2015/16
ANNUAL REVIEW

The Brittle Bone Society
Working with people who live with Osteogenesis Imperfecta

Living life well with Osteogenesis Imperfecta
GOVERNANCE & OPERATIONAL STAFF
The Brittle Bone Society is the sole UK charity supporting people with Osteogenesis Imperfecta (OI).

Board of Trustees

Chairman: Elaine Healey
Vice Chairman: John Phillips
Treasurer: Robert Gordon
Secretary: Mirrick Koh
Trustees: Harry Venet, Helen Chappell, Andy Mills, Yvonne Grant, Professor Nick Bishop, Professor Faisal Ahmed

Staff

Chief Executive: Patricia Osborne
Support Development Officer: Coreen Kelday
Communications Officer: Karl Henry
Fundraising & Admin Assistant: Marthe Handling
Auditors

Bird Simpson Chartered Accountants
144 Nethergate, Dundee, DD1 4EB

MEDICAL ADVISORY BOARD

Professor Nick Shaw
Consultant Paediatric Endocrinologist Birmingham Children's Hospital

Professor Nick Bishop
Professor of Paediatric Bone Disease Sheffield Children's Hospital

Professor Faisal Ahmed
Professor of Paediatric Bone Disease Royal Hospital for Sick Children, Yorkhill

Dr Catherine DeVile
Consultant Paediatric Neurologist Great Ormond St Hospital for Children

Dr Christine Barren
Consultant Paediatric Endocrinologist & Diabetologist Bristol Royal Hospital for Children

Professor Zulf Mughal
Consultant Paediatrician Saint Mary's Hospital for Women & Children, Manchester

Dr Jennie Walsh
Consultant Physician Northern General Hospital, Sheffield

Mr Ashley Cole
Consultant Spinal Surgeon Sheffield Children's Hospital

Mr Rod Duncan
Consultant Paediatric Orthopaedic Surgeon Royal Hospital for Sick Children, Yorkhill

Elaine Walker
Clinical Nurse Specialist Sheffield Children’s Hospital

Claire Hill
Physiotherapist Sheffield Children's Hospital

Chris Clark
Occupational Therapist Great Ormond St Hospital for Children

Dr Kassim Javaid
University Lecturer Metabolic Bone Nuffield Dept Musculoskeletal Science University of Oxford

Dr Richard Keen
Consultant Rheumatologist Royal National Orthopaedic Hospital Stanmore
The economic conditions under which the Brittle Bone Society operated during 2015/16 continued to present challenges.

During the financial year the Society benefited from a generous legacy donation which allowed us to fund a number of projects which hadn’t been prioritised in previous years.

Our remit to maintain existing conferences and launch new events continued to grow and attract interest and recognition. In 2015/16 we continued with programmes like ‘VOICE’ now completing its 7th year and maintained funding to offer our ‘Cool Bones’ project for 11-15 year olds – now in its 4th year. The Charity also continued with its hospital Patient Day events first launched on Rare Disease Day, February 28th 2015 in Scotland, a format closely supported by local hospitals and bringing The Brittle Bone Society mini conference experience to more people across the country. These events have been well supported by funders and are popular with members.

Communications with our supporters in both Northern Ireland and the Republic of Ireland remain constant and have been aided by setting up an All Ireland Forum and representatives of this met up in early 2016 in Belfast and Dublin. The Charity continues to expand their catalogue of films explaining living with OI. Relations with partner organisations in Europe and beyond continue to flourish, seeing the Charity take up membership of EURORDIS and ensuring support for appropriate ERNs (European Reference Networks) to help spread expertise in all matters OI across Europe. The BBS also supported and endorsed election of the OI representative from Norway to represent members’ views on the new EUPATI forum.

We reflect on our past year’s work with full acknowledgement to all our hard working volunteers, fundraisers, BBS support groups, employees at HQ and the Trustee Board; to the many Trusts and grant making institutions who enable us to carry out the vital work of the sole charity in the British Isles set up to assist people who are born and live with OI.

We continue to steadily increase our participation in research steered by our Medical Advisory Board. The increase in contact by media outlets coming to the BBS seeking views, practical input and accessing our Healthcare Professionals for comment on content for national television documentaries and dramas has risen helping raise awareness of OI in programmes including BBC’s Countryfile reaching circa 8 million viewers.

The Charity Patron, Miss Jordanne Whitey, MBE has been secured and regularly references our Society on social media and works with our Charity to promote our work through various opportunities.

