



Issue 36 Newsletter by the Chief Executive



Rarely can a death in sport have cut into the quick of public consciousness more sharply or have illustrated more graphically how undiagnosed heart conditions can suddenly kill apparently fit and healthy young people than when Manchester City and West Ham footballer Marc-Vivien Foe died during a televised football match whilst playing for his native Camerouns. We received an avalanche of public and media enquiries after this tragedy which led to 4 national newspaper articles and a BBC National News interview with CRY's Trustee Dr Sanjay Sharma and an interview on Sky with CRY's Chairman Dr Greg Whyte.

This tragedy provoked considerable interest in our programme and in particular our screening campaign. It was providential that shortly afterwards we had the opportunity of securing the services of Research Fellow Dr Jayesh Makan who will be training under Dr Sharma, Consultant Cardiologist at Lewisham University Hospital



Jayesh taking an ECG at the Eton ECG testing

Our bold decision to have our own CRY funded Research Fellow working in tandem with our screening programme, has already made a significant difference not only to facilitating screening events but also because we now have access to virtually online medical expertise to respond to urgent queries about our conditions and so can offer a very special facility to all those who contact us.



The CRY team outside the Eton Medical School

Jayesh's services proved invaluable when we were invited by Eton School to test their students. As with so many schools a congested timetable means availability of pupils is limited and at this event we were required to ECG test 299 boys in a period of 2 days which was successfully achieved thanks to our remarkable CRY screening team, which on this occasion included technicians working in tandem from a bank of 6 ECG machines.

Our inaugural Bereavement Support Day, funded by the grant awarded by the Department of Health, was held in June at the Institute of Child Health and exclusively dedicated to all those

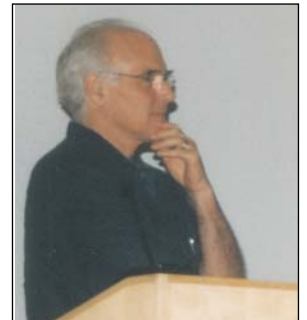
parents, partners, grandparents, siblings and friends who had suffered the loss of a young sudden cardiac death.



Our CRY Bereavement Supporters

110 delegates registered for the event and were able to meet our 11 Bereavement Supporters who have been recruited from all over the UK to help others who suffer from a similar loss. Our first group of CRY Bereavement Supporters have just completed their 2 years of counselling training based at the CRY office and a recognition of their commitment is the calculation I made that they had spent over 1,000 hours in travelling time alone to achieve their Skills and Theory Certificates.

The morning sessions focused on our outstanding speakers. CRY Patron Professor Bill McKenna and British Heart Foundation (BHF) Research Fellow Dr Elijah Behr explained how young people can be harbouring these potentially lethal cardiac conditions, and why they cannot always be detected at Post Mortem; this was followed by an extended Q and A session; Dr Sanjay Sharma gave us all a privileged insight into the perspective of the cardiologist in dealing with families of victims of young sudden cardiac death; and CRY's Counselling Course Tutor Julia Cayne discussed emotional learning and bereavement.



Professor Bill McKenna

The afternoon workshops concentrated on the specific nature of the loss, and gender issues in bereavement, and enabled delegates, many of whom were for the first time meeting others in a similar position to themselves who were coping with the same aspect of grief, (sibling/male/female/partner/parent) to start to vocalise their feelings in the knowledge that they would not only be heard - but also understood.



Dr Elijah Behr

Our Rainbow Group exclusively for young people under 15 offered the opportunity for children to attend and meet other youngsters, and charities that promoted the event (British Heart Foundation, Cardiomyopathy Association, The Compassionate Friends, Children's



Dr Sanjay Sharma

Heart Federation and Child Bereavement Trust) had information on their organisation displayed which was also included in our Bereavement Support Day leaflet especially printed for the occasion. Next years event will be in the same venue on Saturday June 12 and the Agenda and Reservation Form will be advertised on our website from January 2004.

Jeff Morland, Chair of Labour Party North, responded to an invitation to speak at his old school in memory of his son Levon who died in his sleep age 22 of Wolfe Parkinson White. Levon and his twin brother Aran had also attended the school, who voted unanimously to choose CRY as their charity for the Great North Run with 70 students flexing their muscles and proudly sporting the CRY vest to run for the Levon Moreland Memorial Fund. Such an impressive turnout of young people from one school is guaranteed to raise awareness of CRY and helps so much to focus public attention on our aims.



Great North runners in memory of Levon Morland

The Medical Technology Group, founded in February 2000, aims to raise the profile of how medical technology can both save and improve quality of life for patients. As a Founder Member I was invited to give a talk on CRY's aims and achievements at a recent Patient Advocacy meeting hosted by Medtronic, one of the company's involved and was particularly pleased to have the opportunity of highlighting the work we do with our Surgery Supporters Club. Medtronic is a large international organisation that amongst other devices makes Internal Cardiodefibrillators (ICD's) that has been a long term supporter of our aims.

Kay Linnington's story in the BHF Flyer

After the publication of their 3 Research papers earlier this year the British Heart Foundation worked with CRY on their flyer "a ticking time bomb" sent to their donor base which told the tragic story that affected CRY's County Representative in Oxfordshire, Kay Linnington, and how she lost her 28 year old partner, Ian. The appeal "the tragic mystery of SADS" focused on recent BHF research, giving CRY's website and highlighting our mutual attempts to help raise awareness of "this hidden killer."

CRY supporter Jean Johnson was invited to speak on Radio 4's Home Truths about the sudden death of her son Craig, the terrible suffering his death had inflicted on her family and her dream that all young people should be given cardiac evaluation before they leave school to identify whether they are suffering from an undiagnosed, potentially lethal heart condition.



UK campaign launch; Mrs Pat Russell, Jean Johnson, Linda McAvan, Julie Carder, & Mayor Richard Russell

Jean, joined by Julie Carder, expounded the same pertinent message, in their CRY sweatshirts, when they launched the MEP's World Health Organisation (WHO) initiative with CRY. They were also invited on an extended slot on BBC TV's "The Politics Show" in response to the news of the MEP's crusade, which was launched by Labour MEP's Linda McAvan and Catherine Stihler in the European Parliament in Brussels calling on WHO to officially recognise and name as Sudden Death Syndrome the deadly heart conditions that we believe claims up to 8 young lives a week in the UK. Linda became involved after the 20 month old son of her Parliamentary Researcher Tracy Cook died and invited CRY to work with them to highlight their initiative with the media to raise awareness across the globe of young sudden cardiac death linking with SADS Australia and QT Kanga (see Julie's Interview in Kids for CRY).



The Tait's with Catherine Stihler, QT Kanga & CRYTeddy

The launch of the WHO campaign in Brussels to recognise these deaths with an International Disease Code displayed our literature and resulted in further interviews on Carlton, Radio Five, Radio Sheffield and Greater Manchester Radio.

MEP (Labour Health) Catherine Stihler met up with CRYTeddy and QT Kanga and Divisional Representatives in East of Scotland, Andy and Maggie Tait, drawing attention to the campaign north of the border. These two appealing little ambassadors have already had a wonderful reception from CRY families in the UK with so many exciting invitations that their diary for the next 3 months was filled within 10 days of our first mailshot!

Thank you for welcoming them and helping us in our efforts to develop every opportunity we can to reduce the death toll of devastating loss that these appalling tragedies leave in their wake. Deaths which strike swiftly, without warning, may be genetic, unexplained, and inflict such grievous suffering on those affected.