

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](#)