



NEWSLETTER FROM THE CHIEF EXECUTIVE



General News

As some of you might be aware I was awarded the MBE for Services to Healthcare in the Queen's Birthday Honours List 2007. This award is a tremendous acknowledgement of the courage and suffering of affected CRY families and a recognition of the dedicated contribution they have made towards CRY's progress in raising awareness of Sudden Cardiac Death in the young; improving the diagnosis and management of potentially fatal conditions; and campaigning for change, to reduce the terrible roll-call of tragedy of young sudden cardiac death.

Significant progress has been made in this area since CRY's inception in May 2005 - particularly from Friday March 12th 2004 when Dari Taylor's Private Members Bill was heard in the House, which led to the development of NSF Chapter 8 and the interest now being shown in young sudden cardiac death. This has been due to the determination of our bereaved families and all CRY supporters to ensure that every tragedy suffered will make a difference and to redress the terrible imbalance between those that have died and those young people diagnosed in time to be treated.

It gives me immense pride to know that our work has been accepted and recognized at the highest level. This in spite of the challenging stand we have taken on so many of the crucial issues and the independence of the position we have fought for and maintained regarding addressing the impact of the death toll of young sudden cardiac death, which has motivated our agenda for change. Speaking on behalf of all CRY staff - the resolve of all of our supporters that our voice should and would be heard has been the motivation and inspiration for all of us in the CRY office.

January 10th



Dr Sanjay Sharma, Director of Heart Muscle Disease at King's College Hospital London, invited us to join him at the opening of their superb £32 million Research Centre. The Princess Royal led the accolades to King's, a world-class teaching hospital with Foundation status at the forefront of UK and international research.

New research includes addressing the fundamental pathophysiology of heart muscle disease and its progression; better diagnosis; improved risk stratification; improved multi-disciplinary care models for patients across secondary and primary care and testing the potential use of gene therapy and cell transplantation. It was an excellent opportunity to meet some of the key people in Sanjay's new team, and encouraging to learn of their support for CRY.

January 19th

We had a landmark meeting at the Department of Health, with NSF Chapter 8 Administrator Mike Yates; the Medico-legal Secretary of the Coroners Society, Dr Bill Dolman; and Brian Paterson representing the Department of Constitutional Affairs. The meeting was to discuss the possibility of CRY funding coroners' referrals to our expert cardiac pathologist Dr Mary Sheppard at the newly established CRY Centre for Cardiac Pathology at the Brompton Hospital.

This coroner/pathology initiative was inspired by comments I received after I had spoken to the Coroners Society Conference in September 2005, when I was told that expert referrals were what all coroners would like but not what they could all afford. Receiving overwhelming approval from the critical parties involved enabled us to progress this ambitious project.

January 24th



Divisional Representative for the North West, Ruth Lowe, represented CRY at the Lancashire and South Cumbria Cardiac Network meeting on Managing Arrhythmias and Sudden Cardiac Death - including the clinical implications of NSF Chapter 8. As Chapter 8 Administrator Mike Yates was unable to attend due to the snow in London, Ruth was asked to speak at this meeting (with 30 minutes notice!) and presented the parent's perspective of losing a child to SADS. She told Andrew's story, highlighting the importance of raising awareness with both the public and GPs, and the importance of clinical expertise in diagnosing the conditions. She also mentioned her imminent CRY family screening event; the bereavement support CRY offers; and, as the only display stand at the event, found there was considerable interest in the CRY literature. Ruth was subsequently asked to speak at the next event.

A Clinical Nurse Manager attending reported to me: "Mrs Lowe is a wonderful ambassador for CRY. She was put on the spot at a conference in Preston and asked to talk in front of Clinical Professionals from across the Lancs and South Cumbria cardiac network, and delivered a clear and moving account of her experience as a parent. I am sure the GPs and other health professionals there will take the information forward and improve the care they give to patients and relatives in similar situations. I know I will." Ruth has now agreed to be our Conference Representative for the North of England with Eddie Farrow responsible for the South of England.

February 1st

Was the day our new Screening Programme Administrator, Wendy Wright, went 'live' with our online booking system for CRY clinics. This has made managing the clinics much easier with a lot of the administration taken care of automatically. This major improvement in procedure gives a clearer picture of how the clinics are developing.

February 26th



Paddy Jelen asked me to attend her daughter Nina's Inquest in Stamford Lincolnshire, where the first person called by Coroner Gordon Ryall was the prominent neurologist Professor David Chadwick - President of the Association of British Neurologists - who immediately and unreservedly apologised to the family for his department failing graduate Nina Jelen.

Nina had been found dead in bed by Paddy on July 23rd 2005, 18 months after she had visited A&E at the Walton Centre in Liverpool. She was tested and followed up by Professor Chadwick who had been unable to explain to her why she had suffered a seizure in her sleep.

