Living life well with Osteogenesis Imperfecta

2019/20
ANNUAL REVIEW
The Brittle Bone Society is the sole UK charity supporting people with Osteogenesis Imperfecta (OI).

**Board of Trustees**

<table>
<thead>
<tr>
<th>Position</th>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chairman</td>
<td>Elaine Healey</td>
</tr>
<tr>
<td>Vice Chairman</td>
<td>John Phillips</td>
</tr>
<tr>
<td>Treasurer</td>
<td>Robert Gordon</td>
</tr>
<tr>
<td>Secretary</td>
<td>Mirrick Koh</td>
</tr>
<tr>
<td>Trustees</td>
<td>Professor Nick Bishop, Garreth Cumming, Yvonne Grant, Professor Margaret Smith, Angie Stewart</td>
</tr>
</tbody>
</table>

**Staff**

<table>
<thead>
<tr>
<th>Position</th>
<th>Name</th>
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</thead>
<tbody>
<tr>
<td>Chief Executive</td>
<td>Patricia Osborne</td>
</tr>
<tr>
<td>Support Development Officer</td>
<td>Coreen Kelday</td>
</tr>
<tr>
<td>Fundraising and Communications Officer</td>
<td>Richard Daglish</td>
</tr>
<tr>
<td>Finance and Admin Officer</td>
<td>Megan Crookston</td>
</tr>
<tr>
<td>Auditors</td>
<td>Bird Simpson Chartered Accountants</td>
</tr>
</tbody>
</table>

**Interim Chair**

Prof. Nick Bishop  
Paediatric Consultant, Sheffield Children’s Hospital

**Medical Advisory Board**

<table>
<thead>
<tr>
<th>Name</th>
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</thead>
<tbody>
<tr>
<td>Prof. Richard Keen</td>
<td>Consultant Rheumatologist Royal National Orthopaedic Hospital, Stanmore</td>
</tr>
<tr>
<td>Dr Aerial Mason</td>
<td>Consultant in Paediatric Endocrinology Royal Hospital for Children, Glasgow</td>
</tr>
<tr>
<td>Lisa Mills</td>
<td>Occupational Therapist, Bristol Royal Hospital for Children</td>
</tr>
<tr>
<td>Dr Raj Padidela</td>
<td>Consultant in Paediatric Endocrinology Royal Manchester Children’s Hospital</td>
</tr>
<tr>
<td>Dr Susan Parekh</td>
<td>Consultant Paediatric Dentist Great Ormond Street Hospital for Children</td>
</tr>
<tr>
<td>Dr Megan Riddington</td>
<td>Clinical Psychologist Great Ormond Street Hospital for Children</td>
</tr>
<tr>
<td>Dr Vrinda Saraff</td>
<td>Consultant Paediatric Endocrinologist Birmingham Children’s Hospital</td>
</tr>
<tr>
<td>Miss Angela Stewart</td>
<td>Layperson</td>
</tr>
<tr>
<td>Dr Jennifer Walsh</td>
<td>Consultant Physician, Northern General Hospital, Sheffield</td>
</tr>
</tbody>
</table>
Support that counts
The first part of our financial year saw us build and grow our support for the OI community, including making gains in representing members’ issues around welfare benefits and in particular with PIP (Personal Independence Payment).

New events
We launched new events further to consultation by introducing the OI Can outdoor event and Healthy Living workshops, and we held a successful conference in Reading featuring for all ages including Coolbones and Kids Club forums as well as professional healthcare presentations.

Trustee support
In terms of Governance, we continue to benefit from first class Trustee representation – with the addition of Professor Margaret Smith MBE with a background in the nursing profession and with strong policy knowledge.

NHS
NHS healthcare specialists grow in number who regularly contribute to our events and support planning – and relations with the NHS couldn’t be stronger.

Growing our presence
Our members continue to build their presence across the disability and wider sector – and I am proud we enlist as many ordinary members as we can into the framework and delivery of our charitable services and events.

Strong planning
Resources continue to be a challenge – and we rise to every one! We secured funding and belief from funders to secure finances to host our new Healthy Living workshop but sadly due to Covid19 (March 23rd) and subsequent lockdown, and like every other operation and business and charity in the country, our plans had to be drastically postponed and further adapted.

Communication
I am proud we managed to alter our course and continue to provide first class communication and support to the wider OI Community. Delivering first class NHS health information webinars, fun social events and delivery of packs to children in hospital.

Campaigning
Our campaigning around Wishbone Day saw us reach thousands with our Powtoon and TikTok messages about OI and despite this further setback and no grants from Government we continue to offer useful support to the OI Community.

Fundraising
Fundraising for our wider work and specifically for wheelchairs and equipment continues on track and despite the challenges from the worldwide pandemic we have managed to continue to contribute to the OI community – and without the need to furlough staff.
WHAT IS OSTEOGENESIS IMPERFECTA?

