Minutes of the Annual General Meeting of the Guillain-Barré Syndrome Support Group held on Saturday 20 April 2013 at the De Vere Village Hotel, Wirral

1. Chairman's Welcome

The Chairman James Babington Smith welcomed all members (52 in attendance) to the 28th Annual General Meeting and Conference, noting that this year there would be a rather long Agenda to get through.

2. Annual Review

The Office Executive Caroline Morrice tabled the Annual Review contained in the Trustees' Annual Report for 2012 annexed, which updated Members on the Charity's "Achievements and Performance".

3. Apologies for Absence

The following apologies were given:

Michael and Heather Tighe Anne and Ian Bennett Ann and Roland Price Sandra and Michael Dickson Ian McFadyen **Professor Richard Hughes** Pat Thompson Shirley Richardson Ilse Eton Bob and Sue Fairclough Colleen and John Comber John Larkin Ray Ponsford Janet Wild Andy and Maggie Leitch Jane Ware

The Chairman made particular mention of Maggie and Andy Leitch whose brother was terminally ill and asked all present to join him in wishing Andy and Margaret best wishes, compassion and sympathy at this very difficult time.

4. The Receipt and Adoption of the Examined Accounts for 2012

The Treasurer David Wada outlined the abridged version of the Annual Accounts annexed, which was tabled to all Members. A full version of the Accounts would be made available on request. Particular mention was made of the minus figure for the "Excess Expenditure over Income" (£31,409.64) at the bottom of the first page, which the Treasurer explained was set out as per the Independent Examiner and is in fact the excess of Income. Also noted was the "Board of Trustees Costs" (£2,480.93), which the Treasurer was pleased to announce accounted for less than 2% of the Charity's overall expenses. The Treasurer welcomed questions from the floor, and also indicated that he would be equally happy to answer any questions should Members wish to email him via Head Office. There were no questions, and the Chairman thanked the Treasurer for preparing the Accounts.

It was proposed by Laurence Wilson and seconded by Janet Cuff that the Examined Accounts for 2012 be adopted.

The proposal was carried unanimously.

5. The Receipt and Adoption of the Trustees' Annual Report for 2012

The Chairman intimated that as all Members had had the opportunity to read the Report in advance, and the Charity's activities had been outlined by the Office Executive as part of the Annual Review, he did not intend to paraphrase it. No questions or comments were raised on the Annual Report.

It was proposed by Antonio Sama and seconded by Maureen Foster that the Annual Report for 2012 be adopted.

The proposal was carried unanimously.

6. Election of Trustees

(a) The Chairman invited the Founder and Honorary President Glennys Sanders MBE to hold an election for the appointment of Chairman. Glennys thanked all Members for attending the AGM and advised that a nomination had been received from James Babington Smith for re-election as Chairman and asked for a proposer and seconder.

It was proposed by Maureen Foster and seconded by Howard Saunders that James Babington Smith be re-elected as Chairman.

The proposal was carried unanimously, and Glennys offered her sincere thanks to the Chairman and hoped for continued success.

(b) The Chairman advised that in accordance with the Constitution one Trustee must retire on rotation at the end of this AGM. A nomination had been received from William Harmer who had also been nominated for re-election as a Trustee.

It was proposed by David Wada and seconded by Russell B Hamilton that William Harmer be re-elected as a Trustee

The proposal was carried unanimously, and the Chairman offered his congratulations to William Harmer.

7. Appointment of Independent Examiner

The Treasurer recommended that Aynesley Walters Cohen Ltd be reappointed as the Independent Examiners for 2013.

It was proposed by Glennys Sanders and seconded by S Lawrence that Aynesley Walters Cohen Ltd be reappointed as Independent Examiner for 2013.

The proposal was carried unanimously.

8. Consideration of amendment to membership categories

Recommendations were tabled by the Office Executive as set out in Proposal 1 of the "AGM Proposals" circulated in the Charity's Spring 2013 publication of "In the Know", and copied to Members at the AGM as annexed. Questions were raised relating to the use of a franking machine to keep postage costs down – the Office Executive confirmed that this was already in place. The Office Executive also answered the question in the affirmative relating to whether the Charity would consider dealing with individual hardship cases whereby Members could pay in instalments. It was also suggested that those Members receiving a complimentary copy of "In the Know" should, after 1 year, start to receive an email version to reduce costs. It was also noted by Members that "In the Know' had greatly improved – the Office Executive advised this was down to the efforts of Lesley Dimmock in Head Office.

