



ISSUE 41 NEWSLETTER FROM THE CHIEF EXECUTIVE



It was frustrating returning to the office after the Christmas break knowing that in the 10 months since the Secretary of State for Health, John Reid, had announced the new Chapter 8, instigated as a result of Dari Taylor's Private Member's Bill on Cardiac Risk in the Young and Screening, very little progress had been made in addressing young sudden cardiac death. The new chapter specifically addresses the crucial issues of necessary expertise in diagnosis and pathology and until these guidelines are implemented intolerable, avoidable tragedies will continue to happen.

January



Cecilia Barriga

January 13th, I was asked to attend the Inquest of Cecilia Barriga. Professor Bill McKenna was also asked to attend this inquisition to testify as an expert witness. Cecilia was 16 when she had such a severe faint during her dance lesson that her teacher requested she should see a doctor. Her GP immediately referred her to an NHS consultant but pointed out that this appointment would take several months. Her alarmed parents decided she needed to be seen urgently and paid for a private consultation with the recommended expert 8 days later. This consultant overruled Cecilia's abnormal ECG reading, told her to take Diarolyte if she felt faint, and to carry on dancing. Cecilia's next faint, 48 hours later, was fatal and in his verdict the Coroner commented "The serious nature of her underlying medical condition was not recognised, and she died following a period of exercise."

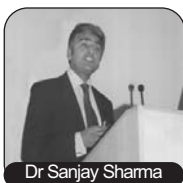


Prof. Bill McKenna

The conditions that can result in a young sudden cardiac death are complicated and need considerable expertise and experience to identify. Cecilia's tragic story is not an unfamiliar one. Families of so many other young people have told me a similar story where a GP - or of even greater concern a consultant - who sees only occasional cases, does not understand the complexities and screening procedures necessary for diagnosis of heart disease in apparently fit and healthy young people and has dismissed symptoms as irrelevant, then been proved tragically wrong. In an effort to raise awareness of the importance of expertise and understanding the significance of symptoms, we are hosting a conference for medical personnel on October 16 on "The Diagnosis and Management of Inherited Cardiovascular Disease" which will follow our CRY Sports Cardiology Conference on October 15



Prof. Greg Whyte



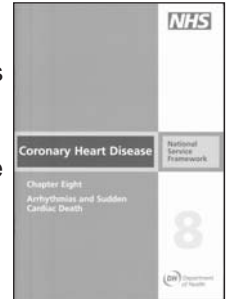
Dr Sanjay Sharma

"From Theory to Practice." Both conferences will be held at The Institute of Child Health and the Scientific Committee is Professor Bill McKenna, Professor Greg Whyte and Dr Sanjay Sharma. The full

programme and flyer will shortly be available and circulated to CRY supporters in the hope that they will urge their GP's practice and/or local hospital to send delegates.

February

We decided to investigate the extent to which the new Chapter 8 was being implemented by the Primary Care Trusts (PCT's) and field a Press Release on the 1st Anniversary of the new chapter in March. This led to a period of intense activity working in tandem with our media team, Redhead PR, as we prepared for the Press Briefing in the House of Commons.



March

March 1st, The Press Briefing was held in Portcullis House and published the results of our survey vindicating our concerns revealing that one year after the introduction of Chapter 8 a staggering 97% of all Primary Care Trusts (PCTs) interviewed said they had failed to develop a strategy for implementing any of the new Chapter's specific guidelines for children and young people. Nearly 100% of all PCTs interviewed said they were aware of Chapter 8 – which made the findings all the more damning.



Jeremy Bates, Andy Scott, Caroline Gard, Alison Cox, Stephanie Hunter, Professor Greg Whyte, Simon Halliday and Mark Cox MBE

The survey of PCTs, GPs and the general public reinforced our experience that no significant progress had been made to address the estimated 400 unexplained sudden cardiac deaths of young people every year. 84% of GPs interviewed said they had experienced a young sudden cardiac death in their practice which suggests that the real number of young deaths is considerably higher than those officially logged. Accurate statistics are not available and CRY believes that 8 deaths a week is in fact a conservative estimate. In the UK unexplained sudden death is frequently recorded as death from natural causes. Until the law is changed and coroners have to refer hearts on to specialist cardiac pathologists the true figures will never be known.

Although nearly 70% of GPs said they had a 12 Lead ECG machine in their practice, rather worryingly, nearly two thirds of all GPs interviewed said they would not refer young people who have had an ECG on to an expert

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Professor Greg Whyte

Cardiologist for diagnosis. It is this level of expertise that should be accessible to all and is vital if specific cardiac problems are to be properly identified and young lives are to be saved.



