

The Year Ahead Let's Get Together!



Alström Syndrome UK
Strength for today, hope for the future

25th April 2023

THE YEAR AHEAD (APRIL 2023)

Welcome to the BDB team



Cathy Chadwick-Rayner
Networks & Outreach Coordinator



Vanessa Williams
PPI & Impact Coordinator



Derek Sankar
Community Inclusion Coordinator

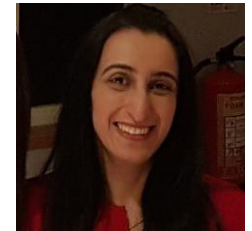


Kerry Leeson-Beevers
Chief Executive



Catherine Lewis
Office Manager

ASUK Team



Introduction



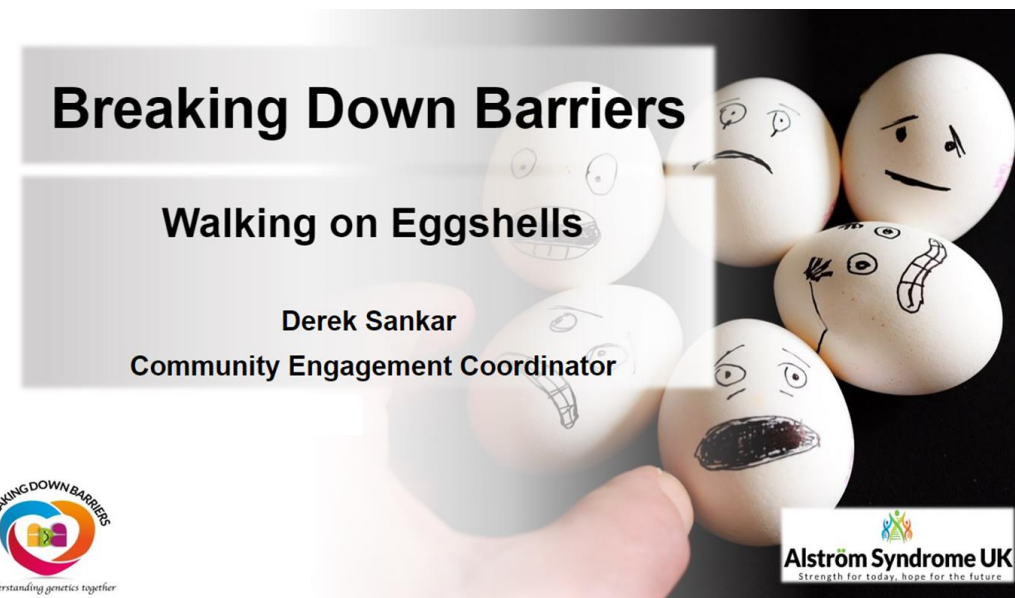
Breaking Down Barriers (BDB) was founded by ASUK and The Sylvia Adams Charitable Trust and has grown into a network of over 60 organisations working together to develop inclusive and accessible services for people affected by rare/genetic conditions.

Working at grass roots level, we support, empower and learn from people with lived experience. We share good practice, provide training and resources, and explore new and innovative approaches.



Community and Inclusion

- Community & Inclusion Speakeasy
- Other-Wise Micro Sessions
- Training
 - Introduction to Equity, Diversity & Inclusion
 - Walking on Eggshells
 - Moving from Challenging Conversations to Comfortable Communication
- Policy Templates and Making them Real
- Regional Events



Regional Events

Leeds – 6th June 2023

Birmingham – 12th July 2023

London – 26th September 2023

Bringing Together

- Key-note Speakers
- Latest from the World of Genetics
- Burning Topics - Identified from the Membership
- Opportunity to Network and Collaborate Together

THE YEAR AHEAD (APRIL 2023)



BDB Outreach North-East and Yorkshire



Workshops: Genes, Family History and Your Health



Free earlobes

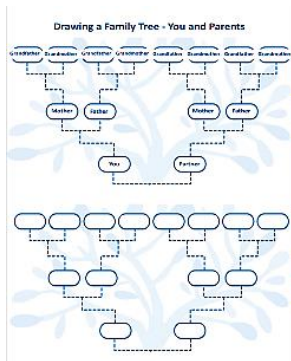
Workshop 1

What makes you – you?



