

Breaking Down Barriers



The Genetic Risks of Cousin Marriage Conservative Muslim Forum

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Jane Young, Director of The Sylvia Adams Charitable Trust



The Sylvia Adams Charitable Trust



Alström Syndrome UK
Strength for today, hope for the future

Kerry Leeson-Beevers

- National Development Manager, Alström Syndrome UK (ASUK)
- Project Lead for Breaking Down Barriers (BDB)
- Patient Representative on the UK Rare Disease Policy Board
- Co-chair of the Patient & Public Involvement Advisory Group for the NIHR funded research study CONCORD (Coordination of Care for Rare Diseases)
- Member of the Patient Safety Communication Advisory Panel, Bayer
- Member of CIOMS (Council for International Organisations of Medical Sciences) Working Group XI: Patient Involvement in Development and Safe Use of Medicines
- Most importantly – the mother of a child with a rare disease



Alström Syndrome UK

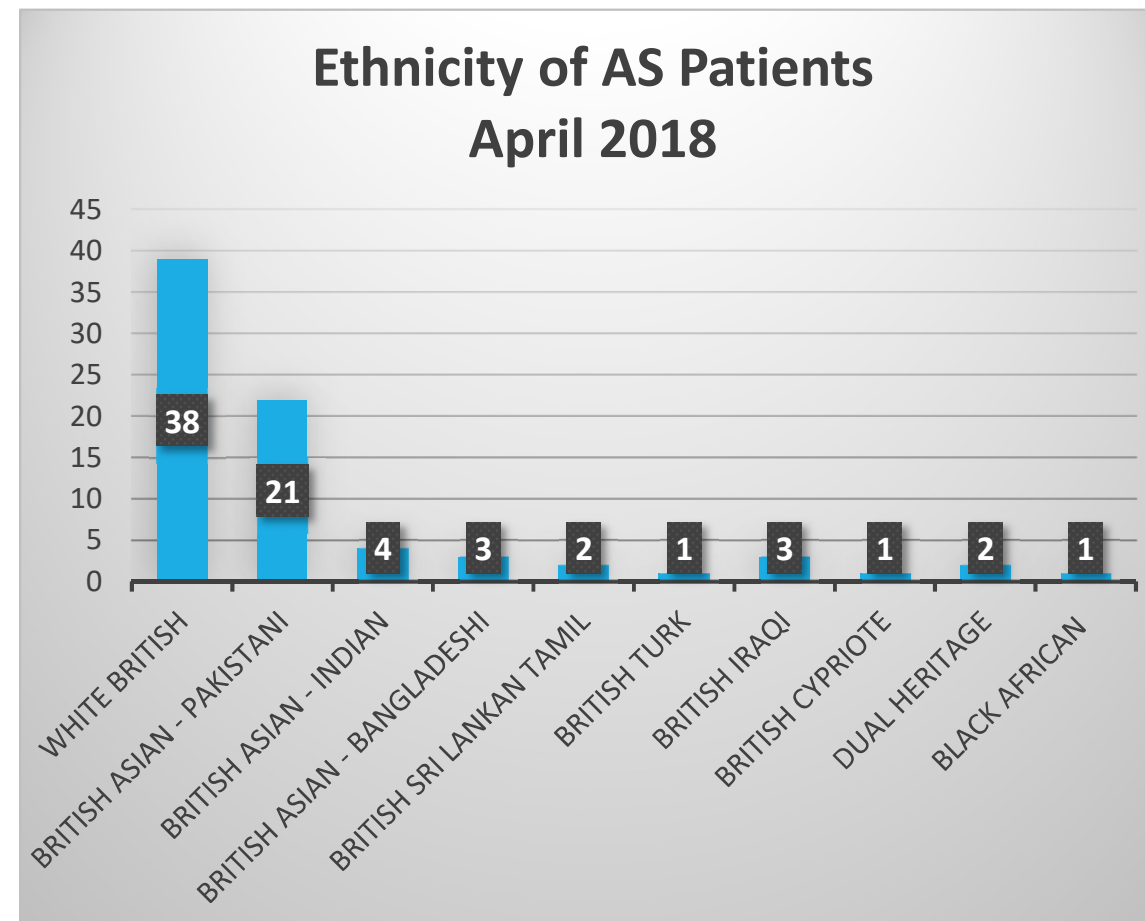


<https://youtu.be/XZx1LSrWZyo>

Initial Project

ASIAN MENTORING SCHEME

- Only 3 known families from ethnic minority communities on our database
- Consanguinity – increased risk of autosomal recessive conditions
- Distinct project to identify & support families throughout the UK
- The Sylvia Adams Charitable Trust
- Success!



