

First ever Aniridia Day

I have written before about my daughter Sofia and the rare genetic condition she was born with – Aniridia. Today is a good day for me and everyone who is involved with the condition either as a sufferer, their parents, friends or siblings. Today is the first ever [Aniridia Day](#) and that is great news for this small community of inspiring people. It signals the next step in worldwide awareness, which will hopefully trigger more fundraising and [research](#).



Being so rare, [Aniridia](#) lacks vital medical research which could give hope to many children and adults around the world who are threatened by complications which can possibly lead to blindness.

Social media has luckily enabled the creation of groups and online communities where people can get together, share information and knowledge and of course awareness aimed at the public.

The [Aniridia Network UK](#) alongside Aniridia associations in [Europe](#) and [International](#) have helped launch the first ever Aniridia Day which is on the same date as the [solstice – a property of how high the sun is in the sky](#) – the brightness and position of the sun greatly affect the quality of vision

of people with aniridia.



Sometimes people give me a sad look after hearing about my daughter's condition. This attitude couldn't be further from the fact that Sofia has been a blessing in more ways [than I can count](#). Her kind, strong and positive spirit keeps amazing us daily!

I choose to see Aniridia as an ongoing hurdle which we overcome one step at a time.

Along the way, we have come across some very very brave small heroes and formed friendships with people who share a strong, focused and powerful goal – to never stop doing the best we can so our children can have the quality of life they deserve.

Today, I hope that from now on awareness will keep spreading, Aniridia will become more known and funds will keep coming in so that research can offer a glimmer of hope for small children whose lives shouldn't be threatened with blindness.

- [Aniridia NetworkUK](#)
 - [Aniridia Europe](#)
 - [Aniridia International](#)
 - [Aniridia Day](#)
 - [Sofia's Aniridia Research](#)
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A rare star is born

On the 2nd of March of 2010, at 10.10 in the morning a very very special girl came to the world, my daughter Sofia. They say that when you have children your life can never be the same again – I say: good! Your life shouldn't be the same again and you have to make it so it isn't. You need to create a better life for your children to grow in! You are obliged to become a better person, evolve, keep learning, expand, heal from your past, and do your best in being the parent your child deserves.

Of course all this is overwhelming and only comes into realization once two new little hands hold your finger and two tiny eyes look at you – that's when it hit me. The 38 weeks of pregnancy and all that comes with it (good and bad), the almost 9 hours of labor and a c-section meant so little, really, compared to the moment that I came face to face with an authentic miracle of life which I would be responsible for appreciating, nourishing, honoring and shaping.

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For the last 6 years, (that have gone by so so so fast), Sofia has showed me that children have the greatest courage. While adults complain about minor daily problems, stress about relationship breakups and are drawing in money worries – **children stare life in the face**. Sofia has taught me that being brave and strong comes from within and that you can get up again no matter how many times you fall.

Sofia has always been a smiley, energetic, happy, kind, loving, giving, sensitive (yes, being sensitive is a positive trait), good hearted, bubbly blonde little girl and having a rare condition called ['Aniridia'](#) hasn't changed that. What it has done, though, is proving to all of us that the greatest inspiration comes from the smallest things. It has also given

us the opportunity to get to know some really great and supportive people.

My perfectly rare girl lovessss dancing and horse riding. learning new things, making friends, Batman, running all the way back from school and cooking with mommy.

She is my hero xxxx

[Support important research on Aniridia to help Sofia and all the children like her ☐ thank you.](#)