Osteogenesis Imperfecta (OI) is a genetic bone condition characterised by fragile bones that break easily. OI is caused by a genetic mutation that affects the body’s production of collagen; which can be found throughout the body. As well as frequent fractured bones, people with OI often have muscle weakness, hearing loss, fatigue, curved bones, scoliosis, blue sclera, brittle teeth and short stature. OI has a wide range of severities and can affect people in many different ways.

OUR VISION – QUALITY OF LIFE

Our vision is that those born with OI can expect to have the best quality of life whilst living with this genetic condition.

OUR CHARITABLE AIMS

- To improve opportunities for children, young people and adults with OI to take charge of their own health.
- Increase the level of independence of children, young people and adults with OI.
- To decrease the levels of isolation felt by children, young people and adults with OI.

FILLING THE GAP FOR 50 YEARS AND MORE

The Brittle Bone Society (formed 1968) never forgets it was formed to fill a gap, to provide support to individuals and families, to raise awareness of this rare condition within the Healthcare setting and wider public and to be advocates for improved treatment and services for the OI Community.

OUR VALUES AND WAYS OF WORKING

Our values remain paramount in the way we conduct our work, how we measure and monitor our success and how we set out achievable targets for future plans.

- We consult with our members, of all ages.
- We support our NHS healthcare professionals, and recognise their success.
- We ensure fair representation of lay personnel on relevant committees and forums.
- We encourage learning – through introduction of our research grants programme and medical symposiums – sharing news on new breakthrough treatments and striving for better care.
- We contribute to the wider rare disease policy landscape through membership of OIFE, ERN, EURRBONE etc.
WHAT WE DO

SIGNPOSTING & PEER SUPPORT
We offer vital support upon diagnosis and throughout life, connecting people with others on the same journey and signposting them to other professional services.

INFORMATION
We publish a series of useful and practical NHS approved factsheets, films, and podcasts on our website.

COMMUNICATION
Our social media presence has grown in strength and we offer all the latest methods and forms of communication including the latest in Powtoon and TikToks, with dialogue crafted to connect on Instagram and Facebook – addressing the appropriate demographics within.

“I have sat intently watching every minute of the films since you sent them to me. I found the links to the seminars helpful to understand from an adult’s prospective, meaning I can now go and explain to my daughter. The Factsheets which will be very helpful with the school to understand the clear cut facts about OI. The statement “invisible disorder” hit the nail on the head for me. life but will just be a little more fragile.”

EVENTS

Support through events

OI CAN
We continue to offer support by holding meaningful live events. After consultation, members told us they would like a family day event with activity the whole family could join in. As such, we introduced the OI CAN event and suspended VOICE for a season and are reassessing the format for this.

HEALTHY LIVING
We also launched our Healthy Living workshops. Our second Healthy Living workshop was due to take place in Spring 2020, but we had to cancel due to Covid19.

FUN WITH EGGHEADS
Following the success of a group of individuals with OI featuring on the popular TV programme, we hosted our own Eggheads celebrity event at BBS Conference which was held in Reading. We also enjoyed a performance from the Basingstone Gang Show.

BBC CHILDREN IN NEED
Coolbones continues to be supported by BBC Children in Need, as does our Support Development Officer’s role. Cool Bones is an event held at our family conference for 11 – 15 year olds.

KIDS CLUB
Our Kids Club for 0 to 10 year olds is also held annually at our conference. This allows parents the opportunity to listen to all the latest updates in the knowledge their children are being looked after.

Number of Enquiries
272

Talks & Films on YouTube
19

Factsheets Downloaded
5580

Podcasts
5

Basingstoke Gang Show Choir at Reading Conference 2019
WHEELCHAIRS AND EQUIPMENT

Funding mobility equipment

On both a fundamental and practical level we continue to fundraise to provide necessary finance for people to obtain wheelchair and other equipment – ensuring mobility needs are met. Whilst there remains inequity in provision of the correct equipment available from National Governments then the Brittle Bone Society will step up and fill the gap.

HOSPITAL CONNECTIONS WITH HISTORY BONES

Our SDO also attended a number of hospitals in our community sharing updates around our History Bones Project.

KIDS HOSPITAL PACKS

We continue to send useful goody bags to kids who are either in hospital or due to go in which are full of items to keep them entertained during their stay.

HEALTHCARE PROFESSIONALS

Joint working with NHS Healthcare professionals

MAB

We held our first full day Medical Advisory Board meeting in London at the offices of Jones Day, which saw us welcome new members with specialisms in surgery Mr Gardiner and dental care - Dr Parekh.

POINT

Our SDO ramped up contact with the members of POINT (Paediatric OI National Team) attending meetings, working on details around wheelchair applications, factsheets and educational project planning.

