Psychological Issues in Reproductive Genetics

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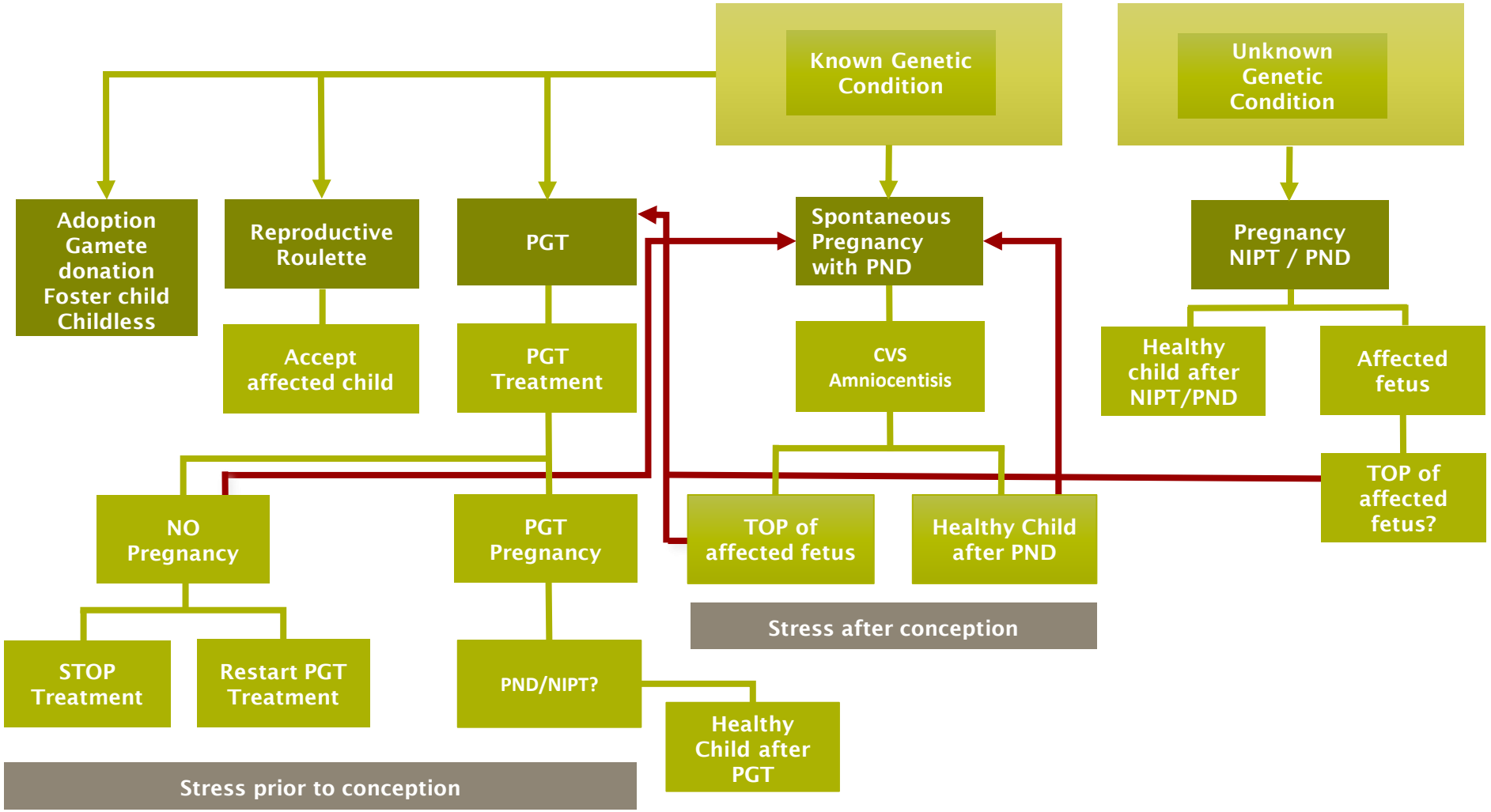
CONTENT

