



Breaking Down Barriers Workshop

19th & 20th September 2018

KERRY LEESON-BEEVERS & ASYA CHOUDRY

House Keeping

- Fire drill
- Assembly Point
- Toilets
- Refreshment breaks
- Outside areas
- Mobile phones on silent
- Interact & ask lots of questions
- Make use of the time together
- Add comments and suggestions on the walls around the room

Introductions

- Name
- Job Title / Interest in BDB
- Organisation
- What do you hope to gain from the workshop?

Breaking Down Barriers



Asya Choudry

Community Engagement Manager for Breaking Down Barriers



The Sylvia Adams Charitable Trust



Alström Syndrome UK
Strength for today, hope for the future

Introduction

- Passion for Genetic Counselling
- GOSH/UCLH
- Genetic Alliance UK
- Ehlers-Danlos Support UK
- EDS-UK BDB year 1 project

My Role- How I can support you

- 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 service for BME communities
- Creating resources and building bridges

Barriers

- Certain families resisting engagement
- Feelings of isolation and insignificance – judgement and ostracisation
- Usefulness of current organisational resources
- Cultural do's and don't
- Use of interpreters and other language barriers
- Missing clinic appointments

Engaging further with BDB

- Be more interactive!!!!!!!
- Do you have an event, an achievement?
- New developments within your organisation
- BDB successes and project update
- Invite us to your events & conferences we can speak/present about BDB

Promote via our pages by Tagging us on Facebook, Twitter and via the 'Latest News' section on our Website

Facebook: Alstrom Syndrome UK / Breaking Down Barriers

Twitter Handle: @AS_UK

Website: www.breaking-down-barriers.org.uk/latestnews

What's in the pipeline!

- Route Maps for newly diagnosed patients
- A booklet on the Islamic Perspective on Genetic technologies and ethics
- Expanding our network and creating a platform of resources that we can all use
- Crossover with Organ and blood Donation work within BME communities
- Genetics glossary for patients
- Genetic awareness event in Leeds/Bradford, Luton, and Sheffield

Useful Resources

- Hospital Chaplains
- Citizens Advice Bureau
- Peer to Peer Support
- Child Bereavement Trust – useful online resources about different religious practices
- Genetic Alliance UK Leaflets – geneticalliance.org.uk/information/services-and-testing/
- Cousin marriage and genetic disorders leaflet – bradford.gov.uk/media/4097/w36205-cousin-marriage-leaflet-final-082417.pdf
- Asian Society in Universities (may be able to recruit medical students as volunteers)
- Asian Carers Groups
- East London Genes and Health www.genesandhealth.org
- www.geneticsaware.org

SELF SUPPORT

Boundaries

Stress relief

Know your Limits

Seek help

Mental Health

Meditation

Supervision

Variety

Questions



Thank You



0782 516 2423



asya.Choudry@alstrom.org.uk



www.breaking-down-barriers-org



Alström syndrome UK



@AS_UK

Developing Resources



Kirit Mistry, Chair, South Asian Health Action
Asya Choudry & Kerry Leeson-Beevers



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<https://youtu.be/XZx1LSrWZyo>

AKU Society



SWAN UK



<https://youtu.be/IAfRfnYWytI>

Other Resources

- BBS list of resources – handout
- Seeing Beyond the Eyes – Resource Pack
- Bardet-Biedl Syndrome Patient Journey
- HDA list of resources – handout
- <https://www.undiagnosed.org.uk/support-information/> - leaflets in English and Urdu
- ‘Please, write to me’ Writing outpatient clinic letters to patients – Guidance (September 2018), Academy of Medical Royal Colleges
- Charity Leaflets

Group Discussions

Review Resources

- What do you like about the videos, leaflets and other resources?
- How could the videos and leaflets be improved?
- Animation v's real life case studies
- Feedback

NHS Five Year Forward View 2014 – Engaging Communities



‘Stronger partnerships with charitable and voluntary sector organisations. When funding is tight, NHS, local authority and central government support for charities and voluntary organisations is put under pressure. However these voluntary organisations often have an impact well beyond what statutory services alone can achieve. Too often the NHS conflates the voluntary sector with the idea of volunteering, whereas these organisations provide a rich range of activities, including information, advice, advocacy and they deliver vital services with paid expert staff. Often they are better able to reach underserved groups, and are a source of advice for commissioners on particular needs. So in addition to other steps the NHS will take, we will seek to reduce the time and complexity associated with securing local NHS funding by developing a short national alternative to the standard NHS contract where grant funding may be more appropriate than burdensome contracts, and by encouraging funders to commit to multiyear funding wherever possible.’

<https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>