



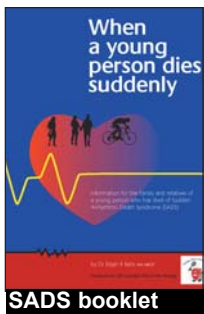
Issue 37 Newsletter by the Chief Executive



The cascade of events that have propelled CRY forward into August 2004 began as soon as we returned from our Christmas break.

On January 5 after the successful 2nd reading of her Cardiac Risk in the Young (Screening) Bill Dari Taylor MP promptly invited our consultant cardiologist Dr Sanjay Sharma and CRY Chairman Dr Greg Whyte to be her medical advisors to draft the medical case for screening for her debate.

Our mailshots appealing for you to contact parliamentarians in support of Dari's Bill resulted in hundreds of letters arriving on the desks of the Department of Health, MP's, Ministers and even the Prime Minister. It produced 80 press articles in 8 weeks and crucially softened the previously intransigent position taken by the Department of Health to the point that they ultimately agreed that a gap in service provision had been identified through Dari's Bill. Doreen Harley (Carlton) and Maralyn Bowen (Tyne Tees) had TV slots highlighting Dari's Bill and an interview with Gloria Moss was syndicated to 32 local radio stations. The BBC Politics Show gave a powerful presentation on Dari's Bill led by Ian Botham's views on screening and also interviewing Sanjay, Jeff Morland Chair of Labour Party North, whose son Levon died of Wolfe Parkinson White (WPW) and Dr David Driver an international athlete being treated for WPW who is a member of the CRY Surgery Supporters Club. Dari was in the studio outlining how totally unacceptable it is that up to 8 young people are dying of sudden cardiac death each week and how the Department of Health and medical establishment had to acknowledge that something must be done.



In February our long awaited SADS booklet, written by Dr Elijah Behr (Clinical Research Fellow British Heart Foundation Scholar) and funded by a grant from the British Heart Foundation, was released onto our own www.sads.org.uk website. The significance of having an independent CRY SADS website exclusively for this definitive booklet means that a family bereaved through a young sudden cardiac death has instant access to downloading this information.

On March 10 we held our second Parliamentary Reception. This launched 4 of the 6 prospective CRY Clinics in Edinburgh, Leeds, London and Colchester and also focused on Dari's Bill. Minister of State for Health John Hutton and Shadow Minister for Health Tim Loughton spoke with great fervour in support of Dari's Bill and Dari spoke passionately about our work and the contribution CRY families had made to the progress of her Bill. TV Sports Commentator Jim Rosenthal spoke movingly of the impact of the loss of their baby son on his friends Mark and Debbie Loveday.

The room was packed with MP's that were surprised and delighted to meet the Founder Members of our Surgery Supporters Club who made a huge impact on the evening with



Rt.Hon John Hutton Tim Loughton MP Jim Rosenthal

their personalities, vigour and jaunty humour.

March 12 found 20 CRY supporters in the Strangers Gallery listening to the excellent debate Dari had orchestrated in the House. This culminated in the announcement by Health Minister Melanie Johnson of the formation of an Expert Group on Arrhythmia and Sudden Cardiac Death that will include CRY in the consultation process for the new chapter to go in the National Service Framework. This offer allowed Dari to withdraw her Bill and was confirmed with a Press Release immediately issued by the Department of Health.



Dari Taylor MP

Dari said that "Almost 100 Members of Parliament from nearly all political parties offered their support. A number of these were MPs already involved with CRY and my Parliamentary colleagues. However, a substantial majority were MPs who had agreed to support my Bill because they had been asked to do so by their constituents - invariably members of CRY.

The working group has the potential to deliver all that we asked for - so I am broadly happy, but very aware that we are not yet home and dry. The terms of reference include all that we asked for, as well as some other subjects; we will have to make sure the other subjects do not swamp our own. The membership of the group will include experts from CRY, as well as representatives from other groups; we will have to ensure that the CRY voice is heard, and the families who have brought this group into existence receive the credit they deserve. The tool of an NSF chapter has all the power we need to implement our goals; but we must make sure that the chapter is comprehensive".

(taken from Julie's interview in Kids for CRY)

April focussed on our major annual fundraising event the London Marathon.



Greg's Research Team of runners with Mat, his two CRY hearts & Teddy & Kanga

Greg's team of CRY heart costume runners were not only the first full costume runners across the finishing line but also initiated and participated in some gruelling research which entailed having blood taken the day before the race, immediately after (giving blood after just running 26+ miles demands a high pain threshold!) and the following day.



More blood please Greg!

Greg's 2003 picture running in a CRY heart is reaching iconic status being one of 5 vignettes used on the London Marathon website, and was also used in 2 other national magazines promoting this prestigious event. Many thanks for all those intrepid runners who not

only gave their all for CRY in achieving record sponsorship (over £100,000 raised) but to those that courageously gave blood 3 times in 36 hours to help Greg's Research.

