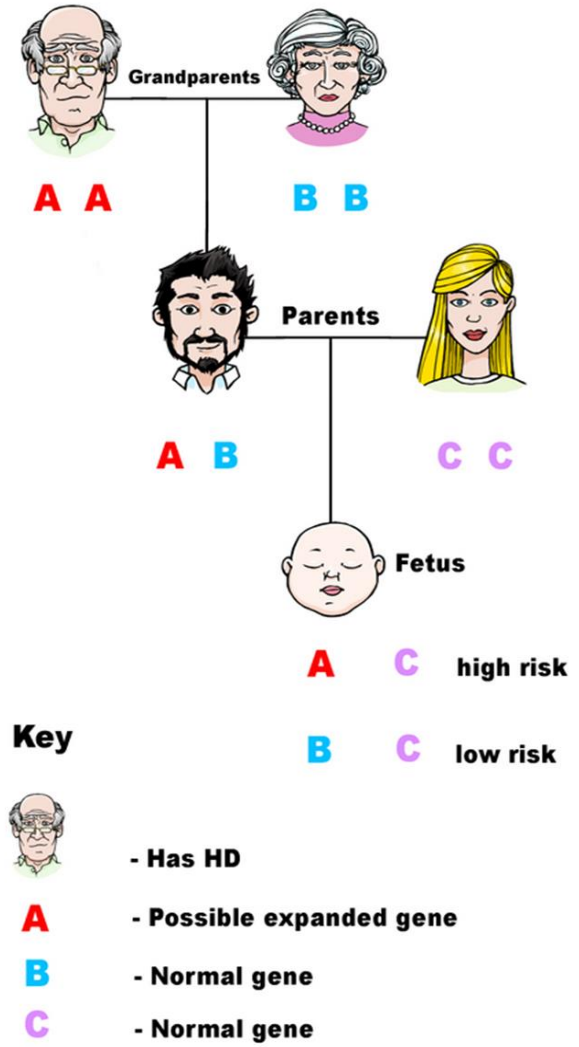
PND

- Fertile (easy to become pregnant)
- To prevent the burden of IVF/PGT (de Krom et al, 2015)
  - Limited success rates – time consuming procedure invasiveness of the procedure
- Uncomplicated reproductive history
- Recurrent failure of PGT (Decruyenaere, 2007)
- Fear for ovarian stimulation in case of cancer (BRCA) (Derks-Smeets et al., 2014)
- Fear of the impact of embryo-biopsy on child development (Derks-Smeets et al., 2014)

