

The Sophie Cameron Trust

Annual General Meeting
Monday 10 November, 2008
at 7.30pm
The Hudson Centre
The Royal High School, Bath

MINUTES

1. The Chairman, Dr. Richard Wharton, welcomed everyone and thanked Miss Linda Bevan, Assistant Head of the Royal High School, for her attendance at the meeting, for the use of the school for the AGM and for the continued support of the school for the SCT.
2. Apologies were received from the Treasurer, Mark Hynes.
3. Extracts of the minutes of the 2007 AGM were read by Sue Lucas. There were no matters arising and the minutes were adopted.
4. In relation to the election of Trustee Officers, there being no-one else who wished to be nominated, the following were duly elected to serve:
Sandy Joakim was proposed as Secretary by Michael Robson and seconded by Sue Lucas.
Mark Hynes (in absentia but with his approval) was proposed as Treasurer by Derwent Campbell and seconded by Bernard Whiteside.
Richard Wharton was proposed as Chairman by Sandy Joakim and seconded by Richard Steele.
5. It was reported that the Financial Statements for the SCT for the year ended 31 December 2007 had been received, considered and accepted by the trustees and that the accounts had been submitted, on time, to the Charity commission. Richard Wharton, on behalf of the Treasurer, spoke to the related report (see Treasurer's Report on file). There were no questions but there was general agreement that it was good that funds raised had now been allocated for research, fulfilling the aims and objectives of the trust. The Treasurer was thanked for all his work in the preparation of the accounts and reports.
6. Richard Wharton proposed that Moore Stephens be re-appointed as auditors for the trust for the coming year. This

was agreed and acknowledgement was made of the hard work of Robert Branch.

7. No formal report was made by the Chairman but he spoke and commented throughout the meeting.
8. The report from the Treasurer was made by Richard Wharton. (See 5. above)
9. Dr Bernard Whiteside gave the report on the current status of fundraising for the trust. He made the point that funds had previously been raised through the loyalty and commitment of many to Sophie, to the trust and to the aims of the trust and that such support had been recognised and greatly appreciated by the trustees. Dr. Whiteside explained that in 2007 the trustees determined that large-scale fundraising activity should be suspended, but that consideration would be given to the disbursement of funds for research projects. He also made reference to a review of the future status of the trust and explained that the amount of £7,700 shown in the accounts reflected only income from interest payments.

Dr. Whiteside gave special thanks to Sue Howell for her commitment to the work of the Fundraising Committee and to Chris Fry for his work on the SCT website.

Richard Wharton expanded on the comments made by Dr. Whiteside in relation to the 'review'. He explained that the trust has now accomplished what it had set out to do and in acting as a catalyst, had significantly raised the profile of EL. He further stated that during the coming year the trustees would consider the options in relation to the future of the trust and would report back at the next AGM. He explained that in the interim the commissioned research would progress and in inviting Richard Steele to speak to his paper, 'Research Developments', he thanked Richard warmly for the very significant contribution he has made to the SCT research programme.

10. Richard Steele addressed the key points of his paper (copy on file). He spoke about the national surveillance project, the textbook on EL being written by Professor Joel Vilensky which is dedicated to the memory of Sophie, the Sophie Cameron Trust PhD Studentship, the importance of the SCT website as a central source of information on EL, the research on the targets of anti-basal ganglia antibodies and the seminar on EL lead by Joel Vilensky. He made the point

that all of these projects have received funding from the SCT.

Richard Wharton commented that Joel Vilensky's lecture in the summer was particular a high point, attracting the attention of numerous eminent neurologists. Dr. Wharton also took the opportunity to provide some biographical information about the PhD student, stating that her name is Priyamvada Dua and that her academic record is impeccable. He suggested that Ms Dua be invited to speak at the 2009 SCT AGM and provide an update of progress with her studies. In relation to the surveillance programme, Dr. Wharton explained that the trustees believed that the programme is very important and therefore had made a recent commitment to provide a further two years of funding for the project. He concluded by thanking Richard Steele once more for being responsible for driving forward and managing the research funding so effectively and efficiently and by reflecting on the fact that earlier sponsorship of a research paper on EL in "Brain" by the SCT prompted a reaction that has taken the study of EL to the international academic research forum and that everyone connected with the SCT should be proud of our achievements.

11. Royce Menezes who lead the physiotherapy research programme with Sophie, thanked everyone who had helped with the programme, adding that his paper is now on the SCT website.
12. The Secretary confirmed that the date for the 2009 SCT AGM will be 'the second Monday of November' at 7.30pm at the RHS. Richard Wharton then invited Sandy Joakim to give her presentation on the research and work of Joel Vilensky. Mrs. Joakim informed the meeting that Professor Vilensky has received funding from the SCT to help with the development of this important study and that Judith Cameron has assisted him with aspects of the book. Sandy began her presentation with a message from Joel Vilensky which highlighted the complexity of EL. She then explained that extracts from both the (draft) book and an article written by Professor Vilensky for "Timeline" magazine had been selected and that both focussed on the 'self-reports'.

Following the presentation, everyone was invited for 'drinks and food'.

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