

October 2007 - [NEWSLETTER](#)

Dear Friends

Following our newsletter last March, I am pleased to inform you that our new website at: www.thesophiecamerontrust.org.uk is now up and running. We are grateful to Andrews Estate Agents who donated the time of their IT staff to build it. Do search on it for full information on past and future fundraising events as well as more detail on the variety of research in which the Trust is involved. You can also sign up on-line for next year's **Bath Half Marathon on Sunday 16th March** 2008. You have plenty of time to get fit and the website even has a suggested training programme. If you can't run, you can still support us on the day and sponsor one of the team.

As always, this year's race was a success and continues to be a major fundraising opportunity with around £6,000 raised. Being a regular member of the team, I do know it's great fun, but equally appreciate how gruelling the training is for the runners. We thank you all and do hope that you will sign up again next year - we need you! Of course, Gareth Lloyd, deputy head of Kingswood School, put in even more training when he competed in this year's London Marathon on behalf of the Trust and we send him our congratulations in raising over £3,000 for our charity.

Much of the money raised by the Bath Half Marathon and Gareth's London Marathon was through our presence on the charity website: www.justgiving.com This allows on-line donations to be easily and securely made as well as automatically claiming back income tax if applicable. Do use it if you can.

We continue to be grateful for the continuing support of the Royal High School who held a beautiful memorial concert to Sophie at the end of March. As always, the quality of the music was exceptionally high and it was understandably well attended with nearly £1,000 earned for the Trust.

This year, the Trust has been very fortunate to be part of Pricewaterhouse Cooper's 'Matched Giving Programme' where staff undertake charity fundraising events and the monies raised are matched by the employer. Roy Fleetwood, a friend of Sophie's family, along with his colleagues organised Quiz nights, Dinners, Auctions, Treasure Hunts and even

a Slimathon. As a result £12,000 has been raised. This is a fantastic gesture made by Roy and Pricewaterhouse Coopers. We very much hope that in consequence, other Trust supporters working for large companies will approach their own employers for similar ventures.

We are grateful for all donations, however large or small, for our worthwhile cause and rest assured that they are well managed by our treasurer, Mark Hynes. Given that all committee members are volunteers, overheads are minimal with over 90% of income committed to the charity's aims in research with any residual funds kept in high interest accounts.

The most exciting news on the research front is that the UK national surveillance program for EL will start in autumn this year, after almost 2 years of planning. This project is led by Prof. Gavin Giovannoni, who is SCT's Scientific Adviser, as well as Dr Anette Schrag (consultant neurologist at the Royal Free Hospital) and Dr Cheryl Hemmingway (paediatric consultant neurologist at Great Ormond Street Hospital). Our initial funding is for 2007/2008, but this is expected to be a long-term project.

We also recently approved a 2-year extension of funding for Prof. Vilensky's work in the US to help with data entry into his database of EL signs and symptoms, and analysis of the results. We hope that this will eventually lead to faster and more reliable diagnosis. Prof. Vilensky recently published an interesting article on "Children and encephalitis lethargica: A historical review" in the journal *Pediatric Neurology*. Details of all SCT's research projects are available on the new website (www.thesophiecamerontrust.org.uk/research-overview.htm).

Our **AGM** takes place at **7.30 on October 29th at the Royal High School Bath**. Please make a note of this in your diary as it is an opportunity for you to hear in detail what the Trust has achieved during the past year and what it hopes for the future. We will be joined by Prof. Gavin Giovannoni and his research manager David Holden who will make a short presentation on the areas of their research that the Trust supports.

It would also be a pleasure to have the opportunity to meet you and have a chat over a glass of wine and canapés. Do approach us if you are interested in becoming a Trustee of the SCT or if you would like to get involved in any future fundraising. One particular event in the past that was a great success was 'An evening with Tony Benn'. We would love to repeat the occasion with another public figure who could fill the Kingswood theatre but to date, the committee have drawn a blank. Do you know anyone who could be interested in supporting

a small local charity in this way? If so, please tell us. But in any case, do come along to the AGM and help us get to know you, our valued supporters.

In the meantime, I send you my warmest regards.

Bernard Whiteside

Chairman

PS. Once again, may I encourage those of you who regularly use the internet to receive this newsletter by email in future. Simply contact us on mail@thesophiecamerontrust.org.uk to help keep our postal costs to a minimum.