



*Living life well with
Osteogenesis Imperfecta*

ANNUAL REVIEW

2014/15

Governance & Operational Staff



Left to right Treasurer Robert Gordon, Trustee Harry Venet and Mirrick Koh with Chairman Elaine Healey at Annual Conference London 2014



Left to right: member Richard Toner and Trustee Andy Mills at VOICE event in Bristol 2014



CEO Patricia Osborne with Trustees' Hon. Secretary John Phillips at House of Commons Event 2014



Trustee Helen Chappell speaking at Conference meeting 2014



Trustee Yvonne Grant attending first Patient Support Day on Rare Disease Day in Dundee 2014



Trustee Jacky Boyd - representing us at EUPATI event Dublin 2014



Samantha Renke



Simon Mckeown

Board of Trustees

Chairman:	Elaine Healey
Secretary:	John Phillips
Treasurer:	Robert Gordon
Trustees:	Harry Venet, Jacky Boyd, Helen Chappell, Andy Mills, Simon Mckeown, Samantha Renke, Yvonne Grant, Mirrick Koh

Staff

Chief Executive	Patricia Osborne
Fundraising Officer	Christine Hope
Support Worker	Rebecca Bramhall (til December 2014)
Interim Support Worker	Coreen Kelday (December til April)
Office Co-ordinator	Coreen Kelday
Admin Assistant	Annette McIntyre
Auditors:	Bird Simpson, Chartered Accountants, 144 Nethergate, Dundee, DD1 4EB
Registered Office:	Grant-Paterson House, 30 Guthrie Street, Dundee, DD1 5BS Tel 01382 204446 Fax 01382 206771 Charity Registration Nos. England and Wales 272100 and Scotland SCO10951



Twitter @BrittleBone UK and
Facebook Brittle Bone Society (Official)

BBS Medical Advisory Board



Chairman Elaine Healey with Chair of Medical Advisory Board Professor Nick Bishop of Sheffield University and Children's Hospital on Wishbone Day 2014



Dr Kassim Javaid (Nuffield Institute) leader of RUDY research programme with Charity Patron Ms Jordanne Whiley MBE and Dr Christine Burren of Bristol Children's Hospital



Professor Faisal Ahmed, member of Medical Advisory Board, resident at The new Royal Hospital for Sick Children, Glasgow



Dr Nick Shaw Birmingham Children's Hospital



Dr Meena Balasubramanian – Geneticist with MAB member Dr Catherine DeVile of Great Ormond Street Children's Hospital

Professor Nick Bishop

Prof of Paediatric Bone Disease
Sheffield Children's Hospital

Professor Faisal Ahmed

Prof of Paediatric Bone Disease
Resident at The new Royal Hospital
for Sick Children, Glasgow

Dr Nick Shaw

Consultant Paediatric Endocrinologist
Birmingham Children's Hospital

Dr Catherine DeVile

Consultant Paediatric Neurologist
Great Ormond St Hospital for
Children

Dr Christine Burren

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

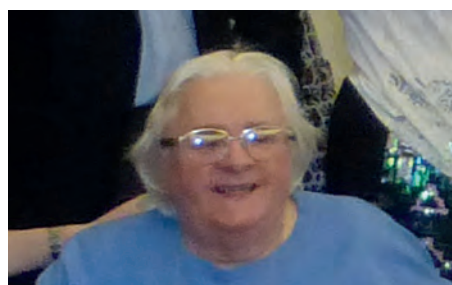
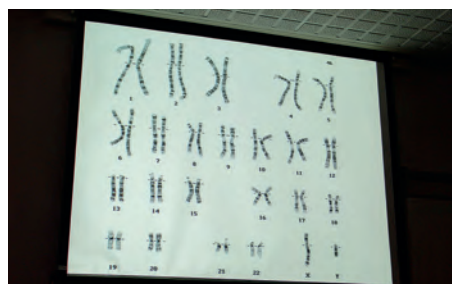
University Lecturer Metabolic Bone
Nuffield Dept Musculoskeletal
Science University of Oxford

Dr Richard Keen

Consultant Rheumatologist
Royal National Orthopaedic
Hospital Stanmore

Osteogenesis Imperfecta (OI)

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 sclerae, brittle teeth and short stature. OI has a wide range of severities and can affect people in many different ways.



