

Family Clinic

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Chronic Granulomatous Disorder Society



Supporting families affected by chronic granulomatous disorder

www.cgdsociety.org

Great Ormond Street 
Hospital for Children
NHS Foundation Trust

- Genetic counselling is not primarily counselling in the psychological sense
- Genetic counselling is practised in a non directive manner
- Our role is to explain facts and give the family accurate information on options that maybe available

Why An Immunology Nurse Led Clinic

- Relationship with family is usually very well established
- CNS understanding of individuals family experience of disorder is invaluable in providing bespoke service
- CNS able to discuss medical management treatment options and outcomes.

Who Do We See

- Carriers of inherited Primary Immune deficiency including patients
- Extended family members who have been invited including partners siblings and grandparents.

What We Do

- At diagnosis provide information to family with regards to family clinic.
- Establish genetic diagnosis.
- Undertake family tree and identify need.
- Discuss impact of diagnosis on family
- Refer to other support networks

Scope of Practice

- Arrange and under take ffDNA testing
- Refer to specialist midwife/obstetrician with reference to CVS sampling and genetic diagnostics and tissue typing
- Provision of written advice with regards to new born care which is disorder specific.
- New born screening and rapid access to tertiary centre if new born affected.

Our experience

- Majority of family's have extended family history with previous affected children
- Mixture of outcomes some children well after curative procedure, some on chronic disease management. Some have had previous deaths with and without treatment.

Parents needs

- May be dependant on cultural/religious beliefs
- Have pre conceived ideas about what they want from clinic outcome
- Clearly benefit from one to one support through which ever process they follow
- Benefit from peer support from other family's

outcomes

- PGD saviour sibling with good BMT outcome
- ffDNA extremely helpful as first step is supporting family's and decision making process.
- Following ffDNA majority of women do not go onto have CVS
- Majority of families continue with pregnancy and test at birth.

Useful Information

Genetic
aspects
of PID

Genetic aspects
of primary
immunodeficiency:
information for families

hello@piduk.org
0800 987 8986
www.piduk.org

Great Ormond Street 
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NHS Foundation Trust


THE
great north
CHILDREN'S HOSPITAL

 PID UK
Supporting families affected
by primary Immunodeficiencies