We have improved our communications strategy by introducing regular e-zines (saving costs on our paper newsletter) and through regular campaigns launched timeously on Facebook and Twitter. On the policy front we maintain strong progress on consultations needed to influence policy documents like the UK Rare Disease plan – calling for better treatment options for those with OI. We have begun to craft an application to seek approval for an Adult OI service, and have made several submissions on proposed changes to commissioning groups structures which affect the outcomes of services for people we support.

Last year AGM members voted in favour of retaining Conference as an annual event, as opposed to biannual.

To help fund this the BBS will attract corporate support and sponsorship.

Elaine Healey (Chairman)  Patricia Osborne (Chief Exec)
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.

WHAT WE DO

PROVIDE SUPPORT & INFORMATION

We offer practical and emotional support, signposting to a wide range of specialised services. We also provide information through our website, Facebook, and through our increasing library of films on YouTube. We distribute monthly electronic newsletters and hard copy newsletters twice a year.

EVENTS

We continue to offer subsided entry to a variety of educational events throughout the country for all ages, offering friendship and networking opportunities. We work closely with the NHS Centres of Excellence and our Medical Advisory Board when planning the programme for all events.

WHEELCHAIRS & EQUIPMENT

We continue to provide a grant application system for those requiring assistance in purchasing necessary wheelchairs and equipment not funded by the NHS. During 2015 we co-funded £145,204.14 for wheelchairs and equipment of which the NHS provided £20,988.69 in vouchers.

RESEARCH

We offer information, the latest updates on research and offer opportunities for members to be involved in relevant research projects. We have been receiving an increasing number of requests to be involved in research and have therefore recently written our first Research Strategy and are applying to become a member of AMRC (Association of Medical Research Charities).

ADVOCACY & AWARENESS RAISING

We are the voice of the people with OI – taking part in relevant Policy consultations, and raising awareness through social media and other media avenues. We are members of and collaborate with Genetic Alliance, Rare Disease UK, Specialised Healthcare Alliance, The Alliance, Eurordis, EUPATI, OIFE and SCVO.

Number of Enquiries 360

Wheelchairs Purchased 44

New Films on YouTube 6

Number of Delegates at Events 385
**SUPPORT & INFORMATION**

The Brittle Bone Society continue to provide support to people with OI and their families in a variety of ways.

Our Support Development Officer handles enquiries from all over the UK and Ireland by telephone, Facebook, and email on all kinds of issues. The Charity continues to work closely with our Medical Advisory Board and POINT (Paediatric Osteogenesis Imperfecta National Team). The BBS provides up to date information through our website, our regularly reviewed factsheets and our ever increasing number of films and talks on our YouTube channel.

During 2015 we recruited a part-time communications officer to assist with our increased use of social media. We communicate daily on our Facebook page, Twitter and our website connecting the online OI Community to news about their peers, about our planned events, sharing news on policy updates on our fundraisers and volunteers progress.

Our annual calendar of educational and informative events is ever increasing, and we continue to seek out funding to enable us to offer subsidies. The Charity also recognises the crucial role of the ‘carer’ in the family unit and have been successful in obtaining grants for carers to offer financial assistance to travel to our events. This extends our reach and ensures no barriers exist.

2015 saw us work closely with hospitals in developing our Patient Day events and planning the programmes to make them informative, relative and up to date. These events were held throughout the country and enabled us to expand our reach to members.

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**REAL LIFE IN YOUR WORDS**

“Our son was diagnosed on the 2nd April 2014 at just 11 weeks old. Again we knew there was a 50% chance but his diagnosis came as less of a shock as additional scans had shown a large head circumference and smaller than average limbs (both tell tale signs) he was delivered by Caesarean at 38 weeks weighing a fairly decent weight of 1lb 14oz. So far our baby has avoided any major injuries although his physical development is very delayed. He took his first steps on the 18th December 2015 at 23 months and 3 days. Time will tell how things work out for him but we’re keeping our fingers crossed :)”

_— Anna_
WHEELCHAIRS & EQUIPMENT
The Brittle Bone Society fundraised a total of £145,205.14 during 2015

REAL LIFE EXPERIENCE

“When she was 5 weeks old at a follow up X-ray we were in disbelief when they discovered our tiny girl had multiple fractures. She has a rare bone condition called Osteogenesis Imperfecta (brittle bone disease). She had been so content and happy, it was hard to take in. We continued to watch her grow and become such a little character and have tried to keep everything as normal as possible. But sadly her femur fractured and our girl was admitted to hospital for 2 weeks, our baby girl was so brave and strong and is coping so well even though she was in lots of pain and was in traction so we couldn’t pick her up for a cuddle. She was still smiling and giggling away. We feel incredibly blessed to be the parents of such an amazing little girl, she makes us more proud every day and we love her so much! Treatment starts in a few weeks to strengthen her bones so we are hopeful that this will avoid her having many more fractures in the future. She is going to have a very normal life but will just be a little more fragile.”