Top to bottom –
Genetic Code.
Margaret Grant MBE – (Charity Founder).
Brittle Bone Society working with members of the OI family.

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Chairman & Chief Executive's statement



Elaine Healey (Chairman)



Patricia Osborne (CEO)

The economic conditions under which the Brittle Bone Society operated during 2014/15 continued to present financial challenges. The staff unit managing the support work and events planning for those diagnosed with Osteogenesis Imperfecta maintained strong results despite cost restrictions for the OI Community in a variety of ways. We funded wheelchairs and equipment to the value of £76,903 and our remit to maintain existing conferences and launch new events continued to grow and attract interest and recognition.

In 2014/15 we maintained success with funded programs like 'VOICE' now in its 6th year and gained funding to pursue our 'Cool Bones' project for 11-15 year olds – now in its 3rd year. The Charity also launched a new localised sponsored patient event on World Rare Disease Day February 28th, a format closely supported by local hospitals and bringing volunteer activists from our Support Group Networks from the entire country to share their own stories of their involvement and achievements.

The Charity has shown strong commitment to all in the OI family and tried to address geographic

barriers to partners in Northern Ireland and the Republic of Ireland by increasing involvement where possible – setting up an All Ireland Forum. The charity has funded a catalogue of films explaining living with OI from children's perspective and from the parent's point of view. We also commissioned films highlighting youngsters enjoying outdoor activity weekends and endorsing so much of what our community can do and not what they can't!

We reflect on our past year's work with acknowledgement to all our hard working volunteers, our fundraisers, the BBS support groups, to employees at HQ, to 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 have increased our participation in research *(RUDY) project, steered by our Medical Advisory Board. There has been a rise in contact by media outlets. Seeking a steer and advice which we have deferred to our Health Care professionals for national television documentaries and dramas like *The Doctors*, *Silent Witness* and *Call the Midwife* reaching circa 8 million viewers. The Charity also secured our first high profile Patron in over 20 years in securing the backing of Miss Jordanne Whiley MBE Wimbledon Tennis Champion. In this review we will list the positive impact we continue to have on the OI community, we look at a variety of outcomes achieved and we provide indicative numbers that demonstrate our value.

*RUDY is a musculoskeletal study in rare disease of the bone, joint and vessels. Undertaken by Dr Kassim Javaid Nuffield Institute Oxford. (Dr Kassim is a member of the BBS Medical Advisory Board).

The work we undertake

Our aim is straightforward; to provide support to people with OI and their families and we do this in a number of ways. We strive to achieve an outcome that involves decreasing the level of isolation felt by those with OI, when often due to the rarity of the condition that person may be the only one in their community with OI. We continue to offer practical support, signposting, renewing and updating our factsheets now in their second revision, funding vital equipment and ensuring families get the opportunity to attend our workshops or events by offering subsidies or devising programmes that are portable and can be taken around the country.

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 or updates on our fundraisers and volunteers progress. It is important we communicate to all ages in our community and we relay our news via our new E-Zines launched February 2015.

The Charity has been keen to promote empowerment and offer opportunities and routes to participate in all our activity and programmes in the past financial year. More members and supporters have been actively involved in contributing to our local, regional and national events and meetings by offering talks or presentations.

Area volunteer co-ordinators from across the British Isles have travelled to various events to participate and so encourage others that their hands on approach matters and is crucial in giving fair representation of what

the OI community wants their charity to be involved in and what is important to them.

The BBS are members of a few key campaigning groups – The Alliance, Specialised Healthcare Alliance, Genetic Alliance and Rare Disease UK. Through all of these groups the BBS is able to keep up to date on important issues on specialised commissioning and so keep up pressure on what matters to us.

We received 255 enquiries last year on a wide range of issues via email, phone and social media. We processed a number of applications for financial support of vital equipment, co-funded £95,219 and purchased £76,903 wheelchairs outright, helped fund repairs and purchased other aids/equipment items.

SUCCESS INDICATORS

- 850 members and supporters
- 320 attend BBS events
- 31 applications - high spec wheelchairs and equipment



Top to bottom – various scenes from BBS patient day events throughout the UK.

