WE CARE Research Strategy

Worthwhile
Efficient
Communicable
Advantageous
Reliable
Effective

Our research strategy ensures that we are always sticking to our principles and core charity aims, whilst supporting and funding quality research projects. To this end we have developed our 'WE CARE' strategy.

Below are the key points of the strategy and how we will ensure that we stick to these key points;

Worthwhile

How?

Ensure that research is intended to provide results for CDH, or it's associated complications relating to cause, prevention, treatment or improving quality of life and outcomes.

Keep up to date with international studies and research by attending conferences and seminars that we know are relevant (so as not to waste valuable charity income and time) and to learn and understand what research needs are in order to avoid duplication of effort and research. Continue to build strong relations with Clinicians, Academics and other relevant professional bodies, networks and organisations.

Liaise with our patients, families and other end users to find out what their needs and research priorities and hopes are now and in the future.

Ensure all internal or external research fund applications or grants are peer reviewed and that processes are robust.

Efficient

How?

Plan and execute call outs for research applications and implement deadlines.

Exercise good grant application, review and monitoring practice and ensure research programme and timescales are adhered to and that management and administration of funds or grants internally or externally are robust.

Communicable

How?

Ensure that a plan for exploitation and dissemination is in place and that it is robust enough for effective dissemination of projects and results/outcomes through presentations, publications and other media and channels for example, ensuring that charities, patient groups and social media are used to their full potential.

Ensuring that results are translatable and transferable and are also provided in lay versions.

Regular updates to patient population.



Advantageous

How?

Maintain good relations with donors, research partners and principal investigators and their teams to encourage further research income and research proposals.

Consider applications worldwide and not limited to the UK, but encourage UK investigators to respond.

Ensure credits are provided to CDH UK when papers are published and presentations made.

Develop guidelines and standards of care with policymakers.

Reliable

How?

Ensure that our strategy is adhered to and that our processes are robust.

Partner only with organisations and researchers who can demonstrate good and robust practices, and who have demonstrated that their research intention is to try to improve outcomes for CDH.

Provide well documented research reports and updates.

Encourage peer reviewing of published papers and open access publications where possible.

Effective

How?

Ensure all of the above points are met to ensure that our Research Fund remains effective in improving outcomes for CDH and regularly review partnerships and processes.

Regularly review research strategy and needs and priorities for patients.

Attend conferences, Seminars, events etc. to ensure that results are being disseminated and communicate with researchers regularly.

Survey patients to engage and ensure that they are aware of advancements and results and that they are receiving information and treatments that are available to them.

For more information on our
'WE CARE' Research strategy or to be involved
in our patient advisory or focus groups
please contact

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