- **Situating the Psychological Issues in pathways of Reproductive Genetics**
- **Identifying, describe the Psychological Issues**
- **Addressing Psychological Issues in counselling**

SITUATING 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**

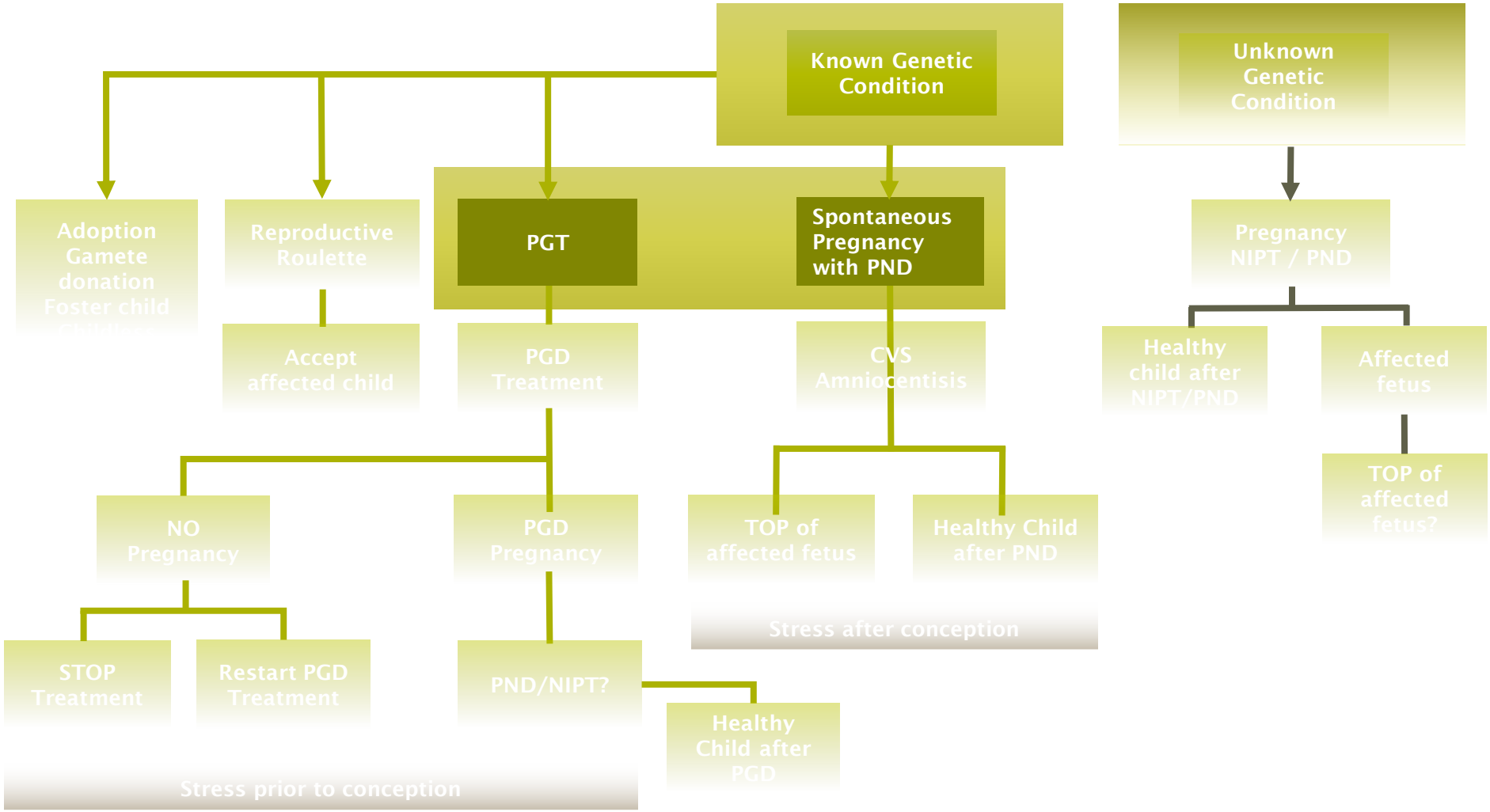
- prior, during, after PGT treatment/pregnancy
- during pregnancy of a fetus at risk
- during and post TOP process

