



NEWSLETTER FROM THE CHIEF EXECUTIVE

General News

It is with great pride that we can announce that the International Rugby Board (IRB) and the Irish Rugby Football Union (IRFU) Ulster Branch are profiling CRY at the Under 19 World Championship, in Belfast from 4th - 21st April.

This was as a direct result of launching CRY Northern Ireland's first independently funded heart screening clinic at the UU Clinic at the University of Ulster's Jordanstown campus in November 2006, offering a subsidised screening service to young people (14 – 35) for £35.

CRY's involvement with the Under 19 World Championship is particularly poignant, as this year's tournament marks the third anniversary of the death of John McCall, the Ulster cup winning captain who died suddenly on the pitch in 2004 whilst playing rugby for the Ireland U19 side in the World Championship in South Africa. It was later found that this superbly fit young man had died of an undetected heart condition.

This is one of the clearest illustrations of the importance of how our cardiac screening programme raises awareness of young sudden cardiac death - which at this major event could have international ramifications.

When I first started CRY in 1995, many in the medical profession derided efforts to screen apparently fit and healthy young people. Although it has taken 12 years for the relevance of screening to become recognised it is interesting to find that some GP's with Special Interest (GPSI's) are now setting up cardiac screening clinics in England, and some consultant cardiologists are setting up screening services for schools. In spite of the fact that Professor Greg Whyte's time at the CRY Centre of Sports Cardiology at the Olympic Medical Institute, and our consultant cardiologist Dr Sanjay Sharma's time in heading up the CRY screening programme, is donated at no charge to CRY, we still subsidise our screening programme (to keep our charges down) by in excess of £100,000 p.a. Hopefully those that are now implementing cardiac screening services for the young are paying due regard to the crucial importance of expertise in evaluating fit and healthy young people.

I would like to take this opportunity to say how hugely grateful we are to our experts for their time, and to our families and supporters whose generous donations continue to fund the constant upgrading of the screening service we offer, and the vital research that results.

October 3rd

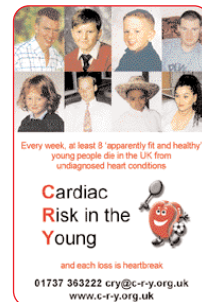
CRY supporters John and Barbara Darby started putting weekly advertisements for CRY in the Daily Mail, Evening Standard and Metro in memory of their only child Ryan who died suddenly in September 2006 age 27, whilst on holiday in Bangkok, leaving his partner and their 2 year old child Harley. John has worked at the Daily Mail for 35

years and has said how immensely supportive they have been in helping him deal with the loss of Ryan. Their unique initiative in a national daily paper with one of the largest circulations in the country will undoubtedly reach people in need and save lives.



Ryan Darby

John says "We are so grateful for all the help CRY have given us and the bereavement support we have had. It is so nice to talk to people who have been through what we are going through now and this has really helped us cope."



October 7th

After the sudden death of their son James, Stephanie and Alastair Paterson approached me 2 years ago wondering if it would be possible to instigate a follow-up to our Annual Bereavement Support Day so that those who felt they needed more "time to talk" could meet further.

As a result of their determination to drive this idea forward we had a very successful pilot event accommodated at the beautiful lakeside Wimbledon Park Golf Club which has led to the reconstruction of our annual Bereavement Support Day into regional events in the North, Midlands, South West and South East of England. Bereaved families will be able to attend any or all of these events.



