



Issue 34 Newsletter by the Chief Executive



When I started CRY in May 1995 some of the more cynical medics suggested that as such deaths were only up to 50 a year a dedicated charity would be a waste of time and that I should find something more useful to do with my time. **Recent information from experts suggest that it is now thought that up to 500 young people a year are dying suddenly in this way.** With such a sobering statistic it is an appropriate moment to announce our first CRY Bereavement Support Day on June 14 which will be held at The Institute of Child Health, near Euston station, London, and which has been made possible by our award last year of a grant from the Department of Health.

We will be introducing our CRY counselling trainees who in March finish their second year of study with the completion of their Skills and Theory training. There will be workshops focusing on young deaths affecting specific groups including loss of siblings, partners, young children, adolescents, and young adults. Presentations will confront some of the issues around coping with the tragedies. Most importantly of all, the day will highlight the support that CRY can offer those affected by the tragedy of a young sudden cardiac death and give them the opportunity to make contact with others who have suffered from the same cataclysmic event.

Our chairman Dr Greg Whyte will launch the event and talk briefly about CRY's unique remit with regard to young sudden cardiac death, CRY's Patron Professor Bill McKenna will explain how undiagnosed cardiac conditions can present as young sudden death and Dr Elijah Behr, Specialist Registrar in Cardiology at St George's Hospital, will be speaking on the Ion Channelopathies (Long QT, Brugada). This will be followed by an extended Q & A session when you will have the opportunity of putting your questions to

Professor McKenna and Dr Behr.

We are pleased finally to be able to progress the support we can offer and are most grateful to the Department of Health for their endorsement of our counselling work with our grant funding award.

Just before last year's Winter Olympics in Utah, our Chairman Dr Greg Whyte was in touch with Professor Michael Vincent, a world expert on Sudden Arrhythmia Death Syndrome and Founder of the SADS Foundation. On learning more about our work from Professor McKenna he invited me to join their presentation at his medical conference last Autumn and speak about our goals. I am delighted to be able to announce that Professor Vincent has subsequently become a Patron. Having the support of a world expert on arrhythmia represents an important step for CRY and will also help us field the large number of enquiries we get through our web-



Peter Mandelson with the CRYette's

site from America.

I recently attended a fundraising dinner in Durham in memory of Levon Morland and was reminded why we have made such advances in Westminster when Peter Mandelson was introduced as a guest speaker, and a letter was read out from Tony Blair apologising for not attending and wishing Sandra and Jeff Morland a successful evening noting "with the money going to CRY it is certainly going to a worthwhile cause."

This year we took the very bold step of investing in having our Christmas Cards printed professionally



Professor Michael Vincent
SADS Foundation USA



Church Eaton, Staffs

and they were a great success with over 1,546 packs being sold. The most popular was a lovely painting by John Bennett in memory of his daughter Laura which sold over 424 packs.

Critical to this success was the support and encouragement given us by Caroline Gard who committed a huge amount of time and energy to developing this terrific chance for us to raise awareness of CRY at a much higher level.

In December I was asked to speak on the impact of sudden cardiac death at The Athletes Heart Symposium. This was a meeting attended by international sports cardiologists, and physiologists, and Dr Domenico Corrado's presentation highlighting the success of the Italian screening programme was particularly pertinent. It was frustrating that the concluding debate on the viability of proactive cardiac screening of young athletes was curtailed just as delegates were starting to vociferously engage in the discussion.

In September we had the inaugural meeting of the CRY SS Club which is being funded by our Department of Health grant. This club is for those young people who have had or are about to confront potentially life saving surgery including ablation, and implantation of ICD or pacemaker, and want to help others going through the same experience. We had an excellent weekend with our course tutor Julia Cayne giving training in listening skills. The highlight



Elijah taking a Q&A session at the first SS Club

of the day was Dr Elijah Behr's Q & A session when those attending were invited to ask the questions that they have never quite got round to asking their own cardiologist! A truly testing time for Elijah who seemed to thrive on the challenge posed by this energized group of young people.

Recently a journalist asked me what changes there had been since a Radio 4 interview over 2 years ago, when the Director of the National Screening Committee Dr Muir Gray and I discussed the value of proactive screening. This was a useful question as

my on-going frustration that we could do more - and better - sometimes overrides what we are achieving. Certainly in the last 2 years there has been much progress. There is far greater awareness not only of these deaths but of the devastation such deaths cause and this has been reflected in our government grant for the development of our counselling programme. Government concern is much more acute which was illustrated by the interest shown in our reception in Westminster last spring and the instigation of our All Party Parliamentary Group which gives CRY access to parliamentarians.



Greg at the CRY Centre for Sports Cardiology

The launch of our CRY Centre for Sports Cardiology now gives all athletes concerned with heart conditions a centre of excellence to receive expert advice and attention.

We have printed our first (100 page) book of CRY's Contribution to Research and our Chairman Dr Greg Whyte and Trustee Dr Sanjay Sharma are working with the National Screening Committee to ensure that CRY's field-gathered data fulfils the criteria they require when evaluating the efficacy of pro-active cardiac screening.

Improvements in medical technology have not only resulted in greater accuracy for non-invasive testing procedures, but also enabled tremendous progress to be made with the development of pacemakers and defibrillators. Instead of these being the size of half a brick and in the stomach, they are now the size of half a matchbox and placed in the chest and our CRY SS Club is a celebration of young lives that are being saved with implantation.

Ultimately this is our goal; this is our campaign: to find young people in time and save lives - and you are the bedrock of any progress that has been made.