**Rare Disease Nurse Network (RDNN)** announces registration as a charity with the UK Charity Commission (Registered Charity Number 1199654).

July 2022 – London, UK.

RDNN Board of Trustees and Management is delighted to announce the recent registration of RDNN as a registered UK charity. This is an important milestone as we strive forward on our mission to provide a network of specialist nurse support for every person with a rare disease.

In 2016 a small number of people came together on the invitation of Kay Parkinson to form the RDNN. Kay is a remarkable lady within an amazing rare disease community and her vision was to set-up an organisation to provide specialist nursing support for all those affected by a rare disease in the UK.

RDNN is grateful to all the support the organisation has received to date to get us to this point – to present and past volunteers (Helena Baker, Claire Adams, Mabella Farrer, Tracey Murray, Natalie Rebeyev, Saakshi Chadha, Brian Flatley, Neil Dugdale, Alex Evans, Michelle Conway and Simon Mouncer) and more recently, pro bono support from Reed Smith to help navigate the path to our successful Charity application.

We particularly want to recognise the contribution of Helena, our first CEO, who has recently stepped down to take a very well-earned break and announce that we are delighted that Michelle Conway has succeeded Helena and is our new Interim CEO.

We also want to thank and recognise the contribution made throughout our journey by Cuttsy and Cuttsy, a healthcare communications agency.

This news which is truly wonderful to announce comes with a request to all those in the rare disease sector:

**We need your help.**  
**We need more advisors, volunteers and experienced Trustees**.

Please contact us to help us and become involved with this quest.

We will shortly be announcing how to help us with fund-raising and growing our network and capabilities.

**About RDNN**

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Description automatically generated](https://www.facebook.com/groups/736923143482177)To learn more about RDNN and how you can get in touch, please visit <https://www.rdnn.org/contact-us> or apply to join our growing Facebook community

To learn more about Kay’s story and vision for RDNN, please visit <https://www.rdnn.org/who-we-are> and click on Kay’s story