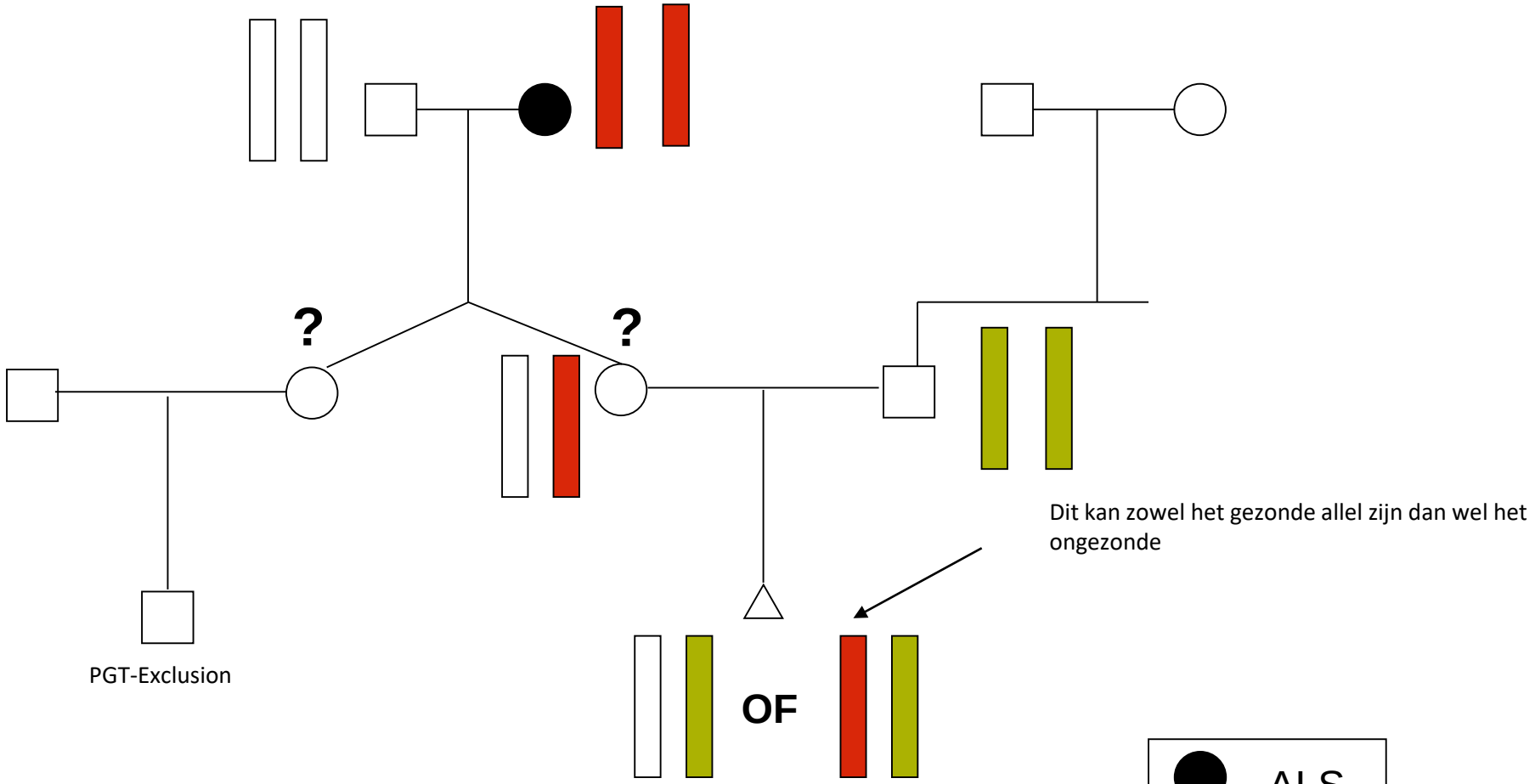
DECISION MAKING PROCESSES: PRECONCEPTUAL LEVEL

Or do patients opt for PGT-exclusion?

- Good reasons not to opt for predictive testing?
- Coping with uncertainty > coping with certainty of future illness
- The ‘resilience’ of the patient and the partner
- Awareness of the impact on success rates?

