

## A SHORT HISTORY OF THROB by Lesley Richards & David Read

With THROB celebrating its 21st Birthday it seemed a good time to review its origins and growth. If for no other reason, it is useful to see in retrospect how THROB has responded to changes in cardiac care in our area over the last 21 years and may influence the way we should go in the future.

### THE START OF SOMETHING BIG (1987 - 1991)

To understand the origins of THROB, one needs to go back several years and review cardiac care in general at that time - thin the blood, watch its pressure and plenty of bed-rest! The first local green shoots of cardiac rehabilitation in East Berks began around 1987 on a General Medical ward at Wexham Park Hospital where Sister Sue Lewis and Staff Nurse Lesley Richards were working with Cardiac Consultant Dr. Roger Blackwood. Having been inspired by a visit to Astley Ainslie Hospital in Edinburgh, where one of the UK's first cardiac rehabilitation programmes was up and running, Sue Lewis approached Dr. Blackwood to obtain his consent to some information classes, post discharge, for cardiac patients and their families. With the consultant's approval Sue worked with Lesley to plan a series of relevant talks and later that year their first course was born. It proved to be a spectacular success, resulting later in Dr. Blackwood asking the two nurses to leave the NHS and continue to design and expand a cardiac rehabilitation course across both Wexham Park and Heatherwood Hospital sites.

Sue Lewis began that task early in 1988 and Lesley joined her in January 1989. The NHS at that time did not have any provision for cardiac rehabilitation, so funding for the nurses was provided by The Wexham & Heatherwood Heart Trust, a local charity that had been set up to support cardiac services locally. The Trust and its fund-raising Committee was staffed by some well known locals - Terry Wogan, Michael Parkinson, Ernie Wise and John Humphrys to name but a few! Large-scale fund-raising events such as the special opening of Frogmore Gardens in Windsor and the Slough Fun Run managed to raise impressive sums of money sufficient for one nurse's salary. Lesley's salary was initially provided by a grant from the British Heart Foundation, who were keen to get rehabilitation started in the UK.

Some of the first patients who went through the rehabilitation scheme such as Mike Wilkie and John Sandall, wanted to help with fund-raising events but came to realise that the money raised was for all cardiac services, not just rehabilitation. As a result they contacted other rehabilitation 'graduates' which led to the formation of THROB in 1991 as a fund-raising and support organisation entirely for rehabilitation in the local area - with a little socialising as well. All those people who joined THROB in that year are now regarded as its founder members.

### EARLY PROJECTS (1991 - 1995)

Finding accommodation within hospital grounds for two non-NHS nurses was tricky right from the start and the situation became critical on a number of occasions. THROB came to the rescue by acquiring and renovating a disused Portacabin, which was finally allowed to be sited within the grounds of Heatherwood Hospital. Another Portacabin was later found for Wexham Park, although in the event, was never sited there. The founder members of

THROB were on a mission and 'pester power' won out in their determination to get accommodation for the nurses. The Portacabin was a little leaky, draughty and occasionally cold in winter, but the nurses at least had a place of their own. A couple of second-hand computers, a filing cabinet or two were acquired for which the nurses were very thankful and they were also grateful for the time and dedication of THROB members in helping them to establish a base.

During the next five years cardiac rehabilitation continued to grow, not only locally but nationally, with the support of the BHF. Sue Lewis left and went on to a senior post in another hospital and Nurse Pauline Wallace was recruited to the rehabilitation team, now run by Lesley Richards. However, things were beginning to look critical at the local level as staff salaries are a never-ending cost and few charities can support them for very long. The Wexham Park & Heatherwood Heart Trust was no exception and with regret the nurses were told that the funding would be coming to an end. THROB was in no position to provide salaries so all might have fallen by the wayside in 1995 but fortunately the Hospitals had become used to having a cardiac rehabilitation service which had gained publicity and kudos nationally and so were reluctant to see it go. As a result, the nurses were offered posts doing exactly what they had been doing but now paid for by the NHS. It was a fond goodbye to the trusty Portacabin and hello to proper office accommodation at long last - and on the bright side, some of the cost of the Portacabins was recouped when they were sold .

In those early days it was all about fundraising and in 1992 THROB raised a staggering £12,500. All manner of functions were tried the most notable being an Auction of Promises, A Marathon Team Walk around Virginia Water, a Fishing Match, a Sponsored Walk and a Fashion Show.

