

British Malignant Hyperthermia Association

Registered Charity No. 1007739



Annual Report

April 2008 - March 2009

Charity	The British Malignant Hyperthermia Association (BMHA)														
Registration No.	Registered Charity No. 1007739														
Address	11 Gorse Close, Newthorpe, Nottingham, NG16 2BZ														
Trustees	<table> <tr> <td>Professor FR Ellis</td> <td>(President)</td> </tr> <tr> <td>Dr J Halsall</td> <td>(Chairman / Medical Advisor)</td> </tr> <tr> <td>Mrs A Winks</td> <td>(Secretary)</td> </tr> <tr> <td>Mrs J Pilkington</td> <td>(Treasurer)</td> </tr> <tr> <td>Ms L Janzen</td> <td>(Member Representative)</td> </tr> <tr> <td>Mrs H Fowler</td> <td>(Member Representative)</td> </tr> <tr> <td>Dr R Robinson</td> <td>(Genetics Advisor)</td> </tr> </table>	Professor FR Ellis	(President)	Dr J Halsall	(Chairman / Medical Advisor)	Mrs A Winks	(Secretary)	Mrs J Pilkington	(Treasurer)	Ms L Janzen	(Member Representative)	Mrs H Fowler	(Member Representative)	Dr R Robinson	(Genetics Advisor)
Professor FR Ellis	(President)														
Dr J Halsall	(Chairman / Medical Advisor)														
Mrs A Winks	(Secretary)														
Mrs J Pilkington	(Treasurer)														
Ms L Janzen	(Member Representative)														
Mrs H Fowler	(Member Representative)														
Dr R Robinson	(Genetics Advisor)														
Governance	The charity (an unincorporated association) is governed by a constitution originally adopted 07/10/1989. It was amended in 1991, 2002, 2003 and by a Scheme made by the Charity Commissions under the power given in the Charities Act 1993 01/02/2005.														
Management	The charity has a management committee who are the Trustees. The committee meets twice a year and there is an annual meeting of members. Recruitment of trustees is via the membership and all members have a vote to ratify new committee members. New Trustees all receive information about BMHA, the constitution, aims and accounts as well as information provided by the Charity Commission for Trustees.														
Finance	Funding is from members' subscriptions, fund raising and donations. Simple accounts are kept by the Treasurer and presented to the membership and the Charity Commission each year. Funds are used for the administration of the BMHA and any surplus is designated for future expenditure, usually to aid research into MH. Our reserve policy is to hold a minimum of £10,000 in reserve, with a preferred amount of £20,00. During the year 2008-09, BMHA received a research grant awarded by the Big Lottery Fund and these funds are restricted.														
Objectives	<p>The object of the Association is to relieve the need of individuals affected by Malignant Hyperthermia. In furtherance of this object but not further or otherwise the Association shall have the following powers:</p> <ol style="list-style-type: none"> to provide medical and medico-social support to affected individuals and families. to provide medical update with regard to safe drugs, screening procedures, etc. to publicise problems encountered by Malignant Hyperthermia subjects especially within the medical and dental professions. to raise funds for research into Malignant Hyperthermia and related topics. 														
Achievements & Future plans	The achievements of the last year and future plans are included in the following report to members.														

August 2009

BMHA ANNUAL REPORT TO MEMBERS (April 2008 – March 2009)

CHAIRMAN'S REPORT

As you are all by now aware, sadly our chairman Ian Leavey died in August last year. Although he had been ill for a while his death came quite quickly at the end. On BMHA's behalf, Alison expressed our sadness at his passing to the family. Ian had been a tremendous help over several years, giving generously of his time especially as he had to travel long distances to attend meetings. His contribution to the BMHA, particularly to the executive committee, was highly valued. He always had a calm steady influence. Quite simply he was a delightful man and it was a privilege to have known him.

Since then I have taken on the role of Acting Chairman as well as Medical Advisor. However because I believe quite strongly that the BMHA is **your** group I feel it is inappropriate for me to take on this role on a more permanent basis. It also opens up the possibility of a conflict of interest especially when deciding how funds are spent. So my main message to you all is to consider volunteering for the post. It is not arduous and requires no particular expertise other than a willingness to be involved.

So please think about it and don't be shy about volunteering.

If you are interested contact either Alison or myself preferably before the AGM in October.

As usual there are lots of people to thank. Everyone on the executive committee for the work they do and to our new executive member, Helen, who has already had some success with publicising MH. Thanks too to all of you for your support, often over many years. Do keep coming to the meetings and give us your ideas about how you think we could improve or develop the BMHA.

