



NEWSLETTER FROM THE CHIEF EXECUTIVE



Alison Cox MBE

CRY Founder & Chief Executive

2007 has been another year when we have again taken on four more staff to cope with the tremendous progress in the development of our services. This includes receiving endorsement from the Department of Health for our fast track services for pathology, screening, and support; setting up of the CRY Centre for Cardiac Pathology at The Royal Brompton under Dr Mary Sheppard which uniquely includes the funding of coroners referrals requiring expert cardiac pathology; employment of a Screening Administrator to co-ordinate online bookings; and the training of our third group of Bereavement Supporters under the aegis of new course tutor Andy Usher who has also taken on the role of Bereavement Support Co-ordinator.

May



Ray Wilkins becomes CRY Patron

I am delighted that former international footballer Ray Wilkins MBE (left) has become a Patron.

Midlands Regional Bereavement Support Day (May 12)

32 people attended this event in Birmingham at the Solihull Arden Club. They were divided into five small groups, each one being supervised by a CRY Bereavement Supporter. Appreciating the luxury of



time to talk, share experiences, listen and to learn they were not alone were comments made at the end of a very emotional day.

www.c-r-y.org.uk/bereavement_support_day.htm



CRY Bereavement Supporters (left to right):
Joan Hillier, Diane Tolley, Ursula Bick and Julie Hatton

CRY Chatroom – Talking Point

In response to popular request we have launched Talking Point, a place where young people (aged 35 and under) who have been diagnosed with a life-threatening condition can talk to other young people in similar circumstances. So that users of the CRY chatroom have the opportunity to be online at the same time we would encourage them to log-on Monday evenings from 7pm. However, please note that Talking Point is not for the bereaved. If you would like to talk to a Bereavement Supporter please call the CRY office. www.c-r-y.org.uk/talkingpoint.htm

June



CRY Representative on TV (4 June)

CRY Divisional Representative for the East of England and Bereavement Supporter Caroline Gard was featured on Anglia TV talking about her clinic in Colchester on 4 June. Caroline's determination and commitment in achieving her goal to introduce regular opportunities for screening in her area has received tremendous support from her community who have raised over £100,000 for CRY's screening programme.



This month also saw publication of Dr Jonathan Holliday's article on sudden cardiac death in *MIMS Cardiovascular* (Volume 2, Number 3, 2007). Raising awareness of SCD in this academic journal circulated to all GPs has been something Jonathan has been focused on achieving for some time. There have

been countless incidents of GPs not identifying clear cardiac symptoms in young people that result in appalling unnecessary tragedies, and having the support of such a pre-eminent doctor raising awareness and supporting screening has been of considerable importance in the development of our schools screening programme. Jonathan is the school doctor at Eton College, which became one of the first private schools to introduce a screening programme and has led to significant interest from others in the field of education.



Dr Sanjay Sharma

CRY Family Conference Day (9 June)

For the last four years we have run an Annual Bereavement Support Day, incorporating both expert medical information and workshops for those bereaved by a young sudden cardiac death. Evaluation forms received suggested that those who found the expert medical information helpful would have liked more time spent on these talks (particularly requesting the opportunity to ask questions) and those who benefited from the bereavement workshops said they would have liked more time for bereavement support.



Dr Elijah Behr



Dr Mary Sheppard

So from 2007 I decided to split the day into two separate events with an Annual Family Medical Conference and Regional Bereavement Support Days to be held in different parts of the country throughout the year.



