

### Greetings from the Editor

Following a request to increase the size we hope you find the larger print in this issue to be an improvement. If there are other improvements you would like to see, why not give the Editor a call? If any reader would like to help with the production of our Newsletter, we'd be delighted to hear from you.

### Changes at the AGM

Sadly we report that David Roberts could not stand for re-election as Chairman this year, for personal reasons, but has stated his intent to return to help us as soon as he can. Joyce Parker, stepping up into the Chairman's role at the AGM, sent thanks to David from everyone in the Alliance for his leadership since inception, along with good wishes for a speedy recovery.

The Executive is now as follows:

Chairman:	Joyce Parker
Treasurer:	Patrick McGrath
Secretary:	John Holt
Executive:	Gill Hall
Executive:	Sandra Paget

Congratulations to them on their election.

### Membership News

Membership of the Alliance now stands at 18, embracing 16 medical conditions. We are delighted to welcome the local Branch of ASBAH which represents people with Spina Bifida and/or Hydrocephalus, and to two individual members with interests in

Ataxia Telangiectasia and Neurofibromatosis. There are several other voluntary groups who are interested in what we are doing, as well as a number of individuals without any support group who might not yet have heard about the Alliance, and expect to report on further new members in the next Newsletter.

### Grants

The fund-raising team has been busy and getting an excellent response. We are thrilled to report the total grants awarded to us to date amount to £11,450. The following have granted us funds and we thank them warmly for their generosity:

The Ammco Trust,  
Berkshire Masonic Charity,  
The Englefield Charitable Trust,  
The Gerald Palmer Trust,  
Greenham Common Trust,  
Millennium Festival Awards for All  
The Sobell Foundation  
West Berkshire Council.

### Therapy at the Sandleford Day room

The grants team has put in a big effort seeking grants to fund a team of specialist neuro-physio, speech & language and occupational therapists. The idea is they will work in the already equipped Day Room at Sandleford which has been offered to us for these purposes. This is a great opportunity for the voluntary sector to work in partnership with the NHS and Social Services. We wish the fund-raising team good luck in their quest for funds for this most worthwhile project.

## Newbury Hospital

No doubt many readers will have seen the artists impressions and write-ups about the new Newbury Hospital in the local press. We can happily report that every existing facility likely to be of interest to local neurology patients which we already have in the existing two hospitals appears in the plans for the new one, as has been promised throughout. We must' of course, be mindful that the prevalence of neurological conditions is increasing, but the hospital does appear able to expand in the event patient numbers go up. There still isn't a specific area we can look at and say 'that's where the hydrotherapy pool will go', but we know we've got a lot of work to do to get that particular ball rolling properly and there seems to be plenty of space for a pool to go in.

## Report on the AGM

'Remarkable progress and a model to follow' said guest speaker, Peter Cardy, the Chairman of the national Neurological Alliance at our first AGM. Similarly Joyce Parker enthused how the Alliance had succeeded in getting its voice recognised by the negotiators for local health care provision, and how members have been able to speak clearly with one voice on many occasions since first convening, despite some very differing needs among the patients they represent. In the last year the Alliance achieved charitable status, secured a remarkable group of Patrons, already represents 14 neurological conditions, (note 2 more since then!) noting there are some 5000 local individuals who have such a condition.

Particular priorities are more provision of a range of therapies, abolition of inequality and an end to postcode prescribing. Research into measuring the gap between current and recommended practice is well under way. The Alliance knows that Newbury's new hospital is basically a like for like replacement yet the forward need is greater. A particular goal is to make sure the new hospital gets a hydrotherapy pool. Some basic research into this has been carried out, but there is much to do before the idea can become a reality. Echoing

Joyce Parker's thanks to those involved, the Alliance's President Lady Hallifax congratulated the group on its many achievements.

Peter Cardy, is a man right at the heart of influencing change. At national level he is pleased to report that the Department of Health is beginning to recognise neurology as increasingly more important. Some 2 million people are affected across the UK, the number growing as our general survival rate improves and more treatments take effect. By contrast, the National Institute for Clinical Excellence, NICE, whose role is to make recommendations on health treatments to the government, shows little understanding of neurology conditions and their impact. 'Writing a list of disabilities and impairments isn't the same as living with the condition' chided Mr Cardy. 'The NICE process seems to be balanced against neurology disorders' is his diplomatic analysis, while he is encouraged by the way all levels of the medical profession have united with the voluntary sector in making the same criticisms of NICE.

The national Neurological Alliance clearly has a refreshed mandate and an important mission under Peter Cardy's lead and their growing list of activities and progress looks impressive. Their agenda complements that of the local West Berkshire Alliance very well, as the exchanges throughout the meeting kept revealing. Both organisations have much to do in their respective roles.

## Diary date to note:

Open meetings (all are welcome):

1400 hrs on Thursday, **25th January** 2001 at 11, Croft Lane, Newbury. Guest speaker to be announced.

1400hrs on Thursday, **22nd March** 2001 at 11, Croft Lane, Newbury. Guest speaker Mark Charters, West Berkshire Social Services.

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