Caroline Gard

However, CRY's robust campaign to raise awareness of young sudden cardiac death is proving effective and 65% of the general public are aware that the condition is something which can affect people aged 35 and under. Significantly, nearly 30% knew of a young person who had died from an unexplained or sudden cardiac death.



Stephanie Hunter

Both samples of PCTs and GPs, 78% and 82% respectively, said that where a young member of a family (35 and under) dies as a result of an unexplained or sudden cardiac death, they would approve or refer other members of that family to be seen at an Inherited Cardiovascular Disease Clinic.



Andy Scott

As well as the media, the Press Briefing was attended by our Patrons Mark Cox, Jeremy Bates and new Patron Simon Halliday. Our Chair Professor Greg Whyte spoke as did our East of England Divisional Representative Caroline Gard; Andy Scott the professional footballer who was diagnosed with cardiomyopathy by Dr Sanjay Sharma after he was unable to return to the pitch when feeling unwell during a match; and Stephanie Hunter who spoke about the loss of her husband and



Simon Halliday

her son as a result of incorrect pathology after her husband's death. Simon introduced the very moving video that he has had made for his CRY Sportsman's Dinner.

Campaigners seek action to prevent sudden heart deaths among young

Cardiac arrest takes lives of 400 under-35 a year
Many doctors unaware of genetic conditions

Polly Curtis
Health Correspondent

Eight young people die without warning every week from starting heart conditions, many of which could be prevented by screening programmes and better education for doctors, the Campaign for Young Cardiac Health in the Young and Prevention (CRY) says. The charity says that the condition will have been to a doctor via a family doctor or cardiologist under the age of 35, but many are not aware of whether they have a genetic condition, such as Long QT syndrome, which can lead to sudden cardiac death in the young (SCD).



FAQ: Hidden killer

What is sudden cardiac death?
It is a rapid loss of heart function, usually from the age of 35, but can occur at any age. Symptoms include chest pain, fainting, dizziness, or palpitations or chest pain.

What can it affect?
Anyone, although most of the conditions are genetically linked.

How do you tell whether you might be affected?
There are often no symptoms.

Are there treatments?
Some people can be treated with drugs, but some may need surgery or a heart transplant.

said this should ensure doctors do not miss a young person, it is being done through a series of steps. It is being done through a series of steps. It is being done through a series of steps.

CRY research yesterday suggested that all GPs should be asked to refer patients to a specialist cardiac clinic. CRY said this step would have been given five years to complete the task and many were asking for a programme for the GP to provide. "We, we're impatient. There are at least 100 cases a year and we need to see that's done in the first year. At least that should be done."

Some 700 of 1,000 people questioned in a poll by Action on Heart Disease in the Young were unaware from one of a range of conditions, such as Long QT syndrome, which can lead to sudden cardiac death in the young (SCD).

The Department of Health spokesman said: "We are committed to ensuring that the public are aware of the risks of sudden cardiac death and to supporting the work of charities such as CRY."

Subsequent coverage appeared on Page 12 of the News section in The Guardian; a page in The Metro and an urgent request to appear on This Morning (3 million viewers) which featured the tragedy of Bill Preest with "Phil and Fern" focussing on the importance of expert pathology and the value of screening.



Alison Cox with Helen Preest on 'This Morning' with Phil and Fern



Kevan Jones, Dr Sanjay Sharma, Tim Loughton MP and Dari Taylor at the All Party Parliamentary Group Meeting

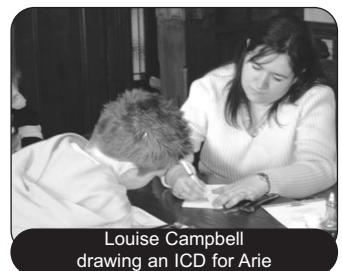
Immediately after the Press Briefing there was a CRY All Party Parliamentary Group meeting when MP's were frustrated to learn the results of the CRY survey with PCT's and agreed that members (now 89 strong) should be asked to write to their PCT's.

Tim Loughton MP raised an Early Day Motion, EDM 1719, applauding CRY's work and contribution to the new chapter to coincide with the first anniversary. This EDM currently has 102 signatures and Tim would be delighted if you could consider asking your MP if they would support it.



