



Breaking Down Barriers

BBS UK are contracted by NHS England to provide facilitation and support services to the specialised BBS clinics held in London and Birmingham and every year we are required to send a report of the year's activity, highlighting any issues and including evaluation data collected through the year. We also have to collect, collate and send Service User Data, which includes the age, gender, location and ethnicity of our patients. The BBS UK membership and patient group is ethnically diverse, with approximately 58% recording themselves as 'White British', so at BBS UK we are keen to ensure that our support services are reaching all aspects of our membership.

To that end, in May 2016 BBS UK applied to take part in a three year project called 'Breaking Down Barriers', organised by Alstrom Syndrome UK and funded by the Sylvia Adams Charitable Trust and were delighted to be accepted onto the programme. Funding, mentoring and workshops will be provided across a three year period to help patient organisations join together to support families that have an increased risk of having children with genetic conditions within diverse backgrounds and who have difficulty accessing mainstream services.

The Sylvia Adams Charitable Trust was set up in 1996 with money left from the sale of Sylvia Adam's personal collection of antiques, in line with her wishes. From 1996 to 2015 grants have been given to projects supporting children and young people, those with a disability, those living in poverty or socially excluded. In 2011 The Sylvia Adams Charitable Trust contributed funding towards Alstrom Syndrome UK's Asian Mentoring scheme. This funding enabled ASUK to work within the South Asian communities to develop a greater understanding of their cultures and beliefs, the barriers and challenges they face and to raise awareness of Alstrom Syndrome, a rare autosomal recessive condition causing childhood blindness, hearing loss, heart failure, kidney failure, type 2 diabetes and many associated problems. The project was a great success which led to The Sylvia Adams' Charitable Trust committing funds to the Breaking Down Barriers project.

The project will enable BBS UK to develop a greater understanding of and provide greater support to ethnically diverse families and individuals and to facilitate greater access to the specialised BBS Clinics. It is important to BBS UK that we give all families and individuals informed choices about the importance of ongoing health management and that all of our members feel fully understood and heard whatever their ethnic background.

The project runs across a three year period and our Year 1 Action Plan has been accepted:

In the first year BBS UK aims to:

- ✓ Ensure all newsletters contain relevant information for the entire BBS UK membership demographic

- ✓ Ensure all information leaflets are recorded in an appropriate language for South Asian members for the BBS UK YouTube Channel
- ✓ Plan small gatherings in an appropriate central location to encourage families to meet for mutual support

In years two and three, in addition to the above, BBS UK aims to:

- ✓ Identify a member of BBS UK to be a point of contact for our Asian families and to attend the BBS UK Clinics in the Birmingham area
- ✓ Organise an information day at a Birmingham hotel for local families and patients
- ✓ Engage an Asian Mentor to provide support alongside BBS UK staff and volunteers at the BBS Clinics

We are very excited to have been accepted onto the Breaking Down Barriers Project and look forward to working with Kerry Leeson-Beevers (ASUK) and the Sylvia Adams Charitable Trust. We will keep members updated with the project and developments over the coming newsletters, in the meantime if members would like to get involved with the project or would like further information, please contact Julie Sales: julie.sales@bbsuk.org.uk or by telephone: 07917 252585.

BBS UK Coffee Morning: 17th May 2017

BBS UK hosted their first Breaking Down Barriers coffee morning in Birmingham on the 17th May 2017 at the Cobden Hotel. The event was well attended with guests travelling from as far away as Leeds to take part.

Clinicians from Queen Elizabeth Hospital and Birmingham Children's Hospital joined us for the morning, including Sarah Borrows, CNS; Marie McGee, Transition Co-ordinator; Hilary McCoubrey, Dietitian; Stephanie Bryan, CNS and Anne Chessborough, from Sense. Our guests were very grateful for the chance to discuss their concerns and questions in an informal setting. Iram Shah who has been working alongside us for the BDB project, provided translation services and general support which was greatly valued.

Many new friendships and contacts were made and the feedback has been very positive; we will be taking all suggestions forward for the planning of our next event, which will be in October – more details to follow.