



# Issue 38 Newsletter by the Chief Executive



It is remarkable that in this, CRY's 10th Anniversary Year, we are able to celebrate the introduction of a new chapter in the National Service Framework (NSF) on Arrhythmias and Sudden Cardiac Death.

It is widely acknowledged that this new chapter was instigated by the support received for Stockton South MP Dari Taylor's Cardiac Risk in the Young Screening Bill, debated in the house last March and backed by CRY's successful lobbying of MP's. Dari's Private Member's Bill "pushed a foot in the door" which had previously been kept firmly shut. Lobbying through our Postcard Campaign will maintain this pressure with the aim being to engage every part of the UK in our efforts to keep the profile on young sudden cardiac death.

**August:** The response we have had since the publication of our SADS booklet last February which has a dedicated [www.sads.org.uk](http://www.sads.org.uk) website, and Dari's Bill has resulted in a 30%+ increase in our office workload and the employment in August 2004 of 4 new members of staff taking our total to 13.

This included a researcher to undertake a study addressing the issues raised in the NSF document, specifically focusing on families who had suffered a bereavement due to a young sudden cardiac death. Anecdotal evidence from interviews with those affected by a sudden death, suggested that young people with heart conditions were being treated differently to older people with heart conditions - with young people finding it much harder to get their heart concerns taken seriously. Thus, in focusing on heart conditions in the young (under 35), the study sought to explore this under-researched area.

Our consultation document went to 600 selected bereaved CRY families. 150 (25%) respondents yielded important research data and our first analysis of this information has been submitted to the Department of Health.

The South West launch of our Raising Awareness Postcard Campaign was organised in Exeter, Devon by our newly elected Representative Chris Pitman. Chris had been a successful athlete until he collapsed and was diagnosed with cardiomyopathy, and then had to redirect his ambitions to focusing on the coaching of elite athletes. Special thanks to Chris and the Exeter Arena for allowing us to use this venue, our supporting families from Devon, Somerset and Cornwall, and Ironbridge Runner for their sponsorship.

**September:** 20 CRY delegates were invited to attend the Department of Health's consultation meeting for the new NSF chapter. This new chapter on Arrhythmias and Sudden Cardiac Death was called by the National Clinical Director of Heart Disease Sir Roger Boyle, who is Chair of the committee of experts who directed 4 sub-groups. The over-riding view from our delegates was that though there was great potential for progress to be made, young sudden cardiac death represented such a small statistic (4%) of the total deaths, that there was a real danger of our tragedies being obscured by sudden death in the older age groups.

This threat was the inspiration for our Postcard Campaign.

The North East Postcard launch was organised by Maralyn Bowen our Divisional Representative, at Redcar, Cleveland. The contest for the Hartlepool Labour seat vacated by Peter Mandelson was belatedly announced to be on the same day as our launch which unfortunately meant our supporting Labour MP's were unable to attend. However Dari made a diversion from Hartlepool through Redcar to join our launch making an impassioned speech supporting the endeavours of CRY families for her Bill. After being interviewed at length about the cam-



**Dari Taylor MP & CRY families at the NE Postcard launch**

paigned by Tyne Tees TV, Dari spent time talking to each of the families that attended before returning to canvassing support in Hartlepool for her colleague Iain Wright - one of whose first decisions on being elected was to join our CRY APPG.

Special thanks to Maralyn Bowen for organising this event, our supporting families from Tyne & Wear, Cleveland, and Durham; Thorn Lighting for their sponsorship in memory of Levon Morland, the Redcar Cricket Club for donating the venue and lunch, and Ann Wilson for the delicious iced fruit cake she made that included the name of every young person on the North East Postcard.

**October:** Some of you might remember reading the dramatic story 6 years ago of 21 year old Julie Mills who collapsed and was rushed to 3 successive hospitals as medics fought to save her life. She arrived at the John Radcliffe Hospital 20 minutes before full organ failure and was put on life support with the use of an artificial heart. Julie's heart was rested for 5 days while the virus Myocarditis ravaged her heart. Her miraculous survival led to her subsequently re-evaluating her life and I am most grateful that in the re-organisation she has volunteered to help us and will be managing our Surgery Supporters programme.

A special thank you (as always) to Dr Sanjay Sharma for giving up precious family time on a beautiful Sunday afternoon to



**Tony, Kerry, Sanjay, Julie, Louise and David at the Surgery Supporters Club meeting**

attend the final 2004 meeting of our Surgery Supporters Club. Our intrepid travellers come from all parts of the UK to attend these unique meetings, have counselling, spend time with their peers and to talk informally to a consultant cardiologist which is undoubtedly the highlight of the event.

This month witnessed the first of 5 Sudden Cardiac Death and Screening sub-group meetings held in the Department of Health. The select group chaired by CRY Patron Professor Bill McKenna had 3 CRY representatives invited; our Chairman Dr Greg Whyte, Dr Sanjay Sharma and myself.

