



Brittle Bone Society Strategic Plan

(2022 - 2026)

Glossary of Terms

AMRC – the Association of Medical Research Charities

ABPI - Association of the British Pharmaceutical Industry

CEO – Chief Executive Officer

SAB - Scientific Advisory Board of the Brittle Bone Society

HCPs – Healthcare Professionals

MAB – the Medical Advisory Board of the Brittle Bone Society

NHS – the National Health Service

NICE – the National Institute for Health and Care Excellence

NIHR – the National Institute for Health Research

OI – Osteogenesis Imperfecta, a rare bone condition, also known as brittle bone disease

OIF – the Osteogenesis Imperfecta Foundation

OIFE– the Osteogenesis Imperfecta Federation Europe

OT – Occupational Therapist

RUDY – a study in rare disease at Oxford University



Brittle Bone Society Strategic Plan (2022-2026)

Please note on request this document may be available in various formats and languages

Mission

The Brittle Bone Society's (BBS) mission is to ensure that the needs of people in the UK and the Republic of Ireland living with Osteogenesis Imperfecta (OI) are understood, respected, and fully met. BBS will work towards improving the quality of life for people in the UK and the Republic of Ireland diagnosed with OI and provide advice, information, and signposting. The BBS will continue to provide financial support for wheelchairs and equipment and raise awareness of the condition. BBS will also support and work with specialist NHS and other HCPs.

BBS Aims

The key aims of the BBS are as outlined below:

1. Increase awareness of OI
2. Advocate for and with the OI community
3. Develop and improve BBS services
4. Maximise relationships with HCP's
5. Sustain funding and develop ways to support research
6. Improve operational efficiency and effectiveness

How BBS will achieve these 6 overall aims:

- **Opportunity:** BBS will improve opportunities for children, young people, and adults with OI to take charge of their own health.
- **Independence:** Increase the level of independence of children, young people, and adults with OI and decrease the levels of isolation felt by children, young people & adults with OI.
- **Mobility:** BBS will offer continued access to ensure people who require assistance with

mobility and equipment by offering a fair grants application process.

- **Empower:** BBS will work to empower the people we support, to lead better connected and fulfilled lives and make their own informed life choices. Their input will be key in all BBS do!
- **Community:** BBS offer a sense of proud history and community and belonging; BBS will enable people to develop, grow and be heard; promote meaningful, healthy living and believe our people and resources should make a positive contribution to society.
- **Quality Events/Info:** BBS will regularly review our popular and extensive programme of health approved information and resources, and by arranging a wide range of interesting events both live and online. BBS events will consist of a mixture of healthcare professional input and members with OI who will lead on presentation of events.

Background summary

The BBS was founded in 1968 and is governed by a Trustee Board, who are highly skilled, passionate, and committed. BBS are the main and leading organisation addressing the needs of people with OI in the UK and Republic of Ireland. The progress and developments made by the BBS are regularly reviewed through our own systems and processes. The BBS are realistic in measuring our strengths and weaknesses and to addressing all areas required to ensure the Charity's sustainability.

What is Osteogenesis Imperfecta?



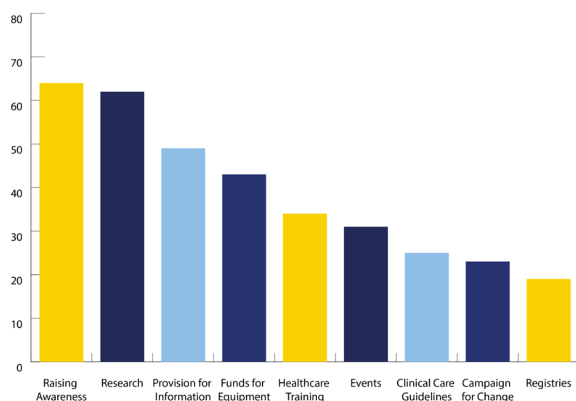
OI is a genetic bone disorder characterised by fragile bones that break easily. A person is born with the condition and is affected throughout their lifetime. As well as frequently fractured bones, people with OI (may) have muscle weakness, hearing loss, fatigue, joint laxity, curved bones, scoliosis, blue sclera, Dentinogenesis Imperfecta (brittle teeth), and short stature. There are varying degrees of severity. OI is rare; 1 in 15,000 people are thought to have the condition - roughly 5,000 people in the UK.

