

# Breaking Down Barriers

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Community Engagement Manager for Breaking Down Barriers



The Sylvia Adams Charitable Trust



**Alström Syndrome UK**

Strength for today, hope for the future

# Introduction

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- 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

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- To support and assist our member charities in successfully engaging hard to reach communities
- Expanding our network and platform of resources to further facilitate the aims of BDB
- Engaging certain hard to reach 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 those hard to reach communities
- Creating resources and building bridges

# Barriers

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- 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

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- 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

Twitter Handle: @AS\_UK

Website: [www.breaking-down-barriers.org.uk/latestnews](http://www.breaking-down-barriers.org.uk/latestnews)

# What's in the pipeline!

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- 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
- Trying to promote Organ and blood Donation from BME communities
- Genetics glossary for patients
- Genetic awareness event in Yorkshire

# Useful Resources

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- 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/](http://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](http://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](http://www.genesandhealth.org)
- [www.geneticsaware.org](http://www.geneticsaware.org)

# SELF SUPPORT

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Boundaries

Stress relief

Know your Limits

Seek help

Mental Health

Meditation

Supervision

Variety



# Questions



# Thank You

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