



**NCBRS WORLDWIDE FOUNDATION**  
**NICOLAIDES-BARAITSER SYNDROME**  
*ALONE WE'RE RARE, TOGETHER WE ARE **STRONG***

## Co-Founders' Statement

28th January 2022

It is with great sadness that we announce, our Co-Founder and Chair of Trustees Helen Robinson is stepping down from her role at the end of March.

Helen joined our NCBRS family in October 2014 when her son Kyle was diagnosed with #NCBRS after 21 years of searching for a diagnosis. In 2015 after flying all the way from Canada we first met Helen at a family conference in the UK, and as a result, became so passionate about helping other families that on her return home she and her husband Andrew immediately began working on our original parent support website.

Over the course of many years and many conversations between myself and Helen, we dreamed of taking the NCBRS Parent Support Group one step further. As the syndrome is so rare (with only about 200 confirmed cases worldwide), it was important to us to increase awareness and so it was decided we would try to start a global organisation. In June of 2020, this dream became reality with the creation of the NCBRS Worldwide Foundation.

Helen has been integral to the creation and success of NCBRS Worldwide Foundation and has been key in the transition from the original NCBRS Parent Support group. Helen has also been very instrumental in spreading awareness of NCBRS, starting our website, supporting families through our family Facebook group, designing apparel, creating an online store, establishing the Foundation, organising face to face meetings in Canada which have had families attend from all over North America and of course our global NCBRS Patient Registry and so much more...

We are so honoured to have had Helens as a voice for our rare syndrome. We will forever be grateful for her love and dedication to our NCBRS family. We are

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forever grateful for the many years of friendship we have shared with Helen and her family, which we know will continue after her departure as Chair of Trustees.

Our sincerest gratitude goes to Helen for making a difference in the lives of so many families around the globe, we will miss your passion and dedication greatly and wish you every happiness and success for the future.

Thank you and best wishes from all our NCBRS families, the NCBRS Worldwide Foundation Board and your Co-Founder.

Lee Reavey



## THANK YOU HELEN

 **NCBRS** WORLDWIDE FOUNDATION

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