Professor Chadwick's apology was because Nina's abnormal ECG was not identified and acted upon, and he confirmed to the coroner that if it had been detected he would have referred Nina to a cardiologist. 3 months after Nina's death, the Walton clinic altered their practice to routinely check for Long QT in cases of blackouts. Paddy commented that, "Of course I am pleased but it is a bitter pill to swallow.....The loss is huge but you have to learn to live with it. That feeling will never go away. It just becomes part of who you are."

NEWSLETTER FROM THE CHIEF EXECUTIVE



March 6th

Progress made after our meeting on January 19th led to a Press Briefing to launch the CRY coroner/pathology initiative at the House of Commons.

Attending were:

Professor Greg Whyte, CRY Chairman; Dr Bill Dolman, Medico-legal Secretary of the Coroners Society; Dr Mary Sheppard, Senior Lecturer/Consultant at The National Heart and Lung, Royal Brompton Hospital; Tim Loughton MP, Vice Chairman of the CRY All Party Parliamentary Group; Alison Cox, Founder & Chief Executive of CRY; Paddy Jelen, bereaved CRY family. The full transcript is available on www.c-r-y.org.uk/coroner_pathology.htm and extracts from the speeches are as follows:



Professor Greg Whyte, CRY Chairman:

"One of the key issues that was raised in Chapter 8, was the issue of how families are dealt with when they have a sudden death and I think this particular process that we are going to be launching today is principally the first step in moving this forward, so that families who have had a young death can access through the Coroners and onto expert Pathologists, the diagnosis and the right support for the family."



Dr Bill Dolman, Medico-legal Secretary of the Coroners Society:

"We are looking for answers. Rule 36 of the Coroners' Rules demands that Coroners ascertain who the deceased was and how, when and where the deceased came by their death. For many of the families, it means that there will be an Inquest, even though the cause may be found to be natural. We very much welcome the opportunity of having expertise and an expert cardiac pathologist to provide some answers, not only for the Coroner, but the families. I really do applaud this project, absolutely as strongly as I can and - on behalf of all the Coroners in England and Wales - we welcome this."



Alison Cox MBE, Founder & Chief Executive of CRY

"If a family can just get the answers within two to three weeks, as we hope will happen now, in terms of 'what has gone wrong here?' and learn of the genetic implications, we can stabilise the situation as much as is possible and we can help them and give them the bereavement support that, as Bill said, is so badly needed and which we feel so strongly that our experience can make a real contribution to."



Dr Mary Sheppard, Senior Lecturer/Consultant at The National Heart and Lung, Royal Brompton Hospital:

"I am so appreciative to CRY for giving me money for building up a Research Team to carry out the appropriate research and also in helping the Coroners in expediting the cardiac tissue for an expert opinion. This is tremendously important and I think it will be a major step forward in helping the families and giving a rapid reply to them as to the cause of death."

Paddy Jelen - Bereaved CRY family

"What I would like to add is this expert service is going to be so welcome. We are a medical family. I'm medical, my husband's medical, and even we were left floundering and had to find our own way [after Nina's death] and it took a long time."



Tim Loughton MP, Vice Chairman of the CRY All Party Parliamentary Group:

"As Paddy said, and on behalf of all the other families who have been affected, to have some explanation and recognition provides some comfort at a very difficult time. The fact that the Coroners are now working in partnership with CRY and the help that CRY is providing to get the medical research done by an expert cardiac pathologist to provide the Coroners with information, is absolutely essential."

March 7th

John Lundy, our Divisional Representative in Northern Ireland, contacted me to tell me that the programme 'Newline' had been transmitted on national TV, and in his opinion, "...was the best coverage CRY has had in Northern Ireland. There were close ups of all the young people on the postcard focusing on each one about four times." We launched the Northern Ireland postcard in Belfast in May 2005. It was this launch that led to the development of the Northern Ireland screening clinic. Key speakers on the programme were Ian McCall, who talked about losing his son John in 2004 during a televised Under 19 international rugby match in South Africa; and Dr. Webb, who spoke about the clinic.

The CRY screening clinic booking number was shown, and as a result our phone lines were jammed with enquiries for the Northern Ireland screening clinic which filled within days of the broadcast.

Screening Administrator Wendy Wright said, "I took so many calls I felt that I'd spoken to every family in Northern Ireland! They were all so friendly and enthusiastic that this service had made its way to them. It felt great to be helping so many people."



It was announced that all the Ulster Rugby Academy players will have been tested for cardiac abnormalities by the end of March. The High Performance Manager of the Academy, and Northern Ireland Patron of CRY, Gary Longwell, said "The Ulster sports community has become acutely aware of Sudden Death Syndrome in the past few years following the tragic and untimely

deaths of two top young sports stars - Cormac McAnallen (Tyrone GAA) and John McCall (Irish U19 Rugby). I am pleased that the Ulster Rugby Academy has introduced testing for all athletes and I am hoping this will help publicise CRY's campaign as it attempts to raise awareness, support screening programs and medical research and, vitally, counsel the families affected by instances of tragic loss."

