

# The Sophie Cameron Trust



September 2006

Dear Friends

As I am sure you will have heard, Sophie died unexpectedly on May 30<sup>th</sup> from a virulent chest infection. She was at home with her father at the time of her death and suffered no pain. We are all grieving but send our heartfelt condolences to her family. After a summer when our thoughts have been very much with Sophie's family, the trustees met to consider the future. The strong feeling was that the trust must continue in Sophie's name, and build on the firm financial foundations thanks to your help that we have established, to support research into Encephalitis Lethargica, increase awareness of this devastating disease and help its victims.

On the research front, we are pleased that the national surveillance programme for EL is moving forward. SCT will be cooperating with the department of health which plans a programme to monitor all types of encephalitis in the UK. We will support the salary of the research worker, and hope to identify cases nationally through neurologists in NHS hospitals. Also, those already known to have had the disease are being contacted by letter. Dr Gavin Giovannoni, our scientific adviser, has recently been appointed Professor of Neurology at Barts and the London Hospitals, and will be developing a research team there, who we hope will continue the work on the causes of EL which we previously sponsored at Queens Square, London. We will be meeting with Gavin during the autumn, but meanwhile congratulations to him on his prestigious appointment.

There is growing international interest in Encephalitis Lethargica we are pleased to have supported Professor Joel Vilensky with his publication in the USA of "Diagnosing EL" in Practical Neurology, and further work to be undertaken on Russian literature on the disease.

Closer to home, The Royce clinic is continuing to work with Kelly Brooks, who has made great strides in her mobility and independence under Alison's capable tutelage. She can now get onto her buggy and travel to school or town. Alison and Royce have also laboured long and hard on the research paper emanating from their work with Sophie, which is almost complete. The clinic is also housing equipment used for this project, until a new user can be found.

With the evenings drawing shorter, I hope you will find time to participate in one of the planned fundraising events for this autumn. We are delighted to enclose the menus for the renowned **Pot Luck Dinners** during the period **27<sup>th</sup> October – 9<sup>th</sup> November**. This is a wonderful way to enjoy excellent food with friends or meet new people. Our other event is a **Rock'n'Roll** evening with live band '**Revival**' on **Friday 1<sup>st</sup> December** at **Oldland Village Club, Bristol**. Please return the tear off slip at the end of this letter for tickets at £12.50 each to include a bangers and mash supper.

**Patron: Baroness Warnock    Scientific Adviser: Dr Gavin Giovannoni**  
**The Sophie Cameron Trust is a registered charity no. 1092190**  
**107 St Thomas Road, Trowbridge, Wiltshire, BA14 7LT**  
**Tel: 01225 785024    E-mail: [mail@thesophiecamerontrust.org.uk](mailto:mail@thesophiecamerontrust.org.uk)**  
**[www.thesophiecamerontrust.org.uk](http://www.thesophiecamerontrust.org.uk)**

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Earlier this year, the Bath Half Marathon raised £6,300. We apologise for the difficulty in finding us on the day and promise that next year, our presence will be more noticeable. Nevertheless, it was a brilliant day and we thank all our supporters but particularly the Illingworth family for their tremendous efforts and success in raising funds. Needless to say, I ran again and will do so again next year but what about you? **Sign up now for the 2007 Bath Half Marathon on Sunday 25<sup>th</sup> March** on our website [www.thesophiecamerontrust.org.uk](http://www.thesophiecamerontrust.org.uk) As long as you are healthy and build up the training schedule gradually, it is easily attainable and the adrenalin rush afterwards is truly amazing! We are in the process of arranging for details of a sustainable training schedule suitable for new runners that will be soon posted on the website.

We are very grateful once again to Anna Bernard and the Royal High School Bath for the beautiful concert performed at the end of March of **Fauré's Requiem** and **Debussy's Petite Suite**. As always, the standard of the performance was superb and £1,000 was raised for the Trust.

Finally, with the ever expanding use of internet, would you prefer to receive your bi-annual newsletter on-line? Simply drop a line to [mail@thesophiecamerontrust.org.uk](mailto:mail@thesophiecamerontrust.org.uk) and next spring, your newsletter will turn up on your screen instead of your doorstep.

Sophie was a very special person; thank you all for your continued support of this very special charitable trust.

Kind regards

Bernard Whiteside  
Chairman

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Cut along here -----

Please send to: Theresa Whiteside, 46 Barry Road, Oldland Common, Bristol BS30 6QY

**REVIVAL'S**  
**“Rock’n’Roll Extravaganza”**  
in aid of  
**The Sophie Cameron Trust**  
At Oldland Village Club  
West Street, Oldland Common, Bristol BS15 6QR  
Friday 1<sup>st</sup> December 2006 From 8.00pm to 12.00pm  
With Licensed Bar

Please send me ----- tickets for the Rock’n’Roll Extravaganza at £12.50 each to include a supper of bangers and mash. I enclose herewith a self addressed envelope and a cheque for £----- made payable to The Sophie Cameron Trust.

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