Improving services now and in the future



Various photos of children and young people with OI.



The NHS service has experienced change and turbulent times in the past few years. Since the 2015 UK Parliamentary Election, there continues to be focus on what provision there may be for specialised healthcare commissioning. Since the Charity's launch in 1968 treatment for those with OI has developed unrecognisably. People's expectations have risen and living healthy happy lives is a part of what the BBS campaign for.

A year of celebration for the exciting 100,000 Genomes Project and with it calls for better access and involvement in research, interest in defining useful and much needed

registries has grown in popularity. The advent of more people focused healthcare, of listening more to the patient's needs and their individual requirements is something all advocacy groups are doing much better and the BBS is no different and has taken advantage of this shift.

The Charity have supported direct involvement in the new RUDY project an NIHR funded study and one recommended by our medical advisory board. Not just taking part, but helping define all aspects of the programme.

SUCCESS INDICATORS

- 255 enquiries
- 11 factsheets plus two new topics in progress
- £4k raised, thanks to increased supporters signing up to the BBS

Networking with the global OI community



Relations with partner organisations in Europe and beyond continue to flourish and discussions are on-going to bring events from Europe for the benefit of widening horizons for our youth members to reach out and learn from others abroad.

In 2014 the BBS branched out to work alongside and learn more about similar rare bone groups. Through involvement in the RUDY research project and by meeting others who share the same clinicians as those with OI the Charity was able to explore expanding their reach. Additionally, our Charity introduced a network event at last year's Annual Conference in London – Reaching Out and Building Bridges – where we met up with people from other rare bone groups (X-linked Hypophosphatasia, Fibrous Dysplasia and Hypophosphotemia) to discuss common challenges and shared aspirations. Talks involved representatives from OIFE (the Europe-wide OI organisation) and a first contact with Care4 Brittle Bones (a Europe-based organisation focusing on OI research).

The central focus discussed the advent of the European Reference Network (ERN) status, discussions on patient driven healthcare and calls for wider collaboration and sharing of healthcare ideas, treatments and methods throughout Europe.

Databases and registries are all important in recording, monitoring and tracking vital information for people's care plans. The BBS are working to support calls for improvements to adult OI service provision.

SUCCESS INDICATORS

- Nuffield Institute NIHR funded study – RUDY BBS members take part
- Membership of Specialised Healthcare Alliance, Genetic Alliance
- Cross party working group Scottish Parliament

Top to bottom –

- Annual Conference 2014 in London with delegates from Germany and Holland.
- Rare Disease Day in Northern Ireland.
- Cross Party Group on Rare Disease Scottish Parliament.
- New Rare Disease Centre in Birmingham.

Combating isolation, caring for everyone



The Charity recognise the crucial role of ‘carer’ in the family unit and how that impacts on relationships. The BBS have been successful in obtaining grants for carers, so we can offer assistance to more members of the OI community, enabling them to travel to our events. This extends our reach and ensures that no barriers exist that prevent people accessing the BBS.



We continue to provide subsidised entry to any one of our national conference events and by introducing our new smaller regional patient workshop events we can take more manageable sized programmes to more areas. Many tell us they prefer smaller events and this addition to our established ‘main’ programme helps us to further refine how we connect with our supporters; inform, educate and entertain and crucially combat loneliness.



“ I feel generally in everyday life we all rely on support groups for confidence, advice and support. This might be our friends, family, work colleagues, Facebook or Twitter. But where these natural support groups may not be as effective is when the support needed is in connection with something very specific. In this case being affected by Osteogenesis Imperfecta (OI) ”



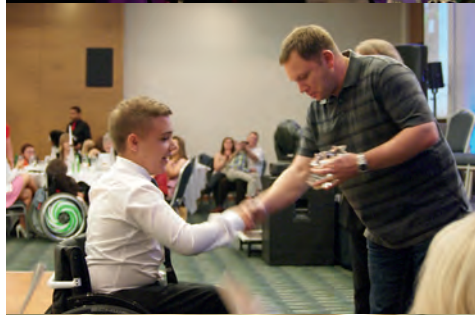
“ Thank you to everyone involved in organising and presenting at the Patient Day Workshop in Dundee today. It was fantastic, very informative and a great opportunity to meet up with friends and families old and new. Being a member of the BBS is like being part of a big, safe, supportive and caring family.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