Michael Burgess

The Family Medical Conference was held at the Institute of Child Health in London. We were again fortunate enough to have our expert consultant cardiologists Dr Sanjay Sharma and Dr Elijah Behr speaking and explaining the life-threatening conditions that can affect young



people. Expert cardiac pathologist Dr Mary Sheppard and Her Majesty's Coroner Michael Burgess also explained their roles after a sudden cardiac death. These talks were followed by workshops where speakers in small groups addressed any questions. The day was considered informative and helpful by those bereaved families seeking to understand how it is possible for a fit and healthy young person to die from a heart condition that they have no idea they have.

www.c-r-y.org.uk/family_conference_day.htm



Heart Screening Awareness Partnership (18 June)

We were absolutely delighted that our Patron David Walliams could lend his considerable support to the launch of the Heart Screening Awareness Partnership, a joint initiative between CRY and Philips Medical Systems. Promulgating the

message in the community that heart disease is not just a problem for the elderly – it kills at least 8 young people every week in the UK – is an uphill battle but one crucial to win as so often clear cardiac symptoms go unrecognised by both the public and medical personnel.



David made a very significant contribution to the launch of the partnership by making a DVD that included Bradley Farrow and Jack Mason, members of CRY's Surgery

Supporters Club (www.c-r-y.org.uk/ssgroup.htm). The DVD, which is available on our website, shows young people that screening is not an intimidating process.

As David says, "The screening process is so easy, it tickles a little and it's a bit funny seeing inside your heart. But the doctors are very good at what they are doing, so you should not be scared. The tragedy is that the deaths of so many young people from cardiac problems are preventable. The support we have from Philips will help us raise awareness and get more young people into the screening centres."

The sooner a patient is diagnosed, the more quickly support can be offered to help manage any situation. Philips is donating advanced medical equipment that will facilitate screening and research.

Gala Dinner (23 June)

Andrew Castle, GMTV Presenter and former Great Britain Davis Cup Player, hosted a gala dinner in central London. WinTennis, who divided profits from the event with CRY. Celebrities attending included Britain's Davis Cup Captain John Lloyd, Peter Fleming who, with John McEnroe, was the dominant men's doubles partnership in

the 80's, and CRY Patron Jeremy Bates. Having been asked to speak at this inaugural event I was delighted to spot CRY Trustees, Sue Mappin and Tony Mason, supporting this glamorous dinner on the eve of Wimbledon.



Lorraine Kelly TV programme

Lorraine Kelly's GMTV programme *LK Today* offered us an outstanding raising awareness opportunity when they invited Margaret and James Lancaster to talk about the tragic loss of their son, Robert (left). It is only when people hear personal stories from families that they truly appreciate the nature and impact of young sudden cardiac death. The immense courage of our families in publicly speaking about their tragedy is something that we very much appreciate.

July



CRY's Annual Raising Awareness Week (7–15 July)

Perhaps our most prestigious annual event is our Parliamentary Reception in the House of Commons Terrace Marquee, held on Wednesday 11 July during our Raising Awareness week.



By popular request David was again our celebrity guest. He said "I think tonight really belongs to the young people here who suffer from this condition and I think their bravery is an inspiration to all us."

Opera singer and new CRY Patron Kathryn Harries surprised the guests with a medley of beautiful songs designed to raise awareness of her Bridges Walk, the first leg of which had been completed from Hampton Court to London the previous Sunday.

Unfortunately the reception clashed with what was popularly referred to in 'The House' as "Blair's Bash" – Tony Blair's farewell dinner for his MPs, which left us bereft of a large majority of the Labour MPs who usually frequent our reception. However, we still had an excellent turnout of in excess of 30 MPs, a number which would be the envy of many charities.

Other guests attending included members of our Surgery Supporters Club, CRY Patrons Jeremy Bates, Simon Halliday, Pat Jennings, Gary Longwell and Andy Scott, representatives from CRY's Northern Ireland Screening clinic, event sponsors Philips, medical professionals, representatives from sporting organisations and our office and screening staff.

Speakers included MPs and leading medical experts.



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Andy Burnham MP (Chief Secretary to the Treasury): "I think the onus is on all of you to put pressure on all of us to do even more and, (as) you say, hopefully one day we will make a difference."



Professor Roger Boyle CBE (National Director for Heart Disease): "There is still an awful lot to be done, but CRY has really been filling many of the gaps that the NHS has not been able to do, which is to sort out all those crucial issues, giving impartial advice, getting fast track to people who do have the expertise to the families that suddenly find themselves in these impossible circumstances."