Developing this Strategic Plan – BBS Consultation

Nb This document has been developed during the Global Pandemic.

- **The OI community** was consulted at the Charity's 50th Anniversary Conference in 2018 and through an online survey about its views on the Charity's strategic direction and the table below is a snapshot of the priorities identified.
- **Subsequent surveys** during 2020 have been collated to support our calls for Adult health service amongst other topics.
- **HCPs:** from both our Medical Advisory Board and Scientific Advisory Boards were consulted, to ensure clinical needs priorities are covered in our operational planning
- **Consultations:** BBS will seek out external comment and review from OIF, OIFE and an external charitable organisation to gain their perspective

Graph depicts a snapshot of what members told us they wanted the BBS to prioritise. (Done in percentages)



Funding

- Funding is generally raised from Trusts and grant making organisations, member and supporter volunteer fundraising initiatives and corporate sponsorship.
- Funding has been adversely affected over the past 12-month period since Lockdown – March 2020 of the Global Pandemic the BBS like all other Charities was severely impacted by reduction in fundraising activity and donations.
- BBS recognises the need to prioritise funding and will undertake a critical review of this period, to factor in any adjustments and measures required to address any shortfalls.

Governance and Trustees

BBS is regulated by the Charity Commission and the Office of the Scottish Charity Registrar. Our constitution provides for between 9 and 13 Trustees. BBS board of Trustees comprises a mix of (1) professional, high level Trustees with a wide range of skills and experiences relevant to our needs; and (2) individuals who, or whose family members, have OI and therefore understand the challenges of living with the condition. Specific areas of expertise amongst the Trustees include experience of living with OI, legal, finance and accounting, human resources, information technology and healthcare/medical expertise.

The Charity is committed to maintaining this variety on the board and to adding additional skill sets where appropriate. 2021 the charity's legal status was changed to unincorporated charitable status.

BBS ensures that Governance costs are kept to a minimum.

The Trustee Board regularly review the requirement to attract Trustees onto the Board to augment the skills needed to manage the Charity.

Staff

The Charity's operations are managed with a clear and positive direction from the CEO. The BBS will maintain strong leadership, enthusiasm and drive through all its staff to achieve the Society's aims as set out in this document. BBS employ a variety of staff, with the pivotal roles of Support Development Officer, Finance and Admin and Communications.

When required the charity enlist external specialisms from film makers, marketing and digital experts and regularly enlist paid students for task specific work. The CEO reports regularly to the Executive and to the full Trustee Board at least three times per year and reports at the Annual General Meeting to members.

Patronage

Many leading charities secure high profile patrons. The BBS will explore a plan to review how this might be implemented into their structure.

Third Party Partnerships/memberships.

BBS will continue to hold membership of various bodies and develop relationships where appropriate.

To regularly monitor other potential affiliations and memberships that could be relevant to the rare bone disease community.

The BBS is either a member or has links with the following – OIFE, OIF, Rare Disease UK, Genetic Alliance, Specialised Healthcare Alliance, The ALLIANCE (Health and Social Care Alliance Scotland). NCVO and SCVO. As mentioned above the Charity is a member of the AMRC, endorsed by the Society for Endocrinology and have utilised CPD accredited courses, however due to cost this was discontinued, and this is reviewed regularly.

BBS are a non-commercial partner with the NIHR.

BBS Aims

1. Increase awareness of OI

BBS will increase awareness and understanding of OI.

Key Objectives:

- To raise awareness of OI
- Engage constructively with our community and the wider public.
- Secure the counsel and input of a wide range of HCPs in the field of metabolic bone health.
- Continue to build the BBS brand and presence.
- *Nb. To suitably honour the memory of the late Dr Margaret Grant MBE (Dec 2020).*

BBS will develop this further:

- Develop our communications strategy and create innovative campaigning.
 - People with OI can have problems with HCPs not understanding the condition.
 - Families of OI children can be suspected of non-accidental injury before diagnosis.
- By increasing our presence at appropriate healthcare conferences (e.g. Radiologists, OT).
 - Pursue funding opportunities or cross promotion agreements.
- History Bones Exhibition "on tour", involving and encouraging teaching hospitals to host.
- Increase the number of training days for HCPs.
- Consider partnership working on remote/digital knowledge sharing platforms).
 - An educational platform of knowledge sharing with international HCP experts.
 - Host various webinars or adopt online tools/resources aimed at HCPs.

