

North Gloucestershire ICD Information and Support Group

Newsletter May 2008

Notes on Group Meeting on 24th April 2008

The 4th meeting of the Group took place at Up Hatherley Church Centre, Cheltenham and was attended by 20 members. In addition we had Laura Nelson and Simon Woodings from The Arrhythmia Alliance; Mr Kevin Dickens from the Great Western Ambulance Service, Kim George from St Johns Ambulance, Gloucester; Nicola Meldrum (ICD Nurse Specialist, John Radcliffe Hospital, Oxford) and Chrissie Jones, from Cardiology Rehabilitation, Gloucester Royal Hospital.

1. Sudden Cardiac Arrest and Cardiac Defibrillation

Work of The Arrhythmia Alliance (AA)

This was the main theme of the meeting, which commenced with Laura Nelson describing the recent initiative of the Arrhythmia Alliance in conjunction with a local company in the Chew Valley, Somerset, where a number of Automated External Defibrillators (AEDs) have been installed in several of the villages/small communities. These locations were chosen as due to their relatively difficult accessibility or distance from a main conurbation, there might be delays in paramedics being able to arrive at the scene of a cardiac arrest within the critical first few minutes. The installation of the AEDs, together with clear signs of where they are located was also accompanied by the training of groups of volunteers in these communities. This venture should be seen within the context of an estimated 100,000 people who die of Cardiac Arrest each year, of whom it is generally thought that up to 70% might survive were defibrillation equipment available and employed within minutes.

Laura also gave a short but comprehensive account of the overall aims of the AA, and particularly how the organisation works as an 'umbrella' under which affiliated groups, such as our own Support Group can work and benefit. The forthcoming Arrhythmia Awareness Week (9th-15th June 2008) was described. We would urge all of our members to join the AA (there is no charge, although as a registered Charity, it depends upon donations). The AA can make available to our members packs to hand on to our GPs describing in some detail ICDs and the implications of living with one – an often voiced concern is that many people's GP practices are unaware of the precise details of ICDs and the needs of recipients. Either contact AA directly or us if you require these.

Work of The Great Western Ambulance Service and St Johns Ambulance

Kevin Dickens and Kim George together described the excellent (and very re-assuring!) way in which their organisations work together to 'save lives' in the context of Cardiac Arrest. The usage of defibrillators was described in detail, and how External Automated Defibrillators (AEDs), when positioned in specific locations may augment the work of the Ambulance service in saving lives. Of particular significance, however, was the information and guidance we received on the vital role of Cardio Pulmonary Resuscitation (CPR) – something that we can all do in the vital minutes following cardiac arrest before defibrillation equipment is located or used. Kim has provided us with CPR Skills Kits by means of which anyone can easily learn how to use CPR. The kits comprise of a DVD, clear pictorial instructions and an inflatable manikin torso, on which one can practice the technique. We are happy to make these kits available to any of our members as this is such a simple but vital aspect of saving lives.

Involvement of North Gloucestershire ICD Group

As well as the very obvious personal interest we all have in defibrillators (!), we are also very interested in the AA initiative to install AEDs in appropriate communities throughout the county. We have already had very useful advice from The Great Western Ambulance Service on this. We have been offered £1500 from a local Rotary Club for the provision of an AED in the vicinity of Bishops Cleeve.

Furthermore, we were somewhat overwhelmed at the Meeting to be handed a cheque for £220 from Anna Browne, one of our more recent members, who had made this collection from her friends at a luncheon to celebrate her Golden Wedding Anniversary. She wants this money to go towards the instillation of an AED – possibly in the Tewkesbury area. This money will be added to that already raised by the Gotherington Singers at their carol concert last December. We feel that with such a promising start, our Group might yet be able to do something useful for the local community in the context of saving lives from Sudden Cardiac Arrest via AEDs and supporting training in CPR.

We hope that all members will support us in these ventures, which are now progressing with the guidance of the Ambulance Service, St Johns Ambulance and the AA.

2. General ICD Group Notices

External contacts. We have been asked to participate in two Arrhythmia Alliance Regional Meetings in Stratford (April) and Bristol (June). In addition, we shall be working with an ICD recipient in Bath to help set up a local ICD support group for that area – as travel to/from the hospital in Bristol is a problem for many there – exactly as we in Gloucestershire find for Oxford. We are finding that by keeping in regular contact with other ICD support groups, our knowledge and experience base grows, and we are gaining numerous ideas/topics for speakers and activities that some of our members might find useful.

Local ICD Downloading. There has been a recent expansion of the clinical resource at Gloucester Royal Hospital such that some patients who have expressed the wish have been able to switch from management of their cases by John Radcliffe Hospital, Oxford to The Gloucester Royal Hospital. The capability to handle new patients is still developing, and we understand that ICD implantation has already commenced. Should any members wish to consider such a switch, we recommend that they discuss this in the first instance with Nicola Meldrum to see if this is appropriate. These are still early days, but this might be a real benefit for patients who have difficulty in travelling to Oxford for downloads.

Membership and the N. Gloucestershire ICD Group. We are keen to extend a welcome to join this Group to any new or potential ICD recipients and their spouses/partners/carers, and we have recently been contacted by two such people. We are concerned, however, at building the membership attendance at our meetings, to warrant the effort and expense, particularly by the speakers. So far, in the year since we started we have held 4 meetings and we understand from comments received that these are of value to people whose lives are ‘touched’ by ICDs. The essence of the Group is for members to exchange experiences in a friendly environment.

We propose to continue to hold meetings at 3-monthly intervals for the remainder of the year, but this will depend upon whether we get reasonable attendances. We do not intend to resort to charging a membership fee, but as meetings cost us in the region of £50 to set up and report back to members, we do rely upon the generous contributions that people have made at our meetings – at our most recent meeting a total of £60 was donated, and we are very grateful for this.

We would appreciate some feedback from members, however, as to any areas or concerns they might have regarding living with an ICD. Also, if anyone feels the venue for our meetings is inappropriate, or the dates/frequency is inappropriate, please let us know.

As ever, we recognise how fortunate we have been in the support given to us by Nicola Meldrum, who has always been prepared to travel to our meetings from Oxford to provide help and advice, and also to Chrissie Jones from Gloucester Royal Hospital. To be able to talk to specialist clinical staff in the relaxed atmosphere of our meetings is greatly appreciated.

Next meeting. We propose this to be Thursday 24th July at the Hatherley Church Centre. We are fortunate in having staff from Medtronic attending, who will talk to us about ICDs generally, and specifically remote monitoring (ie routine downloads from the comfort of your home, via a telephone link). This is a feature that The John Radcliffe Hospital is now moving to for certain ICD recipients. Also, we are also fortunate that Nick Butler, the Clinical Pharmacy Manager at Gloucester Royal Hospital, has agreed to talk about drugs that patients with ICDs are typically prescribed, their direct and side effects and any precautions we should be aware of.

Medtronic has also very kindly agreed to sponsor the costs of the meeting, and a buffet will be provided. This will enable us all to interact socially and ask questions of the speakers. Nicola Meldrum has said she will also attend.

Please make an attempt to attend, as we think these speakers will make valuable contributions to our understanding of the technology that we depend upon.

To help us in organising the meeting, particularly the catering, it is a very great help to us to know whether or not you intend to come. Please get back to us as soon as you can by phone, mail or email.

We also have future meeting dates proposed and they are Thursday 24th July and Thursday 23rd October, all at the same time and same place.

Colin Prottey
Robin Harvey

May 2008