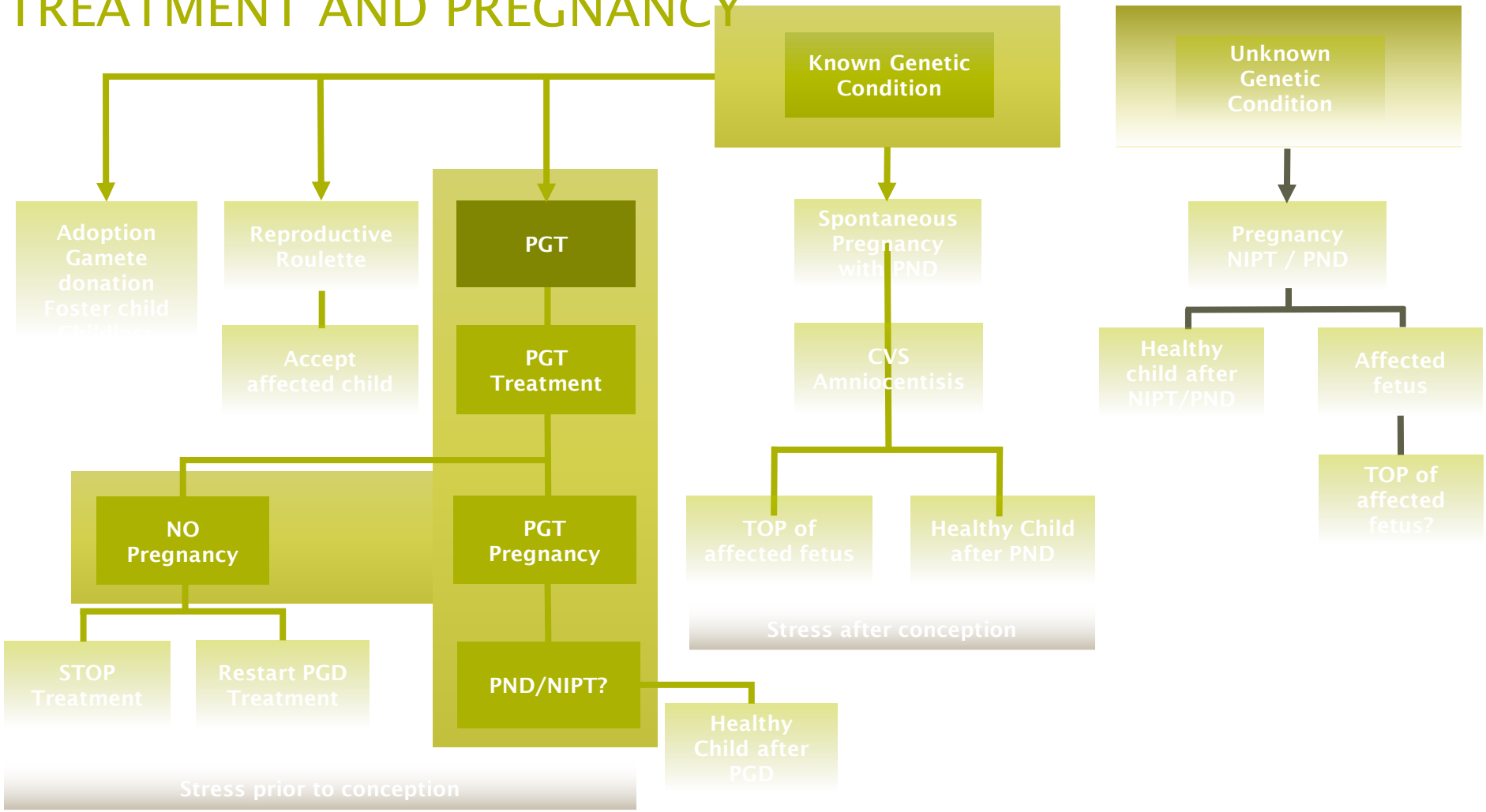


DECISION MAKING PROCESSES: EXCLUSION TESTING



PSYCHOLOGICAL ISSUES

PGT TREATMENT AND PREGNANCY



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PSYCHOLOGICAL ISSUES: PGT TREATMENT

Positive experiences

- Greater feeling of empowerment and control (Karatas, 2010b)
- Learned to be patient, open minded, cope with difficulties (Järvholm et al, 2017)
- PGT treatment stress seems more bearable than 'uncontrolable' reproductive trauma's: miscarriages, care for sick child, TOP's (Roberts & Franklin, 2004)
- PGT stress (anxiety and depression) during treatment in women are comparable to other IVF / ICSI procedures (Järvholm, 2016)

Stressfull experiences

- Ambivalence: Combination between MEDICALIZED TRAJECTORY and UNCERTAINTY (Pastore et al., 2019)
- Waiting time between ET and pregnancy test (Lavery, 2002)
- Waiting time between E-biopsy ➔ healthy transferable embryo's (Karatas, 2010b)
- More male anxiety's during PGT treatment ➔ reinforced by a living ill child (Järvholm et al., 2016)
- Emotional draining (Karatas, 2010b) = anxiety & depression
- Even on the long run (Järvholm et al., 2017) although ➔ **"It is better to have tried"**

PSYCHOLOGICAL ISSUES: PGT PREGNANCY

PGT pregnancy can be experienced in various ways as each pregnancy

- **Tentative** (Rothman; 1986, Karatas, 2010)
- **Precious, burdend and loaded** (Teixara, 2011)

if people already had **previous reproductive trauma: TRIGGER**

➔ "**the body keeps the score" (**van der Kolk, 2015)