“The Brittle Bone Society has offered indispensable support to my family and I over the last 12 months. I have experienced first hand the support they can offer and without them the World would be a much scarier place for us.”

“The casts and surgery scars are obvious signs, but he also has a day-to-day struggle that you can’t see on the surface. Most nights he finds sleeping difficult as he suffers from hip and back pain. He has a lower immune system and also will tire quicker than typical children his own age. He often struggles to walk when he gets his “sleepy legs” or “sleepy hands” at school when writing. But he does not complain, he just cracks on with life with a determination that is inspiring.”

BBS FUNDED £104,861.59 TOWARDS WHEELCHAIRS
BBS CO-ORDINATED FUNDING £34,331.52 FROM A VARIETY OF OTHER TRUSTS
BBS OBTAINED £20,988.69 IN VOUCHERS
BBS RECEIVED 44 APPLICATIONS FOR EQUIPMENT
COLLABORATION AND RESEARCH

In 2015 the BBS continued to reach out to work alongside and learn more about similar rare bone groups. BBS Patient Days also included invitations to other rare bone groups X-linked Hypophosphotemia, Fibrous Dysplasia and Hypophosphatemia (HPP) to discuss common challenges and shared aspirations. BBS continue to work on the NIHR RUDY Study and have been supporting various calls for patient participation acting as co-applicants in important trials and handling a growing number of invitations from eminent research bodies to collaborate with the BBS.

The ERN (European Reference Network) extols an ethos and spirit of collaboration and co-operation. Despite the recent decision to exit the European Union, the BBS alongside NHS Healthcare Professionals shall continue to work together in sharing information and ways forward in rare disease.

BBS has in the past financial year participated in various forums involving our friends in EUPATI. We will use the methods and toolkits available to continue to inform our members about the value of involvement and participation in research.

HEALTHCARE PROFESSIONALS WORKING WITH THE BBS

BBS continue to have leading Healthcare Professionals working hard on our MAB, two of whom became Trustees on our Board in September 2015.

“Attending a BBS Patient Day is a great chance to meet others, talk about experiences and understand what people are going to through. Great to meet with the Chairman of the BBS and others to discuss the setting up of a Softbones UK. We hope it will be a success like yours.”

“Thank you to everyone involved in organising and presenting at the Patient Day Workshop in Dundee today. It was fantastic, very informative and a great opportunity to meet up with friends and families old and new. Being a member of the BBS is like being part of a big, safe, supportive and caring family.”

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The Brittle Bone Society runs a variety of events throughout the year aimed at all age groups offering, friendship and networking opportunities. Through our events we inform and educate offering all the latest up to date information.

Conference continues to attract families from all over the country. During our 2015 conference held in Manchester we live streamed talks for the first time.

Cool Bones now in its third year and currently funded by Children in Need for children age 11 to 15 years. Children had fun with the team from Spy Games being 007 agents.

Throughout the year we held 4 Patient Day events in conjunction with local hospitals. These were held in Sheffield, Glasgow, Belfast and Dublin. These 4 events proved to be incredibly popular and were attended in total by 220 delegates.

Voice, the youth event for 16 to 30 year olds was hosted in April 2015 at Kielder Outdoor Centre. This was the first time we took the event outdoors and challenged individuals to take part in archery, clay pigeon shooting, zip wiring and abseiling.
THANKS TO FUNDRAISERS
Who have jointly raised £62,004.97

