

# ERN GENTURIS patient journey: counselling on reproductive options for individuals with a cancer predisposition syndrome (CPS) and relevant family members

## Counselling on reproductive options

Surrogacy,  
PGT, no children, PND,  
natural conception  
without genetic test,  
gamete donation,  
adoption.



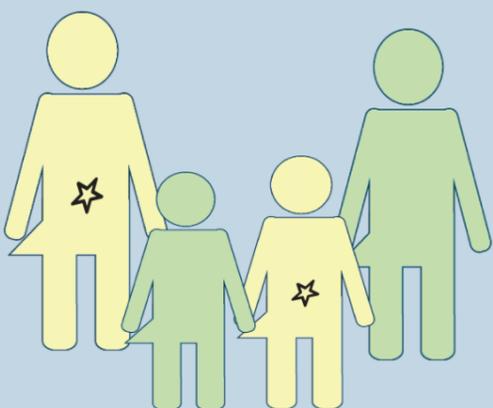
## Involvement of the multidisciplinary team



## Diagnosis of a CPS in different life stages



## Offer (diagnosis and pre-symptomatic) counselling on multiple occasions and to the relevant family members



To the parents of the child

To the adolescent and its parents

To the adult and possible partner

When considering childish

To the children in reproductive age of the elderly person with CPS

**Disclaimer:** The ERN GENTURIS patient journey is intended as a general overview of the clinical and diagnostic pathway for the specific genturism or its suspicion. It should not replace an individual clinical and genetic counselling at an expertise centre. It also does not intend to address all specific challenges of the complex genturism syndromes covered by the patient journeys. Specific clinical guidelines, diagnostic criteria and nomenclature may change at short notice and therefore are only referred to in this patient journey.

**A cancer predisposition syndrome (CPS) can be diagnosed at different times in a person’s life. Because of this, it’s important to offer counselling about reproductive choices more than once, and to include relevant family members:**

Life stage in which CPS is diagnosed	Child	Adolescent	Adult	Elderly
To whom or when counselling should be offered	To the parents of the child	To the adolescent and its parents	To the adult and, if relevant, their partner when they are thinking about having children	To the children in reproductive age of the elderly person with CPS

The [ERNGENTURIS guideline on reproductive options for individuals with a CPS](http://www.genturism.eu) can be found on the ERNGENTURIS website ([www.genturism.eu](http://www.genturism.eu)), section [guidelines](#).

### Genetic Counselling

Individuals with a personal or family history of a CPS need clear and up-to-date information about what the diagnosis means. This includes understanding the cancer risks at different ages and what surveillance or treatment options are available. They also need timely and accurate information about all reproductive options. This should include tailored discussion of:

- Personal medical and family history
- Genetic test results and how the condition is inherited
- Description, accessibility and timing of available reproductive options (e.g. prenatal testing, pre-implantation genetic testing techniques etc.)
- Possible limitations and outcomes of all reproductive options
- Emotional impact of family planning and personal values/beliefs
- Psychosocial support throughout information giving and decision-making process
- Support in sharing of information with relevant family members as appropriate

Information regarding the diagnosis of CPS including gene variant interpretation, associated cancer/tumour risks, surveillance, treatment and reproductive options may be subject to change over time.

### Counselling on reproductive options

As CPS are characterised by an increased risk of cancer/tumour, and the diagnosis can be made at different life stages, discussion about reproductive options is indicated throughout life and may be appropriate for the individual with the diagnosis and/or other relevant family members.

Reproductive counselling should be offered to individuals with a CPS and all relevant family members, on multiple occasions as appropriate. Information about reproductive options should be provided in appropriate language and personalised to the individual and their circumstance.

Individuals with CPS may want to access updated information to share with their relevant family members as they reach reproductive age and should be supported with this.

### Involvement of the multidisciplinary team

Reproductive decision making in CPS is complex and involves medical, psychological, ethical and social dimensions. It is therefore crucial when offering reproductive counselling to patients with CPS to involve a multidisciplinary team to support informed decision making. This multidisciplinary team may include:

- A genetic counsellor/clinical geneticist with experience of the CPS
- A clinician experienced in performing and interpreting prenatal diagnostic tests
- A fertility doctor to provide guidance on pre-implantation genetic testing, gamete donation
- A psychologist
- Other experts as required