SUCCESS INDICATORS

- 7 support groups across the country
- 11 support meetings held
- 56 new contacts registered
- 1962 likes on Facebook
- 1140 followers on twitter

Events

“ Last year 2014 we attended the BBS conference at Heathrow Airport Hotel; it was full of amazing information regarding NHS treatment for people living with OI. What amazed me most was how much my son really enjoyed himself and had a very wonderful time. For the first time in my son’s life he felt normal and happy in himself as he met other wheelchair users and people like himself, this gave him so much confidence and joy which has carried him through the year. ”



“ As parents we too need a support mechanism and attending the conference gives us this. As there are new drugs and treatments being developed as well as studies, it is beneficial to us as parents to make informed decisions in relation to these. We, never really appreciated the importance of attending conferences in the past as we didn’t want to spend more time talking about the condition that can dominate our family life at times. However we now realise the importance of education and support to families who have this condition. The conference is an ideal opportunity to meet others, learn and develop friendships to support each other for another year. ”

“ It was a really nice feeling being in the company of other people with O.I. particularly as I get older and becoming slower and not able to do what I used to be able to do, you realise you are not alone and other people have the same fears. Having a rare disease can be isolating as everyday living is so much different from others who don’t have the condition. ”

“ It will be a chance to meet other people with OI that I wouldn’t usually get to do, to lessen the isolation I feel. I want to find out more about upcoming and current medical information I can take away with me to discuss with my own medical professionals as my OI progressively worsens. ”

Top to bottom – Chairman Elaine Healey and photos of BBS members at conference events.

Quality of Life & Mobility

Tobi and her new electric wheelchair!

Since I received my new wheelchair I enrolled in my university course studying TV & New Broadcasting Media combined with Dance BA Hons, attended my first Brittle Bones Conference in Heathrow and cooked many meals, with my Permobil at home. I love my new found independence!

“When I am at university, I can easily get around my campus and occasionally go out with my friends shopping. I feel so free with my new chair; it’s given me freedom because I am able to go out when I like, particularly when there’s cold or wet weather. Previously, with my manual wheelchair, I would struggle with the rain, especially if I have somewhere far to go, or when I’ve had a bad fracture. Trips to the supermarket are now so much easier and quicker for me. I can no longer imagine a life without my powered chair; my future has been improved massively because I can get to and from places safely and comfortably. My day runs smoothly and now I have a huge weight lifted off my shoulders; the stress of being trapped indoors has been removed”.

Thank you so much T.



BBS secures Patron

The Charity secured their first high profile Patron in over 20 years in securing the backing of Miss Jordanne Whiley MBE Wimbledon Tennis Champion.



Jordanne has already previously given her time to attend the Brittle Bone Society’s popular youth event VOICE to talk about her sporting career, share updates on the challenges she has faced and how she has made it to the top of wheelchair tennis. Jordanne is a wonderful role model and inspiration for members and we appreciate how fortunate we are to have her agree to be patron of our charity.

“ I’m delighted to become patron of a charity that is very close to home for me and I hope I can inspire more people with brittle bone disease to aspire to achieve as much as they can and show that anything is possible. ”

SUCCESS INDICATORS

- £15k Scottish Government Grant
- £10k Awards for All Lottery Funding – Patient Day Events
- £15k BBC Children in Need

Fundraising Highlights

Linda Baker - 10 mile sponsored walk - £899

Lisa Barnikel - with 2 friends ran the Wales half marathon - £1692

Chris Batterby - Fun day - £1825

Franck Crosnier - Loch Ness Marathon - £710

Paul Deadman - Sahara Trek - £1188

Olivia Jones and her friends - Loom bands - £751

Mark Kane - Bristol half Marathon - £329

Amanda Davies - Oxford half marathon - £720

Siobhan O'Halloran - Great Run Manchester - £729

Sammy Rose, Manchester 10k - £1700

Metter Thielman - birthday party - £3880

Jenny Jones - Gala Ball - £1255

Des Kealey - through Oakham School, parishoners of The Sacred Heart and St. Oswalds - £3561

