

# North Gloucestershire ICD Information and Support Group

## Newsletter January/February 2008

### Notes on Group Meeting on 24th January 2008

The Third meeting of the Group took place at Up Hatherley Church Centre, Cheltenham and was attended by 25 members (16 existing members and 9 new ones, attending for the first time). In addition we had Mrs Trudie Lobban from The Arrhythmia Alliance and 3 staff members, Mrs Nicola Asson from St Jude Medical, Mrs Jenny Tagney, ( Cardiac Nurse Consultant, Bristol Royal infirmary); Mrs Nicola Meldrum (ICD Nurse Specialist, John Radcliffe Hospital, Oxford.

#### **1. The British Heart Foundation Video 'ICD's – A Guide for Patients - "The Beat Goes On"**

This 20 minute DVD was presented by Jenny Tagney, and covered the history of ICDs and included interviews with clinical staff at the Bristol Royal Infirmary, Queen Elizabeth Hospital, Birmingham, John Radcliffe Hospital and St George's, London. The history of ICD's was described as well as the experiences of ICD recipients from several ages and walks of life, portraying their confidence and how they had overcome initial fears and misgivings. The DVD also covered patient preparation, the actual procedure of implantation, guidance for the immediate post-procedure period and follow-ups and downloads. This is a very reassuring presentation, particularly for new recipients/carers.

We hold copies of this DVD, and it is available for any member to borrow, which we strongly advise to new/impending recipients of ICDs.

We do have additional DVDs, one issued by St Jude Medical, entitled 'Living with your ICD'. This is 25 minutes in length and somewhat similar to the British Heart Foundation video, although it is designed for American audiences, and so is somewhat different in its approach. We also have 'ICD Implantation Techniques', also provided by St Jude Medical and is a demonstration by Dr Thomas Mattioni and his team in Arizona. This is 1hr in length and is very explicit in showing the surgical techniques of implantation, particularly the preparation of the site and subsequently how the generator and leads are implanted and then tested. This is also available for members to borrow, but we would add a word of caution to anyone who may be a little squeamish of explicit surgical procedures.

In response to questions, Jenny gave examples from her experience over more than 10 years on topics including the differences between heart attacks and cardiac arrests, angina and arrhythmias. In response to a question on the likelihood of an ICD shock intervention during actual driving, this is recognised as being very uncommon – and given that a recipient will first have fulfilled the DVLA 6-month ban from driving after shock therapy, it is accepted that this provides an appropriately very high level of confidence of safety for all parties subsequently.

An important point emphasised by Jenny was that ICD patients and their carers do occupy key intermediary roles between hospitals and their GP Surgeries, given that many patients may be the only ones in their practice with such a device, and that many GPs or Practice Nurses may not be very familiar with the technology or specific patient and carer needs. It thus behoves ICD patients to acquire as much information as they can in order to help their GPs to help them. The video was produced before the Arrhythmia Alliance became fully functional, although it is still very salient. Now that the AA is fully resourced and committed to providing patient information (see below), as also is the British Heart Foundation, we are in a very favourable position with regard to the provision of reader-friendly information and guidance via pamphlets, posters and booklets.

The British Heart Foundation has produced a 'Progress Record' – a diary in which a patient can record details of their condition, ways of Reducing Risk Factors, Medication and Treatment, Local Contacts and

Symptom Record. Whilst this diary has been primarily directed to those who have had heart attacks, it is eminently appropriate for ICD recipients too, as it provides a very useful summary of things experienced or done by patients between down-loads. Moreover, we believe it will aid ICD Recipients to adhere to the discipline of Life-Style changes that are called for, but always difficult to achieve.

We will apply to the BHF for a supply of these Diaries. Members should contact us if they require one.

## **2. ICD Technology - St Jude Medical**

The main presentation was by Mrs Nichola Asson of St Jude Medical. A very comprehensive presentation covered ICDs, from their inception in the 1960's, and early devices (said to be the size of house bricks) to the present day Atlas and Epic devices that are generally as small as Zippo lighters. As some 80% of the bulk of the modern device is battery, it is felt that sizes will not reduce significantly further until there is a radical change in battery technology.

