



Issue 39 Newsletter by the Chief Executive



January; Our 10th Anniversary year began on January 7 with our Wales Postcard launch organised by Paulette Smith our new Divisional Representative in South Wales. Thanks to Paulette's endeavours this event effectively became the launch of CRY in Wales with requests for 15,000 postcards made and a considerable amount of press coverage achieved.

Paulette chose Morrision Hospital Post-Grad Centre for the Wales launch, arranged for Novartis to sponsor the lunch and INCO to sponsor the Postcard. The event was supported by families from Vale of Glamorgan, Cardiff, Flintshire, Pembrokeshire, Swansea and Conwy.

Attending was a galaxy of VIP's including Welsh Assembly MP Edwina Hart; the Deputy Lord Mayor of Swansea Mair Gibbs; and geneticist Professor Mark Rees based at the new Institute of Life Science in Swansea. Mark contacted me after returning to the UK having spent 5 years in New Zealand researching inherited cardiac defects in families who had suffered the loss of young relatives from undiagnosed heart conditions. Speakers included our Patron Rob Jones



Paulette Smith

Divisional Representative in South Wales



Martin Caton MP

who told of his feelings when a few months after he had joined CRY to help fundraise in memory of Christiaan Smith he suddenly heard that his 32 year old cousin had dropped dead from SADS; Gower MP Martin Caton who spoke about the importance of our Postcard Campaign in raising awareness and Consultant Cardiologist Dr Mark Anderson, who has been representing Wales on our NSF sub-group on sudden cardiac death and screening, concluded the talks by making an impassioned speech that changes that would hopefully be implemented in England through the work of our sub-

group would only happen in Wales if pressure was brought to bear through the Welsh Assembly. Marks appeal was for support to ensure that all the work being done would not be in vain for Wales.

Paulette did a superb job hand-delivering invitations to every department in the hospital, resulting in a packed reception with 93 people attending - including most of the cardiology department! Those that came were able to talk to our families and learn of the unbelievable circumstances of the deaths of their children and young partners. Doreen Harley who had been unable to attend the Wales Postcard launch subsequently assembled her local MP's in North Wales to promote the campaign with great success and further publicity.



CRY Patron

Rob Jones MBE

On January 12 CRY Representatives were invited to attend the Department of Health Research Forum on Genetics at which selected stakeholders participated in identifying the issues they felt would most help progress the genetics programme. The taking of family history, long advocated by Professor McKenna as the simplest and most cost effective tool in identifying those at risk, featured strongly in recommendations by delegates as

a crucial and attainable first step to reduce deaths from these conditions.

For the best possible reasons the first appointment of our CRY funded Research Fellow, Dr Jayesh Makan, had to terminate 6 months early as Jayesh managed to obtain his national training number in cardiology in the highly sought after Northwest Thames London Deanery (the most competitive rotation) in January rather than June! We are very proud that, as he has fully acknowledged, his work with CRY undoubtedly assisted his early selection. Our new Research Fellow, who will be again assisting Dr Sanjay Sharma with our screening programme, started in July.

This month also witnessed the 2 final meetings of our Sudden Cardiac Death and Screening sub-group when expert submissions were collated, formulated and presented to Dr Roger Boyle by Chair Professor Bill McKenna. The final document was forwarded to various committees, policy branches, financial departments, Ministers and Cabinet Ministers before being signed off in preparation for its introduction.

The Cardiovascular Research Funders Forum (CVRFF) held a meeting with international speakers on Premature Death and the Heart on January 31/February 1 at the Institute of Physics with 5 Sessions over 2 days. Session 4 on the Experience of Sudden Death featured 2 speakers from CRY. Supporter Julie John gave a deeply moving talk (that reduced many of the delegates to tears) about "The Family Experience" and how the loss of her 32 year old husband and the diagnosis of Long QT in their 2 children Laura and Danni had changed their lives, and I was invited to speak on "The Counsellors View" in dealing with affected families. Propitiously, at the end of the meeting it was announced that the European Cardiac Society had just recommended that all athletes should be screened. This led to a barrage of calls and publicity for us, and the issue was given extended coverage on BBC's on-line website highlighting CRY's advocacy of screening.



