



# ISSUE 40 NEWSLETTER FROM THE CHIEF EXECUTIVE



The second half of our 10th Anniversary Year was led by our first CRY Raising Awareness Week. 29 families held stalls to raise awareness some of them combining this with a fund-raising event or local Health Week. They were pleased with the interest shown although many expressed concern that there is such a low level of awareness with the public.

Some time ago Dave Pover suggested that we sell rubber wristbands but it was not until our Northern Divisional Representative Dee Shackleton managed to source these that we were able to progress this excellent idea that came to fruition with a delivery of 5,000 just in time for our Raising Awareness Week. As Dave had predicted they have proved a huge success and were sold out within 5 weeks with a re-order of 10,000 immediately being made.

## June



Tim Loughton MP

**June 8th**, saw an Early Day Motion (EDM 286) on Cardiac Risk in the Young tabled by Tim Loughton MP who was delighted that 127 MP's signed this motion - a similar number to those offering support to giant charities such as Amnesty International and Help the Aged. EDM's are an excellent way of raising the profile of CRY within the House and also assessing how much support there is for our aims.

**June 9th**, The Coroners Officers Annual Conference requested 65 CRY SADS booklets to display after a raising awareness initiative of Andy Tait former Police Officer (and our Divisional Representative in the East of Scotland) who wrote to the 44 Police Forces in England, Wales and the Police Service of Northern Ireland. This resulted in 620 CRY SADS booklets being requested by various police forces and culminating in the booklet being distributed at the Coroners Officers Conference.



Andy Tait

Divisional Representative for The East of Scotland



**June 11th**, Our Raising Awareness week was launched on Saturday June 11 with our third Annual Bereavement Support Day at the Institute of Child Health in Russell Square with 92 delegates attending. This day is exclusively devoted to those bereaved by a young sudden cardiac death. Our Chairman Professor Greg Whyte introduced the event; other speakers were CRY Patron Professor Bill McKenna Professor of Cardiac Medicine The Heart Hospital London; Dr Elijah Behr Clinical Research Fellow (British Heart Foundation) Cardiological Sciences at St George's Hospital Medical School; Dr Sanjay Sharma Consultant Cardiologist at Lewisham University Hospital; and Dr Mary Sheppard Senior Lecturer/ Consultant Department of Histopathology National Heart and Lung Institute Royal Brompton Hospital London.

**June 15th**, our third Parliamentary Reception in the middle of our Raising Awareness Week was considered a highly successful event by MPs and guests with in excess of 70 MPs estimated to have attended. We were elated that our President Ian



Ian Botham OBE  
Honorary President

Botham was able to come. Ian's novel idea that it should be achievable to have a team of buses throughout the country visiting schools that could screen for a number of undiagnosed conditions, including heart and diabetes, commanded considerable attention. Rosie Winterton MP Minister of State for Health Services, spoke at length about CRY's astonishing progress over 10 years and in particular our success with the Cardiac Risk in the Young (Screening) Private Member's Bill which had made such a strong impact with MP's; Tim



Minister of State for Health Services

Loughton MP, Shadow Minister for Health and Children spoke passionately about the Bill and our work in raising awareness to reduce the death toll and described our Postcard Campaign as the most effective that he had seen in his time in Parliament; and Dari re-inforced the message that had inspired such support for her Private Member's Bill - that changes must be implemented to save young lives. Speeches are available live on, [www.c-r-y.org.uk/CRY\\_parliamentary\\_reception\\_2005.htm](http://www.c-r-y.org.uk/CRY_parliamentary_reception_2005.htm)



Dari Taylor MP

Secretary of the APPG

Many thanks to our sponsors for the event Guidant and Siemens and to our other sports celebrities CRY Patron Mark Cox MBE, Roger Taylor MBE, who had chosen CRY as his charity to toss the coin at the Men's Singles Final at Wimbledon last year, and Simon Halliday who has been working with us to develop our screening programme with the Rugby Football Union.