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

- after childbirth

➢ **Concerns about Child development**

SITUATING PSYCHOLOGICAL ISSUES
DECISION MAKING: PRECONCEPTUAL LEVEL



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IDENTIFYING PSYCHOLOGICAL ISSUES
DECISION MAKING PROCESSES: PRECONCEPTUAL LEVEL

Why opt for PGT (over PND)?

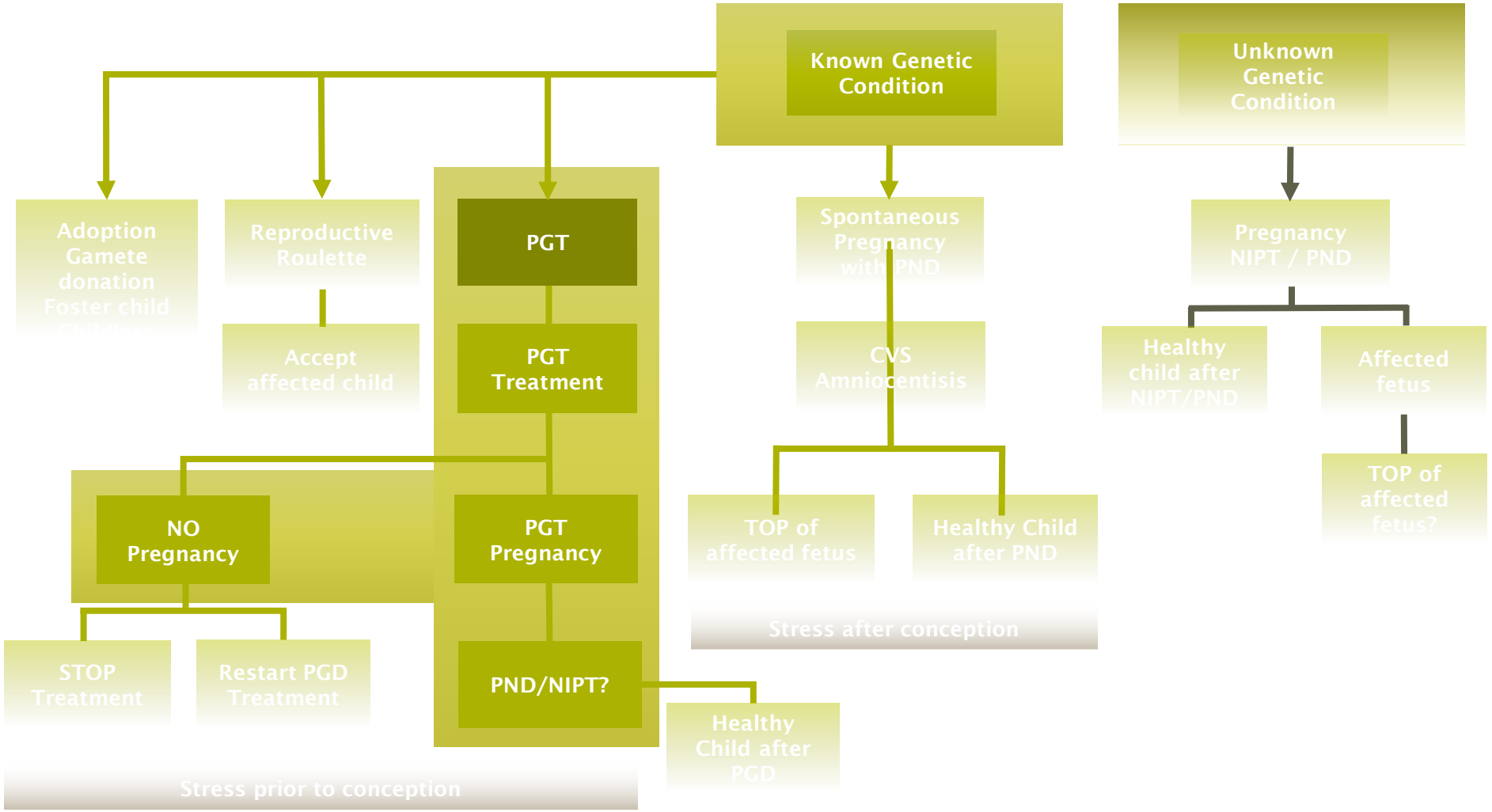
- To prevent/avoid trauma of TOP after PND
- Having a history of TOP (van Rij et al., 2011)
- Having fertility problems
- If the FEMALE partner prefers this over PND. Hence, the female partner decides (van Rij et al., 2011)
- Sex of the carrier, mode of inheritance and clinical impact of the disorder = 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)

