

North Gloucestershire ICD Information and Support Group

Newsletter December 2008

Recent Group Meeting

The sixth meeting took place on Thursday November 6th, 2008 at the Up Hatherley Church Centre, Cold Pool Lane, Cheltenham, at 16.00. It was attended by 24 members, together with Nicola Meldrum of the JRH, and Ben Fry, Jo Burke and Mary Rustic of the Arrhythmia Alliance. We welcomed a few new faces, who had been introduced to the Group at the CareLink meeting in June. Unfortunately, some of our regulars could not attend due to various ailments or transportation problems, but who gave us their apologies.

- Cognitive Behaviour Therapy

The main presentation was by Nicola Meldrum on the technique of Cognitive Behaviour Therapy. This is a technique that is recommended for helping with anxieties experienced by people suffering from a range of ailments, and it seems particularly to be suitable for the sorts of problems that many of us experience with having with ICDs, whether recipients or carers. This is covered further below.

- Benefits and grants available to keep you warm and well.

As well as his activities with the Group, Robin also works for the Cheltenham Citizen's Advice Bureau. In this capacity he gave a presentation on the ways in which we can seek advice and financial help via grants to keep our homes warm in winter. Included in this was advice on how to keep well during winter months, as well as saving money. This initiative has been funded by Gloucestershire Warm and Well. To illustrate his presentation, several leaflets were distributed, explaining some of these points in greater detail. Should anyone require copies, please let us know. Free samples of low-energy light bulbs were also distributed – we have none of those left, however. The Gloucestershire Warm and Well may be contacted on 0800 512 012 for advice and a free survey of your home.

Recent Activities

- Heart Rhythm Congress 2008, Birmingham - Patients' Day

We attended the Patients' Day at this event for the second year running, held at the Birmingham Metropole Hotel.

We had been asked if we could give a presentation on *The Experiences of Patients*, based upon the discussions and feedback from Group members over the past year or so. Robin gave an illustrated talk (see the Group Website) which was very well received, particularly from members of other support groups around the country.

Headlines of papers we heard and sessions we attended are as follows:

- Several European Countries are becoming embraced by the AA, and this can only be good for improving the knowledge, support and lobbying power of arrhythmia sufferers in Europe.
- We are all reminded that there is a 24-hour Help Line manned by the AA for anyone who has a problem – call 01789-450-787
- Remember that AA has a very powerful website www.heartrhythmcharity.org.uk (Also do not forget that this Group also has its own website www.icd-gloucestershire.org.uk)
- The 2009 Heart Rhythm Congress will be 18th-21st October, 2009, with the Patient Day on Sunday 18th. This is a deliberate move from Monday to Sunday, particularly for the benefit of arrhythmia sufferers and carers who are at work, to allow them the option of attending the Patients' Day.

We personally recommend that members should consider attending this function. The Patients' programme it is not heavy clinical material and includes latest trends, patients' experiences, and contact with other groups and reviews of various aspects of arrhythmia by experts in easily understood fashion. In 2009 the AA will subsidise the entrance fee for patients.

- Strong interest was expressed in various quarters in the BHF "Start the Heart" campaign, to install AEDs in the community – already the BHF has supported the installation of 3000 of these. More on this is below.

- Cardiac Rehabilitation Classes for Patients with Heart Disease. The British Heart Foundation Campaign is to elevate the status of Cardiac Rehab in the country – currently less than 50% of heart patients who require rehab. actually get it. Moreover, rehab. is not available for patients recovering from implantation of ICDs or Pacemakers.

This subject was widely discussed – with an excellent presentation by Sue Armstrong of Leicester University Hospital. Currently, there is no NHS commitment to providing Rehab. for patients recovering from ICD Implantation. We are gratified that the key hospitals such as Oxford, Bristol and St George's London are aware of the issue, as is the Arrhythmia Alliance. We intend to discuss this broad issue with Arrhythmia staff Gloucester Royal Hospital in the near future – our feeling, based on personal experiences, is that a prescribed exercise regime for patients recovering from implantation would probably alleviate many of the reported problems of 'frozen shoulder' or subsequent weakness in the musculature of the torso. Moreover, we believe that were ICD patients able to meet regularly for rehab. classes soon after implantation, this would also provide the opportunity for sharing experiences and misgivings, so that many of the 'psychological problems' that can develop might be nipped in the bud.

