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

June 30th 2021

One year on!

Today, we are celebrating the first anniversary of the NCBRS Worldwide Foundation, so we would like to let you know a bit about us and what we have achieved in our first year of operation.

Several years ago we, two parents who each have a child diagnosed with NCBRS, met through the NCBRS Parent support group. Over the course of many years and many conversations, we dreamed of taking the NCBRS Parent Support Group one step further. As the syndrome is so rare with fewer than 200 confirmed cases worldwide it was important to us to increase awareness and so it was decided to start a global organisation, and one year ago this dream became the NCBRS Worldwide Foundation.

After establishing the NCBRS Worldwide Foundation we got a new look and rebranded our NCBRS website along with our logos and graphics. We also welcomed an additional four Board Members to help the Foundation fulfil its mission. An online NCBRS merchandise store was created with a range of apparel and other items available to purchase which helps to promote awareness as well as supporting the Foundation financially.

We have created a global patient registry where de-identified data is stored to help better understand NCBRS and to support possible research studies. We have partnered with the FaceMatch project in Australia, to see whether facial recognition technology can determine a diagnosis in cases where genetic testing is not available. And we have partnered with many other organisations including Rare Disease International, Genetic Alliance UK, Canadian Organization for Rare Disorders (CORD) and the Rare Disease Day campaign to help further spread awareness and support.

We held our first-ever global awareness day on October 9th 2020. This date was chosen in honour of June, who was the first person with NCBRS described in scientific literature and this date will continue to be the official annual awareness day in years to come.

We held several virtual Zoom meetings with our NCBRS families from all over the world, which has been an amazing way to form relationships and is something we will continue to schedule on a regular basis.

It's difficult to believe how much we have accomplished in this year since starting up our Foundation in the midst of a global pandemic. The achievement we’ve made would not have been possible without the continued support from our other board members, families and medical professionals, as well as our many supporters who have donated, purchased merchandise, shared social media posts, spread awareness and so much more.

We cannot thank you enough for all your kindness, encouragement and efforts in supporting us, the NCBRS Worldwide Foundation and all the NCBRS families.

Thank You, Yours sincerely.

Lee Reavey	Helen Robinson
Co-Founder/CEO	Co-Founder/Chair