1. Minutes of 2018 BBS AGM meeting
Elaine Healey (Chairman) EH welcomed all to the AGM.

EH confirmed copies of the minutes were to be found on tables, with a copy of the extract of accounts and a list of Candidate biographies.

EH confirmed apologies were listed.

Members raised concerns that they would prefer more time to read over the previous year’s AGM minute prior to the meeting. A short discussion followed.

Proposer; Steve Edney and seconded by Yvonne Grant

2. Chairman’s Report (EH)
Highlights of the year

Events
- Successful 50th Celebration event in Dundee, a year-long campaign on our Charity’s impact!
- Parliamentary events –
  o Westminster and Holyrood attended by leading Parliamentarians including the FM of Scottish Parliament.
- Launching OI CAN Event, Lake District
- Launching our new Healthy living workshops, Dundee
- History Bones on Tour Project launched (with plans for future exposure)

Patronage
- Continued support from Peers Lord Shinkwin and Lord McAvoy

Policy/advocacy/collaboration
- Adult OI campaign for an NHS service for rare bone service
- Collaboration with other rare bone groups: HPP, XLH, FD & Achondroplasia
  o PIP campaign Raising issues around members dissatisfaction e.g. PIP

NHS/relationships/profile raising
- Great Ormond Street, Royal National Orthopeadic Hospital, (SDO)
- Bisphosphonate conference in Sheffield (history Bones)
- First full day Medical advisory Board meeting at Jones Day, London
  - updates and new factsheets,
Operations HQ / Fundraising / Communication
- Fundraising success - benefitting from incredible members like the Edney family
  - nationwide media campaign, celebrity endorsement, National TV coverage
  - significant rise in our social media reach

Wheelchairs
- In past financial year co-ordinated over £120k of finance for wheelchairs and equipment for 29 individuals.
- Currently we are dealing with circa 21 applications for support totalling £81,825.00

Research
- we continued with support for RUDY
- began to explore involvement in Registries.
- This conference will cover European reference networks –
  - ERN’s and the work the rare bone community Europe wide.

Medical Symposium
- Our International symposium was held in conjunction with the Dundee 50th Event.
- Experts from around the globe to chart ‘what has been achieved in the past 20 years in OI’.
- A direct outcome from that is a resolve to get our **clinical care guidelines** completed.
- Our dialogue and communication continues to be a success so much so -- it does mean less people feel the need to attend annual family conference.
  - A stark reality we still really need to look at.

Trustees
- Thanks for the hard work and the dedication of entire Trustee Board.
  - A great decision to co-opt Professor Margaret Smith MBE a prominent NHS professional who held the post of Dean of Nursing and Midwifery at the University of Dundee, a lifelong career in the NHS and sound experience as trustee and chair of the Charity MS Revive.
  - “It’s been a passion to improve the information and support for pregnant women are given when their baby is suspected of having OI. ‘I believe Margaret will help us achieve this and I hope that you will all support Margaret’s appointment to this board, we are very fortunate to have her with us’. EH

Healthcare Professionals
Thanks to medics on our Medical Advisory Board with layperson Trustee Angie Stewart and thanks also to our Scientific Advisory Board – steering our research grants programme.

Charity Staff
Well done to staff very ably managed by our CEO Patricia Osborne – thankyou Coreen and staff on outstanding work!

Pharma support
BBS are grateful for all the financial grants we received and highlighting consistent support from pharma and bio pharma companies: Alexion, Mereo BioPharma and Kyowa Kirin.

3. **Treasurers Report Robert Gordon**

As outlined in the reports section of the Accounts as distributed in the room.

- We continue to distribute grants funding to families to enable them to access our events
- Trustees agreed grants of £5k to cover conference.
- Last year we allocated 28 x grants
- Years previous we allocated 19 and 12 respectively
- This year we are sitting at 27 in the month of August and still a month to go
- Perhaps we need to decide if we up that figure?
- We spent £35k on necessary upgrades,
  - office repairs,
  - new windows,
  - roof and guttering,
  - new energy efficient lighting,
  - decoration and refresh,
  - upgrades to the kitchen area
  - installation of a new disabled toilet,
  - other plumbing and essential repairs to HQ.
  - new flooring
  - head office is a large property and Trustees thought prudent to execute necessary works whilst we had a surplus and as we know many trusts will not fund if applicants have surplus funds.
- £60k allocated for research last year
- £40k for outstanding projects steered by Chairman of the Scientific Board Prof Faisal Ahmed.
- We may need to agree a budget to cover more travel/awareness raising to take Educational Medical Exhibition or History Bones (or a project further refined to that – to more UK areas).

3. **Secretary’s report delivered by Vice Chairman John Phillips**

To agree with Chairman Elaine and also congratulate the efforts and input of the staff members – Coreen, Nikki, all managed by Patricia.

To propose that you accept Chairman’s report (copies of which are on the tables) and accounts as detailed by Treasurer Robert Gordon.

*Proposed by Steve Edney and seconded by Yvonne Grant*

4. **Resolutions presented by Vice chairman John Phillips (in the absence of Secretary Mirrick Koh)**

The following resolutions are proposed at this AGM:

- To approve and accept the Society’s annual report and accounts for year ended 31 March 2019.
- To re-elect Robert Gordon as Trustee and Treasurer.
- To elect Professor Margaret Smith OBE as Trustee.
- To appoint Bird Simpson as auditors for the year ending 31 March 2020.
The Trustee Board ask that you agree to elect Candidates as outlined in our Calling Notice and – whose biographies are listed on the current website and are also placed on the tables before you. If we may have a proposer and seconder please for each candidate.