2. Advocate for and with the OI community

The BBS will continue to act as an advocate for and with people with OI.

Key Objectives:

- Build on our knowledge and experience for people with OI as a successful Charity.
- Consult and gather the views of those in our community.
- Champion specific causes on behalf of those we represent.
- Encourage our members to be ambassadors for the BBS.
- Build on partnerships with other rare bone groups (HPP, XLH, Fibrous Dysplasia etc).

Advocacy – what BBS will develop

- BBS will continue to advocate for improvements in NHS care for people with OI (transitional, adult, and multidisciplinary care services within the NHS and clinical care guidelines*).
- Continue to work with and collaborate with various national organisations: (see list above *).
- BBS will submit recommendations and respond to Govt and other consultations. (e.g. UK Rare Disease Framework 2021)
- BBS will ensure they react and campaign accordingly to issues – welfare or otherwise.
- BBS will continue to attend appropriate meetings and gatherings at Parliamentary events.

3. Develop and improve BBS services

BBS will continually improve and deliver best possible quality of support to individuals and families.

Key Objectives

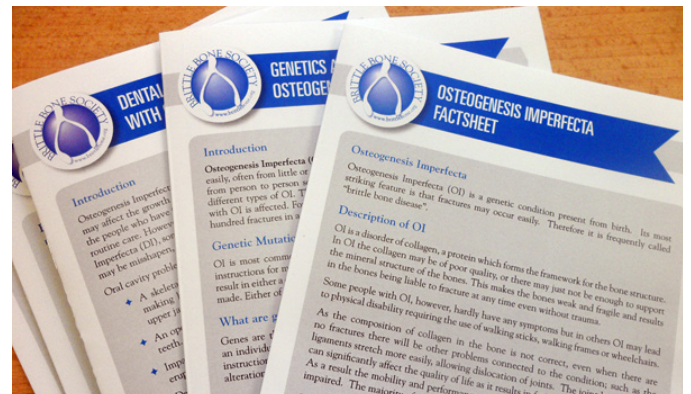
- Enable people of all ages with OI to identify the support they need.
- Fund specialised equipment ensuring mobility needs are met.
- Provide high quality events that cater for people of all ages.
- To maintain and continually review and

improve our information and literature.

- Increase our funds to support our overall work strategy.

How this will be structured by BBS:

- Design creative social media/online forums & webinars.
- Continue to fund equipment for all ages.
- Address lack of OT assessments within Wheelchair services (Adults).
- Continue with Annual conference.
- BBS will replace VOICE with a project that will attract this age group.
- Continue with Cool Bones activity for this younger age group.
- Continue with Kids Club activity plans.
- Continue with (Calvert Trust type/outdoor) activity events, consultation type (PPI) events, and training events for volunteers and HCP's.



4. Maximising relationships with HCP's

The BBS believes it is important to work alongside the NHS and HCPs in order to achieve all of its objectives.



Medical Advisory Board

Key Objectives:

- Develop and extend our links with HCPs, the NHS and agencies like NICE.
- Continue to recruit HCP's from NHS to serve on our MAB and Scientific Advisory Boards.
 - Support all relevant NHS initiatives.
 - Attend and contribute to NHS. Commissioning meetings when required.
 - » See National HSS Paediatric Bone Meeting reviews.
 - » Attend Paediatric Osteogenesis Imperfecta National Team (a group of Allied Healthcare Professionals).
 - Develop training initiatives with NHS and others.
 - Host our own scientific symposiums e.g. national and international Bone Conference events.

BBS will strengthen our ties with HCP network:

- Develop/expand our links with allied HCPs especially within NHS Adult Services.
- Communicate / more directly with HCP's via our E-Zine/newsletters.
- Develop educational resources (training events, webinars, online resources) for HCPs.
- Develop clinical care guidelines (both paediatric and adult) and seek approval by NICE.

- Develop our relationship with NICE:
 - Including increased awareness of data gathering in support of both current and future Clinical Treatments which may be submitted for approval. E.g. Robust health economic data. (i.e. Burden of Disease data).
- Explore and agree a plan to set up a patient registry and seek out sponsorship/grants funding to support this.