Our new Screening Manager Mat Wilson both ran in a CRY heart and supported a huge CRY heart on his shoulders with Kanga and Teddy clinging on enjoying the ride, and the view! Mat's extraordinary time carrying his double-whammy of CRY tack of 4.26 was "the hardest marathon I have ever done - now lets see what we can do next year....."

April 29 Kevan Jones, MP North Durham & Chairman of CRY Parliamentary All Party Group introduced an Early Day Motion (EDM)1103 "That this House congratulates CRY for raising awareness of Sudden Cardiac Death Syndrome; applauds CRY for the support it offers those who have suffered loss from sudden cardiac death; praises its promotion of heart screening as a simple way of diagnosing most cardiac abnormalities; notes the tremendous contribution CRY has made to medical research into Sudden Cardiac Death Syndrome"

So far 106 MP's have signed. However the EDM is still open and if you refer to the CRY website/CRY's work in Parliament, for this list of MP's you will be able to see if your MP has supported us and if not perhaps can ask him/her to do so.

May 4 The BBC Northern Ireland Spotlight programme featured Greg giving a superb explanation of how these conditions impact on the heart and the importance of screening. The programme referenced our screening programme to a viewing audience in shock after 2 of their top athletes had died suddenly within one month.



Caroline Gard with 4 players from Colchester United Youth Team at the launch of the Colchester ECG Clinic

May 29 saw the CRY team at Caroline Gard's launch of our first CRY ECG testing clinic in the cardio-thoracic unit of Colchester General Hospital an event attended by our Patron Mark Cox and local MP's Ivan Henderson and Bob Russell.

June 11 was our annual Bereavement Support Day at the Institute of Child Health. Greg introduced our speakers Professor Bill McKenna, Dr Elijah Behr, Dr Sanjay Sharma and the President Elect of the Coroners Society, Michael Oakley. Once again this annual event offered a unique opportunity for bereaved families



Sanjay talking to CRY families

to meet, have the opportunity of asking questions from experts and the chance to get to know our Bereavement Supporters whose training has been funded by our Department of Health 3 year grant of £105,000.

July 4 was The Wimbledon Mens Singles Final and produced a surprise for our supporters (and over 100 million viewers worldwide that tuned in), when they heard Sue Barker announce that 14 year old Laura John from the CRY Surgery Supporters Club resplendent in her sky blue CRY polo shirt, had been selected to toss the coin for Roger Federer and Andy Roddick. This was an initiative of 2 times Wimbledon semi-finalist and past Davis Cup Captain Roger Taylor who chose CRY as his charity for this years event.



Laura John (founder member CRY SS Club) with Wimbledon Finalists Andy Roddick and Roger Federer

Five Live ran a documentary "Sporting Chance" about Sudden Cardiac Death in the young and featured the tragedies of top athletes Laura Moss and Cormack McAnallen. Prior to the programme, I was invited to the studio to discuss the merits of screening on Julian Worricker's Sunday Morning programme in a debate with Professor Stuart Logan, epidemiologist for the National Screening Committee speaking from the Exeter studio.

The programme included interviews with Dr Domenico Corrado explaining the importance of the Italian screening programme, Dr Alan Hodson FA Medical Director on their screening initiative and CRY Patron Professor Bill McKenna's overview on screening.

On July 14 Dr Roger Boyle, National Clinical Director of Heart Disease and Chair of the new NSF chapter on Arrhythmias and Sudden Cardiac Death confirmed that Sanjay and Greg would be members of the sudden cardiac death and screening group being chaired by CRY Patron Professor Bill McKenna. July 15 found the CRY team launching our Postcard Campaign in the House of Commons, an initiative of Kevan Jones. This



Kevan Jones and Patrons Jeremy Bates and Mark Cox with CRY families at the launch of the Postcard Campaign

national campaign was covered on the BBC Health Home Page for one week and is designed to run in tandem with the consultation process for the new NSF chapter to ensure that young sudden cardiac death remains a focal point for consideration and to make sure - as Dari said - that CRY's voice is heard.

Our Postcard Campaign highlights up to 8 deaths a week and will be launched in a different part of the UK each month with a different postcard representing 8 young deaths from each area. 1,500 new postcards will be printed each month and special thanks to Rob Thorne who has subsidised the printing of the postcards in memory of his son Nicholas. Postcards will go to MP's, asking them to support CRY with this fantastic window of opportunity that Dari has achieved for us and our fundamental goal - the crucial issue of prevention of young sudden cardiac death.



Sandra Pearce collecting a cheque from the Director of Johnson Apparel Master sponsors of the first Postcard.