



Bristol Royal Hospital  
For Children

**NHS**

**University Hospitals Bristol**  
NHS Foundation Trust

# The 1<sup>st</sup> Barth Syndrome Service Family Day

In conjunction with

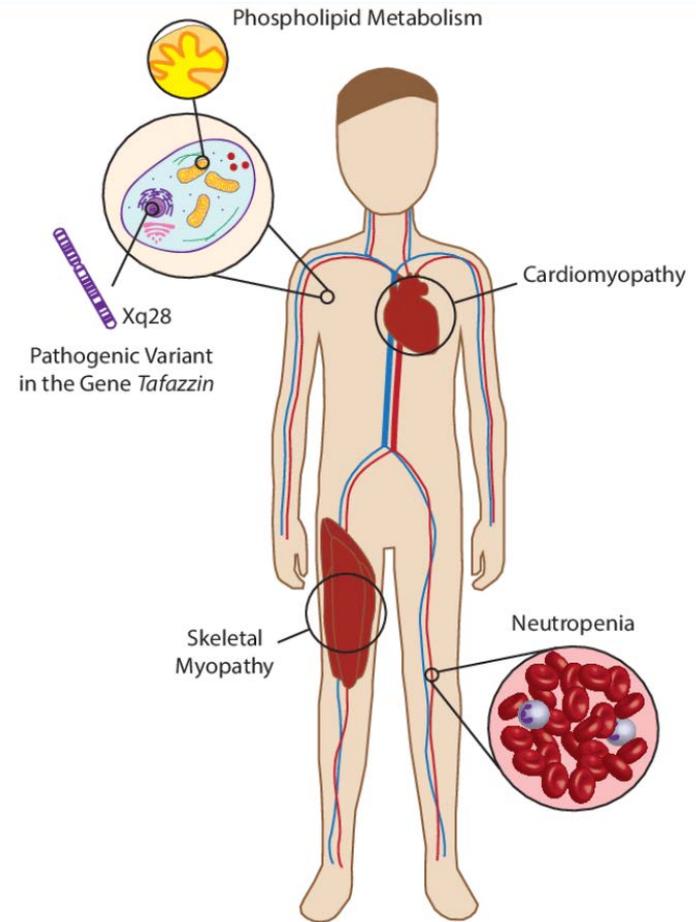


7<sup>th</sup> March 2020

Black Country Living Museum, Dudley

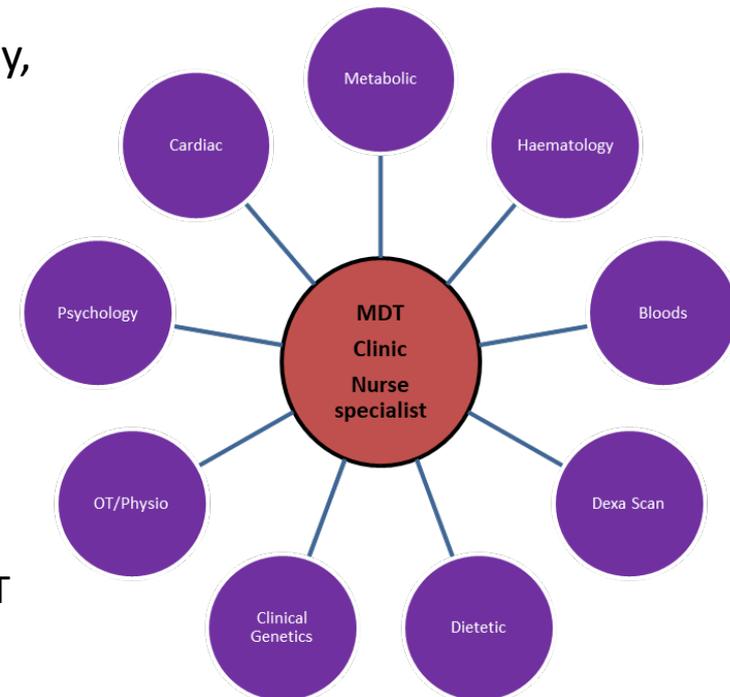
# Barth Syndrome

- An X-linked disease which was first described in 1983
  - Cardiomyopathy
  - Skeletal myopathy
  - Neutropenia
  - Growth failure
- Ultra-rare disease

