The Brittle Bone Society | Annual Review 2016/17

joining in

Supporting people affected by Osteogenesis Imperfecta | 2016/17

Contents

Governance

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 Officer:	Patricia Osborne
Support Development Officer:	Coreen Kelday
Communications Officer:	Karl Henry and Natalie Eudelle
Fundraising & Admin Assistant:	Marthe Handling

Auditors: Bird Simpson, Chartered Accountants, 144 Nethergate, Dundee, DD1 4EB
Charity Registration Nos. England and Wales 272100 and Scotland SC010951

Medical Advisory Board

Prof Nick Shaw (Chairman)	Consultant Paediatric Endocrinologist, Birmingham Children's Hospital
Dr Paul Arundel	Paediatric Consultant, Sheffield Children's Hospital
Dr Avril Mason	Paediatric Consultant, Royal Hospital for Children, Glasgow
Dr Catherine DeVile	Consultant Paediatric Neurologist, Great Ormond St Hospital, London
Dr Christine Burren	Consultant Paediatric Endocrinologist & Diabetologist, Bristol Royal Hospital for Children
Dr Raj Padidela	Paediatric Consultant, Royal Manchester Children's Hospital
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 Children, Glasgow
Elaine Walker	Clinical Nurse Specialist, Sheffield Children's Hospital
Claire Hill	Physiotherapist, Sheffield Children's Hospital
Chris Clark	Occupational Therapist, Great Ormond St Hospital, London
Dr Kassim Javaid	University Lecturer Metabolic Bone, Nuffield Dept Musculoskeletal Science, University of Oxford
Dr Richard Keen	Consultant Rheumatologist, Royal National Orthopaedic Hospital, Stanmore (& Chairman Adult OI Forum)

Research Committee (established October 2016)

Prof Nick Bishop (Chairman)	Professor of Paediatric Bone Disease, Sheffield Children's Hospital
Prof Faisal Ahmed	Paediatric Consultant, Royal Hospital for Children, Glasgow
Prof Nick Shaw	Paediatric Consultant, Birmingham Children's Hospital
Dr Wolfgang Högler	Paediatric Consultant, Birmingham Children's Hospital
Prof Stuart Ralston	Professor of Rheumatology, Centre for Genomic and Experimental Medicine, and Institute of Genetics and Molecular Medicine, University of Edinburgh; Western General Hospital, Edinburgh
Mrs Joanna Cannon	Lay member of Brittle Bone Society

Foreword

1 in 15,000 people in the UK are thought to have Osteogenesis Imperfecta.

Charity staff worked tirelessly to deliver support, creative campaigns, and events such as our Family Conference and Patient Days to support people affected by Osteogenesis Imperfecta (OI) across the UK and Ireland. We continued to fund wheelchairs and equipment to the value of £104,861.59.

Despite challenging economic conditions, we delivered our successful Family Conference and Cool Bones event in Reading, England, and VOICE youth event in London. Furthermore, we hosted our first Scientific Symposium in over 25 years that was attended by leading healthcare professionals from around the world, at the prestigious Jones Day law firm offices in London. We were fortunate to continue to benefit from generous funding to deliver Patient Day events in Birmingham, London and Bristol. We welcomed 485 people at these events. During the previous financial year the Society did continue to benefit from a generous legacy donation which allowed us to fund projects, but this also resulted in a surplus which meant that we did not qualify for some grants.

We continued to communicate effectively with our members and supporters, through regular newsletters and e-zines.

Our communication with the wider audience, including decision-makers, continued, aided by our relationships with other OI organisations around the world and the production of our fantastic short films featuring our members. The charity launched a wheelchair fact film explaining how vital getting the right chair is for people with OI. We continued to work in collaboration with the NHS and other partners towards securing an NHS Adult OI service.

We are the leading UK charity supporting people affected by OI, and so we thank the volunteers, fundraisers, Trusts and grant-making organisations that enable us to carry out our work. We launched our current strategic plan in August 2016 to lead us in to the future. With the continued passion of our Trustee Board, and the commitment and input of our Medical Advisory Board and Research Committee, we were admitted to the Association of Medical Research Charities (AMRC) - a great honour for our charity.

We are thankful to everyone who **joined in** with the BBS in supporting people affected by Osteogenesis Imperfecta.

Patricia Osborne, CEO

Elaine Healey, Chairman

OI and about the charity

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. 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.

We have been working to improve the quality of life for people affected by OI since 1968, offering support, equipment, advocacy and, most recently, research. This can include providing emotional support, signposting to a wide range of specialised services, and providing accessible, factual information about the condition through channels such as our website, quarterly newsletter, and email updates.