Kevan Jones MP

Chairman CRY APPG

Again we were able to present - this time to the Chairman of our APPG Kevan Jones MP - one of John Bennett's beautiful and much appreciated paintings of Westminster done in memory of his daughter Laura who died aged 14 giving a presentation to her school class.

Perhaps the most celebrated guest of the evening was baby Dylan who escorted his Aunty Laura (age 16) a member of our Surgery Supporters Club. As always the young members of our Surgery Supporters Club focus minds most acutely on our goal of diagnosing young people in time and saving lives. 2 of our Surgery Supporters, both with defibrillators implanted after they were diagnosed with Long QT, have had babies since last year's reception. Work commitments meant neither were able to attend but baby Dylan

was the most powerful representative possible of our clarion call - that young people whose lives are saved through diagnosis and treatment have a quality of life worth fighting for.



Ian Botham with Julie, Laura and baby Dylan

## July

**July 5th**, we held our first conference with the Cardiomyopathy Association on the new National Service Framework for Arrhythmia and Sudden Death; Implications for Primary Care. Heart Czar Dr Roger

Dr Sandeep Basavarajaiah



CRY's Research Fellow

Boyle opened the conference whose speakers included Professor McKenna, Dr Sanjay Sharma and Dr Elijah Behr as well as contributions on the role of the GP and Coroner from respectively Dr Jonathon Geldard and Gordon Ryall; A Personal Experience from Caroline Gard whose son Andy died suddenly age 17; and Strategies for Supporting Families from myself. During the conference

Dr Sanjay Sharma introduced me to our new Research Fellow Dr Sandeep Basavarajaiah (Dr Raj), who has now replaced newly qualified consultant Dr Jayesh Makan. Sandeep will be training under Sanjay at Lewisham University Hospital.

**July 6th**, saw us at Westminster again for our All Party Parliamentary Group (APPG) meeting when Dr Clare Hinkley explained to MP's her research initiative for visiting Primary Care Trusts to evaluate how they were responding to the new Chapter 8. Our APPG has now recovered from the blip suffered when many members did not regain their seats at the May Election. We now have 85 members and are steadily approaching our goal of 100. (Please visit [www.c-r-y.org.uk/pailiament.htm](http://www.c-r-y.org.uk/pailiament.htm) if you would like more information on our work with MP's.)

Caroline Gard



Divisional Representative for East of England

**July 21st**, we launched our East of England Postcard in the Post-graduate Centre at Colchester Hospital. The hospital know CRY well through the endeavours of Caroline Gard who has set up our first CRY ECG Testing Clinic in the cardio-thoracic ward. Caroline organised an excellent event well attended by the Chief Executive of the hospital, echo technicians and representatives from cardiac networks as well as affected families from all over the East of England.

**July 27th**, Brian Gibbons Welsh Assembly Minister for Health and Social Services responded to a question from Swansea East AMP Val Lloyd asking if there was any information on any action to be taken to determine cardiac risk in the young via screening programmes or other such measures. (WAQ43891) Mr Gibbons confirmed to the Assembly that services have been strengthened to ensure that all close relatives of individuals who die from sudden cardiac death are screened and that work to develop quality requirements for the care of people with arrhythmias and who are identified as at risk from Sudden Cardiac Death is currently being undertaken which should lead to improved quality of care for these groups of patients. This

Paulette Smith



Divisional Representative for South Wales

question was an initiative of our Divisional Representative in South Wales Paulette Smith who held an information stall on CRY raising awareness with AMP's in the Welsh Assembly.

## August

This is traditionally our "catch-up" month and during this relatively quiet period, as happened last year, we again addressed the issue of employing an additional 4 members of staff. CRY staff have doubled since Dari's Private Member's Bill, our 2 story office is fully occupied, with space at a premium. We now have 16 paid members of staff and a significant well-organised team of office volunteers that assist with mailshots, Christmas Card distribution, conferences, assembly of literature, maintenance of the CRY van et al!



