



Breaking Down Barriers – Connecting our community across cultures

Wolfram Syndrome UK Breaking Down Barriers Project Update – March 2021

WSUK has recently received approval for our new Year 2 BDB project and our new £5,000 grant will be received later this month! This means we can now get started on our plans and will be inviting you to contribute!

Our plan for Year 2

Our Year 2 project will build on key findings and recommendations from Year 1 (our consultation with 20 BAME members), which highlighted that our BAME community:

- **Need more information** from WSUK - particularly to **support their discussions with GPs and HCPs**. Information in their local language is also important for some people.
- Need WSUK to help arrange **opportunities to meet other people** from the (BAME) WS community, particularly in their age range or locality.
- Would like to further develop their engagement with WSUK – many are very open and willing to **share their stories/experiences** with others across the WS community.
- Include members who do not use the internet and are unable/unwilling to attend the WS conference.
- Need new WSUK projects targeted to support the WS community.
- Typically struggle with daily life – for most people WS impacts everything they do.

In our Year 2 project, we will seek to continue to extend our engagement with our BAME community and involve members of our community across different cultures. We intend to do this through:

1. Development and sharing of information:

a) To support your discussions with GPs, health providers and other stakeholders (such as schools, or employers).

- This will include updating the WSUK handbook and considering how other WS-related information could be shared with you to increase its value and impact.

b) To encourage greater utilisation of the WSUK website, particularly by the BAME community.

- We will develop a new BDB page that will include videos and other information. Some information will be provided in Urdu.

2. Sharing experiences across the community

a) On key topics / themes

We will be asking you to contribute information around specific topics or themes. You will be able to provide your input by phone, email, photos and/or video. We will collate this information, which will be shared on the BDB page and in future Newsletter articles.

b) Buddy-up between members of the WS community

We will extend the existing “buddy-up” scheme to include additional people who would like to connect with someone else, similar in age, location or interests, from the WS community. We will also help to facilitate the interactions where this would be most helpful.

If you would like to contribute to this new project, you can contact the office – email admin@wolframsyndrome.co.uk or phone 01903 211358; or respond to our invitations which will be shared with everyone in the WS community.

We thank everyone who has taken part in this important project so far. We really look forward to collaborating with you again in this new project.

“Breaking Down Barriers” is part of an initiative for patient organisations being run by Alstrom Syndrome UK and funded by the Sylvia Adams Charitable Trust.