We also provide information and updates on research and highlight opportunities for members to be involved in relevant studies and trials. We have recently published our first Research Strategy to enable access to small research grants. Our application to be a member of the AMRC was successful and this will further our work in the field of research.

897 members and supporters

485 people attended our events throughout the year

Established 1968, the Brittle Bone Society is the oldest OI charity in the world

Providing support & quality of life

Our Support Development Officer handled enquiries on all kinds of issues from all over the UK and Ireland by telephone, email and Facebook. We worked closely with our Medical Advisory Board, the NHS Centres of Excellence, and POINT (Paediatric Osteogenesis Imperfecta National Team), particularly when handling support enquiries, producing factsheets and planning events.

Our popular educational events were well attended and increasingly successful, and we continued to offer subsidised entry to a variety of meetings, including our Patient Days, throughout the country for all ages offering friendship and networking opportunities. Our annual calendar of activity saw us take the Patient Day event across the UK & Ireland, and we continued to seek out funding to enable us to offer subsidies.

We offered a voice for people affected by OI – taking part in relevant policy consultations, and raising awareness through social media and other media channels. Our website remained a key portal of information for members and medics alike. We also promoted our regularly reviewed factsheets and our ever increasing number of films and talks on YouTube. Furthermore, we gained funding to improve and develop our literature and upgrade our website.

During 2016/17 we increased our online presence of communication. We continued to deliver updates and news on our Facebook page, Twitter and our website. This connected the online OI community to updates about health studies and programmes they can get involved with and news about their peers. We also promoted our events and shared achievements from our fundraisers and volunteers, to encourage members to join in with their charity.

3,157 likes on Facebook

13 Factsheets

SDO Coreen visiting the new Royal Hospital for Children in Glasgow

Practical assistance

"The BBS got in touch with me as they knew I was really struggling to push or even use my NHS wheelchair due to increasing problems with my shoulders (on top of the usual frequent cracks and fractures) and offered to approach Trusts to enable me to get a suitable wheelchair and add-ons to regain some of the independence I had lost. I am now the proud owner of an amazing titanium Tilite wheelchair and SmartDrive which means I can contemplate doing 50 walks for the BBS. In the few months I've had the chair, I've enjoyed its benefits in so many ways"

£104,861.59 fundraised in the last 12 months towards wheelchairs & equipment

Many people affected by OI require specialist equipment to improve their quality of life, and we continued to provide a grant application system for those requiring assistance in purchasing necessary wheelchairs and equipment which are not funded by the NHS. During 2016/17 we had 31 applications, and fundraised a total of £104,861.59 towards wheelchairs and equipment ensuring that our members had the right equipment at the right time to live their lives independently.

31 grant funding applications over 12 months

Events

Our series of events took place throughout the year, culminating in our Annual Family Conference and AGM which was held in Reading, England attended by 225 delegates. Cool Bones, our mini conference for 11-15 year olds, successfully ran for its third year and was funded by BBC Children in Need.

In April 2016 we hosted our youth event VOICE for 16 to 30 year olds in Stansted, England, and this was open to young people across Europe with the support of the OIFE.

Throughout the year we held 3 Patient Day events in conjunction with the NHS hospitals. These were in Birmingham, Bristol and London. These 3 events proved to be incredibly popular and were attended in total by 170 delegates. They learnt about latest treatments, caught up with our latest endorsed factsheets updates helping prepare youngsters for settling into school, information on dental care, and other issues.

54 medics at our inaugural Scientific Symposium

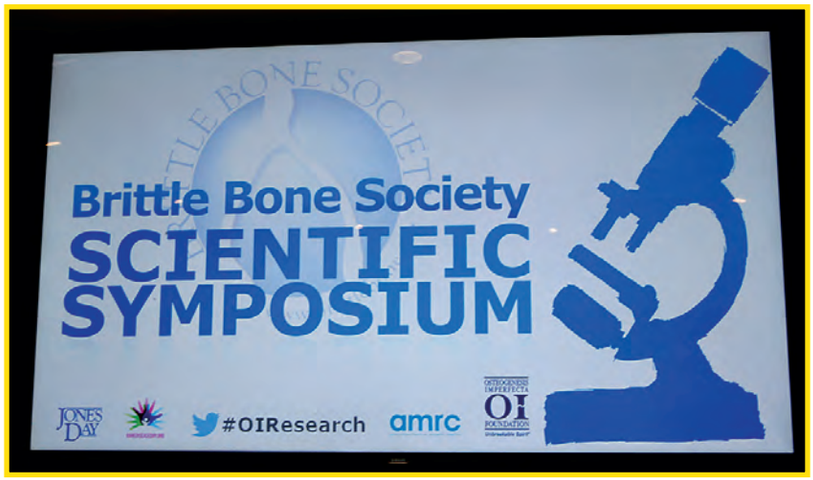
225 delegates at Annual Conference

170 delegates at our Patient Days

35 delegates at VOICE

Healthcare & research

We launched our Research Strategy in February 2017 at the inaugural Scientific Symposium in London at Jones Day law firm, London.



