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SCIENTIFIC ADVISORY BOARD

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

Dr Christine Burren
Consultant Paediatric Endocrinologist
Bristol Children’s Hospital

Dr Vrinda Saraff
Consultant Paediatric Endocrinologist
Birmingham Children’s Hospital

Prof. Stuart Ralston
Professor of Rheumatology
Centre for Genomic and Experimental Medicine,
Edinburgh University; Western General Hospital, Edinburgh

Penny Clapcott
Layperson

GOVERNANCE & OPERATIONAL STAFF

Board of Trustees
Chairman: Elaine Healey
Vice Chairman: John Phillips
Treasurer: Robert Gordon
Secretary: Mirrick Koh
Trustees: Professor Nick Bishop, Garreth Cumming,
Yvonne Grant, Professor Margaret Smith,
Angie Stewart

Chief Executive: Patricia Osborne
Support Development Officer: Coreen Kelday
Finance and Admin Officer: Megan Crookston
Auditors: Bird Simpson
Chartered Accountants
144 Nethergate, Dundee, DD1 4EB

MEDICAL ADVISORY BOARD

Assoc. Prof. Kassim Javaid (Chairman)
Lecturer in Metabolic Bone Disease
Nuffield Department of Orthopaedics, Oxford

Dr Paul Arundel
Paediatric Consultant in Metabolic Bone Disease
Sheffield Children’s Hospital

Dr Meena Balasubramanian
Clinical Geneticist, Northern General Hospital, Sheffield

Dr Christine Burren
Consultant Paediatric Endocrinologist
Bristol Royal Hospital for Children

Dr Catherine DeVile
Consultant in Paediatric Neurology and Neurodisability
Great Ormond Street Hospital for Children

Mr Adrian Gardner
Spinal Surgeon, Birmingham Children’s Hospital

Prof. Neil Gittoes
Consultant Endocrinologist
Queen Elizabeth Hospital, Birmingham

Mark Heathfield
Specialist Nurse, Great Ormond St Hospital for Children

Dr Claire Hill
Physiotherapist, Sheffield Children’s Hospital

Prof. Richard Keen
Consultant Rheumatologist
Royal National Orthopaedic Hospital, Stanmore

Dr Avril Mason
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Royal Hospital for Children, Glasgow

Lisa Mills
Occupational Therapist, Bristol Royal Hospital for Children

Dr Raj Padidela
Consultant Paediatric Dentist
Great Ormond Street Hospital for Children

Dr Susan Parekh
Consultant Paediatric Endocrinologist
Birmingham Children’s Hospital

Angie Stewart
Layperson

Dr Jennifer Walsh
Consultant Physician, Northern General Hospital, Sheffield
MESSAGE FROM CHIEF EXEC, PATRICIA OSBORNE

Strong planning
Resources remain a challenge with Covid from March 2020 we saw our operation drastically alter! We continued to secure funding from tremendous funders but had to postpone various events already planned. We did our utmost to respond to challenges in communication flow to a worried OI community. Support enquiries quadrupled at the start of the outbreak – and we responded! Our MAB did their level best to steer people to get themselves on the shielding lists, and throughout we hosted zoom events and did our best to keep in touch.

Communication
Our comms programme across social media had to respond to new and different challenges due to the pandemic. We enlisted assistance from Purple Goat Agency and welcomed Dom Hyams to lend his expertise to much of our content. Thanks also to all the members who have written, blogged and vlogged to help provide us with interesting and creative content.

Campaigning
Our campaigning around Wishbone Day seemed popular as ever and there was a kind and loving outpouring from the OI community worldwide. Respite we all needed!

Fundraising & Research plans
Fundraising for wheelchairs and equipment continues on track but due to delays in people gaining OT assessments we are set to deal with a rise in applications – however we are confident we can meet the challenge. We are excited that with new prospective treatments underway there will be improvements to people living with OI. Thanks for your support in response to all the surveys we asked you to complete and supporting our various campaigns.

Thanks to you and and staff over over what has been a very tough year!

MESSAGE FROM CHAIRMAN, ELAINE HEALEY

Margaret Grant RIP
With great sadness in December 2020 we lost our beloved Margaret Grant MBE – founder of the BBS. It was wonderful to see our community come together to celebrate her memory in a fitting way. My trustee board are working on a suitable and lasting legacy tribute in Margaret’s memory.

