Undiagnosed Children’s Day, Friday 25 April 2025

Thursday 24 April, 2025

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SWAN UK, the only support community for families affected by undiagnosed genetic conditions in the UK, wants to reach more families as they hold their awareness day, Undiagnosed Children’s Day this Friday.

Having an undiagnosed genetic condition, also known as a syndrome without a name, 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.

Children can have a range of different symptoms and each child is likely to be affected differently, however, many are described as having global developmental delay, learning and/or physical disabilities or complex medical needs.

If families answer ‘yes’ to any of the following questions you can join the SWAN UK community.

- Have you been told your child has global developmental delay (GDD) or failure to thrive but not told the reason why?
- Is your child suspected to have a rare or genetic condition but more testing is needed to try and identify which one?
- Does your child have unexplained medical, learning or physical disabilities?
- Has your child received genetic testing results that were negative or with a variant of unknown significance?
- Did your child take part in the Deciphering Developmental Disorders (DDD) study or the 100,000 Genomes Project, but you still don’t have a diagnosis?

Miriam Ingram, SWAN UK Communications and Engagement Manager says: ‘Having a child with an undiagnosed genetic condition is lonely and isolating, with families having more questions than answers about what the future holds. SWAN UK brings families together to help them navigate the unknown and connect with others who understand the unique challenges that they face.’

Undiagnosed Children’s Day is a nationwide event to raise awareness of children with undiagnosed genetic conditions, also known as syndromes without a name. SWAN UK, run by the charity Genetic Alliance UK, is the only dedicated support community for families affected by an undiagnosed genetic condition in the UK.

Visit: https://geneticalliance.org.uk/swanuk

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Related Keywords:

Undiagnosed :: Genetic :: Genetic Condition :: Global Developmental Delay :: GDD :: Syndrome :: Diagnosis :: Failure To Thrive :: Rare :: Genetic :: 100 :: 000 Genomes ::

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