

UNDIAGNOSED CHILDREN'S DAY

Friday 24 April 2026

SWAN UK KEY POINTS

Undiagnosed Children's Day

- Undiagnosed Children's Day is an annual awareness day on the last Friday in April to celebrate and raise awareness of undiagnosed genetic conditions and SWAN UK.
- Parents of children with undiagnosed genetic conditions often see so many different healthcare professionals. It takes an average wait of 5.6 years for a rare diagnosis in the UK through 8 clinicians and 3 misdiagnoses.
- We have created 3 videos for healthcare professionals so that they have a greater understanding of what it means to have a child with an undiagnosed genetic condition and the challenges that families face. We will launch these on our [YouTube](#) channel during the week of 21 April. If you would like an embargoed copy please get in touch: info@undiagnosed.org.uk.

SWAN UK and undiagnosed genetic conditions

- **SWAN UK (syndromes without a name)** is the only dedicated support community in the UK for families of children with undiagnosed genetic conditions, also known as syndromes without a name. SWAN UK is 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.

- SWAN stands for ‘syndromes without a name’. It is not a diagnosis in itself, 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.
- Children affected by a syndrome without a name can have a range of different symptoms and each child is likely to be affected differently. However, many SWAN children are described as having global developmental delay, learning and/or physical disabilities or complex medical needs. [Watch our animations](#) to find out more about genetic conditions, how genetic conditions are diagnosed and why some genetic conditions remain undiagnosed.
- Without a diagnosis families can struggle to access the right support and feel isolated. They don’t know what the future holds for their child. Will they walk? Will they talk? What is their life expectancy? How will it affect future children?
- SWAN UK enables families to connect online and in person with other families who understand the unique challenges of raising a child affected by an undiagnosed genetic condition.
- We support the SWAN UK community and healthcare professionals, by educating those working in the NHS about the challenges faced by families affected by a syndrome without a name

Terminology

- ‘SWAN UK (syndromes without a name)’ in the first instance then ‘SWAN UK’
- SWAN UK is a support community run by the charity Genetic Alliance UK
- Undiagnosed genetic conditions or syndromes without a name can be used interchangeably

Contact details

To join SWAN UK email: info@undiagnosed.org.uk or complete a short registration form [here](#).

Links

Email: info@undiagnosed.org.uk

Website: geneticalliance.org.uk/support-and-information/swanuk

Facebook: [swanchildrenuk](#)

Instagram: [swanchildrenuk](#)

YouTube: [swanchildrenuk](#)