Family Clinic

Helen Braggins
Clinical Nurse Specialist
Chronic Granulomatous Disorder

Jinhua Xu-Bayford
Clinical Nurse Specialist
Gene Therapy and Immunology
My post is funded by the Chronic Granulomatous Disorder Society

www.cgdsociety.org

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 family's continue with pregnancy and test at birth.
Useful Information