IDENTIFYING PSYCHOLOGICAL ISSUES
DECISION MAKING PROCESSES: PRECONCEPTUAL LEVEL

Why opt for PND (over PGT)?

- 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)

SITUATING PSYCHOLOGICAL ISSUES
PGT TREATMENT AND PREGNANCY



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IDENTIFYING PSYCHOLOGICAL ISSUES
PGT TREATMENT

- **Empowering** by perceived control of reproductive circumstances (Karatas, 2010b)
- Being **fertile** expecting higher average chance of pregnancy and live birth (Kalfoglou, 2005; Karatas 2010b)
- Undergoing PGT is **"easy"** in comparison to undergoing multiple miscarriages, years of infertility and care of a seriously ill child (Roberts and Franklin, 2004)
- **Very stressful** (41%) especially time between ET and pregnancy result notification (Lavery, 2002), availability of unaffected embryos (Karatas, 2010b)
- Stressful and **emotionally draining** (Karatas, 2010B)

IDENTIFYING PSYCHOLOGICAL ISSUES
PGT TREATMENT

- Out of women with **experience of both PND and PGT** (n=20), 7 claimed PGT to be more stressful than PND and 8 less stressful (Lavery, 2002)
- Impact of **previous reproductive trauma** may cause additional stress during the IVF components of the PGT treatment (Karatas, 2010B)
- Patients appreciate treatment staff for **NOT** exaggerating success rates (Roberts and Franklin, 2004)
- Some patients feel **obliged to perform PND** in addition to PGT (Kalfoglou, 2005)

IDENTIFYING PSYCHOLOGICAL ISSUES
PGT TREATMENT

- 1/3 treatment exerted negative stress on the **relationship**, 1/3 positive (Lavery, 2002)

- Among women, difficulties in **reproductive history** increase risk of depression. Women starting PGT vs regular IVF report similar levels of anxiety and depression (Järvholm, 2016)

- Men planning for PGT report significantly **more symptoms of anxiety** than men planning for regular IVF and the presence of a child with a genetic disease was a significant predictor of anxiety (Järvholm, 2016)

IDENTIFYING PSYCHOLOGICAL ISSUES
PGT-HLA TREATMENT

- AIM: Save an ill child by means of a transplantation using haemotopoietic stem cells retrieved from the umbilical cord blood of the compatible newborn sibling.
- Treatment failure is high! 104/162 couples had NO matching liveborn baby. On average, after 3,2 unsuccesfull PGT-HLA attemps, treatment was stopped.
- Reasons to stop:
  - the psychological (43%) and physical (38%) burden
  - maternal medical reasons (38%) in combination with an alternative treatment for the ill child (48%)
  - 4 (17%) mentioned their relational issues as a reason to cease treatment.
- PGT-HLA was regarded as a positive, empowering experience generating a feeling of having tried the maximum to help their child. None of the parents expressed any regrets and 81% would recommend treatment to others.