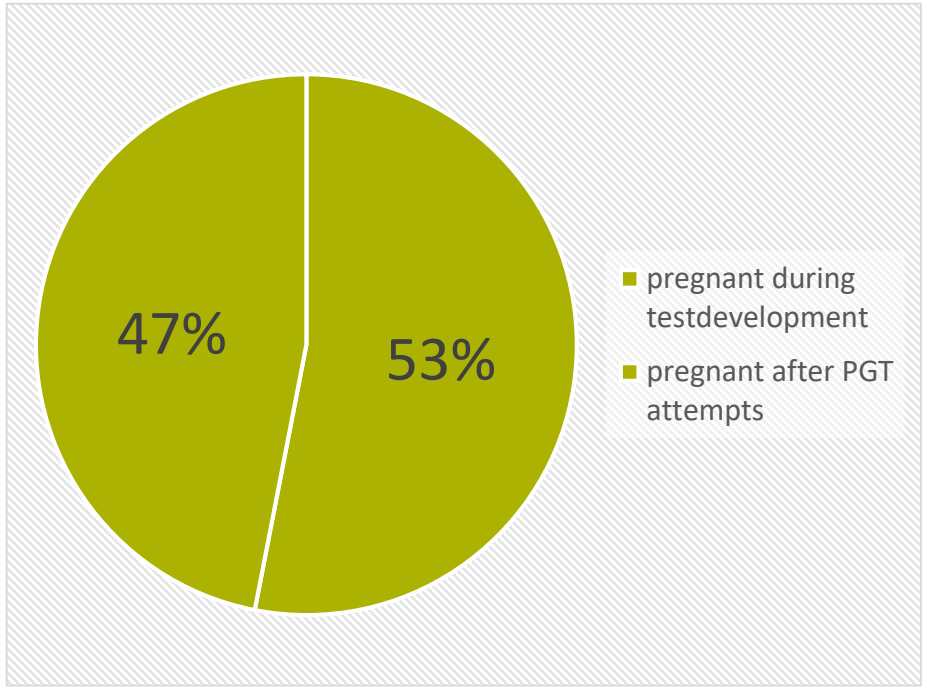
However:

- No higher mental health problems (PGT vs ICSI vs SC)
- Gender differences = along 3 groups
- No differences in prenatal attachment
- Only after invasive PND: prenatal attachment decreases temporarely

(Winter *et al*. 2016)

PGT ➔ SPONTANOUS PREGNANCY: CONSCIOUS CHOICE OR COINCIDENCE?

30/425 (7%) couples got pregnant spontaneously
- During PGT testdevelopment
- After at least 1 PGT attempt



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PSYCHOLOGICAL ISSUES: PGT-HLA

- A child with a (blood-)disease such as leukemia, thalassemia can be cured by a HLA-compatibele donor
- Stem cells from bone marrow tissue or core blood are needed
- Stem cells can be used from a HLA-compatibel sibling
  - Extracted form cord blood after his birth
  - Not dangerous for baby nor the mother
  - Allowed in Belgium

PSYCHOLOGICAL ISSUES: PGT- HLA

PGT-HLA Pro's:

cure of an ill child

by a new-born sibling (win-win?!)

PGT – HLA Con's:

a new-born/sibling is USED = instrumentalisation in order to cure?

Psychological risk factors:

favouritism / jealousy / lifelong guilt /secrecy/

dependency/ not good enough ????

Designer baby ? = selection against illness

PSYCHO- SOCIAL COUNSELING = a reflective thinking process ?

PSYCHOLOGICAL ISSUES: PGT-HLA

Experience after treatment failure

22 couples after PGT-HLA treatment - semi-structured interviews

Why stopping treatment ?

- 43% psychological burden
- 38% physical burden
- 38% maternal medical reasons
- 48% alternative treatment for the sick child

Family secrecy

- 52% of children were informed ➔ no problems with treatment stop

Experience after PGT – HLA?

- high hopes in the beginning, but finally a feeling of **empowerment** and no decisional regrets!

(Nekkebroeck et. al, 2019)

WE DID EVERYTHING WE COULD TO SAVE OUR CHILD

PGT: ETHICAL ASPECTS: ACCESS TO TREATMENT ?

