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SWAN UK

Organisation Details

Description of activity

SWAN UK (syndromes without a name) is the only dedicated support network in the UK for families of children and young adults with undiagnosed genetic conditions. We are run by the charity Genetic Alliance UK.

Joining is free for any family in the UK with a child (0-25) affected by an undiagnosed genetic condition.

As a member of SWAN UK you can:

Make contact with other families who understand the unique challenges of raising a child affected by an undiagnosed genetic condition

Attend free, fun whole-family events

Access 24/7 information and support through our online forums

Receive our monthly and quarterly newsletters

If you answer yes to any of the questions below then SWAN UK is here to support your family:

Have you been told your child has global development delay or failure to thrive, but not been told the reason why?

Does your child have medical, physical or learning difficulties which are currently unexplained?

Is your child suspected to have a genetic condition but the doctors don't know what it is?

Has your child had genetic tests, for example microarrays, that have come back negative or of 'unknown clinical significance'?

Is your child taking part in, or are you hoping they will take part in, genetic research such as Deciphering Developmental Disorders (DDD) or the 100,000 Genomes Project?

Is your child having their exome or genome sequenced, or have they had exome or genome sequencing and the cause of their condition is still unknown?

Email: london@undiagnosed.org.uk to find out more.

For general enquiries email: info@undiagnosed.org.uk

To join SWAN UK email: joinus@undiagnosed.org.uk

Address: Genetic Alliance UK, Level 3, Barclay House, 37 Queen Square, London, WC1N 3BH

Phone number: 020 7831 0883

Website: <http://www.undiagnosed.org.uk/>

Twitter: https://twitter.com/SWAN_UK

Facebook: <https://www.facebook.com/SWANchildrenUK/>

Instagram: <https://www.instagram.com/swanchildreuk/>

YouTube: <https://www.youtube.com/user/SWANchildrenUK>

Contact Details

Contact Name

Jane Curzon

Telephone

020 7831 0883

Email Address

london@undiagnosed.org.uk

Website

<http://www.undiagnosed.org.uk/>

Social Media Links

Twitter Link

https://twitter.com/SWAN_UK

Facebook Link

<https://www.facebook.com/SWANchildrenUK/>

Address Details**Venue Name**

Genetic Alliance UK

Address 1

Level 3, Barclay House

Address 2

37 Queen Square

Town

London

Postcode

WC1N 3BH

Accessibility**Accessible building**

N/A

Accessible toilets

N/A

Parking facilities

N/A

Dietary needs catered for

N/A

Staff have specialist training

N/A

Availability Details**When is the activity or service available**

All Year Round

Is there a cost for this service or activity

No

Which categories suit this organisation?**Services**

Organisations / Charities |

Additional useful information to download**File Attachments**

- Logo (JPEG Image, 133 KB)

Location Map