SWAN UK
syndromes without a name

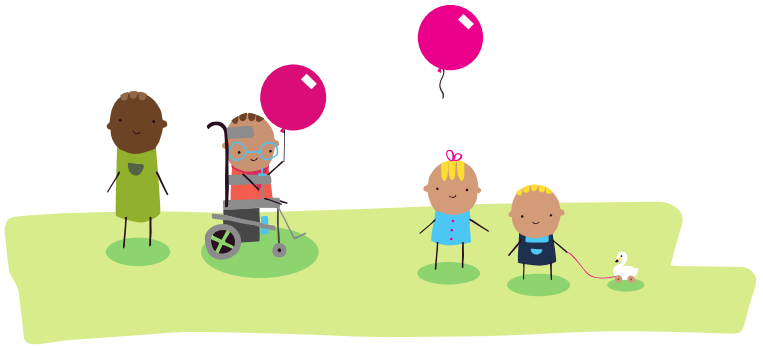
BREAKING DOWN BARRIERS

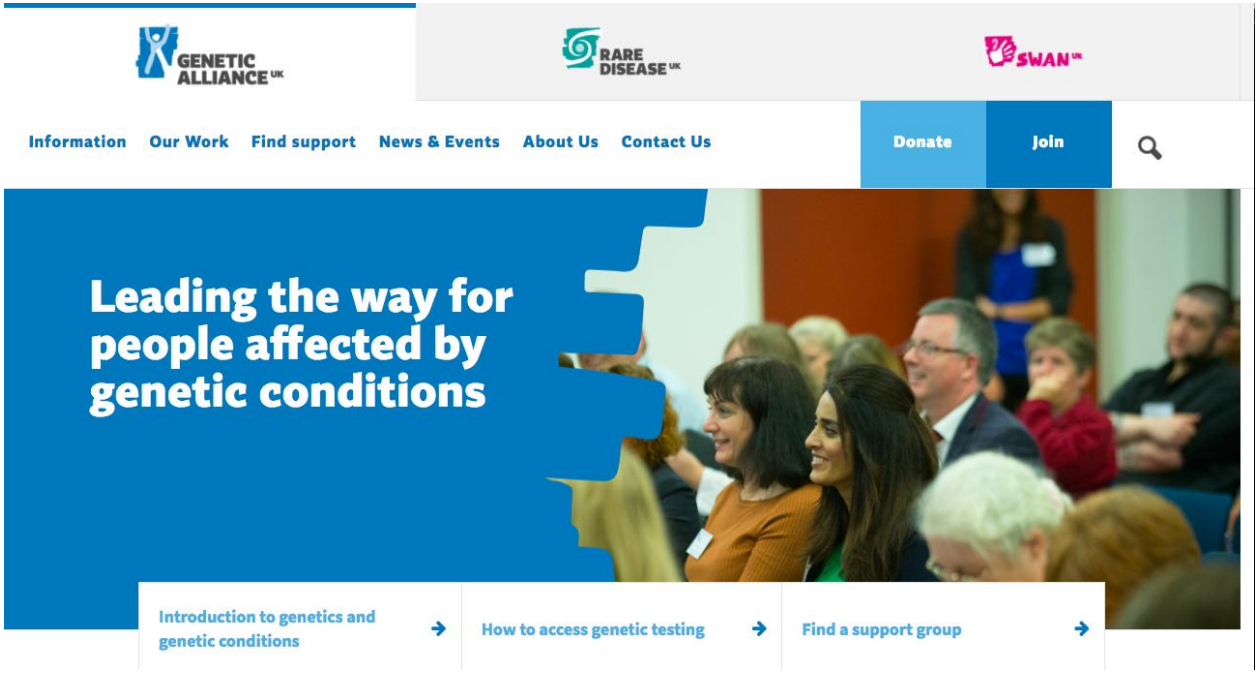
BREAKING DOWN BARRIERS UPDATE

September 2017

Miriam Ingram
Digital Communications and Support Officer

13 - 14 September 2017

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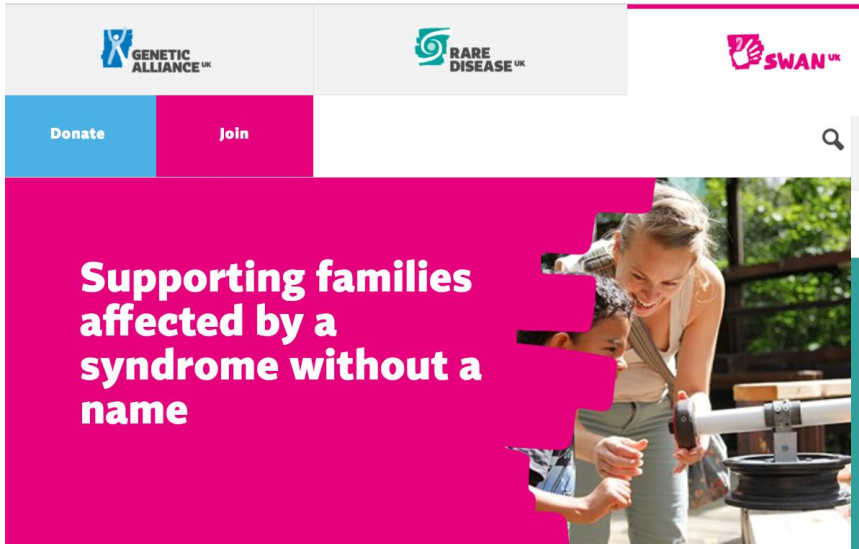
Introduction to genetics and genetic conditions
How to access genetic testing
Find a support group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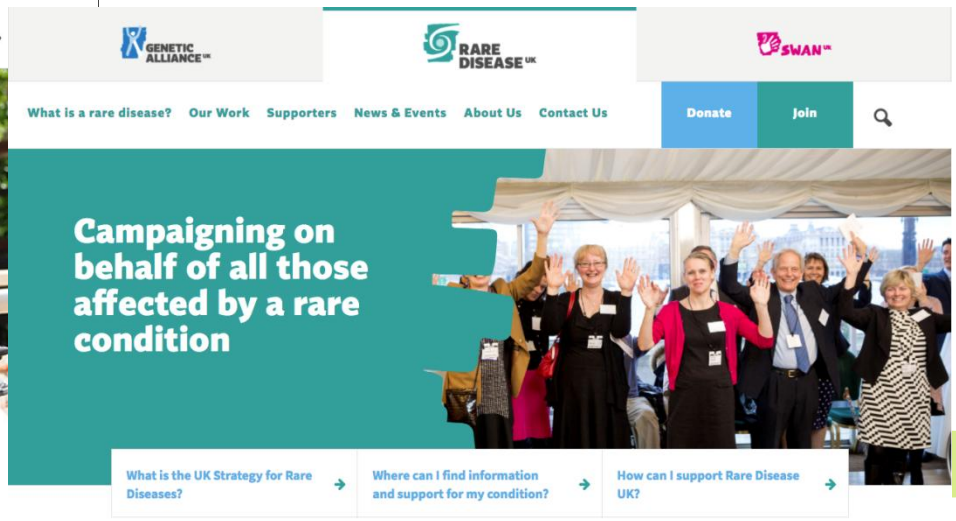
Supporting families affected by a syndrome without a name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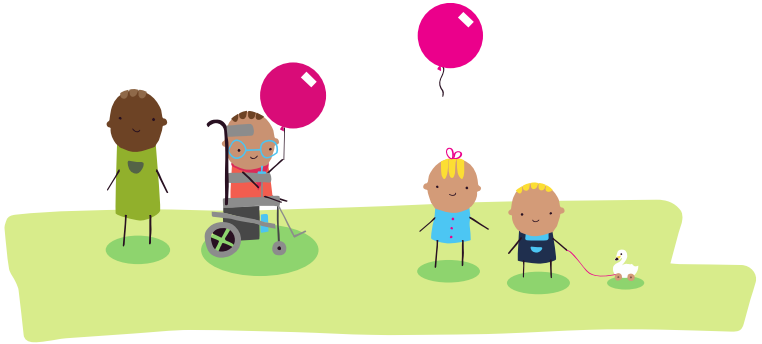
Campaigning on behalf of all those affected by a rare condition
What is the UK Strategy for Rare Diseases?