- **2007**: law on Medically Assisted Reproduction (MAR)
  - Art. 5: De fertiliteitscentra zorgen voor een grote transparantie van hun opties in verband met de toegankelijkheid van de behandeling: ze kunnen ten aanzien van de tot hen gerichte verzoeken een beroep doen op de gewetensclausule
  - No treatment obligation *(Oath of Hippocrates)*
- Quality handbook = internal guidelines
- Welfare of the future child (Pennings 1999, 2007)
  - **The reasonable welfare principle:** the future child has the possibility :
    - to develop normal human interests
    - to achieve life goals, which are generally considered to make human life worthwhile

PGT: ETHICAL ASPECTS: ACCESS TO TREATMENT ?

- **Multidisciplinary team: “Reflectiecel” Brussels IVF/CMG**
- Ad hoc MEETING:

Gynaecologists, psychologists, ethicist, geneticists,

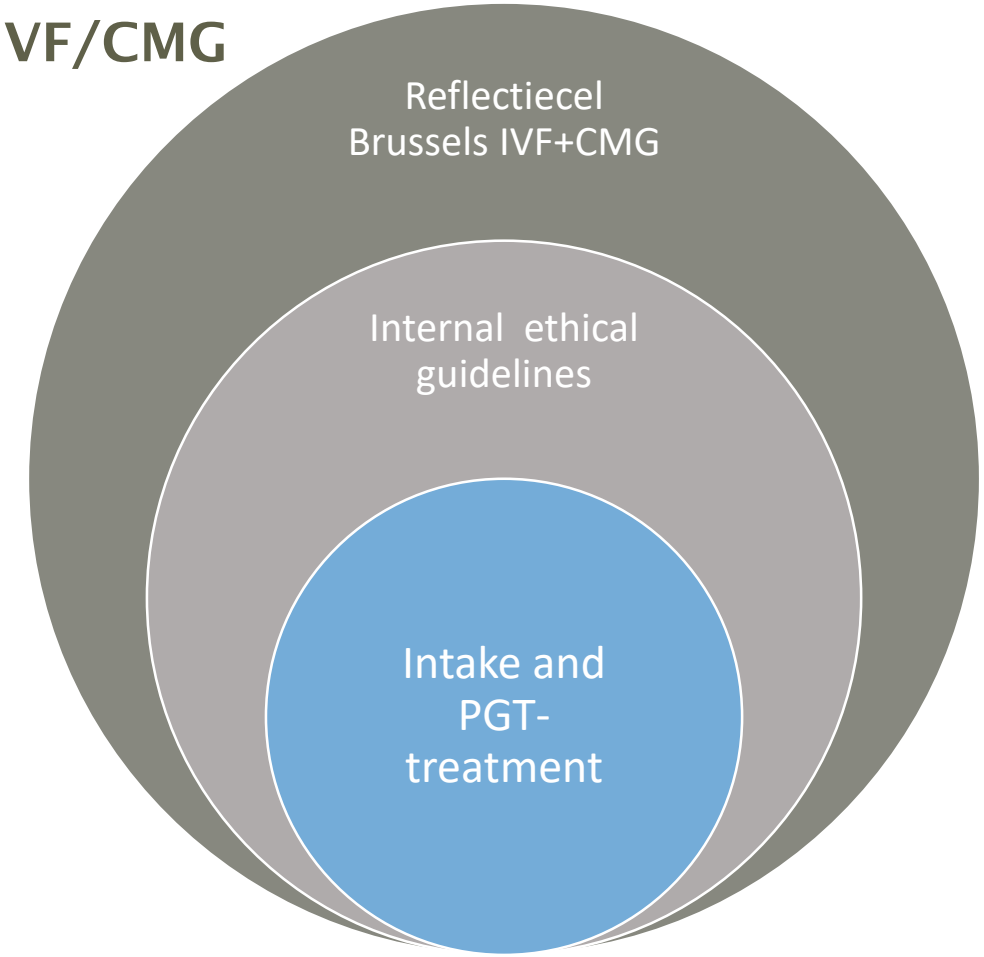
Child psychiatrist, embryologist, nurses,..