It was proposed by Barbara Bradley and seconded by Helen Howell that amendment to membership categories be accepted.

The proposal was carried unanimously, and the Chairman thanked Members for their consideration, stating that Head Office would continue to streamline in these difficult economic times.

9. Consideration of change of charitable status

A new legal structure for the Charity was tabled and discussed by the Chairman, as per Proposal 2 of the "AGM Proposals", and as laid out in the "AGM 2013 – The Way Ahead" circulated in the Charity's Spring 2013 publication of "In the Know", and copied to Members at the AGM as annexed. The Chairman indicated that it made considerable sense to convert to a Charitable Incorporated Organisation (CIO), thereby reducing our insurance costs whilst protecting Trustees from any financial liability the Charity may incur. A new Constitution would require to be drawn up, however fundamentally the aims of the Charity would remain exactly the same as defined, as would any dealings with the Charity. The Charity would still maintain an inactive 'shell charity' under the current GBSSG name in order that we could process any funds or legacies received in that name. It is anticipated that an Extraordinary General Meeting of the new CIO to elect a Board of Trustees would be held in the late autumn of 2013, followed immediately by an Extraordinary General Meeting of the GBSSG in order to transfer assets and liabilities of the Charity to the CIO, which it is proposed should be launched on 1 January 2014. There were no questions from Members, noting that this was a good move going forward and a very wise decision to provide protection for Trustees and to maintain a 'shell charity'

It was proposed by Gerry Hunt and seconded by Janet Cuff that change of charitable status to CIO be accepted.

The proposal was carried unanimously, and the Chairman thanked Members for their consideration, stating that their support was very good news.

10. Name of charity

The Chairman addressed the question of changing the Charity's name from GBSSG, which we have had for 29 years. It was understood that some patients with CIDP and MMN for example did not realise we also existed to support them. It was felt the current name did not reflect the full scope of conditions, particular as we now receive more than 25% of referrals relating to chronic conditions. It was therefore necessary to select a name that would reflect the scope of illnesses whilst retaining GBS in the name. Dr Lunn of the Medical Advisory Board had come up with the name GAIN, an acronym of Guillain-Barré & Associated Inflammatory Neuropathies, which the Trustees had accepted. It was now necessary to convince the Charity Commission. There was a consensus amongst Members and Trustees in favour of the new name GAINS, in particular they felt this was a tremendous marketing tool and an opportunity to re-brand in order to engage with more people, to attract more funding, grow, and therefore help more people. The Office Executive added that in terms of web traffic, all references to the illnesses, whether it be GBSSG, GBS, CIDP, GAINS etc, would all be

linked to our new website by association, with the aim of being the number 1 site for such illnesses.

However, there followed a discussion amongst Members with regard to the existing tortoise logo. The Chairman announced the Trustees would run a competition for a new logo as there was an argument that the tortoise was no longer felt appropriate as not all patients were "getting better slowly", and indeed it did not now suit all the different variations of the disease such as CIDP. However, the majority of Members were in favour of retaining the tortoise logo as this was seen as part of the historical legacy of the Charity and easily identifiable. The Chairman stated that as there had been a clear majority in favour of retaining the tortoise logo, the Trustees would still run a competition and Members could send in their tortoise designs and the winner would receive a bottle of Champagne. Competition entries would need to be accepted by 20 May 2013 for inclusion in the June issue of "In the Know", and Members would vote for their favourite tortoise logo. The top 3 logos chosen would be voted on at the Extraordinary General Meeting anticipated to be held in the late autumn of 2013.

11. Closing

The Chairman closed the 28th Annual General Meeting and Conference by thanking all those attending, and proposed a special note of thanks to Caroline Morrice, Lesley Dimmock and Graeme Morrice for all their hard work in setting up the Conference. Particular thanks go to Graeme Morrice who is not a Trustee and yet plays an invaluable part in organising the day.

12. Date of Next Meeting

17 May 2014 in Swansea.