ROHHAD Association - Research Proposals

Criteria for 2019/2020 funding applications

Explain in detail each of the following;

1. What will be the primary aim of your research, specifying clear and concise objectives.

2. Why you feel your intended research is important for children/ adults with ROHHAD and the likely benefits of this research to them.

3. Describe the research design and methodology that will be used, explaining why you feel your proposed methods are suitable and feasible. Please specify the means by which data will be collected, analysed and interpreted.

4. State the environment where the research will be carried out, describing the facilities and laboratory space.

5. Why you feel this research matters.

6. Specify what the objectives will be and describe concisely the goals of your research. You may wish to include hypotheses to be tested and whether you expect certain outcomes, and if so what you anticipate these will be.

7. The expected duration for any research, including any foreseen impediments that may hinder the time frame and also contingency plans for how those may be overcome.

8. A tentative timetable/ plan for achieving your research objectives within your suggested timeframe.

9. The total amount that you wish to apply for detailing all anticipated costs for example: salaries, equipment, lab costs etc. Your total costs must not exceed the available funding for 2019/2020 grants which is £275,000.00 GBP in total.

10. Any deadline for receiving the funding you require.

11. A suggested timeframe for reporting on research progress. Please note that if you enter a funding agreement and contract with the ROHHAD Association we will expect a minimum 6 monthly report and statement on progress of the research as well as a more detailed report every 12 months.

12.  Expected date of completion for your research.

13.  Your plan to disseminate the research results and how we may be of assistance with that.

14. Will your research include the use of animals for testing purposes. If so please explain why and how you intend to carry out the animal testing. Any animal testing must be carried out humanely and conform to regulations.

15. Whether your research will require children/adults diagnosed with ROHHAD to be physically involved, for example blood tests. Please give as much detail as you can regarding this, so that we may help put you in contact with families.

16. Do the birth parents and siblings of the children diagnosed with ROHHAD require to be physically involved for example blood tests.  As above please give as much detail as you can regarding this.

17. Provide the full names, contact details and qualifications of all those who will be participating in this research study, specifying the lead professional and whether it is a collaborative project.

18. Any previous research that has been done in relation to your proposal and the outcome of that research.

19. Any other information relevant to your research that you feel we should know.

20. Lastly all proposals must include at least **one** of the ROHHAD Associations Research Priorities.  The priorities were decided after consultation with families directly affected by ROHHAD Syndrome. The priorities are:

1.    Understanding ROHHAD better by focusing on finding the cause or trigger for the disease.  To date, no research has led to a definitive cause for ROHHAD Syndrome. If you can find the cause of the disease, be it autoimmune, genetic or something else entirely, knowing a cause will help physicians understand ROHHAD better and could lead to an earlier diagnosis, improve treatments and even a cure therefore any research that focuses on understanding ROHHAD better and finding the cause of the syndrome/disease is our main priority.

2.    Improving treatments for ROHHAD Syndrome are very important to the the quality and quantity of life for those directly affected by ROHHAD.  Therefore research that focuses on one particular area of the ROHHAD syndrome acronym will be considered, so long as it is trying to improve treatments relating to that particular area of the syndrome.

3.    Shaping or devising a care pathway for ROHHAD Children/Adults.  Due to how rare ROHHAD Syndrome is and how little is understood about the disease there is no definitive care pathway for those affected.  Care Pathways for other rare diseases have been proven to help improve the quality of life for the patient affected.  If your research proposal could potentially lead to a care pathway or if your research proposal includes developing a care pathway then it will be considered.

4. Collaboration between doctors and researchers who are actively working on ROHHAD Research or who wish to actively work on ROHHAD Research. Collaborative working is encouraged as it will hugely benefit ROHHAD Research.  Therefore we will consider all proposals from those who are working together collaboratively with other doctors or scientists from anywhere in the world.  That is not to say that we will not consider individual applications however collaboration proposals will be given priority when being considered provided those involved are qualified to be working on ROHHAD Research.

5.    Finding a cure is and always will be a primary aim for the ROHHAD Association and everyone affected by ROHHAD. While research applications for exploring a cure will be considered for funding we recognise that this area is likely to require extensive research and improved understanding of ROHHAD Syndrome first, therefore this is not a requirement for funding to be approved during this round of funding applications.