

# Newsletter

June 2003

Dear Friends

We are writing once again with news from The Sophie Cameron Trust, and initially invite you to join us at our next important event:

## **A Political Life:** an evening with **Tony Benn**

Following the success of his appearances at the Edinburgh Festival and various venues across the UK, Tony Benn is supporting our Trust at **Kingswood Theatre Bath on Friday 19<sup>th</sup> September 2003 at 7.30 pm**. To obtain tickets at **£15 each**, please complete and return the attached form.

We continue to be delighted with the incredible support and local interest for Sophie and the Trust. Once again, we had excellent support for the **Bath Half Marathon**, with over 40 runners from far and near and our team double-decker was a focal point for drinks and snacks. It was a beautiful day and the atmosphere was wonderful. Photos and details are on the website [www.thesophiecamerontrust.org.uk](http://www.thesophiecamerontrust.org.uk) as well as an on-line form for you to enter next year's event. You need to register as soon as possible – due to the oversubscription of the run, many latecomers had to be refused this year. We have already received £6,500 in sponsorship from the event and money is still arriving daily.

On a personal note, it was 3 years ago that I first ran in the Bath Half Marathon, which coincided with the launch of the Trust. It was an opportunity to raise some funds, to cajole my son to take part and to complete the course with the feeling of a job well done. But then the Bath half became a major event in support of the trust. I could not resist and returned year on year and developed a desire for more.

Where has that led me? Yes, to The Big One! A full marathon. Not London, but **New York** on November 2nd. On route I will need to maintain the momentum so, hopefully will raise some funds for the Trust along the way. So I am taking part in both the Plymouth and Bristol half marathons – please support me if you can.

Participants in a more sedentary experience raised over £2,500 last Autumn with the **Pot Luck Dinners**. A wide variety of venues and cuisine was enjoyed by the 100 guests. We are grateful to the local restaurants and hotels who contributed to the event as well as many private supporters of the Trust. The feedback following the Dinners was very positive and we plan to repeat the experience early in 2004.

At the **Royal High School** on 31<sup>st</sup> March, there was a gathering of over 100 girls, singers and instrumentalists, who performed to an audience of parents, governors, and staff in the School Chapel. The varied programme of soloists, duettists, saxophone quartet, harpist, the Orchestra, *Cantilena*, the Madrigal Group, *Polyphony*, clearly demonstrated the aim of all concerned – to display the results of weeks of rehearsal, both personally challenging and socially rewarding. Individual highlights included soprano Alice Usher's moving and controlled aria by Handel, "Farewell, ye limpid springs", and Julie Sharp's exciting Brahms sonata movement for clarinet. These girls led the way for younger talent that included Charlotte Fox's "I could have danced all night" and Zoë Bristow's confident keyboard dexterity; both enthusiastically received.

The Madrigal Group, who had won their class in this year's Mid-Somerset Festival, demonstrated an enviable degree of ensemble and involvement, the result of firm friendships amongst its members. Smiles were everywhere at the conclusion of the evening as *Polyphony* sang "Bohemian Rhapsody" with a fervour that was almost tangible. Mr Cockerham and Mrs Bernard were the tireless and inspirational directors. We are very grateful for the continued support of the Sophie Cameron Performing Arts at the school which has raised a total of £514.63 this year.

We would also like to thank the **FFKES** (the committee of Former Fathers of King Edward's School Bath) for their continued support and generosity to our Trust following their Burn's Evening celebrations earlier this year.

Another event planned to support the Trust is the **Glitter Ball** to be held at the Assembly Rooms on December 13<sup>th</sup> 2003. We are very grateful to have been chosen as one of the two charities to benefit from this renowned Christmas celebration which has been resurrected this year. Tickets are £40.00 per person and will be on sale later this year. For further information in the meantime please contact Vivien Hynes (tel: 01225 317891).

The Trust's **Research Programme** is now up and running with two main areas of funding. Firstly, we are undertaking a national retrospective study, to establish the numbers of cases of Encephalitis Lethargica (EL) in the UK in the last two decades. This will enable us to proceed to study these cases for clues as to the causes and treatments for the disease. A pilot study in the South West is almost complete, and the full national study is planned to be completed this year. Secondly, we have established links with the British Institute of Neurology at Queens Square London, where researchers have a strong track record including an interest in EL. We will be sponsoring a programme to look at Brain Proteins in EL, which may help to understand what happens when this disease strikes, and how we can modify this process. This is a long term project, which we hope will lead to further research projects investigating EL. Further information on this project is posted on our website [www.thesophiecamerontrust.org.uk](http://www.thesophiecamerontrust.org.uk)

The Trust also continues to help **Sophie's treatment** and has obtained an electrical ankle mobilizer in preparation for standing posture as well as a newly developed unit that allows her to be suspended in the standing position. The suspension unit has the added advantage of being able to measure how much weight Sophie takes through her own legs. A few months ago, Sophie was able to take all her body weight for a few seconds and this has built up to several minutes and she continues to progress. Sophie has recently been doing some assisted exercise on an elliptical trainer as well. This is to try to teach her the walking pattern and hopefully she will be able to progress to a treadmill in time.

Sophie's friends and family continue to be hopeful for her future and are enormously grateful to the support the Trust has been able to give.

We are once again enclosing a Gift Aid form for signature. **Please note this is NOT a request for money**, merely a signature from those of you who are tax payers and have, in the past supported the Trust with a donation. With this form signed, we can benefit from the tax paid.

In the meantime, many thanks for your continued support of the Trust to help Sophie and others with her condition. Do order your tickets for the Tony Benn evening and put the date in your diary as for the Glitter Ball.

Yours sincerely

Dr Bernard Whiteside  
Chairman