Support Groups

Over the past 4 years Nicola Meldrum has been very active in supporting the establishment of ICD Support Groups to cover the greater Oxford area. Such now exist in High Wycombe, Milton Keynes, Oxford, and Gloucestershire and possibly soon in Northampton. We have also been busy advising a new Group in Coventry, as well as visiting recently the United Hospital, Bath for the first meeting of that support group, which had 23 patients and carers present. The questions they asked were similar to those we have encountered in our initial meetings – such as how the ICD works, differences between AF and VT; threshold settings of ICDs and what a ‘shock’ feels like. We continue to maintain contact with established groups in London, Bristol, The Midlands and north of England. We feel this is important for exchanging salient information of Group activities and how different issues pertinent to ICDs may be addressed

Automated External Defibrillators (AEDs)

We have now opened a Group bank account, which contains over £1000 donated to us and there is another £1500 pledged by a local Rotary Club – these funds are to be put towards installing AEDs in Gloucestershire.

Our progress on AEDs so far: we have had a couple of meetings with the Great Western Ambulance Service and St Johns Ambulance., as well as valuable guidance from the SADS Trust. We are now working closely with the Arrhythmia Alliance, who, in conjunction with the British Heart Foundation, may be able to obtain grants towards the total cost on AEDs, as well as framing the way to go about meeting the various regulations and hurdles to AED installation and maintenance in the community. We are working with the GWAS to identify specific locations for AEDs; -equally we would welcome any suggestions from members for likely locations.

The BHF ‘Start the Heart’ Campaign is also being championed by the SADS (Sudden Adult Death Syndrome) Trust – and is strongly urging us to support the Parliamentary Early Day Motion 365, initiated by John Barron MP, entitled “Cardiac Arrest in Schools” – to persuade the Government to make AEDs available in all schools (Wales and Scotland are likely to go ahead on this!), and it is already law in the USA. The EDM 395 is particularly focussed on the variety of causes of Sudden Cardiac Arrest in the younger population where AEDs might serve life-saving functions, such as: Catecholaminergic Polymorphic Ventricular Tachycardia; Hypertrophic Cardiomyopathy; Long QT Syndrome; Wolff-Parkinson-White Syndrome, False Epilepsy, in addition to life-threatening arrhythmias arising from ischaemic heart disease that are more common in the older members of the community.

We have already written to our own MPs, and should any of members wish to get more information, and possibly do the same, we can provide a ‘sample letter’ to guide people. This is also given on our Web site.

We have had meeting with the Arrhythmia Alliance to identify how to go forward quickly. Needless to say, any further contributions will be welcomed to help make this a significant drive.

An integral aspect of the AED project involves training volunteers to be ‘first responders’ when AEDs are needed. Particularly, this involves Cardio Pulmonary Resuscitation (CPR) and we are investigating ways in which this training can be delivered.

Further to the demonstration on CPR given at our April 08 Group Meeting by Kim George of St Johns Ambulance, should any members require further guidance, do let us know. We were provided with free samples of the St Johns Ambulance CPR skills kit, which are available for loan by members.

Home Monitoring

An update on ICD Home monitoring was presented at the Congress and the situation in the UK is that the major ICD manufacturers have introduced Home Monitoring in some regions. Should any members require further guidance on this, they are advised to contact Nicola Meldrum. Those of us that are now using the Medtronic CareLink system, introduced following the presentation to the Group in June, are very satisfied with the facility.

Patients' Education Day, held at the JRH, Oxford on December 1st

About 150 ICD recipients and carers (including 14 from our Group) who attended this were treated to an excellent programme compiled by Elaine Watson. Dr Kim Rajappan gave a very insightful presentation of instances where ICDs are being implanted in instances where the patient has not suffered a myocardial infarct or ischaemic heart disease, using the NICE Guidelines as reference. As briefly mentioned above, such instances generally follow genetically inherited problems, such as CPVT, Brugada's, Wolff-Parkinson-White Syndromes, etc. Such has been the progress in detecting such cases, together with the more widely availability of ICDs, we can hope that the UK will be able to move significantly up the European/global league table of ICD implantation per capita from its current lowly position.

Helen Jackson, a Heart Failure Nurse Specialist gave a presentation on heart failure, and covered the importance of diet, habits and drugs on the management such a condition.

The most compelling speaker was Dr Diane Saunders, a Clinical Psychologist, who explained in a very lucid and encouraging fashion the nature of anxieties and depression in relation to disease, with particular reference to ICD patients. Dr Saunders exemplified Cognitive Behaviour Therapy as a powerful tool for dealing with such problems, and her presentation complemented that given by Nicola Meldrum at our recent Group meeting.