THROB initially envisaged a purpose built rehabilitation unit of 5,000sq.ft to be sited near Wexham Park Hospital containing a gym, offices, kitchen, toilet, showers and changing rooms. The projected cost, excluding the land, was £200,000. This project never really took off and what monies had been raised were used to buy the Portacabins. The next big project was to purchase a treadmill for Heatherwood. At that time, patients were unable to return to work or to do further rehabilitation classes until they had undergone a successful treadmill test. The lack of treadmill availability was a great hindrance and was the spur to THROB to acquire another machine. Once the treadmill was up and running fundraising was at a lower level and the money used for a range of smaller projects, mostly equipment for the Hospitals and the rehabilitation team. In 1994 The National Heart and Lung Institute at the Royal Brompton Hospital undertook a study to compare which approach to exercise based cardiac rehabilitation was most effective. The comparison was between clinically supervised rehabilitation undertaken in a hospital setting, a home based rehabilitation programme using a self-help manual (The Heart Manual) developed by Dr. Bob Lewin in Edinburgh and rehabilitation based on the provision of leaflets and advice provided at the time of discharge from hospital. THROB was contacted by Dr. Jenny Bell, an exercise physiologist, who had been asked to set up the research project. During her search for hospitals which were running supervised exercise based programmes, she met up with Lesley Richards and Pauline Wallace who had established a successful programme in Wexham Park and Heatherwood Hospitals and were, with the help of THROB, offering community based exercise classes for patients who had completed the supervised hospital programme.

During their collaboration Jenny and Lesley realized the importance of exercise specialists, physiotherapists and nurses pooling their respective skills in order to optimize the effectiveness and safety of programmes offered to cardiac patients. So successful was their collaboration that during the three year Brompton project Jenny Bell liaised with the British Association for Cardiac Rehabilitation (BACR) to develop guidelines for training exercise instructors to run community based programmes for cardiac patients. In parallel Lesley and Jenny, supported by THROB extended the provision of community based classes in Berkshire and in true pioneering style, were one of the first to take the clinically supervised programmes out of a hospital setting into the community, which facilitated a seamless transition for patients who wanted to continue exercising in the community in the longer term. In late 1995 The British Heart Foundation provided funding for the development of a national training course (BACR Phase IV training for exercise instructors) which was launched in 1997 and quickly became the industry standard for instructors wishing to work with patients in both hospital and community settings. By 2001 another course was written for nurses and physiotherapists wishing to learn more about exercise physiology and prescription. The BACR under the umbrella of the British Cardiac Society now have an extensive educational arm to their work. As part of this educational programme, THROB participated in the production of a training video for potential Instructors providing the 'actors' under the guidance of Joy Martin in a typical exercise session. Joy is now one of our regular instructors running a class each week and is, in addition, an Examiner for instructors wishing to qualify to BACPR standard. (Note that BACR has now become BACPR, the British Association for Cardiovascular Prevention and Rehabilitation.)

On reflection, Jenny Bell likes to see the collaboration as the meeting of minds with a common concern which is to give cardiac patients the best possible long-term outcome and to prevent patients from thinking of themselves as invalids. In addition, the unwavering support and energy of local patients of diverse backgrounds has made THROB into a hugely innovative, efficient and enthusiastic group.

### GROWTH OF THROB

The membership increased dramatically in the first year and by the end of 1991 stood at 124. The rate of increase over the next ten years was about 35 new members each year and by 2005, the rate had dropped off to stabilise the membership at about 400. Why this has happened is not clear. People come and go and the incidence of the 60-70 year old group moving on retirement probably reduces the numbers. Also, there are more deaths per year among the elderly, a group on which our membership largely relies, so there is constant wastage which reduces numbers.

At its formation THROB ran but two classes each week, one at Wexham and the other at Heatherwood. The number of classes has increased over the intervening period to the present by about one new class per year. By 1997 there were ten classes running, five at Heatherwood Red Cross Hut, three at Wexham and two at Maidenhead - one at the Magnet Centre, the other at the Holiday Inn. By the end of the century this had risen to 15 classes every week.