March 8th

We launched our Scottish Postcard - the last of our 12 UK regions - in the Scottish Parliament. Many thanks to David Gordon, who joined CRY after losing his son Ewan age 15, for securing this very prestigious venue; MSP Jeremy Purvis for hosting the event; Alex Fotheringham, Divisional Representative for the North of Scotland, who spoke of her loss of Joanne and the first CRY school screening in the Western Isles which they funded through Joanne's memorial fund; and our sponsors the Royal Bank of Scotland.

Thanks also to the support of so many MSP's who dropped in during the morning including Cathy Craigie, Donald Gorrie, Euan Robson, Jeremy Purvis, Richard Baker, Dave Petrie, George Reid and Kate McLean; CRY Patron Gregor Townsend MBE for attend-



NEWSLETTER FROM THE CHIEF EXECUTIVE



ing (see Julie's Interview) and most of all to the 50 bereaved people from all parts of Scotland who attended.

Also special thanks to our intrepid Family Screening Manager, Tony Hill, who supported me, resulting in him organising 3 major events in 4 days. These included a raising awareness event with MSP's in the Scottish Parliament with the Medical Technology Group the day preceding the launch of our Scotland postcard; followed immediately by the Bowens' annual family screening event in Redcar - a total roundtrip covering 901 miles in 5 days on the road.



March 15th

The NSF Chapter 8 Implementation Board meeting included a report on the national mapping of Internal Cardiac Defibrillators, a discussion of the sudden cardiac death blueprint and the issue of appointing a co-ordinator for all necessary services. I emphasised that young sudden death should be treated as a separate issue with its own co-ordinator as the catastrophic, complicated and on-going ramifications were now widely accepted as having a far more destructive impact than that of deaths in the older age group, and should not therefore be treated as part of the same problem.

March 16th



Ruth Lowe again represented CRY at the National Service Framework meeting for Arrhythmias for the North West held in Nantwich, Cheshire, and reported that approximately 700 attended. The meeting was mainly concerned with arrhythmias and ICDs and confirmed that - as we are aware - Primary Care Trusts are at various stages in applying the implementation of

Chapter 8, but with many being preoccupied with bigger issues and the pressures imposed by financial stringencies. CRY's fast track initiative for expert cardiac pathology was mentioned when the issues of coroners, expertise and pathology referrals were highlighted. It was recognised that more training was needed for staff, and there was a lack of cardiac physiologists, expert cardiologists, and specialist nurses. Ruth's overall impression was that everyone knew what needed to be done - but all were at different stages of implementation with finances and resources being a problem resulting in changes being made, but slowly.

March 21st

Was another glittering occasion for CRY at the London Grosvenor Marriott for our annual Rugby dinner, organised by David Trick - a

former Bath rugby team-mate of CRY Patron Simon Halliday. 500 attended the event at which Sir Clive Woodward, coach of the victorious 2003 World Cup England Rugby Team, was Guest Speaker and who very generously donated his speaking fee to CRY.



Sir Clive Woodward speaking at CRY's Annual Rugby Dinner

Sir Clive's presentation on how to achieve success so inspired me that I abandoned my prepared speech and talked instead about CRY's ambitious and controversial aims, in particular the importance of our unique coroner/pathology initiative and - echoing Sir Clive - the challenges of introducing innovative ways to tackle historic problems, including the setting up of the first expert cardiac pathology laboratory under the aegis of Dr Mary Sheppard at the Royal Brompton Hospital. The core funding for this was raised by Simon's two hugely successful events last year in memory of Howard and Sebastian English, and I was very moved that Seb's mother Stephanie spoke to me afterwards to reaffirm the family's support and commitment to our coroner/pathology project. Dr Sanjay Sharma had taken a table for this event and had invited Stephanie and Alastair Paterson, our expert cardiac pathologist Dr Mary Sheppard and her husband, and myself to join him.



Simon Halliday collecting his picture

I took the opportunity to present Simon with a watercolour painting of Bath by artist John Bennett, in appreciation of his enormous contribution to the development of our programme. John Bennett is CRY's special "artist in residence" and paints for us in memory of his daughter Laura who died suddenly age 13 in 1998, shortly before giving a presentation to the class in an English lesson.

March 27th



I was on holiday when I did a radio interview at 10pm for Liverpool's Radio City Pete Price Late Show, at the request of Michelle Wilson. Michelle lost her brother Kevan age 23 last year, and was on work experience when Pete's Producer, Jay Hynd, stepped aside for her so that she could produce a show completely on her own. Michelle called her topic Sudden Adult Death. This was presented by Pete Price, and lasted 2 hours, including interviews with the family's MP George Howarth - a member of the CRY APPG - who helped them to get fast track expert screening; Michelle, who spoke about the impact on the family; and myself, talking about CRY and the conditions that, if not diagnosed, can result in sudden death.

