

End of Grant Report: Nineveh Charitable Trust April – September 2023

Ring 20 Research and Support UK CIO (Ring 20) were extremely grateful to receive a generous grant of £4,000 towards our CEO's part-time salary, awarded by the Nineveh Charitable Trust in April 2023. We have used this funding to cover 50% of our CEO's salary for six months, with the remainder paid for from our reserves.

What we achieved with the Nineveh Charitable Trust's support

When we applied to the Nineveh Charitable Trust for funding, we identified four medium term targets we would aim to achieve within the six-month funding period, which support our wider aims of supporting families affected by Ring Chromosome 20 Syndrome (r(20)) and championing research into this little understood condition.

Our Measures of Success

In our proposal, we identified four measures of success, which we report on here:

a) The Natural History and UNRAVEL projects will have contracts agreed and signed, with both projects underway and progressing as expected according to the terms of each project.

- UNRAVEL Phase II is underway with samples sequenced. Illumina are currently analysing the results, with publication to be co-written with them once this is completed.
- Unfortunately, we have been unable to progress the Natural History study with Glasgow University, but we continue to engage with them. They have agreed to provide a draft contract and ethics statement, but this appears to be subject to an unknown delay. In the meantime, we have asked our new Scientific Advisory Board to engage with the Natural History team going forward, and we are also drafting our own contract and ethics statement in a bid to move things forward.
- We have successfully set up an additional research project in the last six months: our CEO-developed Patient Reported Survey Questionnaire with Newcastle University, which will

inform the Natural History study and other future research projects on r(20). We have interviewed approximately 70 patient families. The results will be analysed from November 2023, supported by researchers from NU, with a joint publication to be written with a target date of Q1 2024.

b) We will monitor membership numbers to identify increases. Membership surveys and feedback will be used to measure the impact of our member support services. Social media output will be monitored, as well as measuring page visits/likes etc.

- We have succeeded adding 7 new subscribers to our mailing list, which includes 5 new member families. In addition, as part of our mission to improve patient support for all people with r(20), we are supporting our members in Belgium with setting up a branch of the charity in their region. This will increase our reach in the Belgian area, and also enable access to local funding.
- Our recent Patient Survey included questions gauging the success of our family support services, and what other services our members would like us to provide. Unfortunately, the results of this survey are not yet available, but will be published in due course. Please do contact us if you would like to hear more about these survey results when they are available.
- We have made 99 posts to our social media during this period (Facebook, Instagram and LinkedIn), with total engagement with posts at 2,163, interpreted as reaching over 20,000 people. Posts cover a range of subjects including thanks to our fundraisers, building the rare disease community, awareness raising of r(20) and other epilepsies among many other things.

c) We will report on the implementation of our volunteer recruitment campaign, including any new volunteers.

- We recruited 8 students on volunteer placement from the London Metropolitan University who supported us on two projects:
 - updating Ring20 branding and promotional materials

- Building a new UK Rare Epilepsies Together (UKRET - founded by our CEO) website.

d) We will aim to develop several new ideas together with our members and volunteers, with at least one being ready to apply for funding or immediate implementation (depending on project type) within six months.

- In response to an expression from families for improved support, and to improve our processes and procedures, we have begun fundraising for a new Family Liaison Administrator, who will develop our family support as part of a three year project, including making one to one contact with families in person or online, in order to assess their needs so that we can provide the support to families that is really needed. This role will also include administrative duties, which will give more time to our CEO for volunteer recruitment and management, pursuit of research opportunities and her vital ambassadorial role to improve awareness of r(20) among medical professionals, researchers and pharmaceutical companies. The project will also include development of signposting and information packages for things like employment support, which our members have asked for. We have made 5 grant applications in support of this project so far, and we have had an increase in fundraising from members due to sponsored marathons and other events.

Summary

The last six months have been a busy period of change for Ring 20 as a charity. In addition to the progress in research and increasing our reach, as detailed above, we have also begun to consolidate our processes and strengthen our team, including introducing our new Scientific Advisory Board, so that we are in a stronger position to continue to provide support and information to our Ring 20 family. The support of Nineveh Charitable Trust has been vital in helping us to achieve this, and we thank you sincerely.