

ORIGINAL LETTER SENT TO MH FAMILIES AT THE START OF BMHA

Dear

For you to be receiving this letter, you, or your family must be affected by Malignant Hyperpyrexia. I hope you have had the problem properly explained to you, but if not you can always write to me or ring me up and I will try to answer any queries you may have. If I can't, I promise to get an answer for you.

I am setting up an association for people affected by this problem and very much hope that you will want to join me. I enclose an information sheet which tells you of my aims and gives a few ideas for the future. But maybe I should tell you about myself and my connection with MH.

My name is Alison Winks and I live on the Notts/Derby border with my husband Geoff and daughter Tracey, and until January 1982 we also had a son, John.

As both my children were born with cleft lip and palate, hospital visits and operations had become a way of life, Tracey had had 3 operations and John 6 with no problems whatsoever. When, in January 1982, he went into hospital for his 7th operation he was a cheerful, mischievous, beautiful, blonde 7 year old.

When I arrived at the hospital to be there when he came back from the operation the bombshell fell. They had had problems during the operation, the anaesthetic had caused his muscles to contract violently and upset all his body chemistry, and by the time they noticed his rise in temperature it was very difficult to do much about it. Mid afternoon he was taken to Intensive Care and we were allowed to sit with him. We watched more people than I can remember fight to save his life, but at 8.30 in the evening he died.

We have all been tested in Leeds now. I am negative, but both my husband and daughter are positive and will always need to be careful.

I work for the Health Service, but when I told people about this problem, very few of them had even heard of it. People accept anaesthetics as part of our way of life, they help us, not make matters worse - or so we all think. Well perhaps they do, but a few of them can be devastating, as I am sure you all know. About 50% of you will recognise the story above. Others of you may not be aware that it can be so devastating and final. I do not want to frighten you, just to help inform people of this problem and how it can affect people. I want to tell the rest of the medical profession about it and make sure they take it seriously. I want to get them to monitor temperature during operations as a routine, not at the whim of a particular hospital.

Please read the information sheet and think seriously about joining me in trying to get this association off the ground. I look forward to hearing from you all.

Best wishes

Alison Winks

ORIGINAL INFORMATION SENT TO MH FAMILIES AT THE START OF BMHA

(Please note, this is old & some of the information may no longer be valid. See our page 'About MH' for up to date information)

MALIGNANT HYPERTERMIA ASSOCIATION - INFORMATION SHEET

IF MALIGNANT HYPERTERMIA IS SO RARE, WHY IS THERE A NEED FOR AN ASSOCIATION?

I am sure a lot of you have lived with this problem for the last few years without an Association and may feel there is no need for one. I hope my letter helps give you some idea of why I feel there is a need, and I would like to set out below some aims, and ideas for the future, but first let me set out my most important message.

PLEASE, PLEASE, DO NOT TAKE THIS PROBLEM LIGHTLY. MAKE SURE ALL YOUR FAMILY KNOWS WHAT IT IS CALLED. GET THEM TO WRITE THE NAME DOWN, SO THAT THEY DO NOT GET IT WRONG. MAKE SURE THEY REALISE THEY MUST NOT HAVE ANY ANAESTHETICS, EVEN AT THE DENTIST, WITHOUT TELLING THE ANAESTHETICIST OF THE PROBLEM. UNTIL TESTED THEY MUST ASSUME THEY ARE SUSCEPTIBLE IF AN OPERATION IS NECESSARY. THEY CAN ALWAYS CONTACT LEEDS FOR ADVICE.

Aims:

- 1.To link affected families together and make them realise they are not alone. To help them realise how important the problem is. We can send you a booklet explaining MH and a sheet for your family.
- 2.To keep affected families in touch with current research and inform them of new drugs etc. which must be avoided.
- 3.To help Dr Ellis and his team, by keeping a register of all those affected and by helping him to inform other medical people of the problem and its effects.
- 4.To help new families find out about the tests in Leeds, their necessity and importance. To help them realise what to expect before they go.
- 5.To be a source of information about the problem for people to write to or ring up if they have a problem or just want to talk to someone similarly affected who has been affected by the problem.
- 6.Eventually maybe to start putting pressure on the hospitals to monitor temperature, a simple procedure which I understand could save many lives.
- 7.To link, eventually, if not immediately, with other Associations throughout the world and pass on their comments and ideas to you.

Any funds at the moment would only need to cover printing, postage etc. but any excess funds will always be passed on for research if and when they build up to a useful level. We envisage a membership fee of £5 per year for an information sheet on current research, drug situation etc. We could, if required, attempt to arrange an annual symposium for us all to get together with Dr Ellis. If you want drug information but nothing else, we envisage sending that out anyway, but obviously help with postage would be useful. The application form also provides an opportunity for you to let me know if you would like to help in any way. Perhaps you are a printer and could help reduce our printing costs. Or a solicitor who would answer any of our legal queries if we have any. May be you would just like to organise a jumble sale locally and send us your proceeds.

PLEASE HELP ME MAKE THIS ASSOCIATION WORK FOR YOU, YOUR FAMILY AND OTHERS.