



THE BRITTLE BONE SOCIETY

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 useful 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

This is our first Research strategy which we shall continue to refine and develop throughout the next 2-3 years.

- To provide support to people with OI and their families
- 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.

Managing the direction of 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.

Strong Board Leadership

Given that there are treatment advances likely in a number of rare bone disease areas in the next 2-3 years it was agreed to create our own strategy at this time.

Research

The BBS Research Advisory Committee 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.

This will comprise of a call for an initial grant application (one side of an A4) – before final decision by an internal panel.

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 (Objects C No. 5).

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 a range of grants.

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.

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