Where can I find information and support for my condition?
How can I support Rare Disease UK?

WHAT DOES ‘SWAN’ MEAN?

SWAN stands for ‘syndrome without a name.’ It is not a diagnosis, but a term used when a child or young adult is believed to have a genetic condition and testing has failed to identify its genetic cause.

- It is estimated that 6,000 children are born in the UK each year with a syndrome without a name.
- 50% of children undergoing genetic testing in the UK won’t get a confirmed diagnosis.

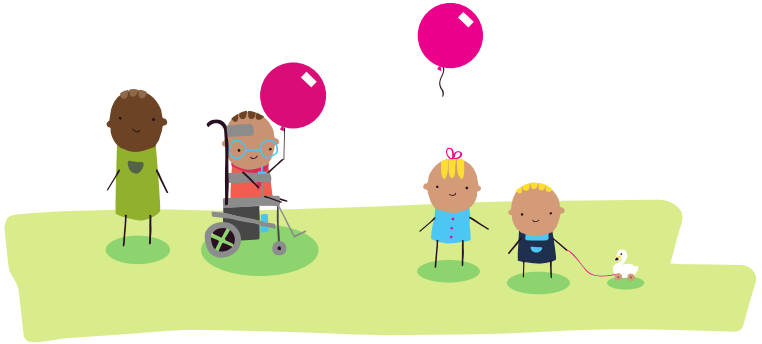


WHO WE SUPPORT

We work with families of undiagnosed children/young adults (0–25) where the child/young adult:

- is having/about to have genetic testing.
- is taking part/is about to take part in genetic research.
- has genetic changes of unknown significance.
- has an ultra rare diagnosis.