£3,150.21
Extreme Fundraising

£3,069.30
Churches/Coffee Mornings/Cake Sales

£4,198.81
Quiz/Tombola/Raffles

£1,256.11
Collection Cans

£6,599.36
Everything in between

£1,328.06
Corporate & Matched Giving

£5,751.32
Parties/Fundays/Comedy night

£20,206.67
Marathons & Cycles

£6,636.00
BBC Radio 4 Appeal

£6,840.00
Social Clubs/Longridge/Wokingham

£5,751.32
Parties/Fundays/Comedy night

£2,968.13
Schools
### INCOMING RESOURCES

<table>
<thead>
<tr>
<th>Note</th>
<th>Unrestricted Funds £</th>
<th>Restricted Funds £</th>
<th>Total Funds 2016 £</th>
<th>Total Funds 2015 £</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Voluntary income</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>304,329</td>
<td>114,267</td>
<td>418,596</td>
<td>236,801</td>
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<tr>
<td>Activities for generating funds</td>
<td>60,950</td>
<td>11,678</td>
<td>72,628</td>
<td>77,929</td>
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<td>Investment income</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>1,118</td>
<td>–</td>
<td>1,118</td>
<td>681</td>
</tr>
<tr>
<td><strong>TOTAL INCOMING RESOURCES</strong></td>
<td><strong>366,397</strong></td>
<td><strong>125,945</strong></td>
<td><strong>492,342</strong></td>
<td><strong>315,411</strong></td>
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### RESOURCES EXPENDED

Costs of generating funds:

<table>
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<tr>
<th>Note</th>
<th>Unrestricted Funds £</th>
<th>Restricted Funds £</th>
<th>Total Funds 2016 £</th>
<th>Total Funds 2015 £</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fundraising trading: cost of goods sold and other costs</td>
<td>(90,973)</td>
<td>–</td>
<td>(90,973)</td>
<td>(86,369)</td>
</tr>
<tr>
<td>Charitable activities</td>
<td>(93,370)</td>
<td>(191,250)</td>
<td>(284,620)</td>
<td>(237,540)</td>
</tr>
<tr>
<td><strong>TOTAL RESOURCES EXPENDED</strong></td>
<td><strong>(184,343)</strong></td>
<td><strong>(191,250)</strong></td>
<td><strong>(375,593)</strong></td>
<td><strong>(323,909)</strong></td>
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</table>

**NET OUTGOING RESOURCES BEFORE TRANSFERS**

<table>
<thead>
<tr>
<th>Note</th>
<th>Unrestricted Funds £</th>
<th>Restricted Funds £</th>
<th>Total Funds 2016 £</th>
<th>Total Funds 2015 £</th>
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<tbody>
<tr>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>9</td>
<td>182,054</td>
<td>(65,305)</td>
<td>116,749</td>
<td>(8,498)</td>
</tr>
<tr>
<td>Transfer between funds</td>
<td>(21,913)</td>
<td>21,913</td>
<td>–</td>
<td>–</td>
</tr>
</tbody>
</table>

**NET OUTGOING RESOURCES FOR THE YEAR**

<table>
<thead>
<tr>
<th>Unrestricted Funds £</th>
<th>Restricted Funds £</th>
<th>Total Funds 2016 £</th>
<th>Total Funds 2015 £</th>
</tr>
</thead>
<tbody>
<tr>
<td>160,141</td>
<td>(43,392)</td>
<td>116,749</td>
<td>(8,498)</td>
</tr>
</tbody>
</table>

### RECONCILIATION OF FUNDS

| Total funds brought forward | 204,003 | 120,341 | 324,344 | 332,842 |
| TOTAL FUNDS CARRIED FORWARD | 364,144 | 76,949 | 441,093 | 324,344 |

The Statement of Financial Activities includes all gains and losses in the year and therefore a statement of total recognised gains and losses has not been prepared.

All of the above amounts relate to continuing activities.
TREASURER’S REPORT

The practice of fundraising to co-fund equipment or services continues. The Charity offers subsidised entry to our educational and conference networking events throughout the year.

The Brittle Bone Society’s finances continue to be monitored and expended as efficiently as possible.

As well being as Treasurer for the BBS I have worked on the Trustee Board’s sub committees developing the overall strategic plan, our new communication strategy and fundraising strategy and our soon to be launched research strategy. Finances run throughout all of these individual areas and it is important that I am able to keep close to all the new projects as they develop and see what funds they need to operate effectively whilst ensuring we stay on track with our overall charitable objectives.

Considerable costs savings to undertake our Governance responsibilities continue to be enjoyed thanks to the offer of free meeting room space, and facilities at the offices of Vice Chairman John Phillips’ law firm Jones Day in the centre of London. In the past year a significant legacy donation was received which enabled the Society to carry out a number of refurbishments to the property which had been long overdue and postponed in previous years, including installation of electric roll shutters for the front door entrance, and tarmac of the charity car park.

The Charity has continued to seek out appropriate funding and support to pay the rising costs for existing and increasing new and improved events. A number of grants continue to be received year on year from BBC Children in Need and the National Lottery.