With my medical advisor's hat on, the new GC equipment funded with BMHA monies is fantastic compared to the old almost defunct machine – Helena our chief technician is delighted – so thank you all.

And finally we are all relieved that the Lottery project after many hiccups has finally and successfully finished. I think hats off to Alison for the effort she put in – I don't think she will be persuaded to do another!

Dr Jane Halsall

SECRETARY'S REPORT

25 Years: BMHA celebrated 25 years last October. Considering the rarity of MH, the fact that MH is not a condition which causes day to day problems, and that we do not receive any sponsorship or funding (not counting the BLF grant, which was research specific and restricted) other than membership fees and donations, we feel it is remarkable that we are still here. We are still run entirely by volunteers.

Lottery project: This financial year has seen the end of the lottery project. Dr Carpenter took over responsibility for the testing at the beginning of November 2008. She left the Leeds Unit at the end of June to take up a post in Nottingham. Fortunately, the testing for the project was virtually complete. However, rather than ask for permission to end the project at that point (technically 6 months early) we decided to continue to the end of October as planned. This allowed time to finish some outstanding tests and for the final reports to be put together. The final report was sent to the Big Lottery Fund and was deemed compliant. Our final duty is to present BLF with our Accounts for the financial year and the file will then be closed, although we understand that they keep the records for 7 years and so we will do the same.

Committee member: At our Annual Meeting last October, we elected a new committee member, Helen Fowler. Helen is a nurse and particularly wanted to help publicise MH to the professions. We welcome her to the committee.

Annual Meeting: We had an excellent meeting last October. We were celebrating our 25th Anniversary and the end of the Lottery Project. Leeds had been planning to ask patients to attend for blood tests and decided to time this to coincide with our meeting. We were very happy that quite a few of these people decided to stay for our meeting.

We had a wonderful complement of speakers including 4 current and ex-members of the Leeds' Unit; Professor Urwyler from Switzerland; Professor Allen from the USA and we also welcomed a visiting geneticist from New Zealand. With the end of the lottery project, we felt it was the perfect opportunity to look at MH, past, present and future, as well as include a final report on the lottery project.

The meeting was held at the Thackray Medical Museum in Leeds and members were able to go around the museum free of charge. A very successful meeting.

Equipment: As funds had not been donated to Leeds during the lottery project, we had a build up in the accounts. We therefore agreed that we would ask Leeds if there was something they required which would help their work up to an amount of ~£20,000. It was eventually decided that we would purchase a Gas Chromatograph and associated equipment, which specifically helps with testing and quality control. The quality control work is something which they take on for the EMHG and which we are happy to support.

Alison Winks

TREASURER'S REPORT

Opening Amounts: The opening balance on the accounts for the year was £83,766.47, which differs from the opening balance shown on the bank statement of £83,885.31. This difference is the amount of an un-presented cheque that was not taken account of in the final accounts for 2007/08. The closing balance is £7,442.88.

Un-presented cheques: There are no un-presented cheques to take into account for this year.

Donations: Donations came to £1,621.98 and I would like to thank all those members that gave so generously without wanting any recognition. This money will continue to be used towards the very necessary research that continues at the Leeds laboratory.

Membership Income: Income raised from membership fees came to £4,096.93, which shows a slight decrease of about £48 on last year, so the membership has again remained quite consistent throughout the year.

Emergency Discs: Sale of emergency discs brought in £731.50, which when we deduct the amount it costs to supply them, gives us a net profit of about £193, which is slightly up on last year. Once again, thank you for your support through the purchases and to Ruth for continuing to organise the discs on our behalf.

The AGM: As last year was an extra special year for the BMHA, we made the decision to conclude the lottery project with a free event that was once again held at the Thackray Museum, and we had a fantastic turn out, that saw us welcome old and new friends from far and wide, and we got to listen to the incredible journey that Alison and the team at Leeds have taken with the group. The cost of hosting this event came to £760.85 but we look forward to greeting many more people at Kegworth, which is to be our location for this year.

Big Lottery Fund: As the previous year was the final year in which we received money from the Big Lottery Fund, we had to pay back the under spend, which along with the expenses incurred in the final year of the project, brought the total costs to £63,141.73

Donations to Leeds: As we had surplus funds in our account, the Executive Committee decided that we should put the money to good use, and we purchased some essential equipment for Leeds, and we hope that this has now made their job much easier.

