

The Sophie Cameron Trust

Minutes of the Annual General Meeting held on Monday 30th October 2007 at 7.30pm The Royal High School, Bath

Those Present:

Richard Wharton	Chairman
Mark Hynes	Treasurer
Bernard Whiteside	Chairman of the SCT Fund Raising Committee
Michael Robson	
Sue Lucas	

David Holden Guest Speaker

Judith Cameron, Phillip Cameron, David Edmonds, Sue Howell, Tony Howell, Vivien Hynes, Henrietta John, Royce Menezes, Alex Menezes, Jo Seddon, Teresa Wharton, Theresa Whiteside,

1. Apologies were received from Sandy Joakin, Richard Steele, Derwent Campbell and Professor Gavin Giovannoni
2. The Chairman read out the minutes of the last AGM. There being no matters arising the Chairman duly signed the minutes.

Proposed By Bernard Whiteside Seconded by Sue Lucas

3. The matter arising regarding the re-election of the Trustees who had already served a 5 year term was addressed. Derwent Campbell had kindly researched this and the rules of the charity trustee constitution were redrafted so that Richard Wharton, Sandy Joakin, Derwent Campbell, and Michael Robson were able to stand for another 5 year term of office.

There were no new nominations for the officer posts and it was agreed that the officers should therefore be re-elected.

Richard Wharton was proposed as Chairman by BW seconded by MH
Sandy Joakin was proposed for Secretary by MH and seconded by MR
Mark Hynes was proposed for Treasurer by RW and seconded SL
Michael Robson was proposed for re-election by RW and seconded by BW

Derwent Campbell was thanked by those present for sorting this out.

- 4 Mark Hynes, the Treasurer, then presented his report (as attached)

The donations from PWC (Pricewaterhouse Coopers) are not included in this analysis.

Sue Howell was thanked for the enormous amount of work that she did in claiming tax refund for donations which amounted to £9,000 plus.

“Just giving” is an efficient way to pay money into the trust but it does obscure where the monies from. The most successful events had been the Glitter Ball, the Bath Half Marathon and the Tony Benn evening.

Mark noted that the expenditure line is research and administration and the administration line is well below the national average.

Richard Steele (Research) expects to spend £25,000 over next year and so that leaves about £100,000 in the bank with HSBC and the CAF interest rate is at 5.4%

The accounts are audited by Moore Stephens.

RW moved to reappoint the auditors, Moore Stephens, Chartered Accountants, Gay Street, Bath, and to fix their remuneration for the financial year. The proposal was seconded by MH

The following points were discussed:

1. Charity Insurance: It was decided that we would remain with our current insurer.
2. Match Giving programme: This was an excellent idea by PWC and we could possibly involve other organisations in this.
3. The income is steady if we add in the PWC contribution. It was noted that the trust has to envisage less income in the future but we do have a good residue of funds.

RW thanked Mark Hynes for doing the accounts.

- 5 The Chairman of the SCT Fund Raising Committee, (Bernard Whiteside) gave his report, (as attached).

The SCT Continues to be grateful to the Royal High School for its continuing support to the Trust. This year a memorial concert to Sophie was held in March and raised £1,000.

BW remarked on the generosity of the local community and also the number of donations that are received from various sources, in particular mentioning the family of Mrs Muriel Knowles. Mrs Knowles suffered from EL and died earlier this year and the family gave the donations of her memorial service to the Trust.

This year the trust has been very fortunate to be part of the Price Waterhouse Cooper’s “Matched Giving Programme” where staff undertake charity fundraising events, and monies raised are matched by the employer. Roy Fleetwood a friend

of Sophie's family along with his colleagues organised several events and as a result £12,000 has been raised for the SCT.

BW commented on the loyalty in the SCT as shown by the reappointment of the trustees and the fund raising committee who all give their time not only supporting the charitable events but also in the mundane tasks such as licking envelopes and shaking tins. He commended to the Chair that it is only through the hard work of this Committee that the fund raising happens and a particular mention of thanks was given to Sue Howell for all her work in the gift aiding revenue, book keeping and fun raising.

A bouquet of flowers was given to Sue Howell.

The SCT web site is now up and running and many thanks were given to Andrew's Estate Agents, Phil Cameron and Vivien Hynes for all their hard work in establishing the site.

Many thanks were also given to all those who ran the last Bath Half Marathon which raised £6,000. A special thank you was given to Gareth Lloyd, Deputy Headmaster of Kingswood School who completed the London Marathon and raised over £3,000 for SCT.

This year's Bath Half Marathon is on Sunday 16th March 2008 and we have 20 gold bond places to fill. David Holden our visiting speaker showed an interest in the Bath Half Marathon and suggested he would share this with his colleagues. He was reminded that they could register online.

BW thanked all the Committee Members.

RW thanked BW and also all the rest of the fund raising committee.

6 Research (paper attached).

Richard Wharton gave the report on Research on behalf of Richard Steele:

Joel Vilensky in collaboration with Dr Mukhamedzyanov has published an article on EL in Russia. Joel Vilensky has been invited by Gavin Giovannoni to give a paper on EL at the Institute of Neurology on 17th June 2008. The SCT is covering some of Joel Vilensky's expenses and it is hoped that this paper will be linked to the SCT website.

Dourmashkin's Electron Microscope research may not go ahead. It is dependent on the university agreeing to maintain the EM.

The most important area of research being funded by the SCT at present is the national surveillance programme led by Gavin Giovannoni, and David Holden is a co-investigator.

RW then introduced David Holden from the Queen Mary University in London who is funded by SCT for 1 day per week. He works at the Neuroimmunology Unit, Neuroscience Centre, Institute of Cell and Molecular Science.

David Holden explained his work to the AGM and gave a summary of the surveillance programme. He was asked if he would write a report for the website and Phillip Cameron was asked to co-ordinate this. This report can now be viewed on the SCT website.

The aim of the National Surveillance programme is to involve all the neurologists and paediatric neurologists in the UK, who are sent a monthly electronic questionnaire. Once a probable case of EL is recorded and consent is given by the patient to be included in the study, then the consultant neurologists and David Holden have access to the patients' notes, CSF and existing blood samples. A letter is also sent to the patient from the SCT at this stage.

David Holden imports the patients' data into a database whose format allows comparison to that collected by Joel Vilensky's historical data.

In reply to David's' talk it was raised that the SCT was excited about this research and wanted to support both the neurologists and the people and families affected by EL. This support to families should be both supportive with knowledge and, if necessary, also financial.

- 7 The chairman RW reported that on the 22nd January 2008 the Encephalitis Trust is holding a seminar in London and it is proposed that the SCT should have a stand with leaflets about the SCT. Volunteers were requested to run this stand.
- 8 Questions were taken as the meeting progressed: one question raised was "where is the trust going" and the reply was that the trustees have a mandate to review this in three years time.
- 9 There were no other matters raised.
- 10 The chairman thanked the Royal High School for making the facilities of the RHS available to the SCT for the meetings. Other members of the audience were also thanked for their attendance and support of the SCT.

Phillip and Judith Cameron thanked the SCT and also David Holden was thanked for visiting and talking to the SCT.
- 11 The date time and venue for the next AGM will be advised as soon as possible and it is noted that appropriate notice needs to be given to allow for publicity in the newsletter.

The meeting was then closed and everyone was invited to remain for “eats and drinks”.