New ways of working
Trustees commend Patricia and her team for finding new ways of working due to the global battle we all lived through due to Covid. We all did our best to meet the support needs of the OI Community and proud of the resilience we have shown.

Invaluable surveys and data
We are all of us a bit zoomed out and tired of surveys, but in the coming months ahead – as policy changes emerge in healthcare and new treatments focus on the horizon, now more than ever we need to ingather data that will demonstrate the gaps in OI Care. I thank you all for your vital contributions and thank you in advance for the future surveys we may ask you to support.

NHS
Thanks to our outstanding healthcare professionals who continue to support our work. For making possible new BBS factsheets, videos and other important resources which we have all benefitted from.

Thinking of all the families out there whose lives have been changed by Covid – we hope you know you can still count on the BBS – we are here if you need us!

What doesn’t break us makes us stronger!

Elaine Healey

What doesn’t break us makes us stronger!
WHAT IS OSTEODEGENESIS 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, EURBBONE etc.
WHAT WE DO
ENQUIRIES AND PEER SUPPORT
We continue to offer frontline and emotional support via access to our Support Development Officer (SDO) – signposting to a wide range of specialised services. Our SDO handles enquiries by telephone, Facebook and email. The SDO deals with enquiries from individuals with OI, parents, and a variety of professionals from Healthcare Professionals to social workers and teachers.

During the height of the pandemic we saw the levels of enquiries quadruple. Individuals had many questions in particular about shielding. We addressed this by holding 2 x Q&A webinars in conjunction with our Medical Advisory Board addressing peoples concerns about the impact of Covid-19 and lockdown restrictions. These webinars are uploaded to our Youtube Channel. We also ensured we had regular updates on our Social Media platforms.

EDUCATION & INFORMATION
We continue to work closely with the NHS Highly Skilled Centres, our Medical Advisory Board (MAB) and the POINT Team. As well as providing up to date information at events, we also provided information through our website, Social Media, and our increasing library of films on YouTube. We distribute monthly electronic newsletters.

More recently we have collaborated with NHS healthcare professionals to develop a series of Pilates videos. During the pandemic many of members were telling us they had increased pain levels during lockdown. Our SDO discussed this with the Physiotherapists and it was decided to develop a series of Pilates videos. These videos have been viewed over 400 times.

We continue to develop and update our NHS endorsed factsheets on a range of topics affecting individuals with OI. We also created a useful document called Mind Matters with a list of support resources which people could tap into if they felt the need.

EVENTS
Due to Covid-19 we moved all Events online, increasing the numbers of Social events, ensuring members could still keep in touch and feel part of the OI community. We hosted a variety of events which including 2 x health webinars, various chat room sessions, weekly pub quizzes, 4 x film club sessions, 2 x singalong sessions.

Some of the comments we have received from members in regards to our online Events.

“Well done to the BBS team, it was really informative conference, with lots of interesting speakers

Really appreciative of the work that has gone in to bringing this event to everyone, fantastic achievement.

The talks were really great this year. Thanks to the medical professionals who gave up their weekends to present to us and the wonderful BBS staff of course!

I thank you for the opportunity to be part of this amazing community!

The weekend was brilliantly run, kept to time and went very smoothly.”
WHEELCHAIRS AND EQUIPMENT

During 2020/21 we co-ordinated funding for 12 Wheelchairs totalling £64,000, as well as funding specialised baby equipment (ie layflat car seats, highchairs, prams etc).

The number of applications was drastically reduced based on previous years mainly due to the pandemic and individuals not being able to get assessments or being able to try out new chairs. Towards the later part of the year we have seen a drastic increase in the numbers of applications we are receiving and in the next financial year expect this total to be more than double.

"This high chair is the most adaptable one we’ve seen. It lays flat and reclines in small stages which is essential to support his spine. He is allowed to have the second setting now only for feeding so still flatish but can see a little better and in turn it has helped his digestion a little. It has been a struggle this past 2 months bending down low to feed him in his rocker but now he gets to be at table height and see his family sat around a table.

I do get so excited at every little milestone for him because they’re so much more valuable when you have to wait longer for them.

We have had a super time eating and playing in this new high chair and each part of it will become more used as he grows. The footrests move, the height moves, there are inserts to support posture. Even with all this we still have to make our own adaptations to it to allow him to have a straight spine but it is so amazing! Thank you so much BBS.