John Bennett's 2005 Christmas Card

August is also the month where we organise our Christmas Card list. This year we had the benefit of another beautiful card especially painted for CRY by John Bennett of Lichfield Cathedral in

memory of Laura, and a painting of Tenby by Sue McBirney in memory of Huw Lewis. Especial thanks to our excellent team of volunteers who were kept busy with orders distributing in excess of 2,750 packs raising £9,000 gross.

## September

**September 17th**, the CRY Surgery Supporters Club met at the Epsom Haywain. Especial thanks to Julie Mills for organising these events and to Sanjay for giving us some of his very precious off duty time to talk to our members.



'One Life' TV crew seen here with the Surgery Supporters Club (SSC)

This meeting was unusual as, after careful planning and "assiduous gathering of permissions", it featured the filming of Lisa Davies for the documentary programme "One Life." Lisa participated in the day with her teenage daughter, hoping to clarify her thoughts to help formulate her decision as to whether or not she should have an ICD implant. Lisa suffers from the condition ARVC which took the lives of both her sisters when they were 27. The programme is



Dr Sanjay Sharma meeting with the SSC

to be shown early in the New Year and will hopefully raise awareness of young people diagnosed with a life threatening cardiac condition, and help promote the support that we offer. The camera crew were excellent, and very sensitive to the stress of the situation, and members of our Surgery Supporters Club were fantastic. As always when outsiders meet them for the first time, they are astonished at their pragmatic approach to life and their concern to help others. Talk of courage always surprises them. They always surprise everyone they meet!



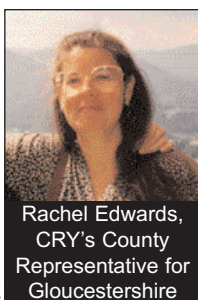
TV Crew Filming

**September 23rd**, saw the Implementation Board for the new NSF chapter meet for the first time at the Department of Health. We were invited on this Board as one of 6 core members - the Chairs of the 4 sub-groups for the new chapter, a representative from the Arrhythmia Alliance and CRY. Issues addressed included the expansion of the Board; immediate and obvious problems that needed to be addressed including communications strategies, new guidance for this specialist area and noting that there was a gap in skills around issues of sudden cardiac death in the young. It was noted that the Board would probably be meeting for several years.



**September 30th**, I was invited by the President of the Coroners Society Michael Oakley, to speak at the Annual Coroners Conference in York. Speaking at the Coroners Conference has been top of my wish list ever since I started CRY 10 years ago. The Coroners role is pivotal in looking after families following a young sudden cardiac death and giving them information and direction on the genetic aspects of the condition that caused the tragedy. How a family is treated by the Coroner at this excruciating time is an experience that will endlessly be discussed, never to be forgotten by those affected. Dr Elijah Behr, who wrote our CRY SADS book "when a young person dies suddenly...." funded by the British Heart Foundation, and is Specialist Registrar in Cardiology at St George's Hospital Medical School talked about the various conditions and the medical research being done. Speaking immediately after the Lord Chancellor, Lord Falconer, ensured that every Coroner in the country (or their representative) was present and as Elijah and I spoke between us for 80 minutes they were given a comprehensive outline of the critical role of the Coroner in young sudden cardiac death, and how our psychological research had highlighted what helped and what hurt - as well as an outstanding Powerpoint Presentation of the medical aspects. Every Coroner was also given a CRY SADS booklet, the Coroners Appendixes for the New Chapter 8 on Arrhythmias and Sudden Cardiac Death and a detailed Flow Chart on how to deal with a young sudden death. Michael, whose niece has had to bring up her baby son fatherless after the sudden death of her husband age 30 whilst exercising at the gym, concluded by telling the Coroners that even 3 years later she was *still* asking the same question for which science was *still* unable to furnish an answer "but why Uncle Michael. Why?"

