FAMILIAL HYPERCHOLESTEROLAEMIA (FH)
Frequently Asked Questions for Primary Care Professionals

- **What is FH?**

  Familial Hypercholesterolaemia is an inherited condition that causes elevated cholesterol levels from birth, generally 3-4 fold increase in levels leading to a high risk of premature Cardiovascular Disease.

  1:250 people are affected by the condition and approximately 7% of these people have been found so far.

  One copy of the gene is needed to have the condition and inheritance risk is 50% for every child born to a parent with FH, it is estimated that 56,000 children are living with FH in the UK and do not know.

  Patients are treated with statins and other lipid lowering medications to protect them from CVD, affected children should be identified and commence treatment by the age of 10 years.

- **What national evidence supports FH?**

  NICE Guidance: https://www.nice.org.uk/guidance/cg71

- **What is the Regional FH Service?**

  - The Regional Service is hosted by York Teaching Hospitals and also includes; Calderdale and Huddersfield, Leeds Teaching and Hull & East Yorkshire Hospitals.
  - The overall aim of the regional FH service is to identify individuals with FH through genetic testing and so offer cascade testing to family members where a gene has been identified. Treatment can then commence for patients diagnosed with FH. Therefore the aim is to:
    - Avoid premature cardiovascular deaths.
    - Achieve quality of life for the population with FH, their family and friends.
    - Reduce the burden on cardiovascular / other health services.

- **Where is the Regional FH Service based?**

  For North East Lincolnshire residents services are available through the Hull and East Yorkshire Hospitals site.

  Clinics are offered at 3 locations, Hull Royal Infirmary, Castle Hill Hospital and East Riding Community Hospital.

- **When did the regional FH service become available to NELCCG residents?**

  - The adult FH service became available to NELCCG residents in May 2018.
  - Hull Hospitals are in the process of developing a FH service for Children. Children under 16 years can be referred to a Specialist Paediatric FH Service by their G.P for assessment and management of FH.

- **Who is high risk of having FH?**

  High Risk- Adults with a pre-treatment Total Cholesterol > 7.5mmol/l (LDL> 4.9mmol/l)

  High Risk- Personal history of premature CVD > 60 years combined with hyperlipidaemia

  High Risk -Personal history of hyperlipidaemia combined with a family history of hyperlipidaemia

  Very High Risk-1st and 2nd degree relatives of someone with DNA confirmed FH

  Very High Risk - Under 30 years with a pre-treatment or current Total Cholesterol > 7.5 mmol/l

  Very High Risk – Over 30 years with pre-treatment or current Total Cholesterol > 9.0 mmol/l

  Very High Risk Physical signs of hyperlipidaemia such Tendon Xanthomas or Corneal Arcus (>50years)

- **Who needs referring to the FH service?**

  Adults over 16 years who have Definite or Possible FH defined by the Simon Broome Criteria and have been screened by their G.P for secondary causes of hyperlipidaemia.

  Adults over 16 years with DNA evidenced LDLR, Familial ApoB defective disorder or PCSK9 mutation in their family.

  Children under 16 years can be referred to a Specialist Paediatric FH Service by their G.P.

- **What about patients with high Triglycerides?**

  Patients with high Triglycerides may have secondary causes of their hyperlipidaemia rather than FH. Patients with a mixed picture of high TC and High TG may have Familial Combined Hyperlipidaemia or Hypertriglyceridaemia and should be considered for referral to local lipid clinic rather than FH services.

- **How do we refer patients to the FH Service?**

  Via the Choose and Book System. Hull and East Yorkshire Hospitals provide 3 FH clinics per week that can be found under Endocrinology and Lipids and booked via the G.P surgery.

- **What information is required for the referral?**

  Pre-treatment or highest Total Cholesterol and LDL levels (include Triglycerides). Personal or family history of Cardiovascular disease < 60 years or family history of hyperlipidaemia (TC>7.5mmol/l).

  Evidence of screening for secondary causes i.e. Thyroid Function Test, Biochemical Profile including Liver Function and HbA1c.

- **Do we have a local Lipid Clinic in North East Lincolnshire?**

  Patients who do not fulfil the Simon Broome Criteria can be referred to your local lipid clinic for assessment and advice regarding their hyperlipidaemia via Choose and Book - **Dr John**
  Lipid Clinic
  Diana, Princess of Wales Hospital Grimsby
  DN33 2BA

- **What happens after the genetic testing is complete?**

  The G.P will be informed of the result by letter and a copy of the gene report included.

  Treatment and management guidance for the G.P will be included in clinic letters and the patient will be discharged back to the G.P when treatment is optimised or back to their local lipid clinic for further management.

- **Can I contact the Regional FH Service to ask a question?**

  Our Specialist Nurses can be contacted via email and are happy to support you in referring FH patients or discussing genetic reports received by the G.P.

  Paula.sutton@nhs.net
  Rachel.dunn2@nhs.net

- **What voluntary sector support is available to patients, outside of NHS services, for FH?**

  - **Heart UK Charity – FH** - https://heartuk.org.uk/fh-familial-hypercholesterolemia
  - **Heart UK Charity – Children and FH (includes access to leaflets)** - https://heartuk.org.uk/fh-familial-hypercholesterolemia/children-and-familial-hypercholesterolaemia-fh
  - **British Heart Foundation – GH (includes access to leaflets)** - https://www.bhf.org.uk/heart-health/conditions/familial-hypercholesterolaemia