We have obtained copies of all of these presentations, and they are available on our Group Website.

Availability of CBT to our members

We have at least 2 members who have undergone CBT therapy, and they are very enthusiastic about its value in untangling much of the irrational thinking and anxieties that commonly accompany ICD implantation. We are aware that within Gloucestershire there are not many CBT practitioners, and their fees are also high (about £50 per session, and usually 5-6 sessions are recommended). Robin has spoken to one such therapist, who would be prepared to run a group session for up to about 8 people, as an introduction to the technique, in the hope that it might help some of us. Should you wish to take advantage of this, you should contact Robin directly, who will deal with this in the strictest of confidence.

Experiences of Other Patients

One of the key advantages of meetings with other people is that we heard of how people deal with the various problems related to arrhythmia; attacks of Sudden Cardiac Arrest; 'shocks'; problems related to drug interactions or intolerances to beta blockers etc.; sleep disorders; box replacement; DVLA and so on. We think it would be very valuable for all of us if members were to send to us little 'snippets' of their own experiences that we can add to our Web Site. We believe across the membership we have, we have encountered most of the 'problems' that may befall any ICD recipient, or the carer. Please write or phone us with anything you feel might be valuable to share with others. Anything we publish will conserve anonymity.

Contact with Gloucester Royal Hospital

We have had a meeting with Sister Audra Rimming, who has been appointed as the Arrhythmia Nurse for Gloucestershire. Audra is currently working as a Sister on the Cardiology Unit at GRH and her new post starts in Jan'09. She has had a personal interest in ICDs and the issues surrounding them for several years and is very enthusiastic about getting this long overdue service started. She is very experienced in all aspects of heart disease. Audra will be working directly with Dr Petersen and Dr Nuta. She expressed an enthusiastic interest in our Group and looks forward to attending future meetings and meeting everyone. As this post is a new, there is currently nothing in place, but Audra has many ideas; she is keen to link in with people early on and see what sorts of issues, problems etc need to be addressed as part of the planning of this service. We heard at one of our earlier Group meetings from Dr Nuta of the intention of the Cardiac Department to enhance the care available for ICD patients in the county and we are excited to have the support of Audra in the future.

Play-back from members

The one feature we notice in running a group like ours is that we rarely get any feed-back from members to our Newsletters – other than a faithful few who telephone or email us. It would be of great help to us if you can say beforehand whether or not you are able to attend our meetings, as that helps with estimating the catering. Generally, we find we have to make upwards of 40-50 phone calls prior to holding a meeting to find out if we are likely to have an audience for our speakers. Moreover, if there are any issues or subjects you want us to pursue, or any subjects you would like discussed at our meetings, please let us know – we are well networked with many similar groups in the country, and seeking information is generally not a problem – whereas trying to identify what ICD recipients and carers require is more difficult. Please phone, use e-mail or write to us.

Our next Meeting

For our first meeting in 2009, we propose a group lunch – we suggest meeting at a pub/restaurant in the Gloucester area, such that it is easier for all to reach by car or public transport. We are mindful that we never seem to have enough time to speak with each other, and to do so in the informal atmosphere of a pleasant lunch seems attractive to us. There is no doubt that sharing 'ICD experiences' with others is a very effective way of easing any concerns that always build up in our minds – across our group, we seem to have experienced all of the things that can happen when you have, or live with someone who has an ICD.

In order to judge the popularity of this suggestion, we have enclosed a Questionnaire that gives the details of our proposed venue and date/time. With regard to getting play-back, we have decided to enclose stamped addressed envelopes, so that we might then get replies from a representative number. You will be aware that this bears quite on-cost for us. Fortunately, some members have generously donated sufficient funds to our petty cash reserves.

Future of the Group

Over the six meetings we have held over the past 2 years, we have averaged about 25 members per meeting, which is very gratifying for us. We will continue with this for as long as we feel we are fulfilling a useful need. We note that new members are joining, particularly those who are new to ICDs, and that some of our original members now do not appear at our meetings – which is fine, as we assume that they are well-adjusted to life with an ICD, and that there is no need to participate so much – which is very gratifying to us too.

We would be grateful if you can take a few minutes to complete the questionnaire that accompanies this news letter, as your views and any needs you have are most important to us.

For further information, visit our website at www.icd-gloucestershire.org.uk.
Any questions should be emailed to information@icd-gloucestershire.org.uk
or by telephone to 01242-260-614/01242-527-588

We wish you all health and happiness for Christmas 2008 and for the coming year

Colin Prottey & Robin Harvey December 2008