**October**  
**October 13th**, our West of England Postcard was launched in Gloucestershire at Cheltenham Junior College and was supported by families from Gloucestershire, Hereford and Worcestershire, Shropshire and Dorset. Special thanks to our County Representative for Gloucestershire Rachel Edwards for organising the event; also to Cheltenham College Junior School for providing the venue and catering. Rachel and her husband Peter spoke movingly of the impact of sudden cardiac death on their son Alexander who died during a cricket match at the school. CRY Bereavement Supporter Keeley Ashley spoke of the work



Rachel Edwards,  
CRY's County  
Representative for  
Gloucestershire

of CRY and the needless loss of life, and how the postcard campaign had given the families the tools to raise awareness. Thank you also to our sponsors Becker (Sliding Partitions) Ltd., and the kind donation from our anonymous sponsor.



Mark Cooke  
ASA National  
Clinical  
Effectiveness  
Manager

The Ambulance Service Association (ASA) has teamed up with the Joint Royal Colleges Ambulance Liaison Committee, Resuscitation Council UK, Heart Rhythm UK and Cardiac Risk in the Young to develop new guidance for emergency care staff caring for patients with heart conditions.

Specifically the guidance seeks to raise awareness of the appropriate treatment for patients fitted with Implantable Cardioverter Defibrillators (ICDs). An ICD is a battery-powered device surgically implanted in the chest to monitor the heart-rate and rhythm. It corrects life-threatening, disordered heart rhythms by delivering a defibrillating electrical shock. The matchbox-sized device can also act as a conventional pacemaker if the heart-rate is too slow. The ASA's National Clinical Effectiveness Manager, Mark Cooke, says, "This awareness campaign has been put together because there are an increasing number of patients with these devices fitted and until now there has been a knowledge gap within ambulance services about how to care for these patients appropriately." ICDs can be fitted in both children and adults and are often fitted to patients who have some history of life-threatening arrhythmia with a likelihood of recurrence. Some patients may have previously suffered a cardiac arrest and been resuscitated. Others may have a high risk of developing a life-threatening heart condition.



We would like to get these guides to every young person that has a device and to every paramedic and technician in the UK. We would like also to get posters to all ambulance stations and training departments and if you have any ideas on how you might feel able to help with distributing these perhaps you could return the enclosed request form to the CRY office.

**November**  
**November 1st**, the highly acclaimed Journal of American College of Cardiology (JACC) published an article on "the physiological upper limits of left atrial diameter in highly trained adolescent athletes" submitted by our new Research Fellow Sandeep Basavarajaiah.

**November 3rd**, Julie Tanner's book "101 Reasons to get up in the morning" was launched by Julie and our new Patron John Inverdale on SKY News. (see Julie's Interview, Kids for CRY.) The main aim of the book was to raise awareness of



New CRY Patron John Inverdale seen here with Eamon Holmes and Lorna Dunley on SKY news



John helping to launch Julie's book

CRY, and if possible raise funds. As well as the SKY News interview there have to date been 12 local newspaper articles, 8 radio interviews, and 2 magazine articles which kept Julie extremely busy during her half term and beyond!

**November 12th**, Julie's book was launched in Caxton's bookshop Frinton. Attending the launch was Divisional Representative Caroline Gard, Douglas Carswell MP and Ivan Henderson the previous local MP who became a personal friend of Julie and helped greatly in getting the quotes of the politicians including Tony Blair. Julie spent all day signing 250 copies of the book which was profiled in the window of Caxtons with a huge poster for several weeks.



Julie Tanner seen here with a copy of her new book



Pat Ure, CRY's special volunteer "8 years and still smiling."