There is no doubt that this power trike will definitely improve the quality of my life (once lockdown rules are over) and I look forward to using it for future social events and holidays. I am so grateful to the BBS for arranging funding for the Triride and improving my quality of life

- Gareth

Thank you BBS for all you do for each of us. I love my new wheels and I’m far more comfortable now.

- Sharon
RESEARCH

We have been members of the Association of Medical Research (AMRC) since 2016 and we are also non-commercial partners with the National Institute for Health Research (NIHR).

Following the 2017 launch of our research grant scheme, our 2nd research grant programme winners were announced in Sep 2019. These projects were all put on hold due to the pandemic. Due to a decrease in income this year our Trustees made the decision not to fund any Research Projects in the current financial year.

CLINICAL TRIALS

There are two ongoing studies at present called TOPAZ (funded by the NIHR). This is a study around treatment with Parathyroid hormone and zolendronic acid. The second study is the Asteroid Trial – (Ultragenyx / Mereo Biopharma) looking at the affect of Sertrusum- ab which its hoped may reduce fractures.

ADVOCACY

We are the voice of the people with OI – taking part in relevant policy consultations, offering educational awareness packs for schools, and raising awareness through social media and other media avenues.

SURVEYS/CONSULTATIONS/QUESTIONNAIRES

Building on the data we have we will produce more detailed analysis reports (currently being written up by the Office of Rare Conditions in Glasgow) to help us not only provide the best services and support but to also help demonstrate health care gaps. This will be useful in our hopes to establish clinical care guidelines for OI, focus in on securing a better NHS health service for adults with rare bone disease.

We have undertaken our own surveys to chart data on OI to help with ingathering health economic data which will inevitably be required. This vital work continues to be done, albeit remotely rather than face to face. The results have already been used and will be used to feed back to Policy Makers and Health care professionals.

FIRST COVID SURVEY AUG 2019

Covid 19 Survey of the OI Community in the UK and Ireland

<table>
<thead>
<tr>
<th>107 responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>63% had a medical appointment postponed or cancelled</td>
</tr>
</tbody>
</table>

- Increased anxiety.
- Feeling low and depressed.
- Impact of Isolation being heightened.

- Impacts on Mental Health:
  - Missing friends and family.
  - Feeling vulnerable being in the shielding group.

- 52% had a telephone or video appointment
- 33% said postponed/cancelled appointments affected surgeries/treatments.

Main 3 areas impacted:
- Delays in starting treatment, Pain management, Bone Density Scans
Covid Survey Results from the OI Community

- **60%** Of you told us you have had a covid test
- **6%** Were actually confirmed positive
- **94/122** Of you had experienced a remote consultation and 64 of you said this is something you would like to see more of but not for every appointment
- **25%** Of you told us you felt your medical needs had been ignored
- **20%** Of you told us you did not go to A&E during Covid to confirm diagnosis of suspected fracture
- **39%** Received a letter from the Government saying you had been identified as someone at risk
- **77%** Of you told us you had received the vaccine
- **7%** Reported having side effects lasting longer than 48hrs

The results of how much you struggled in these categories during the pandemic:

- **Weight and Diet**: Significantly
- **Mobility**: Alot
- **Pain**: Moderate
- **Anxiety and Mental Health**: A little
- **Seeing friends & family**: Not at all
- **Physically active**: Not at all

Registered Charity Nos. England and Wales 272100; Scotland SC010951.
Independent Living Survey Results

33% of you said you can travel to all the places you want.

49% are in employment, with 8% receiving support from Access to Work. 21% are unemployed. The remaining are either students or retired.

54% of you told us you feel in control of your independence most of the time.

62% told us you receive practical help on a regular basis which isn't paid for.

42% of you told us you are homeowners.

61% of you have carried out house adaptations.

30% of you have a degree and a further 23% have a Post Graduate qualification.

55% said you are able to spend time doing things you enjoy or value.

74% told us you do not find it difficult to form relationships.
Collaboration

We are members of Genetic Alliance, Rare Disease UK, Specialised Healthcare Alliance, The Alliance, Eurordis, Eupati, OIFE and the Scottish Council for Voluntary Organisations (SCVO).

We continue to build on good relationships with both NHS healthcare professionals and other patient support groups working with other rare conditions. Our CEO was invited to serve on an important NHS scoping group for rare bone conditions to help construct a suitable health service for adults with rare bone including OI. We had provided strong evidence to support this gap.

We continue to work alongside our partners in the wider rare bone world including the new Softbones UK group HPP (Hypophosphatasia) and XLH UK (X-linked Hypophosphatemia). Throughout the pandemic we have held regular zoom meetings.