Julie John

February; Our South East Postcard was launched on February



Rob Thorne

18 in Smallfield Surrey and was supported by families from Kent, Surrey and Sussex. Special thanks to Rob Thorne for organising this event and whose company HCW Print were not only the specific sponsor for this postcard but have also sponsored the entire postcard campaign by printing everything



Tim Loughton MP

required at cost, in memory of the loss of his son Nicholas age 13; also to the Centenary Hall Smallfield for providing the venue and to the Thorne family and friends who provided us all with a wonderful hot lunch on a cold winters day. Tim Loughton MP Shadow Children's Minister and Shadow Health Minister spoke with feeling of the impact of sudden cardiac death on families and the event was covered by BBC TV SouthEast.

On February 5 the CRY Surgery Supporters (SS) Club met at

the Haywain in Epsom. Special thanks to Julie Mills for organising these meetings and to Dr Sanjay Sharma for again giving us some of his very precious off duty time to come and see our members. It was a particularly memorable occasion as we were introduced to Danni John's baby Dylan who was unquestionably the star of the weekend.



Dr Sanjay Sharma with the Surgery Supporters Club

March; Dari Taylor's Cardiac Risk in the Young (Screening) Private Member's Bill that was debated in the House of Commons on March 12 2004 resulted in the new Chapter 8 in the National Service Framework on Arrhythmias and Sudden Death which was announced by the Secretary of State for Health John Reid on March 4 2005 at the Coronary Heart Disease Collaborative Conference in



Dari Taylor MP

Birmingham. The Department of Health's Press Release featured CRY using the story of Laura John with her superb picture tossing the coin at Wimbledon for Roger Federer and Andy Roddick, and concluded with our quote highlighting the issue of young sudden cardiac death.



John Reid MP

CRY had 4 representatives on the sub-groups during the consultation period for the new chapter and also, most crucially, has been invited onto the New Implementation Board. This ensures that in the vital discussion period when funds are allocated and targets set - young sudden cardiac death will have a significant profile.



Professor Bill McKenna

Professor McKenna said "the consultation process brought together all the elements involved including coroners, geneticists, expert clinics and support groups. It has been very valuable and should result in a dramatic improvement in the prevention of tragedies, and the care and management of those affected. All involved learned. Preconceptions were broken down. Important contributions made. It has realistic and positive potential and, if recommendations are implemented, within 3 to 5 years we will see significant results."

On March 17 we launched the North Postcard at Hull. Special thanks for organising the day to County Representative for Humberside Pauline Jolly; Hull Collegiate School for sponsoring the postcard and Hull High School for providing the venue and the catering. Yorkshire TV's Calendar programme covered the event.



Pauline Jolly



CRY Family's seen here at the North Postcard Campaign Launch

On March 22 I was invited to speak at a training day for civil servants on Private Members' Bills and Secondary Legislation, on how a small charity can successfully lobby for a Private Members Bill. I felt particularly

proud to be able to tell disbelieving delegates that we had achieved this without the backing of any union or sponsorship and guidance from any commercial group - an apparently unheard of achievement!

On March 29 I was invited to the home of our County Representative in Sussex Jenny Cole who organised the press



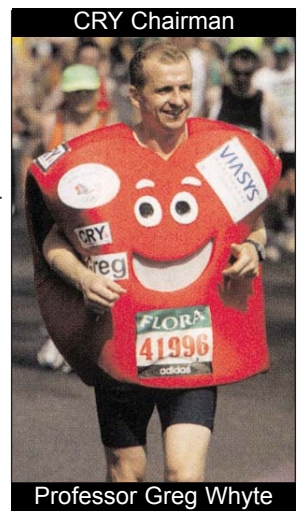
Jenny Cole, Nigel Waterson MP, Charles Hendry MP, Greg Barker MP, Nigel Cole and Alison Cox, chief executive of CRY.

to attend a meeting with 3 MP's: Nigel Waterson, Charles Hendry and Greg Barker, who had all declared support for our campaign.