Ann Keen MP (on her first day as Parliamentary Under Secretary for Health Services at the Department of Health): "I know there is an awful lot of discussion at the moment around screening and how best families can feel more secure.

The tragedy that would happen to a family when you would lose a child, a brother, a sister, a cousin, a friend – all of those family names we can mention, you can't really understand at all unless it has happened to you. What I would want for all of you is what I would want for myself."



Vince Cable MP: "Premature death, death amongst the young is particularly shocking and here is...something that is eminently avoidable in a prevention screening. If the system works, a lot of these deaths could be avoided."

Dr Sanjay Sharma: "Apart from diagnostics and these physiological goals, CRY has also been pivotal in identifying the prevalence of things like Hypertrophic Cardiomyopathy. Nobody in the world has actually ever done that in sportsmen. CRY has just identified that conditions like Long QT are more common than Hypertrophic Cardiomyopathy. Again, nobody has ever done that before."
www.c-r-y.org.uk/CRY_parliamentary_reception_2007.htm

CRY Patron Kathryn Harries in Heart of London Bridges Walk, Part One (7 July)

The first leg of this walk began with the CRY party leaving Hampton Court Bridge after a 7am breakfast for the 32 mile trek, finally arriving at Tower Bridge at 8.30pm. Kathryn accumulated friends and family en route, stopping briefly for radio interviews with LBC and Southern Counties radio and a much needed foot massage from friend Jill Philips.



Heart of London Bridges Walk, Part Two (15 July)

This took place with 400 supporters arriving from all over the UK who between them raised a stupendous £68,000! The superb weather contributed to an emotional

day, with 82% walking in memory of a young friend, partner, sibling or child – deeply loved and tragically deprived of the luxury of having a life to live.



Rob Hayles interviewed on Newsnight

Save Our Athletes (26 July)

The second part of our Philips Heartcare Partnership launched the Save Our Athletes Research Project and found me on 26 July circuiting London's TV studios with three times cycling Olympic medal holder Rob Hayles

MBE. Rob's long day promoting this initiative culminated with an interview on *Newsnight*. Running in tandem with Rob's interviews, Olympic medallists Mark Foster and Karen Pickering attended a promotional event at the Waterfront Leisure Centre in London where they were amongst the first elite UK athletes to be screened.

August



Nova article (21 August)

On 21 August Michelle Wilson was invited to write an article for *Nova International* on participating for CRY in the BUPA Great North Run in memory of her brother Kevin. *Nova* put the article in their online magazine. Michelle said "I know Kevin will be very proud of me taking on such a challenge just ten days after the first anniversary of his death and for raising money for CRY, so that they can continue their work and try to prevent Sudden Arrhythmic Deaths from occurring as often as they do."

Department of Health's endorsement of CRY's Co-ordinated Fast Track Services for Affected Families

This month we welcomed a ringing endorsement from Professor Roger Boyle CBE, National Director of Heart Disease when he congratulated CRY for its "ongoing role in the development of these services." These include:

- **Fast track coroner/pathology service** managed by histopathologist Dr Mary Sheppard and funding coroners' young sudden cardiac death referrals to the CRY Centre for Cardiac Pathology at the National Heart and Lung Institute Imperial College London, Royal Brompton Hospital
- **Fast track screening service** managed by consultant cardiologist Dr Sanjay Sharma at the CRY Inherited Cardiovascular Disease Clinic, King's College Hospital, London
- **Fast track athletes screening service** managed by sports scientist Professor Greg Whyte at the CRY Centre for Sports Cardiology based at the Olympic Medical Institute
- **CRY Surgery Supporters Club** providing counselling, support and help for those diagnosed and holding bi-annual meetings with a counsellor and consultant cardiologist
- **Bereavement Support** through a network of trained individuals whose family suffered a young sudden cardiac death and regional Bereavement Support Days in the North, Midlands, Southwest and Southeast.