Learning

Successful but key learning opportunities

- Name of the project
- Staff – choosing the right people

Key areas of development

- Empathy – parents not professionals
- Was our Board of Trustees truly representative of our members?
- Recruited an Equality and Diversity Officer from Bradford University
- Examining what we could offer families (some families were very happy with the health and support they received locally)

Developments

- Identifying the needs of both parents – language barrier
- Speaking, Reading & Writing
- Religious Occasions – avoid key dates when planning an event
- Planning of events – prayer rooms, halal options, suitable activities (gender specific)
- Residential Holidays – sleeping arrangements, separate cooking utensils, food storage
- Genetic Counselling – all family members
- Developed an understanding of consanguinity
- Support throughout pregnancies – families able to make an informed choice

BREAKING DOWN BARRIERS



Understanding genetics together

Introduction to the BDB Project

“Breaking down Barriers is aimed at facilitating patient organisations and support groups to join together and share examples of good practice and develop new guidelines to highlight effective ways to support families who are at increased risk of having children with a genetic condition but who are unlikely or unable to access mainstream services.”

- Identify barriers experienced by people from ethnic minority communities
- Support to further develop organisations
- Provide financial support
- Provide expertise from our Advisory Panel
- Raise awareness of the project, organisation and genetics as a whole
- Provide opportunities to share examples of good practice
- Develop good practice guidelines



Advisory Group



Dr Peter Corry - Retired Paediatrician & CCG Member

Dr Aamra Darr – Director, Genetics Communication Diversity



Shamshad Hanif – Parent Representative (San Filippo Syndrome)

Dr Denise Williams – Consultant Clinical Geneticist, Birmingham Women’s Hospital



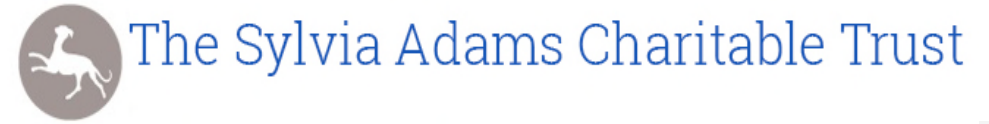
Jane Young – Director, Sylvia Adams Charitable Trust

Dr Sobia Bilal – Consultant Paediatrician, Harrogate & District NHS Foundation Trust



Amy Simpson – Research Associate, Genetic Alliance UK

Working in Collaboration



Understanding genetics together



Developments in Genetics

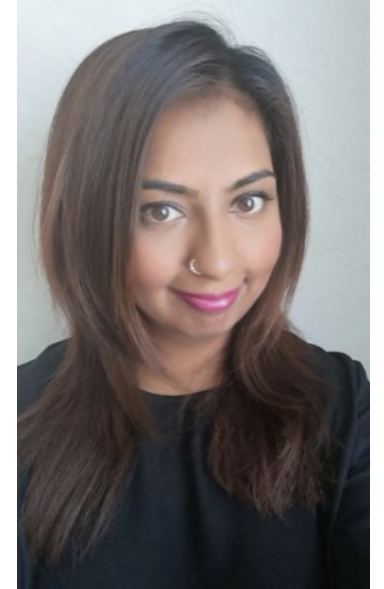
- On the 2nd October 2018, the Secretary of State announced the ambitious plan to sequence 5 million genomes within 5 years with a view to improving diagnosis and access to treatments
- Seriously ill children who are likely to have a rare genetic disorder, children with cancer & adults suffering from certain rare conditions or specific cancers will be offered whole genome sequencing
- 100,000 Genomes Project – target reached in December 2018
- NHS England’s long-term plan was published on the 7th January 2019 with a focus on prevention and early detection
- NHS Genomic Medicine Service – Genomic Laboratory Hubs & National Genomic Test Directory
- NCARDS (National Congenital Anomalies and Rare Disease Registration Service)
- Positive developments but there is already a lack of Genetic Counsellors in the UK
- No specific plans on how to improve engagement with families from ethnic minority communities

Future Developments

- Funding provided for a further 15 organisations
- Big Lottery Funding
- Recognition from NHS England
- Further NIHR Research Projects
- Influence policy & practice
- Continue to monitor & evaluate the impact of BDB

Asya Choudry

- Community Engagement Manager for Breaking Down Barriers
- Passion for Genetic Counselling
- GOSH/UCLH
- Genetic Alliance UK
- Ehlers-Danlos Support UK
- EDS-UK BDB year 1 project – East London Mosque Event