IDENTIFYING PSYCHOLOGICAL ISSUES
PGT PREGNANCY

- PGT pregnancy = **tentative pregnancy** (Karatas, 2010)
- Pre-existing reproductive and perinatal trauma and anxieties
- Complex genetic and family background
- Stressful and draining PGT treatment

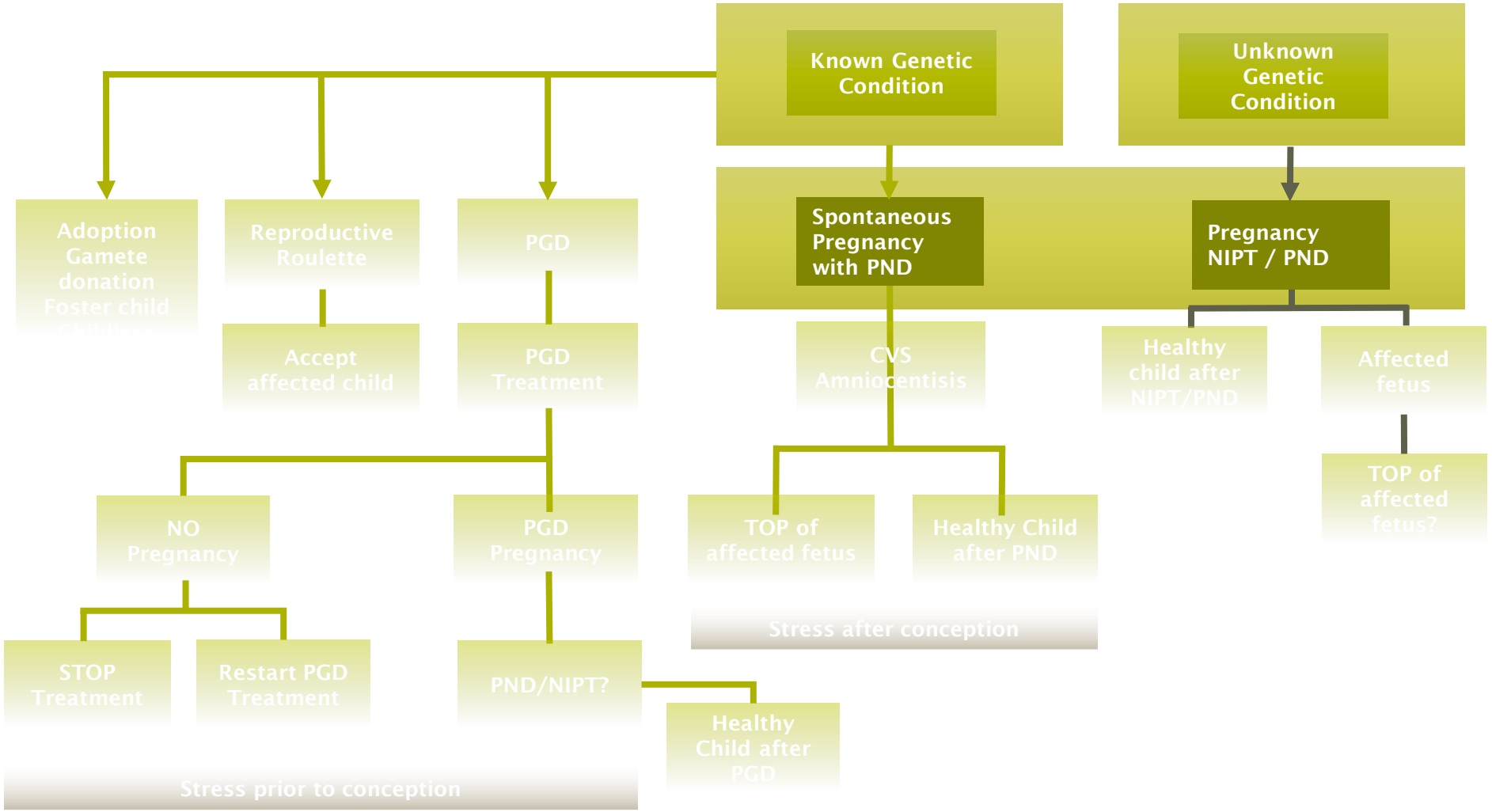
➢ **Hold back from bonding with the fetus** (Karatas, 2010b)

