

Our Achievements

Since its foundation in 2003, BARTH SYNDROME UK has:

- Increased the number of identified member families in the UK from 4 in 2003 to 33 in 2019
- Run volunteer led medical clinics annually from 2004 - 2010 so that patients had access to quality care
- Helped create a dedicated NHS Specialised Service for Barth Syndrome in Bristol, UK from 2010 to date to ensure the clinic is sustainable
- Created a targeted awareness campaign through the creation of compelling family stories, regular newsletters, hospital posters, liaison with specialist centres, presence at conferences, funding of a reliable diagnostic tool for Barth syndrome
- Created a Family Route Map project together with Jeans for Genes to help families navigate through the complex web of care
- Provided members with access to a dedicated website, private email forum and closed Facebook group
- Provided affected families with ongoing, one-on-one support
- Been involved in providing a quality international Family, Scientific and Medical Conference every two years
- Provided outreach events throughout the UK and Europe
- Funded ten research projects to the value of over £215 000 to help diagnosis, better understanding, and treatment of the condition.