



Research Strategy

Mission Statement for Research

The Brittle Bone Society wants a world in which the needs of people in the UK and the Republic of Ireland living with Osteogenesis Imperfecta are understood, respected and fully met.

It is our hope to advance research into the causes, inheritance and management of OI and related disorders and to publish the results of such research.

We will also support and work with healthcare professionals to develop and extend services for all with OI and related bone diseases. We will support research into these conditions with the aim of improving the lives of all those affected by such problems.

Charity's Objectives in relation to Research

Managing the direction of our own involvement in Research that we deem suitable, allows for full control of our charitable objectives in terms of which research best benefits our own community.

To do this we will:

- Maximise our relations with Healthcare professionals, to improve healthcare provision and support research.
- Increase the money we raise to fund and develop and support research.
- To proactively identify suitable projects in research that is relevant to the pathophysiology, diagnosis or management of OI and related rare bone diseases.

Research

The BBS Scientific Advisory Board(SAB) shall meet on a bi-ennial basis to provide guidance on the process of research support. Membership will be appointed by the Executive Committee of the Brittle Bone Society Trustee Board and drawn mainly from the Charity's current Medical Advisory Board. The Chairman will be appointed by the Executive Committee of the Trustee Board.

BBS aims to fund world-class research that benefits those with OI and related disorders as defined by the Medical Advisory Board. This is reflected in our constitution.

Types of Research

All aspects of research will be considered including, but not exclusively, basic laboratory research investigating disease mechanisms, preclinical experimental studies and clinical research (including, but not limited to, novel treatments, supportive therapies, epidemiology, and psychological impact) and health services research.

Whilst the focus may change slightly year-on-year the charity will consider funding and supporting a range of projects. (see BBS Whitepaper on [Research Priorities](#)).

Research Priorities

The BBS will consider funding any application that falls within its Research Strategy as set out above. The evaluation process of each grant application will consider whether the proposed research fulfils a strategic aim of the charity. It is expected that all research funded by BBS will have the potential to demonstrate benefit to those with OI and related rare bone disease disorders.

What we currently do

- We offer quality peer reviewed information about research.
- We provide the latest updates on existing and new treatments.
- We offer opportunities for members to be involved in research in numerous ways from clinical trials, consultations and survey's to involvement in Registries such as the Rudy Study.
- Projects we get involved with are steered by our Scientific Advisory Board.
- We launched our first Research Strategy late 2016 and were accepted into the AMRC
- Our funded Research projects can be found on our [website](#).
- We are non-corporate partners with the NIHR.
- We host Medical Symposiums.
- We consult with members on what they want researched.

Recommendations

- We will continue to support Research Projects, work with Researchers, Pharmaceutical companies and encourage members to be involved in Consultations where appropriate and which have been endorsed by the SAB.
- We will continue to look at avenues to source funding for Research projects (ie Hosting a Gala Ball).
- We could look at funding a Fellowship Post.
- Look at developing a Registry which would ultimately steer our Research priorities
- Continue to develop and promote questionnaires/surveys to ingather stats and feedback to members and relevant bodies on results. Analysis and report writing is an area that could be developed with the consideration of publishing results.

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