NHS RESEARCH

We played our part in supporting NHS driven research; supporting chair of our MAB Assoc. Prof. Kassim Javaid’s plans to ingather views around services from members re – ‘what services are missing’ 200 responses gained with our thanks to the OI community. This vital information will help us shape our plans to petition for improved adult healthcare in the NHS.
RESEARCH
Supporting and funding Research
Since our membership to the AMRC in 2017 we have funded 5 important research programmes into enhancing care for people with OI. You can see them on our website.

LEGACY HELP
Due to a substantial legacy donation received some years ago – Trustees had resolved to set up and begin funding of our Research Grants Programme. This was a real opportunity seized to take charge of our own Research aspirations.

FUNDRAISING RESEARCH
Fundraising plans to supplement this aspect of our work remains challenging, but the benefits to showing our support for better treatments and outcomes for people with OI remain a focus and we will do all we can to ensure this continues.

RISKS
Trustees realise this is a risk –fundraising must first and foremost be focussed on help to fund operating costs, wheelchairs and events.

UNIVERSITY
Partnership working with our project of History Bones has seen the University of Dundee gain a grant from the Wellcome Trust and BBS are invited to co-operate on their working group to further develop this precious archive.

COLLABORATION
Wider rare disease community
Collaboration remains a driving force and one of our big success stories.

Working with other rare condition patient support groups (Softbones UK XLH UK, FDOSUK) – all sharing the same clinicians and harnessing combined enthusiasm and synergy helps to take forward our goal of achieving better healthcare.

MAKING A STRONG CASE
This coming together demonstrates to Government that we recognize the challenges of paying for improved NHS services – and that we can work together.

ADVOCACY
Championing Policy
Key to our work in the coming years is our support of the UK Rare Disease Plan. We do this through membership of various bodies such as SHCA and Genetic Alliance. We remain fixed in our hopes for a service for adults with rare bone conditions in the NHS.

Multidisciplinary Care
We build our case for this on the success of the Highly Specialised Centres in multidisciplinary care already evident across the UK based in Bristol, Birmingham, Sheffield and London.

Valuable support / Parliamentarians
We have benefitted from ongoing support from senior Parliamentarians including the Lord Kevin Shinkwin who helped us present our case about problems associated with the Welfare Benefit PIP (Personal Independence Payment).

Sharing our success
We subsequently contributed to a document called “Conditions Insight Booklet” which explains the condition of OI and should equip the assessor with the facts. We shared this step forward with our friends in other rare bone groups – so they may also benefit from having their own booklet created.

WPP HEALTHCARE
We were approached by WPP in Feb 2020 – we then went on to pick up a silver award for our care of people with OI at the University of West of London from The European Society of Person Centred Care. We aim to use their services to help us complete work on achieving Clinical care guidelines.
THANKS TO FUNDRAISERS
Who have jointly raised £57,018.39

- £1,014.01 Quiz/Tombola/Raffles
- £830.00 Churches/Coffee Mornings/Cake Sales
- £2,250.60 Parties/Fundays/Comedy night
- £9,870.82 Everything in between
- £13,935.95 Marathons & Cycles
- £10,133.59 Social Clubs
- £3,745.48 Corporate
- £5,000.00 In Memory
- £2,630.74 Schools
- £7,607.20 Facebook Fundraisers
- £1,014.01 Quiz/Tombola/Raffles

### Statement of Financial Activities

**Year ended 31 March 2020**

#### Income and endowments from:

<table>
<thead>
<tr>
<th>Notes</th>
<th>Unrestricted funds</th>
<th>Unrestricted funds</th>
<th>Restricted funds</th>
<th>Total</th>
<th>Total</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>general 2020 £</td>
<td>designated 2020 £</td>
<td>2020 £</td>
<td>2020 £</td>
<td>2019 £</td>
</tr>
<tr>
<td>Donations and legacies</td>
<td>3 133,429 -</td>
<td>93,006</td>
<td>226,435</td>
<td>287,906</td>
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<tr>
<td>Other trading activities</td>
<td>4 48,767 -</td>
<td>11,212</td>
<td>59,979</td>
<td>109,341</td>
<td></td>
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<tr>
<td>Investments</td>
<td>5 543 - -</td>
<td>543</td>
<td>420</td>
<td></td>
<td></td>
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<tr>
<td>Other income</td>
<td>6 - - -</td>
<td>-</td>
<td>1,557</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Total income**

\[
182,739 - - 104,218 \quad 286,957 \quad 399,224
\]

#### Expenditure on:

**Raising funds**

\[
57,755 - - 57,755 \quad 70,940
\]

**Charitable activities**

\[
110,080 \quad 42,589 \quad 143,338 \quad 296,007 \quad 315,508
\]