5. Sustain funding and develop ways to support research

BBS launched a Research Strategy in 2016 and established a research grant fund. This fund is overseen by our Scientific Advisory Board and makes grant awards to projects that help foster a greater understanding of OI and/or aim to improve treatments and outcomes.

Key Objectives:

- Improve the quality of life of people with OI.
- Seek revenue sources/new funding streams to safeguard provision of grants.
- Explore opportunities to maintain European research alliances.

NOTE: Since Dec 2020 UK left European Union. As such UK health bodies are no longer connected formally to the European Reference Networks (ERNs) ERN's were formed to tackle complex or rare diseases as well as conditions that require highly-specialised care and expertise. The ERN-BOND is the European Reference Network for Rare Bone Disorders. It brings together 38 highly specialised healthcare providers from ten EU Member States.

BBS commit to communicate and connect where possible into all networks involving healthcare providers around the world

Research – BBS strategy recommendations

- Continue to support research projects, work with researchers and pharmaceutical companies and encourage members to be involved in consultations where appropriate.
- Seek out and source funding from corporate and other areas (i.e. hosting a Gala Ball).
- Determine clear focus on setting up (possibly fundraising for) a patient registry.
- Establish and grow the new project opportunity via (telehealth)
- If funding permits explore the possibility of awarding Fellowship or other status. *Nb. To suitably honour the memory of the late Dr Margaret Grant MBE (Dec 2020)*



5 projects
funded to
the value
of **£60k**

and development including training.

- Increase and develop pro bono input and volunteers.
- Consistently offer Innovative fundraising and other campaigns.
- Deploying the latest and most up to date IT available.

Staff welfare

- All staff working conditions adhere to best practices e.g. health and safety reviews.
- BBS continue to be mindful of legacy planning for both Trustees and staff.
- HR appraisals carried out regularly.
- Ensure recognition, reward and motivation.
- Review job roles and develop planning for skills gaps.
- BBS will ensure the staff have the skills and competencies.

BBS Staff



Patricia Osborne (Chief Executive), Coreen Kelday (Support Development Officer), Megan Crookston (Administration and Finance Officer).

6. Improve operational efficiency and effectiveness

The BBS will continue to operate successfully through securing enough funds to deliver appropriate services for members. Attracting the best people to deliver programmes and support. The services delivered will address those identified by our community and regularly reviewed through consultation and dialogue to ensure our programme is on track with what our members want.

HR, facilities, risk management and valuing our volunteers

The BBS has effective human resources, facilities, and risk management systems..

Key Objectives:

- Ensure BBS attract and retain the best Trustees available to govern the charity.
- Encourage regular staff reviews, appraisals

Running Costs/Risk Management

BBS will continue to review arrangements with all contractors and service providers to ensure best value.

BBS will routinely monitor our Risk Register; taking stock of assets, property, reviewing maintenance and repair costs, updating the Trustee Board and agreeing actions timeously.

BBS routinely assess their property/facility position and do a property review and evaluation taking in to consideration home working as a result of the pandemic.

Pro-Bono Support

BBS have made considerable savings and gained numerous benefits from direct pro bono assistance over the past in areas including legal; venues/meeting room facilities; Finance, HR, and IT. BBS will continue to value and encourage professionals to provide this level of expertise and advice.

Volunteers

BBS will encourage members to participate in activities such as ethics, workshops and other events.

- BBS will promote greater member/supporter uptake in direct participation in our Charity events:
 - This to include a wide variety of activity including e.g. member-participation in the RUDY study (NIHR), attending consultation policy events and representing the Society in talks and at other similar meetings/events. Research workshops, Independent Living etc.



**Thank you to all those
who have supported the
Brittle Bone Society**

Volunteers' reward & recognition

The BBS shall continue to give recognition to volunteers via its website, social media and in its newsletter, and maintain and host a volunteer awards ceremony as part of our annual conference.

Fundraising

As with any Charity, the BBS needs to raise funds to allow it to operate. Income comes to the Charity in either core or restricted funds. Core funding may be used for general purposes. Restricted funds may only be used for a specific project (as directed by the donor).