**November 17th**, we held an "in-house" party to celebrate the (semi) retirement of Pat Ure who has been a core CRY volunteer ever since I first interviewed her in 1996 for a secretarial job at the end of which she said she would like to work for us for nothing! This was an irresistible offer and for 8 years Pat has done crucial secretarial work as well as being our proof reader, sounding board and CRY supporter. I do not know how we would have managed without her and we will always be immensely grateful for the time and help she has so willingly given us.

**November 27th**, the British Journal of Sports Medicine (BJSM) accepted a second research article by Sandeep for publication on "the physiological left ventricular hypertrophy of hypertrophic cardiomyopathy in an elite adolescent athlete - the role of detraining in resolving the clinical dilemma." Sandeep is delighted with his first successful foray into the world of research and his publications will officially acknowledge CRY's contribution and support.

### December

**December 9th**, Julie was requested to do the first of 3 book signings at her school Colchester High with 202 books sold. Waterstone's chain selected the book as a core stock title which resulted in a surge of orders from branches throughout the country and by Christmas the book was sold out. The publishers are currently preparing for a reprint.

**December 12th**, saw the first full meeting of the implementation Board for the new Chapter on Arrhythmias and Sudden Death. It addressed current levels of support and interest in the new chapter; roles and responsibilities of those directly involved in its implementation; concerns, challenges, further developments and focus areas including the development of better specialist cardiac assessment and rehabilitation following device implantation.

**December 21st**, the office was taken over by the film crew making a video on CRY's work, sponsored by double Grand Slam winner and member of the 1991 England Rugby

World Cup final team Simon Halliday. This video will be shown at the Bath Rugby Team Reunion party that Simon has arranged after his epic run for CRY in the Bath Half Marathon on March 19 with many of his teammates, including 6 of the 1991 Grand Slam Rugby Squad, CRY's new Patron John Inverdale, and a group of 58 CRY runners. This unique event is in memory of Simon's friend Howard English who died in John's arms during a rugby training game which Simon was coaching. A decade later, Howard's son Sebastian died of the same heart condition which he unknowingly inherited from his father. For more information on this high profile event please visit our Homepage on- [www.c-r-y.org.uk.simon\\_halliday\\_bath\\_half\\_marathon.htm](http://www.c-r-y.org.uk.simon_halliday_bath_half_marathon.htm)



Simon Halliday

**December 21st**, CRY staff were received like royalty by the Wimbledon Golf Club when we were invited to an exclusive Christmas Dinner hosted by Stephanie and Alastair Paterson in memory of their son James. This included us having a private dining room to celebrate the festivities at this superb venue overlooking a lake and adjoining the All England Tennis and Croquet Club where the Championships are held. We were enormously moved by this very generous and thoughtful gesture from Stephanie and Alastair, who insisted on us having this special treat to mark the finish of our endeavours for our 10th Anniversary Year.



James Paterson

In conclusion and at the end of a very hectic 12 months when there has been a most significant shift in the opportunities that have presented themselves I would like to thank all of you who have worked so hard to raise awareness of these conditions and of CRY's work. Raising Awareness is the most critical aim we aspire to. Helping families find us through your fund-raising initiatives, our web-site, our literature and the media is crucial to progress in keeping pressure up to address the issue of young sudden cardiac death. Our website now has 2,000+ hits a day on the Homepage. There were an unprecedented 12 articles in various national newspapers during the year. A recent article in the Daily Mirror featuring a double page on the sudden deaths of 20 year olds Scott McCollin and Vicky Johnson led to 44 copies of this newspaper being given by friends to one recently bereaved family. When CRY was founded in May 1995 young sudden cardiac death was thought to be very rare. Far too rare for anything to be done. Back then, 50 young people a year were thought to be dying suddenly and unexpectedly. Accurate statistics are still not available but through raising awareness we now know this annual total to be in excess of 400. Our Postcard Campaign message has been drumming out the roll call of 8 young deaths a week, which we believe could be a conservative estimate.

Much has undoubtedly been achieved in 10 years to highlight this terrible death toll.

Much undoubtedly now remains to be done to reduce it.