Building Society: We have not made any payments in or out of the Coventry Building Society. However, we have received £1,003.93 interest, which in today's current economic climate, we consider ourselves lucky to have money in the Building Society at all. This gives a closing balance of £40,693.83.

To Summarise: Taking into account the fact that the lottery project is now complete, it will be nice to get back to some semblance of normality with the accounts, but I would like to say that it has been good to have the support of the Big Lottery Fund, which has helped us no end. Thanks go to all members and people that have donated in memory of loved ones. Every penny we receive makes a massive difference.

Janet Pilkington

MEMBERSHIP SECRETARY

We currently have 377 active members on the database, a slight drop from last year. The number of lapsed members has therefore risen slightly. We had 27 new members during the year and 9 people decided to rejoin. Members are sent 2 reminders when fees are due and are deemed lapsed if payment is not received after the second reminder.

We routinely send out standing order forms with reminders to encourage members to consider this payment option, but when the banks forget, it is inconvenient and time consuming to resolve for everyone. Currently 57% of the membership pay by standing order, up again on last year. This method of payment should be good for a small group like ours, as it removes the need for reminders, ensures payments on time and therefore reduces costs. However, we continue to have some problems as in some cases, banks have failed to make the payment on an annual basis, so a lot of manual checking is still required.

It has always been good to receive donations along with the fees. This year, the donations paid in via the Membership Secretary amount to £1513.50. This is a wonderful amount and we thank all those who were involved in fund raising or who asked for donations to BMHA in memory of loved ones.

Geoff Winks

PLANS FOR THE COMING YEAR

- Prepare a new page for the website especially for Professionals
- Organise publicity to professionals via articles, adverts and the website

OBJECTIVES & PUBLIC BENEFIT

In furtherance of our stated objectives, (and specifically the improvement of medical benefits for patients susceptible to MH and their families) BMHA believes that the following benefits have been delivered during the year.

- 1) To provide information that reassures patients and also improves the quality of patient care. This is in the form of booklets, warning cards/discs and a "hotline" (mobile phone) to a doctor from the MH unit in the event of medical emergencies. Translations are provided for foreign travel. In addition information is available on the internet.
- 2) To arrange an annual meeting that is a forum for good co-operation between the patients and the medical/scientific staff. Patients can voice their worries/ideas, thus leading to a better provision of service to patients.
- 3) To support research with a view to benefiting both patients and the NHS. A 3 year lottery grant awarded to the BMHA ended during this financial year. This grant has enabled the MH Unit to increase the availability of genetic screening for MH to more families. This means that patients can be offered a DNA test using a blood sample collected at their local GP surgery, rather than travelling to hospital in Leeds from all parts of the UK for a muscle biopsy – a surgical procedure. This has clear benefits for patients and also the NHS as it is significantly less costly and reduces waiting list times for those patients still requiring a muscle biopsy. This in turn has resulted in scientific publications so disseminating knowledge of MH to the wider scientific and medical communities. It has also been possible to donate money to the MH Unit to purchase new equipment which will help with both testing and quality control.
- 4) To assist in funding research projects leading to greater understanding of MH and the publication of scientific articles thus sustaining the profile of MH in the scientific and medical communities. Examples of recent publications include:

1: Br J Anaesth. 2009 May 19. [Epub ahead of print]
Epigenetic allele silencing and variable penetrance of malignant hyperthermia susceptibility.
Robinson RL, Carpenter D, Halsall PJ, Iles DE, Booms P, Steele D, Hopkins PM, Shaw MA.

2: Ann Hum Genet. 2009 Jan;73(1):10-8. Epub 2008 Oct 15.
Analysis of RYR1 haplotype profile in patients with malignant hyperthermia. Carpenter D, Morris A, Robinson RL, Booms P, Iles D, Halsall PJ, Steele D, Hopkins PM, Shaw MA.

3: Hum Mutat. 2006 Oct;27(10):977-89.
Mutations in RYR1 in malignant hyperthermia and central core disease.
Robinson R, Carpenter D, Shaw MA, Halsall J, Hopkins P.

4: Br J Anaesth. 2006 Sep;97(3):320-8. Epub 2006 Jul 18.
Mg²⁺ dependence of Ca²⁺ release from the sarcoplasmic reticulum induced by sevoflurane or halothane in skeletal muscle from humans susceptible to malignant hyperthermia.
Duke AM, Hopkins PM, Halsall PJ, Steele DS.

5: Eur J Hum Genet. 2003 Apr;11(4):342-8.