James Paterson

October 8th

4 intrepid adventurers finished the Peru Trek for CRY on October 8th 2006. Emma Beckham, in memory of Ian Strange, raising nearly £3,000; Catherine Wylie and Andrew Bickerton, who chose this as their honeymoon, raising over £3,000; and Alison Mitchell, in memory of her fiancé Adam Corsham, who raised the amazing total of just under £18,000. The trek follows one of the world's most stunning trails with the extraordinary diverse scenery of the tropical Andean rainforests; the snow-capped mountain ranges of the Andes; and Machu Picchu - one of the world's most important archaeological finds. Emma says, "It was really great to meet others fundraising for CRY and made us feel that we were part of a team. There were 56 on the trip and having a CRY 4 was great, especially once we got



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there as we were able to have our photo taken together and share our experiences. I think I speak for all of us when I say that it is the most difficult thing I have ever done and yet the most fulfilling. When we reached Machu Picchu we all got together and really realised why we were actually there and just how emotional it was and that we all had a very special connection. It is good to know that we have raised a lot of money for CRY to help people through what is a really difficult and incomprehensible situation."

October 15th, October 16th



On October 15th and 16th we held our first International Conference at the Institute of Child Health - Day 1 on Sports Cardiology from Theory to Practice; and Day 2 on Inherited Cardiovascular Conditions. This 2 day conference was awarded an outstanding 12 credits for doctors attending, towards their annual Certificate of Professional Development (CPD). This reflected the quality of our speakers which on the home front included Elijah Behr, Perry Elliott, Pierre Lambiase, Sanjay Sharma, Dr Mary Sheppard, Professors Bill McKenna and Greg Whyte; and internationally acclaimed consultant cardiologists Dr Domenico Corrado (Italy) and Dr Paul Thompson (USA).



We also held an innovative workshop with echocardiographer Dave Oxborough who demonstrated the skills required in identifying cardiomyopathy on CRY Patron and

former professional footballer Andy Scott, 32, whose career was suddenly halted after he felt unwell during a match and was referred to Dr Sanjay Sharma who diagnosed Hypertrophic Cardiomyopathy (HCM); and medical student Mike Davies, 22, who suffered a cardiac arrest during a rugby match and was successfully resuscitated by his (medical student) colleagues whilst waiting for the ambulance to arrive. Mike was diagnosed with Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC) and now has a defibrillator.

October 16th

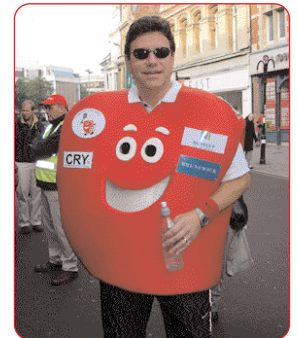
The second day of the conference was particularly challenging as CRY Patron Simon Halliday, his CRY heart costume, and I, left London at 5.30am on a dark autumn morning to arrive in Oxford in time for breakfast prior to a



12 mile walk around the confines, with our Honorary President Ian Botham OBE. Ian had invited a CRY representative to join him for a leg of his round Britain walk for Leukaemia Research, and Kathy Botham invited me to join her.

Simon was extremely impressive as he was somehow able to walk and talk as he and Alastair Campbell took to the road at the rate of knots, managing to match Ian's phenomenal pace "walking" around the city boundary. However my mission – to accompany Kathy – was unsuccessful as she seems to walk even faster than Ian! Fortunately I was able to (discreetly) avail myself of the follow-up motor cavalcade, participating only in the first and last part of the event and arriving back in Oxford town centre in time to congratulate our worthy Patrons! I got back to London in time for the afternoon session of the conference, chastened and much the worse for wear! Especial congratulations to Simon and his old friend Ewan Cameron-Watt who, walking with his wife Penny, between them raised a total of just under £10,000. Also to the CRY support party of Fundraising Manager Rebecca Zouvani and Publications Co-ordinator Mark Fox who interviewed Simon after the event.

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



Ian Botham and Simon at the start of the walk

October 18th

The Draft Coroners Reform Bill, which has taken 5 years, received a poor reception from the British Medical Association and the Coroners Society, who have dismissed it as unacceptable and unworkable.

A Home Office Position Paper in March 2004 'Reforming the Coroner and Death Certification Service' showed what a National Service would look like and accepted the major recommendations for change. This paper was in



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response to the Luce Review and Shipman Inquiry and gave much hope of sensible amendment. These hopes were not fulfilled after the Department of Constitutional Affairs (DCA) took over the service.