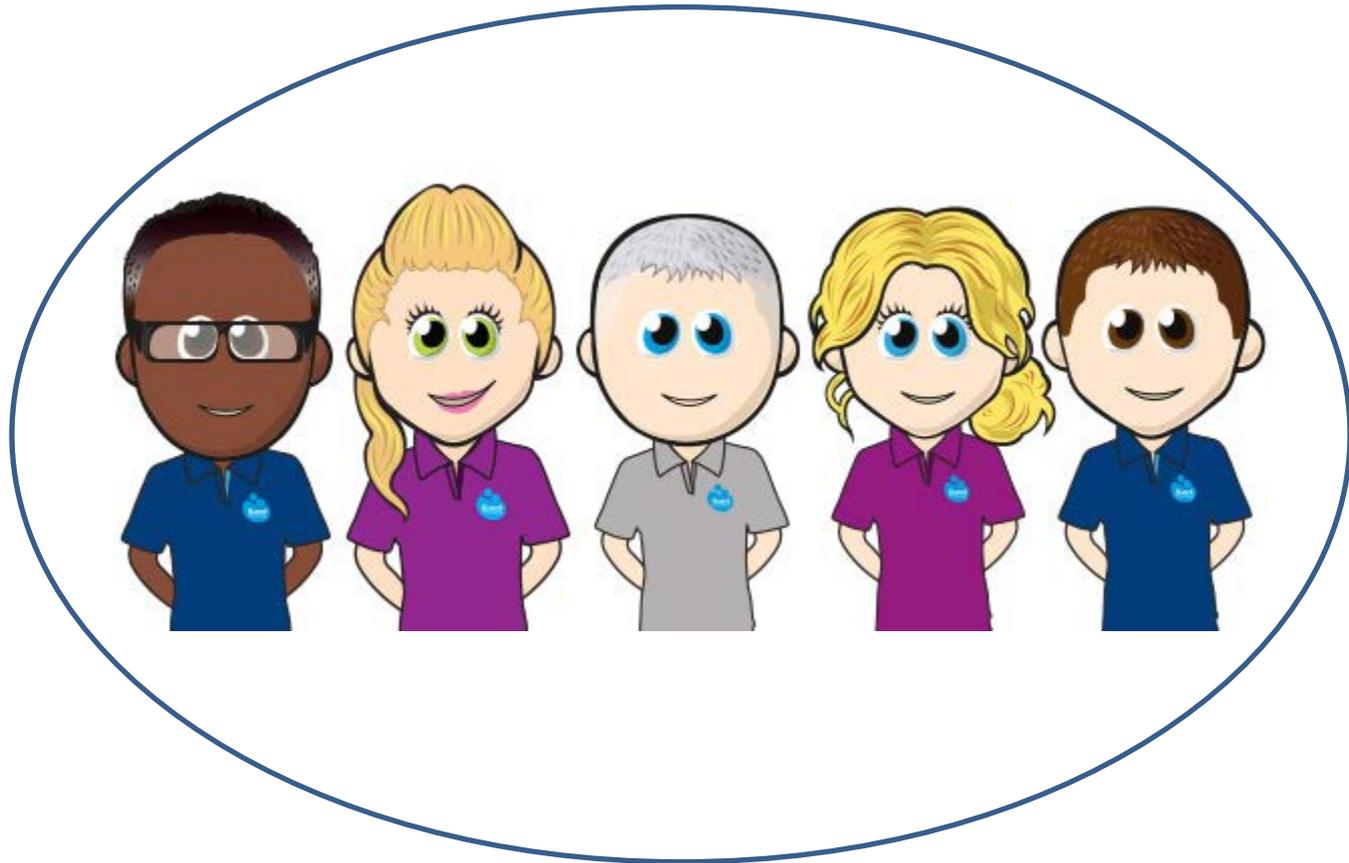


# The National Barth Syndrome Service

- The National Barth Syndrome Service is a multidisciplinary service for the management of Barth syndrome and the first of its type in the World.
- Run informally in Bristol since 2004 by Professor Colin Steward in conjunction with Barth Syndrome UK.
- Funded by NHSE since April 2010.
- Input from consultants in – clinical genetics, cardiology, haematology, metabolic medicine - together with clinical nurse specialist, dietetic, psychology, physiotherapy and occupational therapy care and provides:
  - MDT clinics
  - Testing
  - A G-CSF service
  - Liaison with local/regional medical teams/education
  - Home and school visits
  - Ongoing year round communication with specialist MDT team



# Meet the team



# The Team



Dr Germaine  
Pierre -metabolic



Dr Effie Chronopoulou  
-metabolic



Mrs Sarah Buston  
- Genetics



Ms Victoria Wilkins  
-dietetics



Dr Guido Pieleles  
- cardiology



Dr Oliver Tunstall  
- haematology



Mrs Hannah Bassett  
- physiotherapy



Mrs Dani Goodman –  
occupational therapy



Ms Hayley  
Smith – Nurse



Dr Vanessa Garrett  
-psychology



Ms Olivia Bennett  
-administrator

# Family Introductions

- Who's in the family
- Who has Barth
- Where you are from
- Bit of your story





### *Coronavirus and Barth syndrome*

The symptoms of coronavirus (COVID-19) are: cough, high temperature, shortness of breath -But these symptoms do not necessarily mean you have the illness.

***The increased risk of infection for those with neutropenia is around bacterial infection rather than viral***

Therefore be guided by NHS advice

Call 111 if:

- you think you might have coronavirus
- in the last 14 days you've been to a country or area with a high risk of coronavirus
- you've been in close contact with someone with coronavirus

Isolation is only needed if there is a chance you could have coronavirus. Most people can continue to go to work, school and other public places.

You only need to stay away from public places (self-isolate) if advised to by the 111 online coronavirus service or a medical professional.

***The current NHS advice is to continue normal daily life utilising good hand washing, sanitization, cover your mouth and nose with a tissue or your sleeve (not your hands) when you cough or sneeze, put used tissues in the bin straight away and wash your hands afterwards. Try to avoid close contact with people who are unwell and do not touch your eyes, nose or mouth if your hands are not clean.***