We collaborate across the globe with our OI friends – in USA (OIF) and Europe (OIFE).

We support the work of the European Reference Networks (ERN) including the specialised rare bone disease Network, ERN-BOND. Nb due to the UK’s withdrawal from Europe our formal links with these bodies are now formally severed, however the network of communication and collaboration is determined to ensure knowledge continues to be shared and used for good.

We have worked closely with the Rudy Study since 2014. This is a database developed by the Chair of our Charity’s medical advisory board – Assoc Professor Kassim Javaid, aiming to build a clinical research network that could provide a research platform for patients across the UK with rare diseases of bone, joints and blood vessels. Patients are the key to providing insight into the diseases being studied and offer a more complete picture of the wider implications of rare diseases than clinical records alone.
KIDS AREA

Cool Bones continues to be supported by Children in Need as does our Support Development Officers role. Due to the pandemic BBC Children in Need allowed us to re-allocate our funds to support children virtually.

We also held a variety of virtual events for all age groups and included sessions for Kids Club (age 0-9) and Cool Bones (age 10-15). We held an Elsa sing along party, British Sign Language taster session, a christmas party and a gaming session for the older children.

We continued to send out hospital packs to keep the kids entertained whilst in hospital.

At Christmas the SDO was kept busy sending out a 106 Christmas Good Boxes.

OLLIE OWL

Ollie Owl kept the children busy and entertained throughout the summer asking children to share pictures of what they were up to. We had prize give aways for getting involved in anything from baking, keeping fit, reading a book to drawing pictures.

“Thank you so much for the lovely treat box. He loves books so the googly eye books have really made him smile. Still recovering from a broken femur so it’s wonderful to have something else to keep him entertained.”

“My daughter has just returned from school delighted with her special delivery. Thank you so much for making her smile today.”

“We had a lovely delivery in the post today! Thank you to Brittle Bone Society for the boys little box of Christmas goodies. It is so lovely that you included siblings.”
We would like to thank everyone who fundraised for the Brittle Bone Society during what was a very difficult year. There are too many of you to thank but here are just some:

**Thanks to our Fundraisers**

The Faichney family who walked 25km of the Lomond Hills Park 3 Peaks raising £900

Natasha who was brave enough to cut her hair raising an amazing £739

The Whittacker family who raised £1400.19 participating in the 2.6 challenge.

Eileen and Eimear who walked 100km raising 383 euros

Winnie and her dad who raised £573

And the Hood Family who raised £250 doing the 2.6 challenge.

Steven who held a virtual pub quiz raising £300

Mia who ran a virtual half marathon raising £259

Olivia who raised £540 by staying awake for 24 hours

Steve Edney - ongoing support raising over £6000 to run the London Marathon

Nexus our charity partners for the year who raised a total of £3372 from holding various events, this is an image from a quiz night held before lockdown.

**Facebook Fundraisers**

Our yearly total is £7869.85
## Statement of Financial Activities

### Year ending March 21

<table>
<thead>
<tr>
<th>Notes</th>
<th>£</th>
<th>£</th>
<th>£</th>
<th>£</th>
<th>£</th>
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<tr>
<td><strong>Income from:</strong></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Donations and legacies</td>
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<td>107,097</td>
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<td>64,724</td>
<td>171,821</td>
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<td>Other trading activities</td>
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<td>19,848</td>
<td>-</td>
<td>-</td>
<td>19,848</td>
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<tr>
<td>Investments</td>
<td>5</td>
<td>101</td>
<td>-</td>
<td>-</td>
<td>101</td>
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<tr>
<td><strong>Total Income</strong></td>
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<td>127,046</td>
<td>-</td>
<td>64,724</td>
<td>191,770</td>
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<td><strong>Expenditure on:</strong></td>
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<tr>
<td>Raising funds</td>
<td>6</td>
<td>51,778</td>
<td>-</td>
<td>-</td>
<td>51,778</td>
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<tr>
<td>Charitable activities</td>
<td>7</td>
<td>89,034</td>
<td>1,510</td>
<td>60,936</td>
<td>151,480</td>
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<tr>
<td><strong>Total resources expended</strong></td>
<td></td>
<td>140,812</td>
<td>1,510</td>
<td>60,936</td>
<td>203,258</td>
</tr>
<tr>
<td><strong>Net (outgoing)/incoming resources before transfers</strong></td>
<td>(13,766)</td>
<td>(1,510)</td>
<td>3,788</td>
<td>(11,488)</td>
<td>(66,805)</td>
</tr>
<tr>
<td>Gross transfer between funds</td>
<td></td>
<td>(109,196)</td>
<td>99,470</td>
<td>9,726</td>
<td></td>
</tr>
<tr>
<td><strong>Net (expenditure)/income for the year/Net (outgoing)/incoming resources</strong></td>
<td>(122,962)</td>
<td>97,960</td>
<td>13,514</td>
<td>(11,488)</td>
<td>(66,805)</td>
</tr>
<tr>
<td><strong>Other recognized gains and losses</strong></td>
<td>11</td>
<td>182</td>
<td>-</td>
<td>-</td>
<td>182</td>
</tr>
<tr>
<td>Other gains or losses</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Net movement in funds</strong></td>
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<td>(122,780)</td>
<td>97,960</td>
<td>13,514</td>
<td>(11,306)</td>
</tr>
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<td>Fund balances at 1 April 2020</td>
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<td>285,568</td>
<td>47,040</td>
<td>40,315</td>
<td>372,923</td>
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<td>Fund balances at 31 March 2021</td>
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<td>162,788</td>
<td>145,000</td>
<td>53,829</td>
<td>361,617</td>
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</table>
Treasurer’s report