The details of lead technology and implantation were covered as well as the process of ICD intervention in arrhythmias, with bradycardia pacing, ventricular pacing and cardioversion shocking clearly illustrated with reference to ECG tracings. Nichola also described comprehensively the information available and the parameters measured during a routine ICD checkup.

Particular attention was paid to the advances in therapy of 3-Chamber devices, particularly where asynchrony between the left and right ventricular contractions can be radically improved.

## **3. The Arrhythmia Alliance**

As something of a bonus for our meeting, Mrs Trudie Lobban, the founder and Chief executive of the Arrhythmia Alliance (AA), was able to attend this meeting, together with her colleagues, Laura Nelson, Charles Lobban and Simon Woodings. Trudie gave a short presentation on the overall function of the AA, and re-iterated the point made earlier by Jenny Tagney of the importance of ICD recipients and carers to acquire sufficient information to act as conduits between hospitals, GPs and the general community at large. To coincide with the Arrhythmia Alliance 'Arrhythmia awareness week (June 9<sup>th</sup>-15<sup>th</sup>, 2008), the AA proposes to produce 'Adopt a GP Surgery' - this will be a basic pack for members to take to GP surgeries that are aimed to alert GPs and staff to the specific needs and issues related to arrhythmia sufferers.

Sudden Cardiac Death is the largest single killer in the UK (some 100,000 per year die – and it is believed up to 70% of these could be saved if rapid defibrillation was available). This led to a brief description of the AA joint initiative to install significantly more Automated External Defibrillators (AEDs). This is something that we feel very strongly about, and we propose asking Trudie and Laura to give a more comprehensive presentation on this subject at our next meeting, with demonstrations, and the plans that have been made to extend the installation of AEDs in the community. Members may be aware that Robin has already been active in raising over £500 via a carol concert towards purchasing such a device, and we have further proposal via charity walks to increase this in the future. We will describe our proposals at the next meeting: we hope that our members will support us in this venture.

We have also asked Trudie to describe in more detail the origins of the AA and its current and future plans to ensure that all common interest groups for Arrhythmias can work together with maximum efficiency.

We would strongly recommend members to join the AA – for patients there is no annual charge (though, of course, any donations to the AA, a registered charity, would be more than welcomed). An application form is included with this newsletter for all members.

#### **4. Social Interaction**

We have been mindful that at our first 2 meetings we did not allow enough time for members to interact, to get to know each other, to exchange experiences, and particularly to ask questions of the expert clinical and technical staff who were speakers or attending our meetings. Thanks to the generosity of St Jude Medical, a buffet was provided, which allowed participants in the meeting to talk in a much more relaxed environment, which is never possible when visiting the hospital for a routine download etc. This proved to be very successful, and we now can see the members gelling more into a coherent group that really can give support and advice, sometimes in very humorous fashion, to each other. We hope to repeat this in the future. Our sincere thanks are due to St Jude for allowing us to make this step forward.

#### **ICD Information Morning – John Radcliffe Hospital, January 31<sup>st</sup> 2008,**

Well over 100 ICD recipients and carers attended the above meeting, organised by Nicola Meldrum and Elaine Watson, the ICD Nurse Specialists. A brief summary of the presentations is given here, and we hope to provide copies of the slides shown can be found on our website. members who would like paper copies can contact us.

##### **1. Cardiac Rehabilitation – A whistle-stop tour Marion Elliot, Senior Nurse, Cardiac Rehab.**

The presentation covered those who are eligible for cardiac rehab, (this does not normally include recipients of ICD devices!) and the type of exercise recommended. Also, the need for life-style changes was touched upon, particularly with regard to diet and habits, and specific do's and don'ts related to ICDs.