**Total resources expended**

\[
167,835 \quad 42,589 \quad 143,338 \quad 353,762 \quad 386,448
\]

#### Net incoming/(outgoing) resources before transfers

\[
(8,945) \quad (42,589) \quad (15,374) \quad (66,908) \quad 12,656
\]

#### Gross transfers between funds

\[
(23,746) - - 23,746 - -
\]

#### Net (expenditure)/income for the year/

**Net (outgoing)/incoming resources**

\[
(8,842) \quad (42,589) \quad (15,374) \quad (66,805) \quad 12,776
\]

#### Other recognised gains and losses

**Other gains or losses**

\[
(103) - - (103) \quad (120)
\]

**Net movement in funds**

\[
(8,945) \quad (42,589) \quad (15,374) \quad (66,908) \quad 12,656
\]

**Fund balances at 1 April 2019**

\[
294,513 \quad 89,629 \quad 55,689 \quad 439,831 \quad 427,175
\]

**Fund balances at 31 March 2020**

\[
285,568 \quad 47,040 \quad 40,315 \quad 372,923 \quad 439,831
\]

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.
TREASURER’S REPORT

STAFF AND ENLISTING VOLUNTEERS AND PAID PROFESSIONALS

We employ a small team who demonstrate skill, trust, professionalism, flexibility with a clear demonstration of care and passion for the cause we support.

We do our best to pay fair salaries for the roles we determine we need in today’s fast-moving workplace. Staff need to embrace a strong team ethic and accept a strong multi-skillling approach.

FUNDRAISING IMPACT

After a number of good years, donations and fundraising were down. Whilst this was expected, it was still higher than 2017. The total deficit in the year was £66,908 of which the conference had a net cost of £16,143 and the research grants in the year amounted to £42,589. 2019/20 has been a difficult year for the majority of society with charities suffering from the lack of fundraising events.

PRO BONO HELP AND COSTS SAVINGS

Thanks to Jones Day Law firm we benefit from expert legal advice when entering into any contracts regarding venue bookings, grants applications processes, dealing with Pharma, employment and HR regulations, copyright, General policy review and e.g. drafting terms and conditions for committee work.

GRANTS AND FUNDRAISING

We fund our work through grants funding from amazing Trusts and charitable organisations and you can view the list on the back page.

NO DIRECT GOVERNMENT FUNDING

We receive no funding direct from Government and we also rely on donations and grants from our amazing and loyal fundraiser base.

CHANGING CRITERIA

Despite our best efforts, funders can change their criteria which sometimes impacts on what had been an income route. Some of the significant grants which we weren’t able to secure included Westfield Health £10k, George Imlay Foundation £15k, Robertson Trust £7k and The Gannochy Trust £4k. The application criteria around these altered and we weren’t able to count on this income in the financial year.

PHARMA

We have for a few years benefitted from additional financial support sought out from a small group of Pharma and biopharma companies – namely: Mereo Biopharma, Alexion Pharmaceuticals and Kyowa Kirin.

COMPLIANCE

In order we meet all strict details and in accordance with ABPI rules all contracts entered into are fully ratified by our legal counsel.

LEGACIES

We also receive donations through legacies and have received some in the past financial year.

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THANKS TO OUR SUPPORTERS

We would like to express our heartfelt thanks to all our volunteers and members of our committees for generously giving their time and expertise.

We would also like to thank our members, supporters, fundraisers, corporate partners, trusts, foundations, event participants, runners, and all those who chose to remember the Charity in their will. It is not possible to mention every single person or organisation that has supported our work during 2019. However, we are very grateful to all for their ongoing support and to those who have made a special contribution to our work.

In addition to our dedicated supporters, we are grateful to many companies, charitable trusts and foundations, both in the UK and internationally, which are having a significant impact across all areas of our work.

TRUSTS & GRANT MAKING INSTITUTIONS
Alexander Moncur Trust Action for Kids
Barchester Foundation
Boparan Charitable Trust
BBC Children in Need
Bruce Wake Charity
Caudwell Trust
Elifar Foundation
Equipment for Independent Living
Florence Nightingale Aid in Sickness
Garfield Weston
GM Morrison Charitable Trust
Grand Lodge Scotland
The Headley Trust
Hedley Foundation
Hospital Saturday Fund
Hugh Fraser Foundation
Independence at Home
JHT Charitable Trust
Margaret Fund
Northwood Charitable Trust
PF Charitable Trust
RJ Larg Family Trust
Sobell Foundation
St James’ Place Foundation
St Katharine’s Fund
Sussex Community Foundation
Talleg Ltd
Tay Charitable Trust
Variety Club
Westfield Health
William S Phillips Fund
WM Sword

INDUSTRY
Nexus
Jones Day
Alexion
Kyowa Kirin
Mereo