A very well-supported lobbying meeting for the key charities of the Sudden Death lobbying group of Action for Victims of Medical Accidents (AVMA); CRY; Sudden Infant Death Syndrome (SIDS); Sudden Unexpected Death from Epilepsy (SUDEP) and Victims Voice; was held at the House of Commons and facilitated by Baroness Gould, Chair of the All Party Parliamentary Group on Epilepsy. A number of MPs attended including Dari Taylor.

November 9th

As part of the consultation process for the Coroners Reform Bill, the Department of Constitutional Affairs commissioned MORI to select 12 representatives from the whole country who had recent experience of Inquests. One of these was Karen Finney whose daughter Jenny died of SADS age 18 in May 2005.



Jenny Finney

The meeting was held in the House of Commons and attended by the Solicitor General The Rt. Hon. Harriet Harman MP. Ms Harman took submissions from the panel, encouraged them to discuss their experiences and offer their views on what should be changed. Karen says of her 'all day' experience;

"Harriet Harman said what we were doing was really important. We had all been through dreadful experiences but the ending to the day was very abrupt and there was just no feedback and response at all. We were all saving our punch lines to the end and they said they were noting everything down – I was talking about the work of CRY at every opportunity and how much we had been helped by them and the difficulty so many have getting their family screened after a death. I am suspicious that these people who can make things happen had already made their decisions about the Coroners Reform Bill before our meeting and that it was just an exercise we went through so that it looked as if there had been a consultation with those affected.

The other peculiar thing was that we had been carefully prepared to talk to the Press as we were told there was a lot of Press interest. It was strange to find that although there had been a flurry of Press interest prior to when the meeting had been first arranged on October 18th, there were no Press waiting at the end at all and we felt that as the date had been suddenly changed perhaps the Press had not been re-notified. I was disappointed. I found CRY through a magazine and wanted to be able to get CRY's name in the paper so that someone else could have the chance to find you and receive the help that our family did."

November 1st

We launched Northern Ireland's first independently funded heart screening clinic at the UU Clinic at the University of Ulster's Jordanstown campus, offering a subsidised screening service for £35 available to young people.



John Lundy being interviewed

Our Divisional Representative in Northern Ireland, John Lundy, and UU Clinic Manager John Carruthers, organised a superb reception attended by 90 people to launch the clinic, which was attended by Northern Ireland Patron and the High Performance Manager of the Ulster Rugby Academy, former Irish Rugby International Gary Longwell .



Television interview with CRY Patron Gary Longwell

CRY representation included Dr Sanjay Sharma; Caroline Gard, who assisted with the setting up of the clinic because of her experience in running her Colchester ECG clinic; Deputy CEO Steve Cox, who oversees the screening programme; Screening Manager Mat Wilson; Alastair Paterson and Tony Hill, who facilitated the first meeting of the Northern Ireland Action Group; and myself. Especial thanks to the 2 Johns and the Northern Ireland Action Group, represented by John McCall's father Ian, who spoke on behalf of bereaved families in Northern Ireland.

November 21st

The Heart Improvement Programme Cardiac Networks meeting was held in London, which as well as CRY included presentations from; The Arrhythmia Alliance; The Cardiomyopathy Association and SADS UK. There was

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an enthusiastic response from attending Consultants and Cardiac Networks to aspects of the discussion, but it was alarming to learn that currently there is no established criteria for expertise either for consultants or hospitals, who can self-determine if they have the experience to deal with this very complicated field of cardiac health. It is of great concern that the public are at the mercy of such an arbitrary situation – and frustrating and astonishing that the Department of Health have no authority to establish a mandatory criteria for expertise with inherited cardiac conditions - even though poor diagnosis and management directly results in putting lives at risk.

