

## Parent Testimonies

*“...a great way to share experiences and gain knowledge of past and coming child or adult needs”*

*“lovely to chat to people in a similar situation”*

*“brilliant to finally have somewhere we fit in”*

*“Having a child with no clinical diagnosis can be a very frightening time. Having a dedicated support group could help ease the isolation and maybe help \*Leo thrive.”*

*\*names have been changed to protect the confidentiality of the respondents.*



## Contact Us



Email [syndromeswithoutanameireland@gmail.com](mailto:syndromeswithoutanameireland@gmail.com)

Instagram @swanireland

Twitter @IrelandSwan



SWAN Ireland  
SYNDROMES WITHOUT A NAME

**A support network for children living with a ‘syndrome without a name’ and their families, in Ireland**

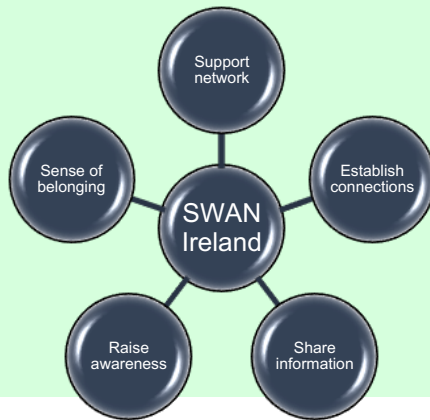
***Established July 2019***

**#rareismany #syndromeswithoutaname**

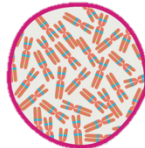
## Who are we?

We are a specifically dedicated support group for children and people with no known diagnosis, and their families, living in Ireland. There are nearly 70 members nationwide in a private Facebook group. We are not yet a registered charity. We aim to establish connections amongst families, foster a sense of belonging, provide a platform to share information and experiences, and raise awareness of SWAN.

### Our Aims



## What is a 'syndrome without a name'?



SWAN is a term used to describe when a person is believed to have a genetic condition where genetic testing was unable to identify a genetic cause. Children might be described as having global development delay. There are three main reasons why a child's genetic condition remains undiagnosed:

- ⇒ A condition that has never been seen before
- ⇒ An unusual presentation of a known condition
- ⇒ Genetic changes are of unknown significance

(SWAN UK, 2017, "What does SWAN or being undiagnosed mean?")

## Origin Story

When Beth (Founder) was working as a Speech and Language Therapist in a disability service in Ireland, the lack of dedicated supports for children with SWAN and their families became starkly apparent. Two families highlighted that they felt they did not 'fit' with other groups of parents whose children had more understood and recognised diagnoses.

Following this, Beth set out to see what supports existed nationally and internationally, reached out to other agencies, and sought to hear from families in Ireland about what they wanted. SWAN Ireland had its first meeting with children and families in 2019 and has been involved in various in-person and virtual events, local and global campaigns, since this time.

## SWAN around the globe



We are the newest member to the SWAN community with SWAN UK and SWAN Australia having been established in 2011 and 2012, respectively. We continue to collaborate with our SWAN partners as well as Rare Diseases Ireland, SWAN Europe, Rare Disorders NZ amongst other groups. We celebrate 'Undiagnosed Children's Day' on the last Friday of April every year with our SWAN UK partners.

## Next Steps

We hope to grow further awareness of the group nationally, to reach more families, strengthen connections between members, and the community, and to continue collaborations with families and other similar organisations who have a shared vision.