Financial review

The financial statements show that the charity had a deficit of £11,306 during the year (2020 - deficit £66,908). Total income for the year was £191,770 (2020 - £286,957). Expenditure for the year was £203,258 (2020 - £353,762).

The pandemic curtailed the majority of the fundraising events scheduled for the year which had a detrimental effect on the donations and fundraising income for the year. Moving the annual conference on-line for the year as well as other meetings did mean that savings could be made.

The trustees are satisfied with the financial position of the society as we look towards the forthcoming year ahead.

Income

There is a wide mix of potential funding sources and the best way of securing funds is judged on a case-by-case basis. We look to cover the cost of events from outside sources, allowing us to increase the spread of services offered by the charity’s own resources. The Charity continues to explore and apply to various funding institutions and continues to seek out relevant sponsorship in particular to boost its wheelchair fund. All of this has been significantly impacted by the effects of the pandemic and we expect this to have repercussions in the following year. Particular funders have reduced the amounts usually awarded and some have closed. The drop in fundraising from all other sources has also been curtailed due to the global pandemic. We have been alerted to some legacy funding which has been welcomed albeit this generally takes some considerable time to process and come through.

Expenditure

As a small-medium sized Charity with limited resources we ensure that all donations are spent as efficiently and effectively as possible. Due to Covid all governance meetings/board meetings and other events usually generating cost have been undertaken online and generated considerable cost savings.

Fundraising

The Charity is grateful to all its supporters and fundraisers. 2020 was a challenging year for fundraising with many events such as marathons being curtailed. The Charity continues to cooperate closely with its long-term supporters and encourages new fundraisers. The Charity remains grateful for Facebook donations and other donations that were indeed possible.

The practice of fundraising to co-fund equipment or services continues.

Staff and Volunteers

We employ a small team who demonstrate skill, trust, professionalism, flexibility with a clear demonstration of care and passion for the cause we support. All staff have been working from home throughout the pandemic.

Often people who undertake work on our behalf, will waive their fee or ask for a reduced fee. However, for 3 years now, Trustees have approved a remuneration towards those experts within the OI community whom we call upon to offer up blog content, or featured/commissioned articles and material and those who help facilitate at our events. These arrangements are on a contractual basis.

Financial review

<table>
<thead>
<tr>
<th>Income</th>
<th>Expenditure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fundraising</td>
<td>STAFF AND VOLUNTEERS</td>
</tr>
</tbody>
</table>
| Staff and Volunteers | 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.
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 2020. 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 AND GRANT MAKING INSTITUTIONS

Barchester  
Boparan Charitable Trust  
BBC Children in Need  
Elifar Foundation  
Equipment for Independent Living  
Florence Nightingale Aid in Sickness  
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  
Misslebrook Trust  
Northwood Charitable Trust  
PF Charitable Trust  
Sobell Foundation  
St Katharine’s Fund  
Sussex Community Foundation  
Tälteg Ltd  
William S Phillips Fund  
William Leech Charity  
WM Sword

INDUSTRY

Nexus  
Jones Day  
Alexion  
Kyowa Kirin  
Mereo