BBS will introduce new income streams:

- Revisiting dormant fundraising streams (Trusts who formerly supported us).
 - This project was completed mid 2020 – and funding applications are being raised.
- Maximising individual fundraising and support group fundraising through a series of activities.
- BBS is set to form a new relationship with educational platform for Medics.
 - This will provide opportunity for further Pharma and other Sponsorship opportunities, it will also increase our network to engage with other HCPs with specialisms which our Charity will benefit from.
- Develop a legacy campaign.
- Reviewing marketing and merchandise opportunities.
- Seeking nominations for e.g. Bio Industry Association Awards.
- Developing high profile Gala Dinners first, Dundee and London etc.
- Reviewing marathon entries.
- Seeking more grants & sponsorships for variety of events.
- Continuing to promote matched giving, text donations, gift aid etc.
- Seeking out pro bono aid and gifts.
- Seeking out educational grants from the pharmaceutical industry and other sources.
- Continuing to seek out corporate sponsorship.

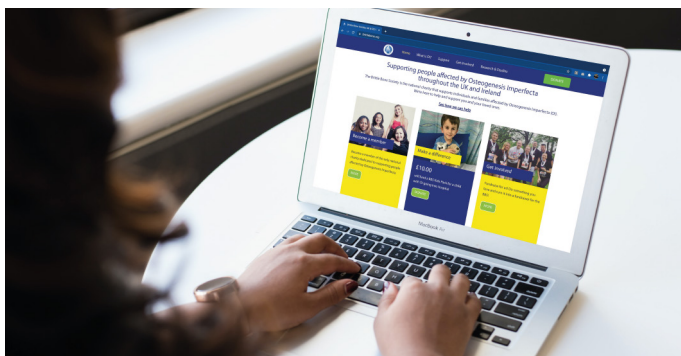


**In the last 10 years
we have raised over
£1,000,000
towards wheelchairs.**

Information Technology

Effective Information Technology and IT support is key to our success

- BBS reviewed and implemented upgrades to our operating system.
- Due to pandemic and the shift to home working March 2020 – IT review was completed Spring 2021.
- Necessary purchases of software/ hardware were installed to ensure staff have the tools needed to take best advantage of communication and fundraising opportunities.
- Computer maintenance agreements are regularly reviewed and assessed against our Risk Register. BBS will secure and agree suitable IT maintenance cover/ security.
- Continue to develop the capabilities, systems and infrastructure of our IT systems to enable us to take advantage of the latest technology: raising awareness, providing guidance, communicating with supporters, fundraising, reaching new audiences and maximising income streams in a more efficient and cost effective manner.
- Ensure appropriate intellectual property protection.



Governance

The BBS Charity believes that effective Governance is essential to achieve its goals.

Key Objectives:

- Board ensures all appropriate policies and T & C's are regularly reviewed and updated.
- Board oversee all partnerships with Pharma (as per the ABPI code of conduct).

- Monitor and encourage sufficient money raised to fund and develop our work.
- Maintain sound financial revenue streams scrutinise best value etc.
- Continue to nurture, encourage, train and value BBS staff.
- Maintain optimum governance procedures and recruit and retain the best Trustees.
- Retain pro bono support in Legal, Finance and HR.
- Implement the best communications strategy possible to keep in touch with the OI community.

What BBS do currently (Governance):

- Cover all legal duties ref policies and external partnerships.
- Support staff especially with home working throughout the pandemic.
- Ensure BBS are not over-reliant on any one source of funds.
- Keep up to date in the use of information technology and utilise IT to work more efficiently.
- Review members/supporters packages and fees and review fees/subscriptions.
- Ensure that BBS acknowledge and thank donors and will actively seek continued support.
- Imaginative use of social media platforms.

BBS will aim to compliment this by:

- Increasing income we generate through fundraising and subscriptions, maximising gift aid etc.
- Improving income from individuals, Trusts and companies.
- BBS will further strengthen our Educational Healthcare events.
- Our constitution as amended due to change in our legal status will be launched early 2022.

Brittle Bone Society Trustees Board



Top left to right:
Elaine Healey (Chairman), John Phillips (Vice-Chair), Mirrick Koh (Secretary), Robert Gordon (Treasurer), (2nd row left to right) Yvonne Grant, Angela Stewart, Gareth Cumming, Professor Nick Bishop, Professor Margaret Smith OBE

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