2016 saw us join in greater discussions around research. In November 2016, we joined the AMRC. With our strategic plan and a Research Committee to compliment the work of our Medical Advisory Board, we also became co-applicants in an important NIHR study called TOPaZ – Treatment of Osteogenesis Imperfecta with Parathyroid hormone and Zoledronic acid. We shared information on a variety of new studies and trials, and we worked with the James Lind Alliance and others on various projects.

We held a very successful scientific conference attended by leading names in the field of OI, managed by the chair of our Medical Advisory Board Professor Nick Shaw, and feedback from the event was incredibly positive. Topics covered included stem cell research and new ways of helping to heal broken bones with ground-breaking technology. We earmarked £40,000 that allowed us to launch our first Call for Research Proposals in Spring 2017.

Attending an international Bone Conference in Lisbon, with leaders of societies and groups from all over the world

Collaboration

We continued to work closely with our colleagues around the world including those at the Osteogenesis Imperfecta Foundation (OIF) and Osteogenesis Imperfecta Federation Europe (OIFE), and our involvement in EURORDIS-Rare Diseases Europe and EUPATI (European Patients Academy) continued. This is of particular importance, as the European Reference Networks (ERNs) continue to share knowledge between professionals across EU countries.

We also worked with those affected by similar ultra-rare bone conditions including X-linked Hypophosphatasia, Fibrous Dysplasia and Hypophosphatemia to discuss common challenges and shared aspirations at our Patient Days.

Prof Nick Shaw, Birmingham Children's Hospital; and Dr Henrik Wehtje, Karolinska Hospital, Sweden

Prof Francis Glorieux, Emeritus Director of Research, Shriners Hospital for Children, Canada; Joanna Cannon, lay member of BBS Research Committee

Paul Connor, Kyowa Kirin; and Elaine Healey, Chairman of BBS

Ian Tucker, Bristol Children's Hospital; Coreen Kelday, SDO at BBS; and Mark Heathfield, Great Ormond Street Hospital, London

Spreading the cost

As well as building a new relationship with the AMRC in 2016/17, we also have continued our work with a number of grant giving Trusts.

We hosted the Birmingham Patient Day in 2016 and were joined by supporters The Boparan Charitable Trust. For the past few years we have managed to refer outright a number of children's wheelchair applications to the Trust for funding, however this also means that whilst we do undertake some work at the outset the funds do not reflect in our accounts.

We remain indebted to The Boparan Charitable Trust for their continuous support, which has allowed us time to complete the difficult task of locating funds for older age groups on an ongoing basis.

Further thanks also go to BBC Children in Need for supporting the bulk of the cost of our vital SDO post and new initiatives such as Cool Bones. Thanks also go to Trusts such as the Garfield Weston Foundation who awarded £10,000 over a two year term, and the Northwood Charitable Trust who have regularly donated £15,000 each year on a long term basis. Thanks to the generosity of so many grant making Trusts, for freeing up time to allow us to concentrate on our core work of supporting people affected by OI.

From left to right: Dom Hyams, Chairman Elaine Healey, Mr Blair Thomson of the Northwood Charitable Trust and Mrs Baljinder Boparan of The Boparan Charitable Trust

> *Gave me insight into future medicines which my son maybe able to have in the future. Brought the OI community together - delegate at the Birmingham Patient Day*

Cool Bones activity workshop funded by BBC Children in Need

Pharmaceutical funding

In the past financial year we gained £45,000 in educational funding support to help cover the costs of our Patient Days, Family Conference, website and literature from pharmaceutical companies: Alexion, Mereo Biopharma and Kyowa Kirin.

The future

Looking ahead, we will continue to work and build relationships with the many Trusts and grant-making bodies who help to support our work.

We are excited to continue our first round of providing small research grants for new projects that could offer new and improved treatments for the OI community. We will continue to involve our supporters in events and consultations. Exciting times lie ahead as Genomics England continue to deliver the 100,000 Genomes Project with the aim to develop new medicines and help advance medical research. We also continue to wish to see adult OI services established as they will give a greater quality of life to people with OI throughout their adulthood.