The first meeting addressed Professor McKenna's full agenda, debated screening issues and included an idea developed by Robert Hall (Medical Director of the Cardiomyopathy Association) of the implementation of an appropriate Referral Pathway so that there would be no further danger of families 'slipping through the net.' Robert's initiative anchored the importance of consistency in dealing with both the event of sudden cardiac death, and prevention, and has provoked on-going discussion at the highest level as to how these should best be handled.

The South Postcard launch was held in Charlbury, Oxford. Special thanks to Hugh Mulcahey, for organising this event, our supporting families from Hertfordshire, Hampshire, Buckinghamshire, Berkshire, and Oxfordshire who attended, The Bell Hotel for donating the venue and the Royal Bank of Scotland for sponsorship in memory of their employee Scott McCollin.

**November:** Our 2nd sub-group meeting focused on the crucial role of the Coroner. Professor McKenna and I also collaborated on an information booklet produced for members of the sub-group, identifying their area of expertise and pin-pointing changes they would like implemented. This booklet was given to all those that attended our sub-group meetings, and the Department of Health.

The North West Postcard launch was held in Stalybridge, Greater Manchester. Special thanks to Dave Pover for organising this event; the Stalybridge Football Club for donating the venue and our delicious hot soup, our supporting families from Greater Manchester, Lancashire, Merseyside and Cheshire who attended and contributed to the lunch and Irene Wickers for securing sponsorship from JDI Flooring in memory of Neil, with a further contribution from Beach Displays in memory of Andrew Parr.

ITV Granada Report covered the launch highlighting the sudden death of brilliant young footballer John Marshall who died in July 1995 the day he was due to join Everton after attending the FA School of Excellence in Lilleshall for 2 years. An excruciating aspect of John's tragic death was that if he had lived another 10 days his condition would have been identified at the screening of the Everton youth squad. This was the first cardiac screening event in football and organised by team physiotherapist Les Helm.

The story of John Marshall and the support of the Marshall family launched CRY in 1995.

Stalybridge and Hythe MP James Purnell squeezed in a flying visit to the launch, leaving a filming commitment to talk to us and the press, before rushing onto his next appointment in Spain.



**James Purnell MP**

**December:** The 3rd meeting of our sub-group addressed genetics. Professor McKenna also invited a contingent from Northern and Southern Ireland to attend including Michael Green, Trustee of CRY Ireland, who have been collaborating with the instigation of a specialised sudden cardiac death clinic at the Mater Hospital in Dublin.

The evening of the same day found the CRY team at our first APPG meeting in the House of Commons. Guest speaker Sir Roger Boyle explained to MP's his hopes for the new NSF chapter congratulating CRY on their "exemplary lobbying" and com-



**Sir Roger Boyle**

**Lord Hunt**

**Kevan Jones MP**



**Dari, Sanjay, Kevan and Sir Roger Boyle**

mending the progressive rise in awareness of sudden death conditions in the House, amongst the general public, and the clinical groups.

Sanjay Sharma outlined to MP's the medical issues that we were confronting and the meeting concluded with the celebration of Dari's 60th birthday with a cake we had bought to mark the occasion to surprise and thank her for the fantastic contribution she has made to our progress. Our APPG has enlarged from 7 prior to Dari's Bill to 65 at the present time.

Shortly before our Christmas break we totalled the number of cards sold this year which amounted to a staggering 21,700 cards = £7,160 gross. Very special thanks again to John Bennett whose beautiful painting for CRY's 2004 Christmas card, in memory of his daughter Laura, was of Bradley Village Church, Staffordshire.

I would also like to take this opportunity of thanking our office volunteers - David Meikle and Pat Ure who have done such sterling work for us every since they joined CRY in 1996; June Dollard our mailshot expert, without whom our unprecedented number of 1994 mailshots could not have materialised; and Elaine Dunne and Joan Clarke who spent so many hours in the office each week translating our Christmas card orders into deliveries.



**Bradley, Staffs painted by John Bennett**

Special thanks go as well to Maureen Ward, who, after 8 years has retired

as our doughty Representative in Wales. Maureen was one of the first families to organise a CRY screening, spoke inspiringly at our Screening Seminar in Wolverhampton in 2000 about the importance of never giving up the fight for our screening programme, and has been an ardent supporter of CRY since she first joined us in 1996 after the death of her son Caradoc.

Also special thanks to Sheila Clarke who has now retired from the job of Volunteer Merchandise Distributor after 7 years of energetic and efficient supervision of the mailing of CRY merchandise from her home.

Our 10th Anniversary year holds great promise for CRY and we are hopeful that our first Raising Awareness week from June 11 - 18 will further promote our goals and highlight our achievements.

To mark our first decade we have designed a 10th Anniversary badge, available from the office. Our absolute hope and belief is that, thanks to the incredible commitment of our supporters whose call for change has been heard in the corridors of power, we can finally afford to be hopeful. We can now trust a future that offers unprecedented grounds for optimism to reduce the toll of suffering through young sudden cardiac death, and recognises that our tragedies can no longer be designated as rare conditions that affect one in a million people.

