Undiagnosed Children’s Day - Friday 26 April 2024

Friday 19 April, 2024

Can you imagine having a child with a genetic condition so rare it doesn’t even have a name?

Around 6,000 children are born every year in the UK with a genetic condition likely to remain undiagnosed. For them and their families the future is unknown.

On Friday 26 April 2024, SWAN UK (syndromes without a name), the only UK support community for these families, will be calling on people to spread the word and help more families find us sooner.

Katie, whose 2-year-old son Stanley has an undiagnosed genetic condition, says: ‘As a parent when you are told that tests are showing that everything is clear, and it is believed your child has an unknown genetic condition that could take up to a lifetime to diagnose, it’s very overwhelming. Life can feel lonely and isolating.

‘When we found SWAN UK it made us realise that we are not alone in this journey. Stanley and I have already made some friends in the SWAN UK community, and we look forward to getting more involved as time goes on.’

SWAN UK’s Communications and Engagement Manager, Miriam Ingram says: ‘We know that for families like Katie’s, life can be extremely difficult as medical professionals can’t give them any answers and this can be a very lonely place to be. Without a diagnosis it can be hard to access all kinds of support because families can’t tick a box as to what is wrong with their child and it can mean they have to fight even harder to make sure that their child gets the help and support they need.

‘SWAN UK is a lifeline to these families, offering peer-to-peer support, events and opportunities, information and a sense of belonging.’

ENDS

About Undiagnosed Children's Day

Undiagnosed Children’s Day is a nationwide event to raise awareness of children with undiagnosed genetic conditions, also known as syndromes without a name

About SWAN UK

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. We offer support and information to families affected by undiagnosed genetic conditions. We work with healthcare professionals educating them about undiagnosed genetic conditions and sharing with them the challenges that people in the SWAN UK community face.

Press enquiries

To arrange an interview with Katie or another parent email: miriam.ingram@geneticalliance.org.uk.

Media:



Related Sectors:

Charities & non-profits :: Children & Teenagers :: Health :: Media & Marketing ::

Related Keywords:

Undiagnosed :: Genetic :: Rare :: Syndrome :: Syndrome Without A Name :: Diagnosis :: Support :: Awareness :: Children :: Parents ::

Scan Me:

Company Contact:

Genetic Alliance UK Ltd

T. 0300 124 0441
E. communications@geneticalliance.org.uk
W. https://geneticalliance.org.uk

Additional Contact(s):
contactus@geneticalliance.org.uk

View Online

Additional Assets:

Newsroom: Visit our Newsroom for all the latest stories:
https://www.geneticallianceuk.pressat.co.uk