There are clear hurdles for NHS-supported cardiac rehabilitation for ICD recipients, and it is our intention to raise this with Chrissie Jones, of the Gloucester Royal Hospital to see how we can progress this for our Group members.

##### **2. Identifying the needs of an ICD patient and carer support group – Robin Harvey, ICD-Gloucestershire**

In response to a request from Nicola, Robin gave an illustrated presentation on how we have set up the N. Gloucestershire ICD Information and Support Group, particularly how we identified key needs, and the way are now going about meeting these. It is generally accepted that such groups are valuable, and already there a 4 within the catchment area of the John Radcliffe Hospital (Oxford, led by Geoff Shaw; High Wycombe, led by Brian Longson; Milton Keynes, led by Sam Shunmooqun and ourselves).

It was agreed that much can be derived from regular meetings between our group and the others, to avoid replication and to 'steal with pride' from other groups and websites ideas and topics for discussion at our individual meetings. In this initiative we have been promised support-by the Arrhythmia Alliance. In addition, we enjoy very good relations with the leaders groups at Bristol and St George's, London. We would remind members that they are all welcomed to attend meetings of these other groups – and we ourselves are now doing this.

##### **3. Pacing in a nutshell – Carly Taylor, Specialist Cardiac Physiologist, JRH**

Carly gave an overview of heart rhythm disorders, the types of ICDs that are used, how the ICD intervenes to correct any events, and the nature of the information that is retrieved during the regular 6-month downloads. We were encouraged to ask more about such information, as this enables the JRH Staff to monitor how well the ICD may be managing our conditions, and whether and trends are taking place that may require changes in ICD settings or medication.

#### **4. Remote monitoring of ICDs – David Powell, Market Development, Medtronic**

This described the type of research and development that Medtronic is pursuing to facilitate the work of hospitals/clinicians and ICD recipients by means of home-monitoring of ICD via telephone/modem links. This is already established in the USA and has been successfully piloted in the UK. There are clear economic/'political'/security issues that have to be resolved before given NHS Trusts can move forward on this front – notwithstanding these, the work offers many attractions to ICD recipients and carers alike, particularly when distance/travelling etc. from the cardiac pacing facility is an issue.

#### **5. Cardiac drugs: Indications and Side Effects – Dr Kim Rajappan, Consultant Cardiologist and Electrophysiologist, JRH**

The presentation covered selected cardiac drugs that are typically used with ICD patients (Anti-platelet agents; beta Blockers; ACE inhibitors and Angiotensin binding site inhibitors; Statins; Calcium channel blockers; Digoxin; Amiodarone; Warfarin; Diuretics, Spironolactone, etc.)

These classes of drugs were addressed from the standpoints of acute versus chronic usage; treatment versus prevention; benefits versus side effects; mode of administration. We plan to have a similar presentation at one of our future group meetings.

Medtronic generously provided a lunch for participants that allowed very useful questioning of all of the speakers as well as fostering stronger interactions between ICD recipients and carers.

It was felt by many of the attendees that this was the most effective 'Patient Day' sessions that have been organised by the JRH staff.

### **Next Group Meeting**

We propose continuing to meet every 3 months, and to use the facilities at the Church Centre Up Hatherley. We ask any members that find this difficult, or who can propose an alternative venue, to contact us as soon as possible. We will try (again) to get Dr Mark Petersen to speak to us, recognising he is very busy. We will also ask Trudie Lobban to speak to us about The Arrhythmia Alliance and the initiative to install AEDs in the community – by that time we will have framed a proposal as to how our Group can pursue this. When we have the date confirmed, we will inform you.

As ever, this Group must be seen as being only as strong as its members, and so we ask if anyone has any contribution to make, either to the Website or at our meetings, to let us know. Moreover, if anyone has a problem or an issue that needs resolution, please let us know. We are now part of an extended ICD community that goes well beyond Gloucestershire, and so our ability to help each other is enhanced.

With our thanks for your continuing support,

Colin and Robin

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