November 23rd

The Mayor of Swansea Councillor Mair Gibbs dedicated her highly successful fundraising during her year of office to helping young people in her community. This was reflected in her choice of charities of which CRY was one and resulted in her sending us £20,396.73 in memory of Christiana Smith.



Christiaan Smith

November 27th

The CRY All Party Parliamentary Group (APPG) met in the House of Commons with guest speaker H.M. Coroner Michael Burgess, speaking to MP's about about the Coroners Reform Bill and its impact on sudden cardiac death in the young. The meeting also addressed the survey of CRY APPG MP's contacting their Primary Care Trusts (PCT's) about the implementation of services for young sudden cardiac death, as a result of Chapter 8 in the National Service Framework. MP's confirmed their absolute commitment to helping CRY families get the referrals for expertise that are so important after a tragedy.

November 29th

We had 2 invitations in 2006 to raise awareness with pathologists. In November I was invited to speak about CRY by Dr Mary Sheppard at her International Cardiac Pathology conference held at the Royal Brompton; and in May the Director of Epilepsy Bereaved had invited me to speak at the Royal College of Pathologists at a conference on Good Practice in the Investigation of Sudden Unexplained Deaths. This conference was for Neurologists and Pathologists and Mary (addressing the pathology) and I (the perspective of bereaved families) shared the Sudden Arrhythmia Death platform.

The motto of the Royal College of Pathologists is "the science behind the cure" and we hope that an outcome of our commitment to setting up the first UK Centre of Expert Cardiac Pathology - facilitating a fast track service at the Royal Brompton with Mary - will be to make a major contribution towards finding the cure for these life-threatening heart conditions.

November 30th



Kasia Ber

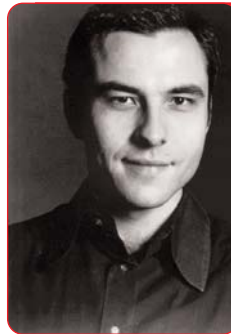
Kasia Ber's Inquest had full coverage in the local papers including the Northern Echo and also a 5 minute slot on ITV Tyne Tees highlighting the tragedy, see www.c-r-y.org.uk/ber_inquest.htm for this video. Kasia had seen her GP because of her shortness of breath, palpitations and struggling to get her breath when woken up by her alarm clock. When Kasia's Dad contacted me I asked how her Mum was coping and he replied that she was finding it difficult as she had been suffering for 20 years from panic attacks and epilepsy prior to her sister's (Kasia's Aunt's) death from SADS. I recommended that the GP should refer the whole family through to Sanjay and to take the ECGs of Kasia and her 2 cousins, whose mother had died 2 years earlier. Sanjay diagnosed 4 with Long QT - Kasia, her Mum and 2 cousins. It transpired that both the GP and the consultant treating Kasia's Mum did not tell her that she had Long QT. There is issue as to whether at that time the treating practitioners had knowledge of Long QT being a genetic condition and accordingly undertaking the appropriate follow up testing of the family.

Representation for the Ber family at the Inquest was through their barrister and solicitor, and Diane and John Ber want to now dedicate themselves to raising awareness of Long QT through CRY.

December 4th

A Chapter 8 Implementation Board meeting was held at the Department of Health, which addressed the issue of centres of excellence and the criteria required. A blueprint will now be developed of what these specialist services should offer, which will bring consistency and also address the issue of how these specialist services will be supported.

December 13th



David Walliams very generously gave us some fabulous tickets (best in the house!) to his Little Britain Live show at The Hammersmith Apollo, London, for our Surgery Supporters Club members. We had a brilliant evening particularly appreciated by the young people that were able to come.

I was reminded again what fantastic support CRY has at every level - celebrities; MPs and of course our medical experts Professor Greg Whyte and Dr Sanjay Sharma, and all our fantastic supporters who dedicate their time to CRY at no charge to help us achieve our aims of reducing the tragic death toll of young sudden cardiac death.