- MONTHLY
- ADVICE:

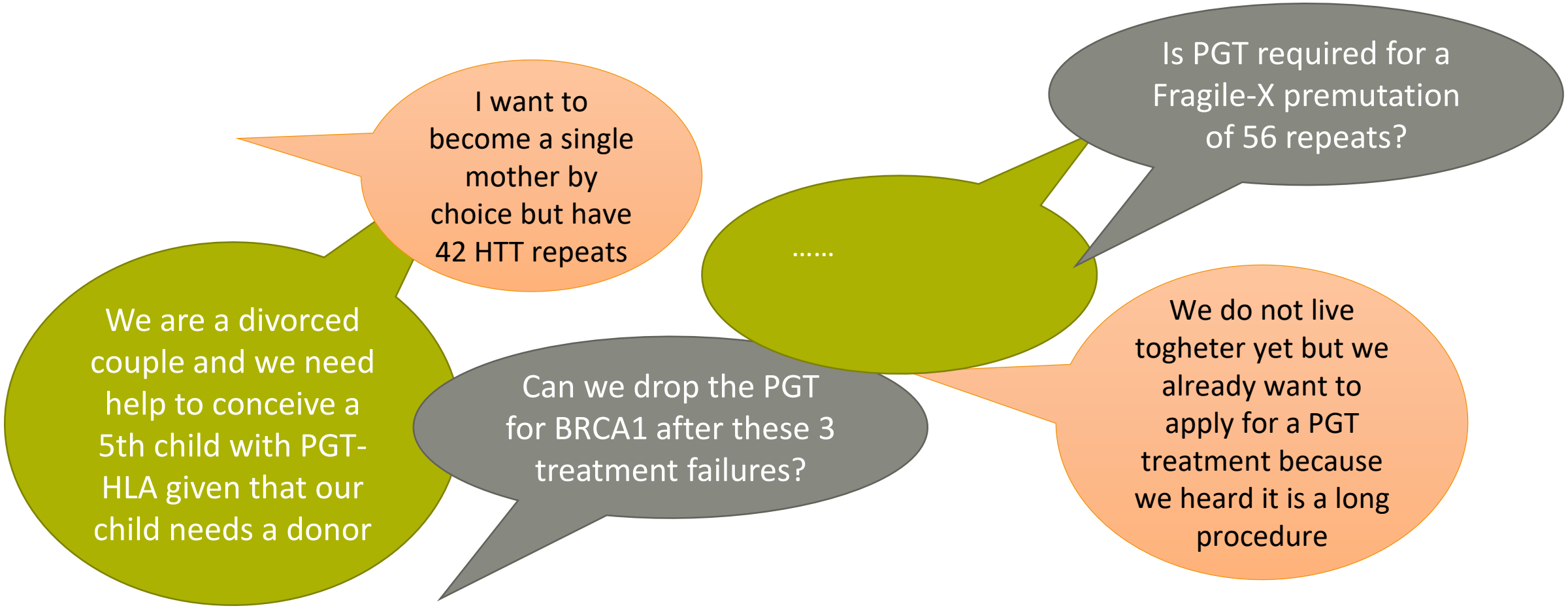
Positive-Negative-’Pending’