IDENTIFYING PSYCHOLOGICAL ISSUES
PGT PREGNANCY

C. Winter et al., 2016 – CMG UZ Brussel

- 59 PGT couples are no more at risk of **mental health** problems than ICSI & SC couples
- **Gender differences** exist but they are not conception group specific
- Conception groups do not differ significantly in their evolution of **mental health issues** or **attachment processes**
- Invasive **PND** has a **temporary negative effect** on parental antenatal attachment

SITUATING PSYCHOLOGICAL ISSUES
PND AND PREGNANCY



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IDENTIFYING PSYCHOLOGICAL ISSUES
SPONTANEOUS PREGNANCY WITH PND (GC)

- Reluctance to become **emotionally attached** to the pregnancy until good news after CVS is given (Decruyenaere, 2007)

- **Secrecy** surrounding the pregnancy and termination because of fear of rejection from others (Decruyenaere, 2007)

- **Decision conflicts**: responsibility to prevent suffering and reluctance towards TOP (Decruyenaere, 2007)

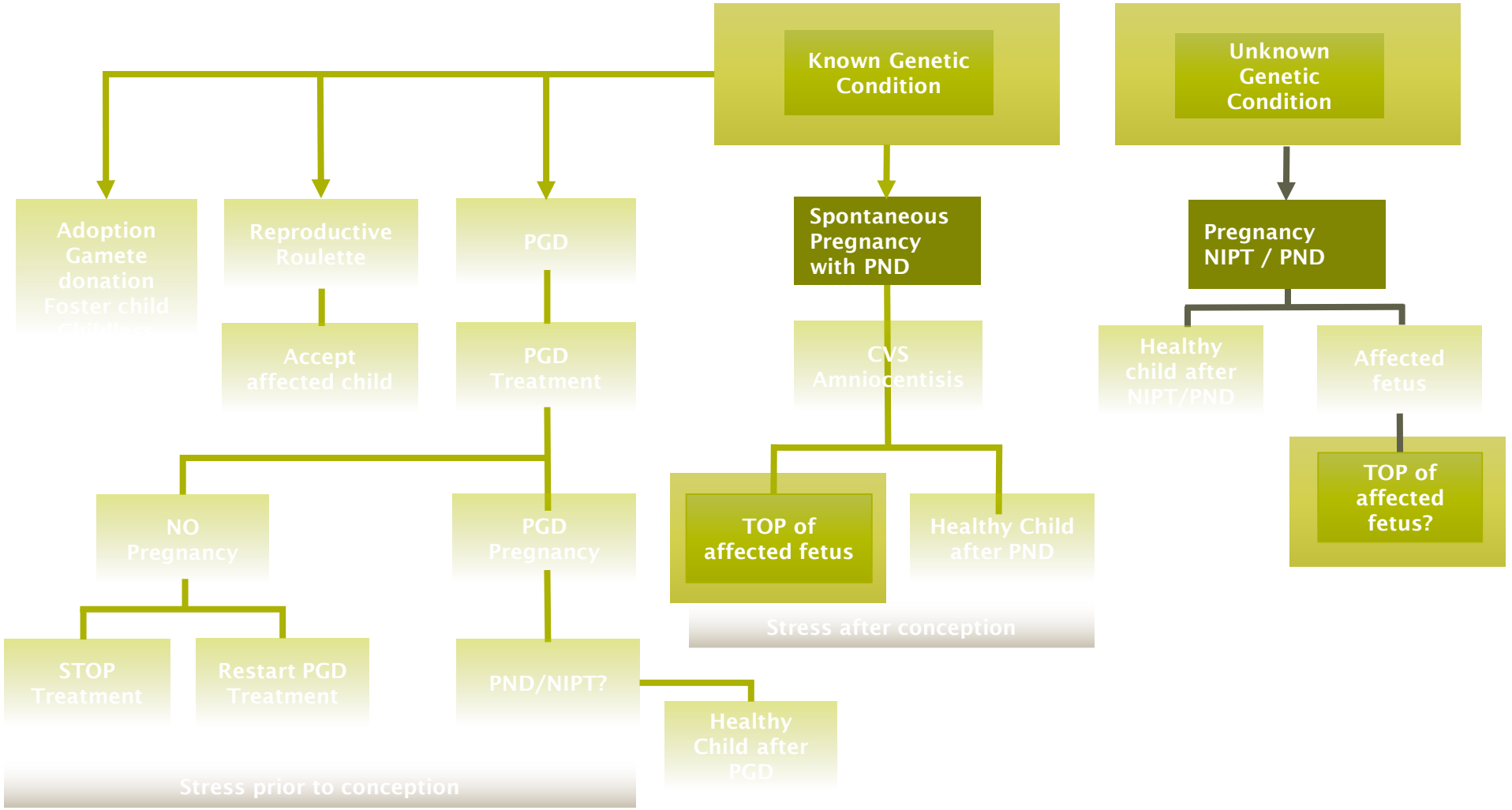
- **Appropriate coping style** leads to anxiety reduction in high risk pregnancies (Birsch et al., 2003)