To re-elect Robert Gordon as Trustee and Treasurer a proposer and seconder.
To elect Prof Margaret Smith as Trustee a proposer and seconder.

Proposed by Steve Edney and Yvonne Grant

5. Vice Chairman’s report – John Phillips

Parliamentary Meetings
JP referenced a number of events he had personally been involved in, including referencing ones that were held in 2018, further, the Parliamentary meetings when we honoured our Medical advisory Board colleagues; recognised the NHS hospitals we work closest with – presenting awards to people like Dr Catherine DeVile – Great Ormond Street Hospital – and others from the Highly Specialised Centres – Sheffield, Birmingham, Bristol and senior staff in hospitals elsewhere in the UK.

JP recalled to membership about the support BBS were fortunate to gain from many senior Parliamentarians, peers, lords and ladies and senior cabinet ministers.

As VC for the Board JP also attended a number of important meetings held in Westminster, with trustee Gareth Cumming, with Dr Richard Keen of the RNOH along with CEO Patricia discussing our hopes for an adult bone service.

JP updated members about roundtable discussions we attended about inadequacies and shortfalls of PIP and with thanks to Lord Shinkwin who helped arrange senior meetings on this topic, we looked at ways we can perhaps change it for the better. JP expressed hope that members take the opportunity to endorse the work we have done on this.

Corporate Support
JP commented on the work generally of the Board - always looking at ways to improve our standing in various circles and at ways of working, new ways to fundraise, like delivering a presentation to our first corporate sponsor NEXUS in London.

NHS, Adult health service & our MAB
We will continue to attend meetings to help push forward the idea of an NHS service for adults and those things that you tell us matter to you.

JP expressed great pride and pleasure of presiding over a BBS Medical Advisory Board meeting held at his offices in London. A truly outstanding full day of in-depth discussion from what are arguably the worlds best metabolic bone specialists, including Prof Bishop, Dr Javaid and others whom the BBS are so very fortunate to have working closely with us. Helping to craft and steer much of what we do and who in turn assist us achieve our aims to improve quality of life for people with OI. We continue to review our policies and our governance within all of this and we are looking at the T & C’s of some of our committees.
6. **CEO report Patricia Osborne**

**Trustees**
To thank Chairman Elaine and wider Trustee Board for all their support this past 12 months.

**Staff**
Well done to my staff to Coreen, who continues to work tirelessly in her responsibilities of support and all the staff at BBS HQ for their hard work. From April 2018 til August 2019 – we handled over 267 enquiries from you! Support on topics ranging from general info, equipment, schools, travel, adult consultancy, accidental injury, genetics, eyes, dental, hearing, Gyny, Benefits, pregnancy, peer support and more.

**Events**
We launched our OI CAN outdoor event, and hope to roll out more of these and our new ‘healthy living workshops’ once we secure more funding.

We continued to be invited and attend healthcare meetings - POINT team and networking with NHS healthcare professionals to ensure they know of our work and to enlist them to our professional network.

**Fundraising**
Well done to our Fundraising officer - In one project idea alone – we set up our facebook fundraiser which has brought in circa £11k and rising.

**Wheelchair Funding**
- In the past financial our FO co-ordinated over £120k of finance for wheelchairs
- That’s equipment for 29 individuals.
- Since March we are dealing with 21 applications for support totalling £81,825.00
- 12 wheelchairs have been ordered totalling £35k
- 9 wheelchairs are outstanding totalling £46k
  - which we are still seeking funds for
- We raised £1 million pounds in the past 10 years towards wheelchairs!

A member posed a question around funding for wheelchairs and the difficulty of funding adult wheelchairs as opposed to those for children. It was agreed this was sadly true. EH and PO replied in agreement. It was pointed out that The ‘Boparan Trust’ routinely accept funding requests for childrens equipment directly and so free up BBS staff to enlist more time (as needed) in pursuit of funding for adult equipment which is more difficult to obtain.

**Pro bono support**
To thank staff at Jones Day - to solicitor and Head of Pro Bono at Jones Day - Mrs Liz Robertson and many others’. we simply couldn’t afford such high level legal support! Special mention to Emily Kerchell and all the friendly, helpful security and reception staff who are all so welcoming to the Brittle Bone Society.

**Volunteers**
To thank all our UK wide volunteers– who undertook fundraising throughout the year, who carried out fantastic work for us in all manner of projects.

Communications:
- We have achieved thousands of views, hits, likes and reactions.
- Our Wishbone Campaign reached 68,500 people Up 24.5% on last year.
  - Co-operating with OIFE and OIF
- Our Facebook following has grown 20% to 4,683
- A whopping 4000 BBS factsheet have been downloaded from our website since Conference 2018
- Instagram has doubled but its only been active less than a year.

Pharma Support
We both acknowledge and appreciate funding this year again from Pharmaceutical companies to help us meets the high costs of this our biggest expense of the year.

7. Closing remarks, Chairman Elaine Healey
Congratulations to Robert Gordon on being re-elected, and a warm welcome to Prof. Margaret Smith, officially to the Board.

I hope you attend our workshops tomorrow and let us know your views on:
- Our PIP campaign and latest on the conditions insight booklet
- Work with us to help shape our hoped for clinical care guidelines
- comment on research
- find out a bit more about why registries are needed

We still need to find funding for wheelchairs and equipment and Patricia and her team will do what they can to bring in grants for that and for educational and fun events, but we do need you to help us in that journey.

Do enjoy being here in Reading and the remainder of our conference. I look forward to our awards event this evening.

Thank you all for your support.

ENDS.