In the short term we look forward to our 50th anniversary event being held in Dundee that will launch our charity's historical exhibition, hold our annual Family Conference, and see us bring leading healthcare professionals to the city for our 2nd international Scientific Symposium. Events will include workshops for our members to contribute to our next strategic plan and programme of activities. At the anniversary event we shall also welcome our friends from OIFE to host their annual meeting and we encourage them to join in our celebrations. It's important we commemorate our heritage and are abreast of what science and research can bring to the world of OI.

We will continue to augment our library of fact sheets and fund equipment. Our programme of events will be reviewed, to ensure that we continue to provide access to information from specialist healthcare professionals, communicate news on services and treatment, and aim to challenge isolation.

> *It's likely the power of the Patient and Public Involvement (PPI) at every level will continue apace, becoming ever more relevant in final decision-making about services that exist or new ones not yet developed. The Trustees widely recognise that policy makers welcome PPI and it has meaningful value - Elaine Healey, Chairman of the BBS*

Chair of Adult OI Forum, Dr Richard Keen, presents results of BBS healthcare survey

Treasurer's report

The practice of fundraising to co-fund equipment and services continues. We offer subsidised entry to our educational and conference events throughout the year.

The charity's support group meetings are increasing and plans to help further develop all aspects of these outreach groups continues. As a small - medium charity with limited resources we ensure that all donations are spent as efficiently and effectively as possible. We continue to utilise the offices of our Vice Chair John Phillips of Jones Day in London to host most of our Trustee and other business meetings thus ensuring all money is being used where possible for charitable activities. There is a continued emphasis on seeking out applications for financial income to fund events, to spread the reach of services offered by the Society.

The number of sponsors attending our annual conference continues to rise and supplement the costs of hosting this, our most expensive event in the calendar year. The impact of pharmaceutical funding support has been of great benefit.

The Society continues to host events funded by various Trusts and grant-making bodies. A number of funders continue to support our work with a notable and welcome addition in funding from BBC Children in Need to compliment the early success of the new Cool Bones (11-15yr olds) programme. Their contribution is in addition to the funding already provided towards our Support Development Officer. VOICE (16-30yr olds) continues to maintain the confidence of funders. The charity recorded a deficit of £15,081 on its unrestricted activities.

Robert Gordon, Treasurer

Finance

Brittle Bone Society

Statement of Financial Activities

Year Ended 31 March 2017

	Note	Unrestricted funds £	Restricted funds £	2017 Total funds £	2016 Total funds £
Income and Endowments					
Donations and legacies	4	99,395	84,835	**184,230**	418,596
Other trading activities	5	43,668	11,467	**55,135**	72,628
Investment income	6	466	–	**466**	719
Other income	7	344	–	**344**	399
Total income		143,873	96,302	**240,175**	492,342
Expenditure					
Expenditure on raising funds:					
Costs of other trading activities	8	82,528	–	**82,528**	90,973
Expenditure on charitable activities	9,10	87,538	115,758	**203,296**	284,620
Total expenditure		170,066	115,758	**285,824**	375,593
Net (expenditure)/income		(26,193)	(19,456)	**(45,649)**	116,749
Transfers between funds		(8,096)	8,096	–	–
Net movement in funds		(34,289)	(11,360)	**(45,649)**	116,749
Reconciliation of funds					
Total funds brought forward		364,144	76,949	**441,093**	324,344
Total funds carried forward		329,855	65,589	**395,444**	441,09

The statement of financial activities includes all gains and losses recognised in the year.
All income and expenditure derive from continuing activities.

Thanks for joining in

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 and organisation that has supported our work during 2016-17. However, we are very grateful to our patrons for their ongoing support and to those who have made a special contribution to our work, particularly as we head towards our 50th anniversary year in 2018!

Trusts

Act Foundation

Alexander Moncur Trust

The Boparan Charitable Trust

BBC Children in Need

Elifar Foundation

Equipment for Independent Living

Florence Nightingale Aid in Sickness

GM Morrison Charitable Trust

The Headley Trust

Hugh Fraser Foundation

Independence at Home

JHT Charitable Trust

Margaret's Fund

Northwood Trust

PF Charitable Trust

PM Ireland Charitable Trust

Sobell Foundation

St Katharine's Fund

Strongbones Children Charitable Trust

Sussex Community Foundation

Tay Charitable Trust

Variety Club

William S Phillips Fund

Hospital Saturday Fund

Clevedon Forbes

Metcalfe Smith Trust

WM Sword Charitable Trust

Garfield Weston Foundation (2015/16)

The Gannochy Trust

The Robertson Trust

Stafford Trust

Barbara Ward Children's Foundation

The Rycroft Children's Fund

Bellahouston Bequest Fund

Celebrating 50 years of providing support to people affected by Osteogenesis Imperfecta in 2018

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