IDENTIFYING PSYCHOLOGICAL ISSUES
SPONTANEOUS PREGNANCY WITH NIPT/PND (NO GC)

- NIPT/PND? Not an innocent choice (S. Helsen)

- 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

SITUATING PSYCHOLOGICAL ISSUES
TOP OF AFFECTED FETUS



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IDENTIFYING PSYCHOLOGICAL ISSUES
DECISION MAKING PROCESSES: TOP OR NOT?

Reasons?

- Save the child from suffering, stigma, sense of not belonging (Mc Coyd, 2007; Järvholm, 2016)
- Save themselves from the burden of care, emotionally, physically and economically (Mc Coyd, 2007; Järvholm et al., 2014)
- Save (future) siblings from the above (Mc Coyd, 2007; Järvholm et al., 2014)
- No hope for a cure in time (Decruyenaere, 2007)
- Strong desire for a child and ambivalence about TOP =>continuation of the pregnancy (Decruyenaere, 2007)

IDENTIFYING PSYCHOLOGICAL ISSUES
IMPACT OF TOP

Importance of decision making process!!

- Conscientiousness of the decision
- Time to take the decision
- Pressure from entourage ?
- Go against religious or cultural prescriptions
- Grieving together?

Advanced gestation and fetal development

- Giving birth
- Ending a life
- Personal deadline

Effects on the long term: Prior level of depression? Coping? Support and understanding?

(Lasker & Toedter, 1991)

ADDRESSING PSYCHOLOGICAL ISSUES

Decision making

- Both PGT and PND are **major life events**
- Decision making influences the **impact** of major life events
- Promote **informed choices** and **psychological adaptation**
- Information and genetic and reproductive **education** (de Die-Smulders et al., 2013)
- Client has ability to **solve own problems** and **make own decisions**
- **Autonomy** of the patient/parents and **non-directive** counseling (S. Helsen) – With Caution!!

ADDRESSING PSYCHOLOGICAL ISSUES

Psychological Distress

- Adjustment to circumstances is supported by **expression** of **emotional responses** to the situation
- Attention to **grieving process** at all stages!
- Experience of PGT/PND depends on **prior level** of depression and anxiety, quality of the relationship, social support
- Important to **identify at risk patients** for problematic coping (interview, questionnaires)
- Involve the **men**!

CONCLUSIONS

Caregivers need to be aware that at different stages in reproductive genetics psychological issues appear and need to be addressed!

At the medical genetics department a multidisciplinary approach is implemented and promoted by the government. Physicians, genetic counsellors and psychologists work together within a RIZIV convention providing a multidisciplinary approach as a standard of care to patients.

THANK YOU!

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Centrum voor
Medische Genetica

Centrum voor
Reproductieve Geneeskunde

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