September



Northern Ireland deaths

Four young sudden deaths in Northern Ireland received considerable media coverage and led to such an overwhelming demand for appointments at CRY's Northern Ireland Screening Clinic that it almost brought our office to a standstill.

Our screening team responded swiftly and pulled out all the stops, with Screening Manager Anthony Shaw forsaking evenings and weekends to meet this unprecedented situation.



Silent at Heart (4 September)

I was privileged to be able to go round this stunning exhibition on my own prior to the launch. I found the artwork of these sixth formers deeply moving and extraordinarily perceptive. Congratulations to all involved and a warm appreciation of the enormous amount of work, innovative

interpretation and commitment to the young people who participated and their tutors and of course to Maurizio Vinvenuti who translated his story to the students in a way that made it so real, having lost his father at the age of 32.

Dr Sanjay Sharma, who acted as Clinical Lead for the project, said "Nobody has actually touched the hearts of parents and school teachers like this project."

Showcasing a range of pioneering works, reflecting the heartbreak felt by many young patients and their families, is an innovative way to raise awareness of sudden cardiac death.

www.c-r-y.org.uk/silent_heart_press_release.htm



Southwest Regional Bereavement Support Day (8 September)

Ten people attended this event which was held at the Bristol Golf and Country Club, a wonderfully tranquil location over-looking panoramic views of the Severn Bridge and River.



CRY Bereavement Supporters (left to right): Barbara Holland, Diana Bower and Vera Looker

The objective of taking bereavement support to the regions is to make it accessible to all and having lower numbers in no way diminished its impact or our resolve to keep offering this service into the community.

www.c-r-y.org.uk/bereavement_support_day.htm

October

Austin Mitchell joins APPG (10 October)

Austin Mitchell MP became the 105th member of our All Party Parliamentary Group (APPG).

CRY International Conferences (12 – 13 October)

Our Annual International Conferences on Sports Cardiology and The Diagnosis and Management of Inherited Cardiovascular Disease were held in London. These academic conferences were awarded the maximum of 6 Continuing Professional Development (CPD) points each by the British Cardiac Society. 210 delegates representing all aspects of cardiac medicine attended from all over the UK including consultant cardiologists, doctors, research fellows, nurses and paramedics. Only doctors were charged, with all other applicants given free places and heard international speakers recruited from Italy, USA and South Africa as well as leading UK experts in their field.

Feedback from conference delegates has been extremely positive, with compliments on the content of the lectures, the quality of the speakers and the overall organisation of the two days. Our report on the event appears on page 12. The conferences will be held again in October 2008.

www.c-r-y.org.uk/cry_international_conference.htm



Classical concert (13 October)

A classical concert held in memory of Cecilia Barriga was highlighted in the *Daily Mail*. Professional musicians joined Cecilia's friends and family in performing at this charity concert to raise funds and awareness.



CRY Schools initiative

A unique initiative was launched in County Durham in memory of Kasia Ber when every secondary school governor received a CRY leaflet during the autumn term's Governing Body meeting and each secondary school received two copies of the CRY DVD. This was supported by an

item in the Clerk's Report to Governors including contact details for CRY.



CRY Bereavement Supporters (left to right): Margi Al Chalabi, Maralyn Bowen and Julie Hatton

Southeast Regional Bereavement Support Day (27 October)

This event was held at Wimbledon Park Golf Club, a superb location overlooking a lake. With delegates able to be

divided into 5 groups, this again proved to be the most well attended of all our bereavement events. We are most grateful to Alastair and Stephanie Paterson for securing the excellent venue and funding the day in memory of their son James.