The number of classes being run since 2008 has stabilised, much in line with the stabilisation of the membership numbers. In the early days the classes were all run in the hospitals but this was changed a year or two after the start of THROB mainly on the grounds

of unsuitable accommodation in the Hospitals. (By this time THROB had defibrillators to provide medical support for the classes.) It was shown that emergency medical cover was best provided by a 999-call, even for an event on a hospital site. Classes are now entirely run in Leisure Centres and Community Halls covering an area bounded by Burnham in the North, Bracknell in the South, Langley in the East and Early in the West. Currently there are about 24 classes running each week in nine locations.

Digging through the records shows that THROB has raised about £2500 each year, on average, since its inception. Specific functions have been arranged to make money but most of the social functions, dances, quizzes, barbecues and the like, are run at a small profit and have thus helped with the charitable work. "Tin shaking" outside Sainsbury's has also been tried and Waitrose has also provided us with opportunities for fundraising.

A wonderful fundraiser for THROB has been the annual band concert given by the Berks, Bucks and Oxon Big Band. These concerts were started in 1995, have been held annually ever since and raised over £20,000 for THROB. The beneficiaries of THROB's charitable work owe a big debt of gratitude to the Big Band.

Another contributor to the fundraising was Her Gracious Majesty Queen Elizabeth the Queen Mother. Her first gift to THROB was a beautiful small Shelley tea service which she gave as a lot for an Auction of Promises held in 1991. To mark our Tenth Anniversary, a further request was made to the Queen Mother and she graciously donated a Minton china clock which was subsequently raffled and the proceeds used to buy an exercise bicycle, complete with a tribute plaque, which is still in use today.

Funds are also acquired by donations which come from a wide variety of sources. Significant among these is the added donations which members make when renewing their annual memberships. The other contributions direct from the membership, are from memorials and through the celebration of "memorable events". The results of giving a donation to THROB instead of giving a THROB member a 70th Birthday present can be quite staggering! Other donations have been made regularly by well-wishers and local companies - one regularly donated the contents of their "swear box" and apologised when the value of the donation fell supposedly due to an improvement in office language! Another source of funds has been from other organisations which raise money and identify charities such as THROB as a chosen charity to receive the profits of a function. The Maidenhead Lions. Bracknell Rotary and Golf Club captains have all supported us in this way. During the 1990s there was an outbreak of Marathon running which brought us sponsorship monies. Notable runners for THROB were Dick Bell and Class Leader Jo Oake who ran the New York marathon in successive years.

#### A CHANGE OF EMPHASIS (2003 - 2009)

Early in 2003 a tragedy befell THROB with the death of Mike Wilkie caused by cancer. Mike was, without doubt, the "prime mover" in the Organisation and committed himself wholly to all aspects of THROB's good works. It was he, together with John Sandall, who initiated the formation of THROB. John unfortunately was not with us either since he had succumbed to his cardiac heart disease in 1996. In order to mark Mike Wilkie's passing, THROB started a bursary in his name as a lasting tribute. The Bursary is funded by all routine unsolicited donations received and is awarded to people training to get BACPR

qualification or others undertaking education in areas allied to cardiac rehabilitation. The establishment of this Bursary brought with it a change in emphasis with regard to financial support given by THROB, moving from equipment procurement to training.

This change in emphasis was also influenced by the Government's launch of the National Service Framework for Cardiac Heart Disease when millions of pounds were provided to upgrade the coronary care facilities of hospitals. The amounts that had been invested in this area by THROB was paled into insignificance and the demand fell away. At this time, THROB put more resources into gym equipment for new classes and also for updating and renewal of existing equipment - not surprising when you consider the hammering it gets week after week! However, during this period THROB also financially supported a number of initiatives designed to reduce the incidence of Cardiac Heart Disease in and around East Berks. In 2006 manuals and compact discs were provided for the Angina Plan, a home-based scheme for angina sufferers developed by Prof. Bob Lewin of York University. THROB was pleased to be able to assist as they had been keen to help people in our area with angina for a number of years. Also at that time there was concern in the Ambulance Service that people were not being timely in calling an ambulance when people were suffering a heart attack. This gave rise to the "pain to call time" initiative where THROB contributed to the advertising of the problem in the area. The public were guided to assess the symptoms and then immediately call 999 if they believed the person was having a heart attack. The advertising was done by printing the message on the back of tickets issued by parking machines in the area and also by issuing Beer/Coffee mats. In 2009 assistance was given to the local hospitals to start a scheme targetting cardiac patients and people who might have a tendency to cardiac heart disease, to improve their lifestyle. In the scheme, participants were given a 16 week course of lectures and exercise sessions with health assessments before and after. This initiative was called "My Action" and was based on work within the EU and their scheme "Euroaction".