Arie Hunt at the Surgery Supporters Club

March 4th, we had our Spring Surgery Supporters Club meeting and by special request were asked by the parents of 10 year old Arie Hunt if they could bring him. Arie had just been diagnosed with Long QT and was finding life pretty tough as he could no longer play football with his friends. However he felt a great deal better after meeting other group members, learnt all about what ICD's looked like, how they coped with them, what their scars looked like (!) and found to his astonishment that doctors could be really nice when he was allowed to ask our Consultant Cardiologist Dr Sanjay Sharma as many questions as he wanted about how he was going to manage. The group were absolutely fantastic and it was an inspiration to see how well they bridged the age gap, and how much they gained from the opportunity of spending time together. Many thanks to Julie Mills for organising the day and as always to Sanjay for his valuable time.



Louise Campbell drawing an ICD for Arie

March 15th, Simon held the first of his 2 back-to-back fund-raising events - a Sportsman's Dinner at the London Marriott organised by former Rugby International David Trick. David generously proposed that the full proceeds of the auction be donated to CRY (and also agreed to run in Simon's team in the Bath Half). Attending the dinner were numerous famous rugby names including Jonathan Webb, Rory Underwood, Peter Winterbottom, Ben Clarke, with Martin Bayfield being the key speaker and giving an



Simon Halliday speaks of his ambitions for CRY



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Speaking to the diners at the Sportsman's Dinner

extremely entertaining and well received speech about his rugby experiences. The dinner provoked huge interest and was a sell-out being attended by 520 people who raised over £50,000.

ankle which ended his rugby career in 1992. He said "It was a great day, a great reunion, and fantastic to see the guys who didn't run too, like [Gareth] Chilcott, [Stuart] Barnes and [Graham] Dawe. It was brilliant to see 70 runners, all in their special CRY gear and all really passionate about CRY".

March 27th, CRY Publications Co-ordinator Mark Fox returned to the office after completing his epic trek in the Sahara Desert and raising £4,000 for CRY. Mark decided to take up this challenge to raise money for CRY in memory of his twin sister Laura who died suddenly in 1998 when changing for a game of tennis. He wrote in his diary of his feelings as he approached the finish:

"100 kilometres of rocks, sand, dunes, wind, blisters, sand, heat, sand, sand, sand. But here we all are. We challenged the desert and defeated it. The weather tried to stop us but we pushed on, our bodies wanted to give in but we would not let them. Whenever anyone was in doubt, we remembered why we were there. To help a cause which is close to our hearts. To remember a loved one whom we had lost. Or to challenge themselves because of a condition they have battled against and won. I walked this trek with, in my opinion, true heroes. Each with their own desert to cross, but ultimately, we all walked the same path together, helped each other through and we can now say we have done it. I believe this trek was more emotionally challenging for me than physically. I conquered the desert in my thoughts and emotions for the first time since I lost my sister nearly 8 years ago, and I'm sure many others did the same."

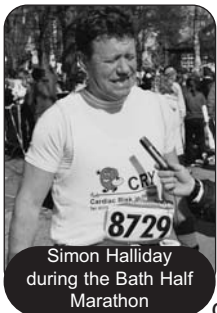
March 19th,

There could not have been a more beautiful spring day than the one we were treated to for The Bath Half Marathon with a plethora of big names from the world of rugby supporting CRY



Will Carling and Simon Halliday enjoy breakfast

and a number of Simon's ex-Bath and ex-England colleagues including Will Carling, Michael Lynagh, Jason Leonard, Mike Teague, David Egerton, Jonathan Callard, Tony Swift, David Trick, Richard Hill, Jonathan Webb, Paul Ackford, Gareth Chilcott, Victor Ubogu, Jack Rowell and more. Simon (who played Centre for England and Bath) was also joined in the Bath Half Marathon by CRY Patron John Inverdale. Simon was coaching Esher RFC when his friend Howard English died dur-



Simon Halliday during the Bath Half Marathon

ing a training session in John's arms. 70 people ran in Simon's CRY team raising over £130,000 in memory of Howard and Seb English. The run was followed by a reunion in the Bath Rugby Clubhouse - the first time many of the players had seen each other since retiring from competitive rugby.



Jonathan Webb, Suzanne Halliday and Richard Hill during the race

The fun run was a huge personal triumph for Simon as it was the first time that he had been able to train and participate in a major sports event since the fusion of his



Mark and Anne Collins supporting CRY in the desert

In concluding I would like to pay tribute to the courage of the thousands of bereaved siblings who so often put their own grief on hold whilst trying to support their parents through the terrible loss of their child - a child who is also their teammate, friend, brother or sister and who have had to dig very deep to find the strength to regenerate their own lives and move forward through their own loneliness, anguish, pain and despair.



CRY's runners for the Bath Half Marathon 2006