REPORTS FROM THE CRY OFFICE



Colin and Sarah

Heart Rhythm Congress (30 October)
I was invited by Consultant Cardiologist Campbell Cowan to chair a session on 'Caring for the Families of SCD Victims' at the Heart Rhythm Congress in Birmingham. Speakers included pathologist Dr Mary Sheppard, consultant cardiologist Dr Elijah Behr, Coroner Dr Roy Palmer, Mike Yates (Administrator for Chapter 8) and Colin Simpson who spoke about the impact of the recent death of his 20 year-old daughter Sarah and the critical importance of CRY's fast track cardiac pathology service.



of 'Renaissance Siena: Art for a City' exhibition at the National Gallery. Guests attending this stunning exhibition on 20 November included CRY Patrons Kathryn Harries, Mark Cox and Roger Taylor, and

members of our Board of Trustees led by Professor Greg Whyte as well as some CRY families.

www.c-r-y.org.uk/cry_breakfast_event.htm



James and Katrina

Media coverage
On 8 October the Channel 5 discussion show *The Wright Stuff* explored the issue of being young and widowed and asked what it was like to lose a partner when you're still in your 20s or 30s. It also addressed the difference between terminal illness and sudden death.

The show featured two women whose husbands had died of cancer and CRY Representative for Kent, James Brown, who appeared on the show to talk about the devastating loss of his wife Katrina who collapsed after the British10 kilometre race in July 2006.



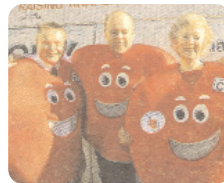
MP mentions CRY (25 November)
Kevan Jones MP (left), Chair of the Cardiac Risk in the Young All Party Parliamentary Group spoke about CRY on SKY news in response to the Queen's speech.

December



Also on 8 October Radio Five introduced the issue of young sudden cardiac death in a programme which featured footballer (and CRY Patron) Andy Scott with Dr Sanjay Sharma, who diagnosed him with hypertrophic cardiomyopathy after he felt unwell during a match.

On Sunday 14 October I was invited, with Professor Bill McKenna and Dr Richard Shilling, to speak on the BBC Radio's *Five Live Report* from 11am to 1pm with presenter Rachel Burden. The programme is Radio Five's flagship investigation programme and this was the follow-up to the 8 October edition. *Five Live* reporter Sarah Mills explored why screening that could save many lives is not routinely available on the NHS.



Children's Charity Awards (28 December)

Daily Mail readers and Royal Bank of Scotland (RBS) staff voted in their thousands for their favourite children's charities from which 90 were selected to receive the RBS 'Children's Charity Awards' of £10,000. CRY was one of the lucky charities. Local MP Chris Grayling (pictured, centre) presented the cheque to us at the CRY office.



Cursitor Street Christmas Lunch (7 December)

Andy Jonesco was one of the many friends of John and Barbara Darby who were appalled to hear of the sudden death of their son Ryan. As Chair he chose CRY to be the main beneficiary from the traditional Cursitor Street Christmas Lunch. 590 people attended this extraordinary, mad event marking the run up to Christmas for the media side of the entire advertising industry. We started celebrations at 12.30 and were finally evicted at 5.30! A very generous private benefactor doubled the total amount raised by guests in memory of Ryan Darby to £9,600.



Freelance journalist Barbara Lentin informed us that she was runner up in the Guild of Health Writers Consumer Writing Awards on 11 October for the feature she wrote for *The Times* on Nina Jelen and arrhythmias. She felt especially proud that it was this piece of three submitted for the award, as the subject had touched her very deeply during the research and writing.

Surgery Supporters Club meeting (9 December)

Dr Sanjay Sharma was again the star guest for our Surgery Supporters Club meeting, held locally at The Haywain in Epsom. These events are for young people diagnosed with life-threatening conditions where they get an opportunity to meet each other, talk informally to an expert consultant cardiologist, and also have a group counselling session where they can discuss any social issues that have proved challenging.

www.c-r-y.org.uk/ssgroup.htm

November

National Gallery Breakfast

GlaxoSmithKline offered us an innovative opportunity to invite corporate guests for breakfast and a private viewing