Workshop 3

Chat with our ancestors



Workshop 2

Family trees and your health



**Community and Partner
Events**

BDB Outreach North-East and Yorkshire

Examples of what we have learned



Courage

'Disease, illness isn't something that is openly talked about in our culture and often not really talked about within families.'



Om – Sound of the Universe

'It is good to talk about these things. It's good to be open and not to worry and keep it in.'



Presence of God

'Everything in the universe is created by God, even genes.'

Next Steps...

Extending BDB outreach.

Health Equity Fellow – Health Inequality Networks.

BDB Let's Get Together - Regional Events

- to share community outreach ideas!



Patient and Public Engagement & Involvement Mission

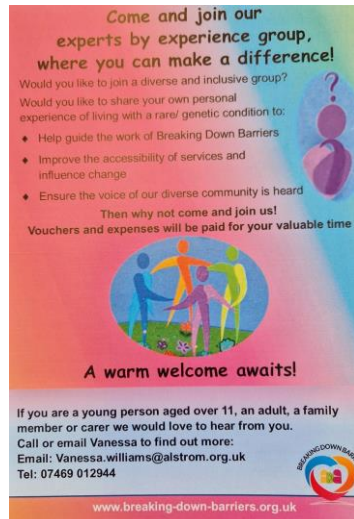
Within BDB we are building a physical library of people with lived experience, to ensure our voices are heard to create the changes that we want to see in services everywhere.

PPI Panels



Diversity in Diabetes

- 5 year project funded by the National Institute for Health and Care Research (NIHR)
- *'Improving outcomes for children and young people with diabetes from socioeconomically deprived and/or ethnic minority groups.'*
- Research is being led by Children's Hospitals in Birmingham and Bristol
- The Young Person's Advisory Group (YPAG) is involved in each stage of the work



BDB Experts by Experience Advisory Group


- Sharing experiences of access/engagement and discussing ideas, solutions and top tips to help make services more inclusive and accessible to all
- Can review and give feedback on resources, projects and services and share thoughts on whether these are accessible and ways they could be improved



Current Focus

- Recruitment to both groups, which includes building an online presence to attract both new members (Expanding Is Key)
- Podcasts with members of the groups to start building resources
- Looking for translators to take part in translating some resources
- Continuing to develop our systems to be able to manage the increase of people and capturing our work
- Engaging with other PPI groups to build relationships and learn from their experiences
- Looking at topics to help support the BDB network – providing opportunities to engage
- Building Relationships with all member organisations and the wider community

Staying Connected



Call us: 07970 071 075 | catherine.lewis@alston.org.uk

BREAKING DOWN BARRIERS
Understanding genetics together

About us | Our Work | Membership | Resources | Reports | Events | News

LET'S TALK DIVERSITY


WE ARE EXCITED TO ANNOUNCE THE NEXT STAGE OF OUR PROJECT CALLED 'LET'S TALK DIVERSITY'. THE FILMS HAVE BEEN LAUNCHED!! CHECK THEM OUT ON OUR CAMPAIGN PAGE AT BREAKING DOWN BARRIERS (BDB). WE ARE ALWAYS LOOKING FOR NEW WAYS TO DEVELOP OUR KNOWLEDGE AND UNDERSTANDING...

Breaking Down Barriers SINCE 2008 Championing Equity, Diversity and Inclusion

We are a network of over 60 organisations working together to improve the lives of families from diverse and marginalised communities, who are affected by genetic conditions so they have equal access to health services.

There is no such thing as hard to reach communities, only services and organisations that can be difficult for people from diverse communities to access.

Addressing health inequalities is at the centre of what we do: finding ways that health services can be shaped to become inclusive and accessible, and working with families to encourage and support them to access those services. The Breaking Down Barriers network of organisations, working at a grassroots level, is sharing good practice and exploring new ideas to help educate, empower, and provide an