Found Tony Hill and myself at our first Regional Bereavement Support Day in Durham. This was our first regional event and was exclusively dedicated to bereavement support.

The incorrigible Kenny Bowen's comment to his wife Maralyn when he first considered attending was: "I can't just talk all day - what am I going to say?"

NEWSLETTER FROM THE CHIEF EXECUTIVE



His comment to me at lunch on the day was, "Well I only came because I wanted to have a chance to talk to you and this is the only way I can do that these days!"

And as the day closed he said to the group, "Well where has the time gone? I can't believe that we have to stop now!"



Granville Staff (centre, red t-shirt) & Maralyn Bowen (centre, blue t-shirt) at the Regional Bereavement Day

Although there was a small group of 12 delegates, they all said how pleased they were that there were not more people, and how much the day had helped them.

Special thanks to our Bereavement Supporters Maralyn Bowen and Granville Staff; and also to Tony Hill.

April 22nd

The 2007 London Marathon was as always a gruelling event, which seems to have a unique energy - a feeling annually reinforced by those who run for CRY.

This year's hot weather caused some concern and tested even the fastest and fittest. In spite of this, Mike Aylott in a CRY heart costume ran an astonishing time of 3 hours 29 minutes, which not only made him the first costume runner over the finishing line but also secured a CRY mention on TV as he did so. Afterwards he said to me, "I am never going to do it again (but I said that last year!). It was really hot, especially in a costume, but the showers en route helped a lot as I felt tired after 13 miles."



Mike Aylott



Mark Knight

Mark Knight got his own place in the marathon and chose to donate it to CRY, running with his wife Helen in memory of the sudden cardiac death of their second child, Oliver. Mark ran in 4 hours 34 minutes and was interviewed by the BBC in a heart costume. He said that the reason he was supporting CRY was because 17 years ago he had lost Oliver to a heart defect at just 3 days old.

Our 85 runners raised 56% more than last year raising (gross) over £200,000. 78 of these runners had a personal reason for choosing CRY. All CRY places had been taken by October and we had to reject requests from 93 people - suggesting that those wanting to run for us really do need to book early.

Post-race support included Tony Hill organising transport to our headquarters in the Hilton Hotel; our massage team who relieved so many aching limbs; and our Fundraising Manager, Rebecca Zouvani, supplying a team of volunteers to help look after participants after the race with supplementary drinks and energy food, and supervising the queue for showers and/or massage.



CRY's massage team

We hugely appreciate being visited by competitors and their supporters after the race, hearing their anecdotes and sharing the often very emotional impact of their experience and sense of achievement. Next year we will have a large reception room at the Hilton which has already been booked, and we very much look forward to meeting CRY entrants and their supporters.

Thank you to all of you that endeavoured to get your London marathon story in your local paper and especially to the 22 of you that were successful.

Thank you also to CRY volunteers Robi and Kate Fox, who were again our photographers for this famous event.



Kate & Robi Fox

April 28th



Our Surgery Supporters Club met again at our base in Epsom where they have both counselling that addresses any social problems they might be experiencing after diagnosis, and time with an expert consultant - usually Sanjay, who normally arrives just in time to enjoy a big chocolate pudding with the gang.

We again enjoyed the company of our very young members Jamiel and Arie, both aged 11, and new member Tianna, age 10, who came from North Wales with her Mum for the first time. We were also delighted to welcome new members Richard and Jo.



April 30th

Dr Perry Elliott, Co-Chair (with Chapter 8 Administrator Mike Yates) of the Coroner/Pathology sub-group and myself, Co-Chair of the Inherited Cardiac Conditions sub-group, met with our respective and very inclusive groups. Both were lively meetings addressing the various and complicated aspects of sudden cardiac death and debating genetic services, and included the possibility of having a co-ordinated service.

In conclusion

CRY's co-ordinated services poster is included with this mailshot and we are delighted that this has been endorsed by the Department of Health. You will see that we now have in place fast track services to deal with all aspects of screening, pathology (including coroners' referrals), and support - both for those diagnosed and for those bereaved.

Our goal now is to secure and keep improving the delivery of this holistic programme for those young people affected and make it an embedded, comprehensive and wide ranging service. The Department of Health's endorsement of our programme is hugely welcomed. Please go to our website, www.c-r-y.org.uk/services.htm

Our aim is that within 5 years, the death toll of at least 8 a week will be significantly diminished, and the research (particularly in regard to the pathology) that we are funding will have made a very significant contribution to finding the causes of these conditions, and have substantial input into how these terrible tragedies can be averted.