Member Charity & Community Engagement

- Supporting 30 charities
- One to one advice & support
- Cultural support
- Genetic understanding
- Aid on home visits
- Big picture thinking – Monitoring Impact
- Trial and error

My Role

- To support and assist our member charities in successfully engaging BME communities
- Expanding our network and platform of resources to further facilitate the aims of BDB
- Engaging certain BME families with the support of the member charity
- Offering training on genetics – making complex concepts simple
- South Asian Language aid
- Cultural awareness
- Helping to build a better all around service and access to services for those BME communities
- Creating resources, building bridges, affecting change

Facts and Figures

- Families from all communities can be affected by genetic disorders
- Marrying close blood relatives, such as cousins, is common in many parts of the world and is preferred among some families and communities in the UK
- In populations where people routinely marry close blood relatives, such as cousins, more children are born with recessive genetic disorders than in populations where people marry outside of the family
- Considering all types of birth disorders, around 5-6 babies out of 100 are affected in communities practicing cousin marriage, compared to 2-3 out of 100 babies in communities marrying outside the family
- Most children born to blood related couples (e.g. cousin couples) are healthy
- Genetic disorders cluster in families. If a gene for a recessive disorder is present in a family (this may be shown by an affected individual in the family or by an infant death), other family members may also carry this gene. Those who marry within the family will be at higher risk of having a child with this disorder than those who marry outside the family

Dispelling Myths

- Yes marrying a close relative does double the risk of inheriting a recessive condition from 2-3% to 5-6%
- However, this doubling of risk must be taken into strict consideration. This is only the case if there is a couple both carrying a gene for said recessive condition from that, the chance of having an affected child is 25%, thus 75% the child will not be affected from said condition
- Therefore the likelihood is that if you marry your cousin there is more chance of having a healthy baby than a child with a recessive condition
- Born in Bradford study- Showing congenital abnormality within a high BME populated area. Results showed that yes Pakistani/British Pakistani were the highest ethnicity that were affected with infant mortality from blood related couples, however high maternal age from a non-related couples also showed a similar doubling of risk
- Studies also show that it is the South Asian communities in the UK who avoid seeking support from genetic/health services for their children due to fear of judgment or stigma by health professionals

Why is there a need for BDB?

- Despite many larger cities in the UK hosting large BME communities, the NHS has done little to reflect this in changing current practice to engage these communities
- With NHS funding and service cuts, there is a large shift of responsibility onto the voluntary sector to support these patients seeking advice, support and access to services
- However, the voluntary sector are not equipped to deal with this influx, especially for those from BME communities
- There needs to be more culturally aware trained professionals and service providers
- It is through these professionals we can engage and educate communities
- Through education, families can be aware of genetic services, support and family planning options
- This in turn reduces costs to the government and NHS if there is a set mindful pathway for patients with long term, genetic or fatal conditions to access support, help and make informed choices with regards to genetic testing and their children's health

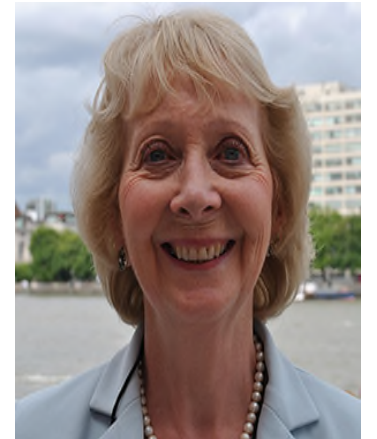
Final Thoughts

- BDB aims to make national change
- How? - By equipping the genetic voluntary sector to engage BME communities
 - By bridging the gap between families and the health service
 - To engage with the NHS to deliver an equitable service for everyone
 - Empowering BME families to understand their condition and make informed choices regarding their genetic health
- We are funding 30 charities now, we hope to continue our progress, learning and success
- We aim to find examples of good clinical practice and mimic this pilot work across the UK
- and finally.... Affect change!

If you are interested in getting involved with BDB, or supporting us then please make contact

Jane Young

- Director of The Sylvia Adams Charitable Trust
- Funder & Advisory Group Member of Breaking Down Barriers
- Early years preventative work in England & Wales
- Breaking Down Barriers
- Development work in Kenya, Tanzania & Uganda



Why Fund BDB?

- Why fund this particular project?
- Vision
- Challenges
- Hopes for the future

Questions



Thank You



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