Dr. Makan's paper in the March 2005 Issue of Heart "Identifying the Physiological Upper Limits of Left Ventricular Cavity Size in Highly Trained Adolescent Athletes" was carried by Reuters and received much attention in the national press.

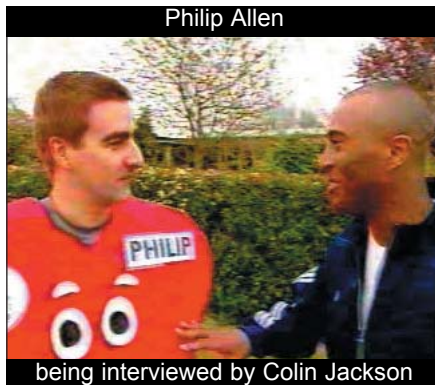
On March 31st The Rugby Football Union circulated a Press Release supporting the development of our screening programme in Rugby with the ultimate goal of extending screening into schools and clubs.

April; CRY had good representation in the London Marathon with 65 Golden Bond and 23 own place runners raising over £110,000 gross. Our London Marathon Reception was again held at the Britannia Hotel. This Reception interfaces with CRY Chairman Professor Greg Whyte's ongoing research into the assessment of cardiac fatigue after prolonged intensive aerobic exercise i.e. whether intensive exercise damages your heart. Special thanks to all those brave runners who gave blood before, immediately after (that really is tough!) and 24 hours later.



CRY Chairman Professor Greg Whyte

Greg was again the first full costume runner (in his giant Heart) across the line, followed by 3 other members of his Heart Team who heard the commentator announce on TV that CRY had got its runners well organised this year as he individually announced each one as they crossed the finishing line in quick succession! Greg's picture has reached iconic status being used on the London Marathon website, running on giant screens as the London Marathon News feature at various airports, and also to decorate a number of magazine features including a Third Sector article about VAT and fundraising events, and EasyJet's inflight magazine.



Philip Allen

being interviewed by Colin Jackson

During the event there was excellent TV coverage for our 10 CRY heart runners which included a sensitively portrayed 5 minute interview by Colin Jackson featuring Philip Allen who explained why the loss of his sister Jane inspired him to run for CRY. Philip and his

sister Katie, who also ran for CRY, had earlier recorded a TV news feature on Anglia TV with Jane's husband Edwin ten Dam and 2 year old Luka to raise awareness.

Many thanks to our intrepid massage team of Stephanie Bray and Donna Willsmore who soothed the aching muscles of so many exhausted runners at our reception at the Hilton Hotel after the race. Their excellent skills saved many from the alternative prospect of excruciating post-race muscle soreness and their cheerful dispositions convinced the pessimists that the pain really was worth the gain!



Stephanie Bray and Donna Willsmore



Professor Greg Whyte and Dr Sanjay Sharma

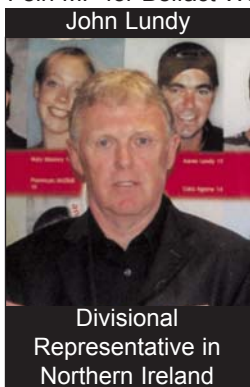
Congratulations to our Chairman Greg Whyte on being awarded a Professorship - possibly the youngest Professor in the country? And CRY's consultant cardiologist Dr Sanjay Sharma who is now the Medical Director of the London Marathon and has also been elected to supervise and manage the selection of CRY as the UK referral point

for rare cardiac conditions by The National Electronic Library for Health (NELH).