It is worth noting due to reserves being higher due to the recent legacy donation it may result in a fall in qualifying for other charitable grants and funding streams.

Funds continued to be set aside in the past financial year to co-fund wheelchairs and equipment with balances sought from external trusts and grant making institutions.

Payment and costs for staff has remained steady, although costs to assist with the project management of a number of new projects - not least the hopes to establish a new Adult OI Service, will be required and provision for this has been earmarked by the Trustee Board.

Other funds which have been earmarked in the past year include a sum to establish the beginnings of our impact in research. Trustees agreed to earmark a sum of £30k that should be then awarded to what is agreed to be the most suitable project. To help with this decision a strategy for research is being finalised and it is hoped that the charity staff will look to refine and develop means to fundraise for research. The research strategy will explain how decisions are reached.

The Charity is pursuing donations and support from corporates and pharmaceutical companies mainly to assist with high costs of events and to assist with payment for marketing, awareness and social media platforms and web upgrades.
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, individual supporters, fundraising events committee members, corporate partners, trusts, foundations, event participants, runners, event organisers, local Support Groups 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 2015. However, we are very grateful to our patrons for their ongoing support and to those who have made a special contribution to our work.

In addition to our thousands of 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

Act Foundation
Alexander Moncur Trust
Astor Foundation
Austin Bailey Foundation
Awards for All Scotland
Boparan Charitable Trust
BBC Children in Need
Bruce Wake Charity
Charles S French Charitable Trust
Crackerjack Children’s Trust
Denman Charitable Trust
Elifar Foundation
Equipment for Independent Living
Esme Mitchel Trust
Farrell Trust
Florence Nightingale Aid in Sickness
GM Morrison Charitable Trust
The Headley Trust
Hedley Foundation
Heinz, Anna & Carol Kroch Foundation,
Hospital Saturday Fund
Hugh Fraser Foundation
Independence at Home
James Weir Foundation
JHT Charitable Trust
Joseph Hopkins Charity
League of the helping Hand
Lloyds TSB Foundation for Scotland
Margaret Fund
Miss Jo Torrington Children’s Fund
Neighbourly Trust
Noel Bennet Charitable Trust
Northwood Charitable Trust
Paul Bassham Charitable Trust
PF Charitable Trust
PM Ireland Charitable Trust
RJ Larg Family Trust
Sheffield & District Hospital Services Charitable Fund
Short Breaks
Sir John Sumner’s Trust
Sobell Foundation
St Austell Brewery Charitable Trust
St James’ Place Foundation
St Katharine’s Fund
South West Ham Child Welfare Charity
Strongbones Children Charitable Trust
Sussex Community Foundation
Surrey Dispensary
Talisman Charitable Trust
Tay Charitable Trust
True Colours Trust
Variety Club
Victoria Convalescent Fund
William S Phillips Fund
CONSULTATIONS

BBS have been responding to consultations that matter in areas where people with OI need to access NHS health services, we have ensured (that where possible) we have given a reply.

PATIENT DAYS

Launched in Dundee February 2015 – travelling across the country and proving to be highly popular.

RESEARCH

BBS really stepping up into research matters.

POLICY

BBS staff attending specialised commissioning meetings held in London, attending cross party working group on Rare Disease events at Scottish Parliament.

AWARENESS RAISING

Helped by our Patron Jordanne Whiley, MBE ensuring that the condition of OI is seen and better understood. Members like young Alice Boyd helping us reach over 25,000 people.

HIGHLIGHTS OF THE YEAR

We held our first outdoor Voice Event in April at Kielder Forest, attended by 20 young people who had fun doing archery, laser shooting, zip wiring and abseiling.

National Metabolic Bone Awareness Week in June, saw our poster campaign on social media reach 19,394 viewers.

We live streamed talks at our Annual Conference for the first time. Talks were viewed by 104 throughout the weekend. Making our events more accessible to the OI community.

In September our BBC Radio 4 Appeal saw us raise a massive total of £6,636... raising awareness of OI to millions of BBC Radio 4 listeners.

Our very own Cameron Allen took part in the BBC Countryfile programme for the Children in Need Appeal. This was viewed by 7 million.

In January we submitted an initial proposal to NHS England for a call for OI Adult Services.

January saw staff travel to both Belfast and Dublin to host Patient Day Events.

SOCIAL MEDIA/EZINES AND INSTAGRAM

2015 saw our social media impact and reach increase dramatically. We also live streamed talks at conference for the first time.