

Breaking Down Barriers



WellChild

Jody Blake

Wolfram Syndrome Family Coordinator



The Sylvia Adams Charitable Trust



Alström Syndrome UK
Strength for today, hope for the future

Project Overview

To raise awareness of the rare genetic condition Wolfram Syndrome within the UK's South Asian Community and Professionals enabling:

- earlier diagnosis which leads to better management of the condition
- families to access the specialist Wolfram clinic at BCH & QEHB
- access to support from Wolfram Syndrome Family Coordinator
- identification of more children and young people who can take part in clinical trial.

Key activities to include:

Awareness campaign to target local paediatric diabetes teams and visual impairment teams (children develop diabetes and optic atrophy in childhood)

- development and distribution of leaflet in English, Urdu and Punjabi*
- Information on WellChild website in identified languages – to include audio information.

Challenges

Working on my own in organisation on project

Deciding on what languages to translate the leaflet into...and deviating from original project plan

Getting English version as simple as possible

Delays in agreeing on English text...this took months

Working with the translation agency

Involving parents in the process (but also very positive)

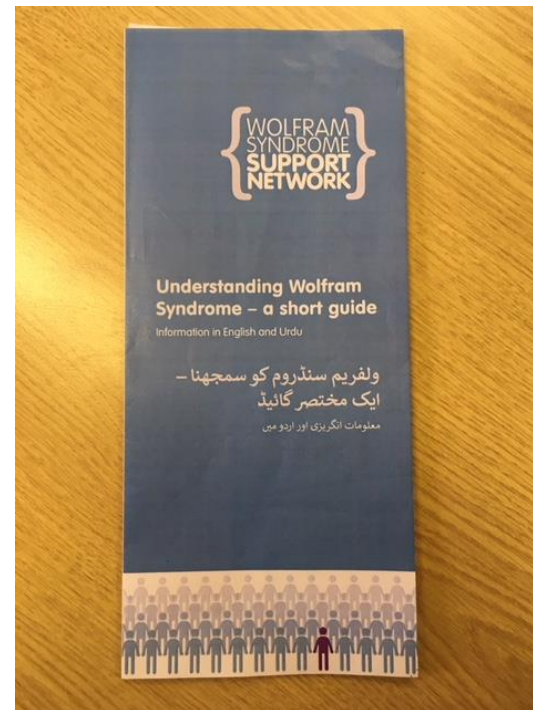
Going backwards and forwards with changes

New data protection laws will make distributing leaflet more time consuming

Everything has taken considerably longer than I anticipated!

Areas of Success

Leaflet finally developed.....



Questions



Thank You



01242 548762 / 07796710848



jodyblake@wellchild.org.uk



www.wellchild.org.uk



Jody At WellChild



@Wolframfamilies