May; The May Bank Holiday found Tony driving the CRY Van to Belfast for the launch of our Northern Ireland Postcard. This was our first visit to Northern Ireland and the launch was supported by in excess of 60 members of families from County Down, Lisburn, Antrim, Derry, Fermanagh and Tyrone. Dr Pascal McKeown Consultant/Senior Lecturer in Cardiology at The Queen's University of Belfast Institute of Clinical Science was the representative for Northern Ireland on our sub-group for the new NSF Chapter. Special thanks to Pascal for spending so much of his Sunday morning helping our families have a better understanding of the medical conditions that can lead to sudden death in the young and answer their questions; the Stormont Hotel for providing the venue and to John Lundy our Divisional Representative in Northern Ireland for all his work in setting up the launch. Shortly after the launch The Reverend Ian Paisley Democratic Unionist MP for North Antrim; Gerry Adams Sinn Fein MP for Belfast West and Martin McGuinness Sinn Fein MP for Mid Ulster all declared support for CRY's endeavours in response to receiving some of the 29,000 postcards requested by our families in Northern Ireland.



Dr Pascal McKeown



Divisional Representative in Northern Ireland

The Postcard Campaign is undoubtedly gathering considerable momentum. We have printed over 90,000 for the 9 launches to date and hugely increased our profile with the public, MP's and the press. If you would like some postcards to send MP's from any of the launches, please contact the office. Your help in

this raising awareness initiative is vital to its success. As the election caused our APPG to lose 20% of its members dropping from 83 to 60 people your MP might have lost his/her seat. If you would like more postcards to campaign with the newly elected member please let us know.

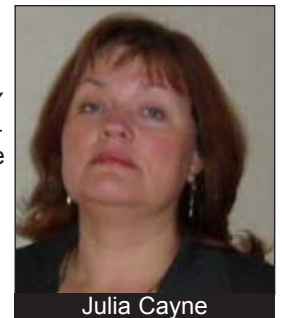
Immediately following the launch of the Postcard we drove to Cavan to attend the All Ireland Line Dancing Championships who had chosen us as their charity of the year and raised the incredible total of £3,700 in memory of Aine McCann who died suddenly age 8 from Myocarditis. Aine's Mum Aravon was the Novice Crystal World Champion in 2001 and her daughter Aisling won the Newcomer Primary World Championships in 2003. Although we were unable to get there in time to see the finals we received a wonderful welcome and enjoyed a spectacular evening of celebration witnessing the champions superb dancing skills in "relaxed mode."



Aravon seen here in relaxed mode after competing in the All Ireland Line Dancing Championships

I was driven to Dublin the next morning by Michael and Marie Green and was delighted to attend a special luncheon meeting of their Trustee Board of CRY in Southern Ireland and learn of the progress being made with their goal of funding a screening programme at the Mater Hospital in Dublin.

After travelling into our office from all over the UK for 12 meetings in 2 years our second Group of 9 Bereavement Supporters received their much valued accreditation for Counselling Theory. Special thanks to Julia Cayne for the training of our CRY Bereavement Support Team of 20 individuals over the last 4 years and to the Department of Health for funding the development of our Bereavement Support programme. As far as we are aware we are the only organisation that funds the training of bereaved supporters with conventional counselling skills which includes the option of further Diploma training if they elect to have it. This gives our Bereavement Supporters the confidence that they have acquired recognised certification to help others, to the considerable benefit of our bereaved families.



Julia Cayne

We have appointed Dr Clare Hinkley (sister of Philip Allen) as our CRY Volunteer Co-Ordinator for Primary Care Trusts. Clare's sister Jane died suddenly age 35. She had been suffering from symptoms that had not been diagnosed. It was not identified at Post Mortem. Her family had to fight for further information, and after being tested 3 members found they also have the condition. Jane left a devastated husband, 2 bewildered children, grieving parents and 4 distraught siblings.

Clare will be meeting with Chief Executives of Primary Care Trusts to report back to our MP's on how the new chapter will be implemented in their hospital. She will be a powerful advocate for the suffering experienced after a loss and we are lucky indeed to have such an articulate apostle dedicating her free time to address what could, and we believe should, be done through the Primary Care Trusts and Chapter 8 on Arrhythmias and Sudden Death to reduce the death toll of young sudden cardiac death.