Binding

Conscience clause



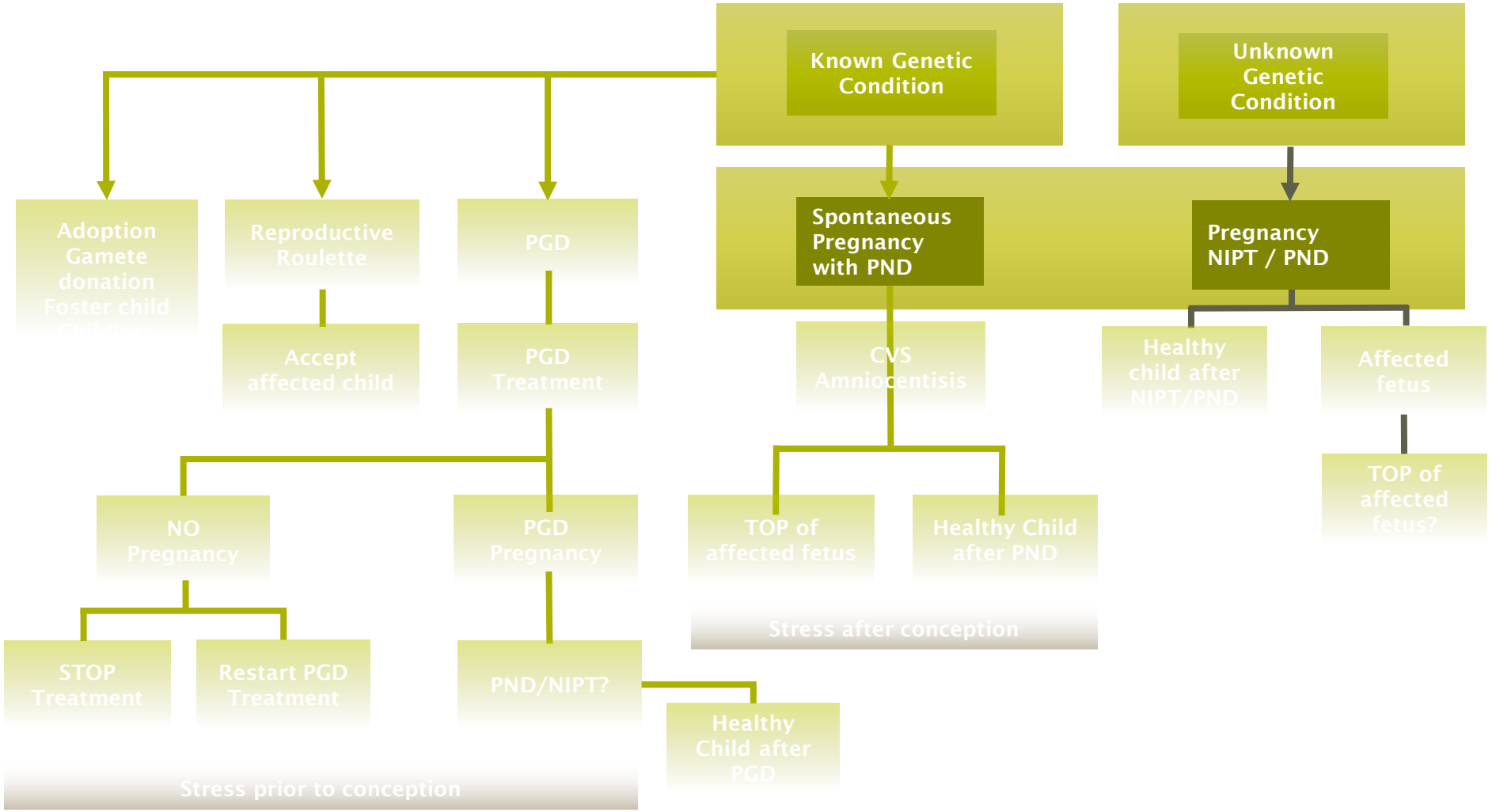
PGT: ETHICAL ASPECTS: ACCESS TO TREATMENT ?



ROLE OF THE PSYCHOLOGIST IN PGT

versus

PSYCHOLOGICAL ISSUES
PND AND PREGNANCY



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PSYCHOLOGICAL ISSUES

SPONTANEOUS PREGNANCY WITH PND (GC)

- Reluctance to become **emotionally attached** to the pregnancy until good news after CVS is given
- **Secrecy** surrounding the pregnancy and termination because of fear of rejection from others
- **Decisional conflicts**: responsibility to prevent suffering and reluctance towards TOP
- Appropriate **coping style** leads to anxiety reduction in high risk pregnancies