Jack Lewington and Ruaridh Harris - Meadows fun run - £1255



Finance

BRITTLE BONE SOCIETY
STATEMENT OF FINANCIAL ACTIVITIES
YEAR ENDED 31 MARCH 2015

	Unrestricted Funds £	Restricted Funds £	Total Funds 2015 £	Total Funds 2014 £
INCOMING RESOURCES				
Incoming resources from generating funds:				
Voluntary income	106,736	130,065	236,801	260,414
Activities for generating funds	68,763	9,166	77,929	74,564
Investment income	681	–	681	427
	<u>176,180</u>	<u>139,231</u>	<u>315,411</u>	<u>335,405</u>
RESOURCES EXPENDED				
Costs of generating funds:				
Fundraising trading: cost of goods sold and other costs	(86,369)	–	(86,369)	(95,831)
Charitable activities	(62,396)	(166,531)	(228,927)	(246,388)
Governance costs	(8,613)	–	(8,613)	(8,267)
	<u>(157,378)</u>	<u>(166,531)</u>	<u>(323,909)</u>	<u>(350,486)</u>
NET OUTGOING RESOURCES BEFORE TRANSFERS				
	18,802	(27,300)	(8,498)	(15,081)
Transfer between funds	(19,132)	19,132	–	–
	<u>(330)</u>	<u>(8,168)</u>	<u>(8,498)</u>	<u>(15,081)</u>
RECONCILIATION OF FUNDS				
Total funds brought forward	204,333	128,509	332,842	347,923
TOTAL FUNDS CARRIED FORWARD	<u>204,003</u>	<u>120,341</u>	<u>324,344</u>	<u>332,842</u>

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



healthcare professional events at Jones Day.

There is a continued emphasis on seeking out applications for financial income to fund wheelchairs and a growing calendar of events, and so spread the reach of services offered by the Brittle Bone Society.

Funding was secured for new themed patient day workshops closely supported by the NHS Centres of Excellence and funded by Awards for All Scotland. We continue to seek out funds to develop an outreach project UK wide.

As a charity with limited resources we ensure that all donations are spent as efficiently and effectively as possible. We continue to utilise the offices of Jones Day in London to host most of our Trustee and other business meetings with plans to host major

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

The tremendous work by staff, members and supporters in the year meant the charity recorded a deficit of only £330 on its unrestricted activities.

R Gordon



Abbi Brown toting a big gun at VOICE.

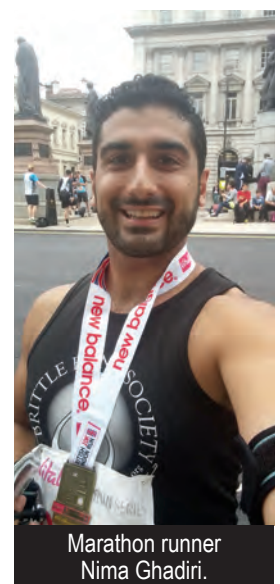
Charity Calendar Highlights



BBS staff and Medics enjoy Kielder, Lake District – Calvert Trust Outdoor Centre.



Nassim, Sahand and Sahar Parvizi, for the London 10k.



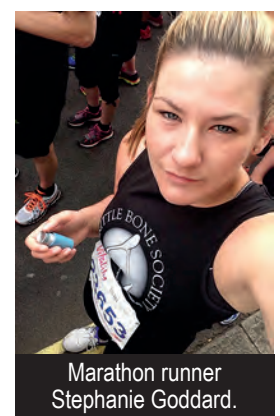
Marathon runner Nima Ghadiri.



Monique Jarrett zipwiring at BBS event!



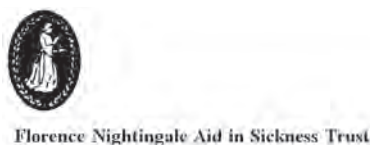
Actor Brian Cox with Patricia Osborne CEO at BBC recording studios, London, March 2014, working on Radio 4 Charity Appeal.



Marathon runner Stephanie Goddard.

Our Thanks go to

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**
 JTH 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**





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Charity Registration Nos. England and Wales 272100 and
Scotland SCO10951