Social Media

BDB website

Regional Events &
Virtual Conference

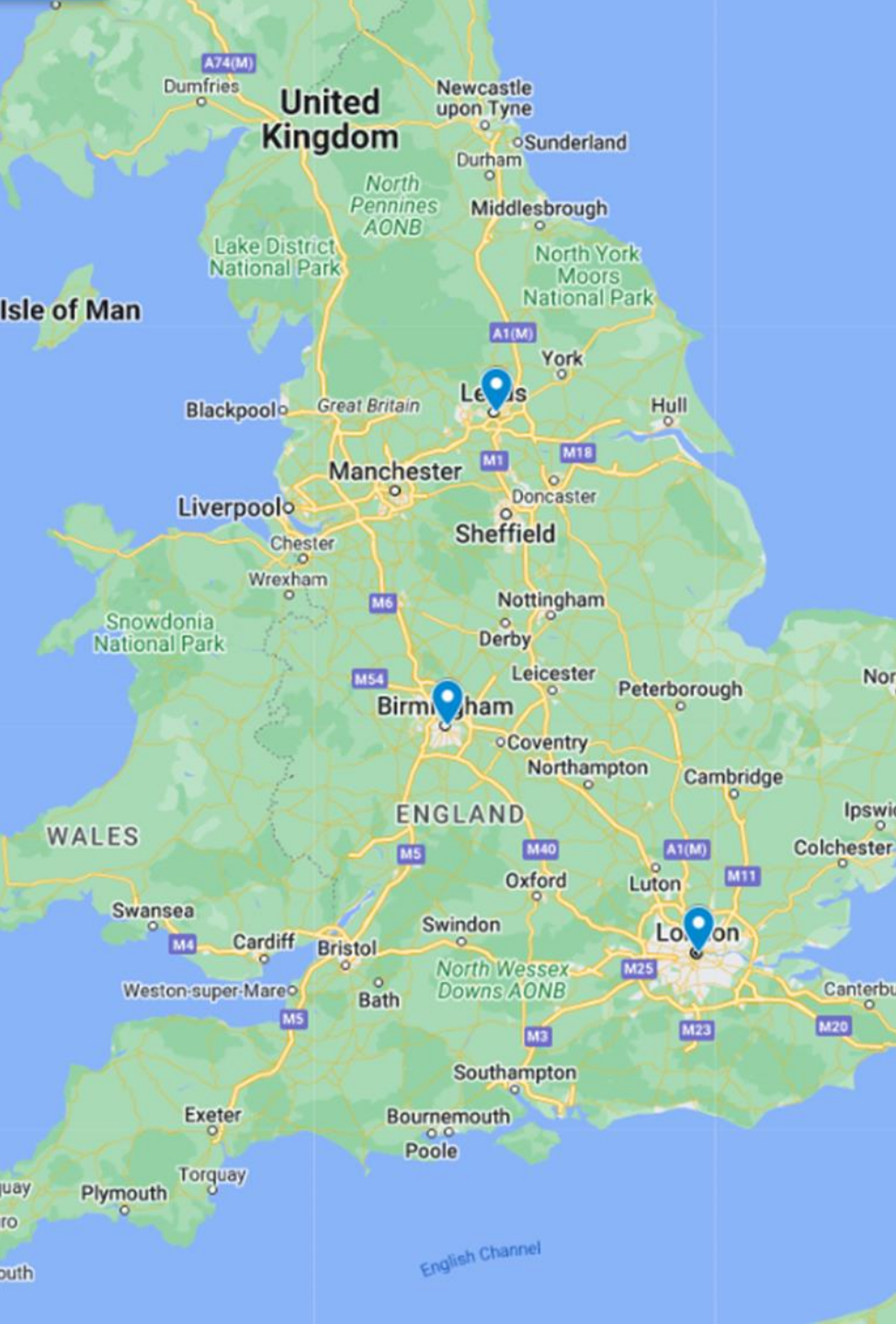
Network News

Working Together

*Alone we are strong...
together we are stronger*



- In the rare/genetic community – we are stronger together
- The UK Rare Diseases Framework – Health Equity
- BDB Involvement in Research
- Community Outreach Project
- Community & Awareness Raising Events
- Connecting individuals, families and organisations
- T-KASH – Transition, Knowledge & Skills in Healthcare
- Joint funding applications
- Joint resources funded by BDB



Save The Dates!

Regional Events – coming to a city near you!

- 6th June 2023 – Leeds
- 12th July 2023 – Birmingham
- 26th September – London

Virtual Conference

- 29th November 2023 - Zoom

Questions



And...

What else can we do to support you?

Contact the BDB team



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Thank You



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