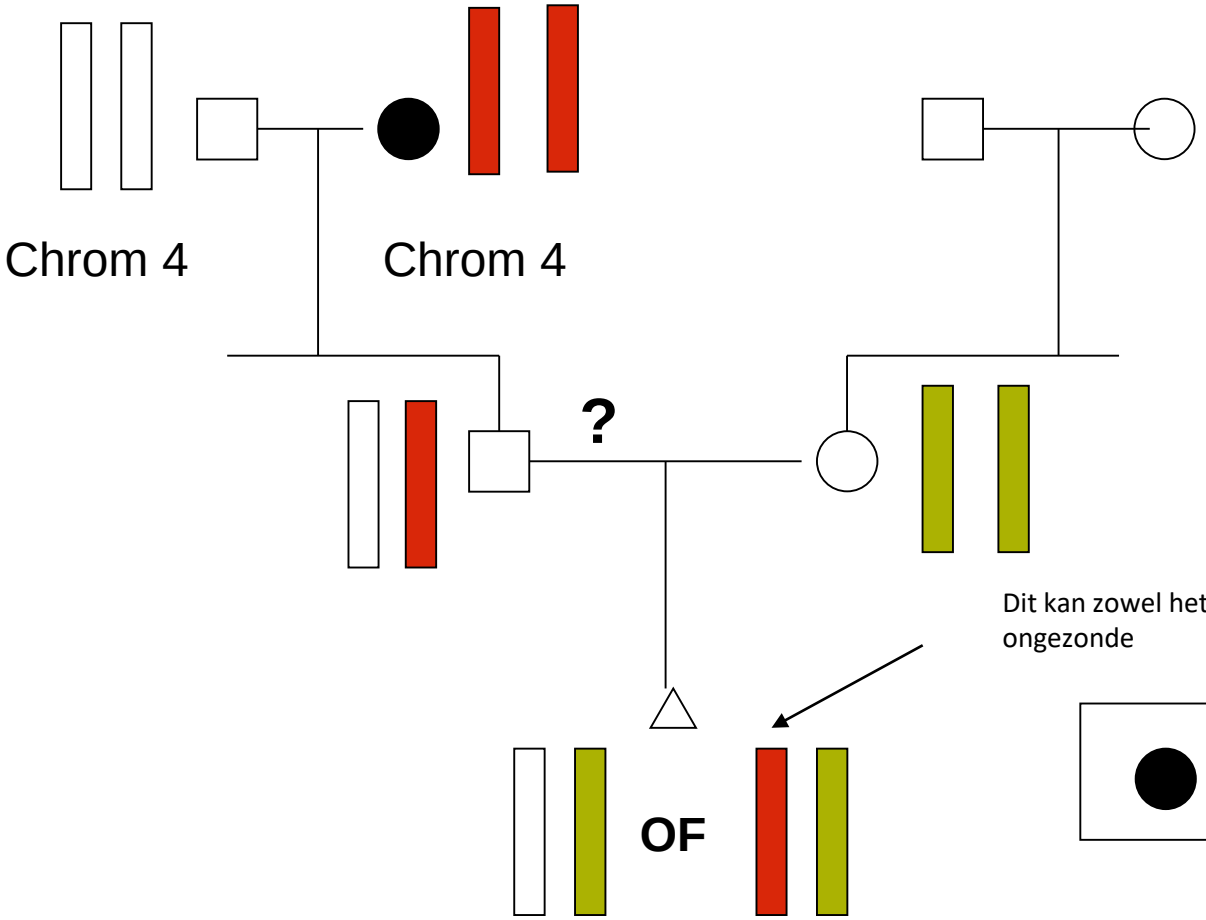
(Birsch et al. 2003; Decruyenaere, 2007)

PSYCHOLOGICAL ISSUES

SPONTANEOUS PREGNANCY WITH NIPT/PND (NO GC)

- NIPT/PND? "Not an innocent choice" (S. Helsen, 2013)
- Mythic expectations (Mc Coyd, 2007)
  - 'our baby will be fine'
  - passing of the 1th trimester = no miscarriages / healthy fetus
  - ultrasound screening is 'fun' and promotes bonding

PND: ETHICAL ASPECTS: EXCLUSION TESTING ?



Dit kan zowel het gezonde allel zijn dan wel het ongezonde

Huntington

➔ TOP for a fetus with ½ risk for HD?

CONCLUSIONS

- Psychological issues
- Appear at different stages in reproductive genetics
- Need to be addressed
- Go often together with ethical aspects

➔ A multidisciplinary approach is key!!

- Geneticists, genetic counsellors and psychologists need to work closely together as standard of care to patients and
- As promoted by the government through a RIZIV/INAMI convention.

THANK YOU

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