## RECENT HAPPENINGS

For many years THROB was reluctant to be affiliated to the British Heart Foundation since any monies raised had to be shared 50/50 with them. Although this might be acceptable to support groups which were essentially "tea and talking groups" it didn't go well with THROB who were equipping gymnasia, training staff and buying things for hospitals. Then in 2008, the BHF dropped this requirement and also offered free Public Liability Insurance to all their affiliates. Needless to say, we signed up.

For some time the Committee had been considering whether THROB should become a Registered Charity and thereby get such benefits as go with it. The first task was to update and improve our Constitution to bring it in line with the requirements of the Charity Commissioners. Once this was done the process went smoothly and our Charitable Status was granted late in 2009. Apart from the respectability which goes with registration there is a financial reward in that we can recover tax through the Gift Aid scheme. The last financial statement showed that almost £1,000 came from this source.

In 2006 one of our Founder Members, Thomas Brooks, died and after his will had been to probate early in 2009, THROB was informed that he had left the Organisation £30,000 with more to follow as settlements were concluded. For some time THROB had been looking for a bigger project to do and with this generous donation the way was now clear.

After discussions with the staff of the new Catheter Laboratory at Wexham it was decided to install an audio-visual link between the Laboratory (where angioplasty and stenting is carried out) and the Post-graduate Centre, for training purposes. Unfortunately these plans came at a difficult time for the Hospital and eventually the project was shelved. The increased funds were then allocated to lesser projects, the main one being the provision of defibrillators in our exercise venues, other community locations and for the volunteer First Responders who support the ambulance service.

#### TAILPIECE

We hope that we have given an accurate account of THROB over the last 21 years and have covered all the essential happenings in the period - if not, letters to the THROBNews editor will, no doubt, put things right. If nothing else, it has been an opportunity to gather together records into a single archive which will be of benefit to the next generation when they review THROB on its 50th Birthday!

(The authors acknowledge the assistance of Dr. Jenny Bell, Dr. Roger Blackwood, Mrs. Lynn Warner and members of the THROB committee in writing this short history)

#### THROB ACHIEVEMENTS SINCE 1991

As part of our 21st Birthday review we have looked back through the accounts to see how our money was spent. The detailed list below shows monies expended (in £ of course) on equipment for the hospitals and other cardiac organisations together with support for THROB itself.

1991	Portacabin for Heatherwood	500
	Portacabin for Wexham	1300
1992	Resuscitation Dummies	350
	ECG Machine for Heatherwood	2000
1993	Four Heart Fitness Monitors	350
1994	Answerphone for W. P. H.	100
	Treadmill for Heatherwood	13,700
	Blood Pressure machine	68
1995	ECG Machine for St.Marks	2000
	Computer for W. P. H./ HW	1300
	Echocardiograph Link	4500
1996	Two Reynolds Trackers	1500
	Overhead Projector	422
	Answerphone for Rehab.Office	50
	Educational films and books	70
1997	Numed Paceview for St. Marks	2500

1998	Demo. Photographs for Phase III	360
	De-fibrillator for Phase III	2400
1999	Sphygnomanometers for Phase III	55
	BP Machines for Phase III	229
	Lifesigns Receiving Centre	4000
	Educational Books	51
2000	BP machine	69
	Three 24-hour Heart Monitors	4900
2001	Heart monitors	4490
2002	Heart rate monitors	360
2003	Overhead Projector and Screen	450
2005	Heart monitors	1200
2006	Angina Plan	680
	Vitality programme	840
2007	Total cholesterol machine	1510
	"Pain to call time" campaign	2100
2008	"My Action" equipment	670
2009	"My Action" further equipment	1000
2010	Defibrillators (exercise venues)	10,100
2011	Defib. for RBWM Sports Club	1500
2012	Two kits for First Responders	5000

The above list amounts to £76,320 to which may be added £29,670 for gym equipment needed in Community Hall venues used by THROB giving a Grand Total of **£106,000**