



Breaking Down Barriers



Bardet-Biedl Syndrome UK 1027384 & SCO41839



Tonia Hymers: BBS UK Service Manager
Angela Scudder: BBS UK Support Officer
Amy Clapp: BBS UK Support Officer



The Sylvia Adams Charitable Trust



Alström Syndrome UK
Strength for today, hope for the future



Project Overview

- BBS UK Newsletter: Include reports on BDB project and activities
- Website: Include reports on BDB project and activities
- Leaflet: Introducing BBS' booklet is in development – to be translated into Urdu and Turkish and recorded/uploaded to the BBS UK YouTube Channel
- Support: Develop closer communications with minority ethnic families and encourage greater involvement in BBS UK events and activities



Challenges



- Minimal take-up of local 'coffee morning' type event
- Development of leaflet time consuming
- Charity website under development
- Events and activities:
 - Travelling to events and cost implications for larger families
 - Planning in conjunction with cultural/religious calendar

Areas of Success

Improved confidence: BBS UK Support Team improved confidence when planning events/activities and communicating with minority ethnic families. Comment received:

“I have never felt such respect for my culture from outside my family group”

BBS UK Conference 2018: Substantial contact with families and BDB budget enabled us to attract increased attendance of minority ethnic families at Conference 2018

- Families feel better informed and supported
- Friendships made and contact information exchanged
- Increase in Facebook member requests

BBS UK Conference Report includes photos showing diversity of delegates which we hope will enable other minority ethnic families feel welcome and accommodated for.

Questions



Thank You



Tonia: 07591 206680
Angela: 07591 206788
Amy: 07591 206787



info@bbsuk.org.uk

tonia.hymers@ /angela.scudder@ / amy.clapp@bbsuk.org.uk



www.bbsuk.org.uk



www.facebook.com/bardetbiedlsyndromeuk/



@LMBBS1