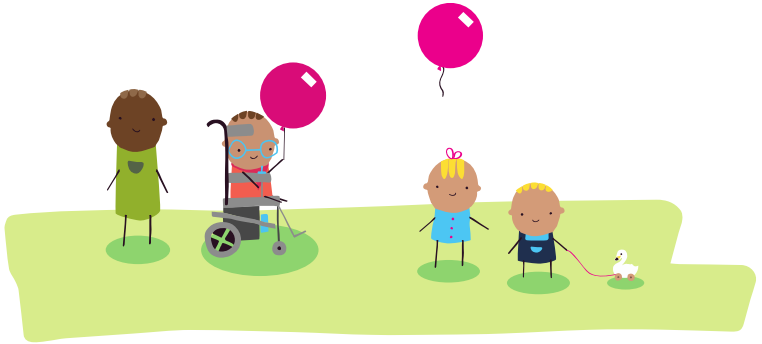
Membership is free.



SWAN UK BDB AIM & OUTCOMES

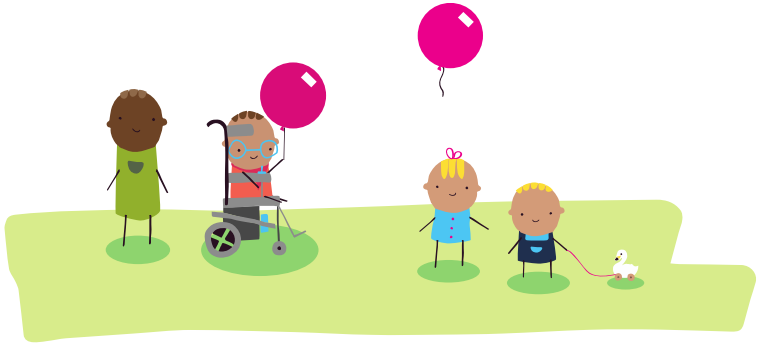
Aim – Engage Asian families of children with undiagnosed genetic conditions.

Outcomes – Asian families affected by undiagnosed genetic conditions will have access to information about genetics and undiagnosed genetic conditions. They will also have the opportunity to identify their own support needs and how they can best be met.



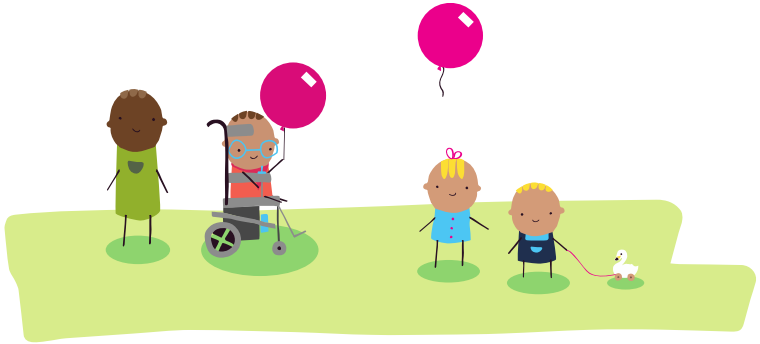
WHAT WE PLANNED TO DO

- Translate a series of leaflets about genetics into Urdu.
- Hold a focus meeting with Urdu speaking families affected by undiagnosed genetic conditions (or who were undiagnosed for a long time).
- Plan updated January 2017 to include making a DVD with information from leaflets and a family story.



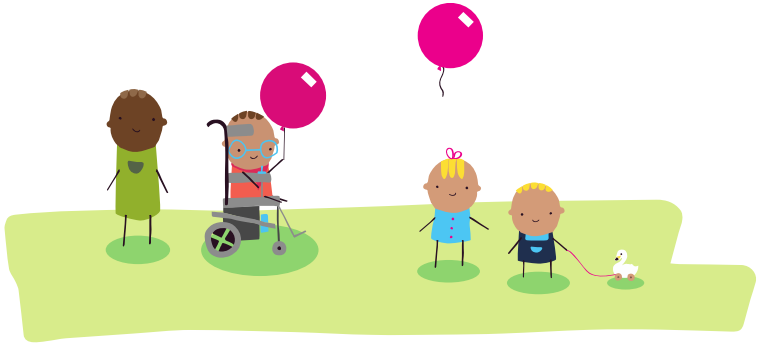
WHERE WE ARE NOW

- Translated two test leaflets – checked by volunteers from SWAN UK community and contact at Birmingham Genetics Service.
- Rest of leaflets translated, recruiting new volunteers to check.
- Finalising plans to meet with parents to discuss support needs.
- Identified film maker and discussed plans, now identifying people to take part.



UNEXPECTED DEVELOPMENTS

- Visit Asian Carers' group in Blackburn.
- Paediatrician in Bristol interested in outreach with Asian community.
- Interest from new SWAN UK member to become a Parent Rep and lead on engaging with other families from South Asian backgrounds.



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THANK YOU

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SWAN UK is support network run by Genetic Alliance UK

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