BLOG GUIDELINES

SWAN UK Family story

Thank you for agreeing to share the story of your experiences of having a child with an undiagnosed genetic condition. Before you get started please read the GDPR statement and, if you agree, fill in the consent form at the end of this document.

THE BASICS:

- We appreciate how personal this is, so please only write about what you feel comfortable sharing.
- If you change your mind about wanting to write this blog piece then that is absolutely fine, please just let us know.
- Please send us a picture or two with the blog. We would prefer a high-resolution image if possible.

- The most important thing to keep in mind is that your story is unique to you and gives readers a sense of how your rare disease has affected you and your family.
- We like our blogs to be quite short – no more than 750 words. Don't worry – we won't cut you off mid-sentence, but we may edit your piece and ask you to review it.
- Try to include sub-headings if you can – it breaks the post up a bit and helps draw attention to key elements.
- Blogs can be as conversational as you like. We encourage bloggers to write in their own voice – after all it's your personal experience!
- Please send us a picture or two with the blog. We would prefer a high-resolution image if possible, and landscape images work best on our website.
- At the end of your post, please include your name and a short biography – a few lines about who you are and what you enjoy. We are happy to publish stories using your first name only or a pseudonym – just let us know your preference. You can also include your website and Twitter handle if you have one.

WHAT TO WRITE ABOUT:

- Please introduce your family.
- How old was your child when you found SWAN UK and where were you in your diagnosis journey when you found us?
- When did you realise that your child was undiagnosed?
- What does it mean to have a child with an undiagnosed genetic condition?
- How long was it until you got a diagnosis/ or how long have you been waiting and what impact has this had on your family?
- What does SWAN UK mean to your family?

OTHER INFORMATION:

- We may edit your post if there are spelling and grammar corrections to be made. If we make any significant changes we'll send it back to you for your approval.
- We will share the link to the blog post on social media including Facebook and X, and will encourage our supporters to do the same.
- Please let us know if you are happy for us to use your full name. You don't have to use your real name if you don't want to and we can also make it anonymous if you would like.

GDPR statement

Thank you for sharing your story with us. Real-life stories are a vital tool for helping raise awareness of genetic, rare and undiagnosed conditions. Your story and any accompanying photos will be published on our website and promoted via our newsletters and social media channels. Unless you have given us express permission, we will not use any photos you share with us for any other purpose than with your story or to promote it. A copy of the story and accompanying photos will be kept securely in our password protected files in accordance and compliance with the GDPR (the General Data Protection Regulation) guidelines (the General Data Protection Regulation). Your contact details will be held on our secure database.

We will not share your story or photographs with anyone else to publish or use without asking your permission first, but please be aware that once they are in the public domain we cannot stop other people from sharing or linking to them from their websites and/or social media.

Your privacy is very important to us. We may edit your story and photos to remove any personal details (such as dates of birth or names badges). If you would prefer, you can remain completely anonymous or choose to use different names in your story. You do not have to provide photographs if you do not wish to.

You can ask us to stop using your photo or story at any time by emailing info@undiagnosed.org.uk and we will remove it from our website within seven working days. We will not however be able to retrospectively remove it from newsletters that have already been sent out or social media posts that have already been published so we cannot guarantee it will never be seen again.

For more information about how we keep your data safe please see our privacy policy. If you have any questions please email info@undiagnosed.org.uk.

Thank you for supporting our work.

Name:

Email address:

Phone number:

Consent - please tick (or put in italics) all that apply:

I consent to:

- Genetic Alliance UK (the charity that runs SWAN UK and Rare Disease UK) publishing my story (and any accompanying photographs) on their website and associated social media channels.
- Genetic Alliance UK saving my details and a copy of my story (and any accompanying photographs).
- Genetic Alliance UK using the photographs I have provided for their promotional activities related to my blog, such as on their website, social media channels and for fundraising materials, or in certain situations where explicit permission has been provided.
- Genetic Alliance UK tagging my personal social media accounts (outlined below) in their posts that share my story once it has been published.

Would you like to share your pronouns with us? – If yes, please share below

My pronouns are:

My child's pronouns are:

My social media handles are:

Instagram:

Twitter:

Facebook: