

## NORTHERN ACQUIRED BRAIN INJURY FORUM (NABIF)

### Minutes of the meeting held at Hunters Moor Regional Neurological Rehabilitation Centre on Friday 15<sup>th</sup> December 2006

#### In attendance

Professor Mike Barnes (Chairman), Alistair McDonald, Viv Watson, Anne Hunter, Margaret Bromley, Amjed Malik, Penny Davison, Simon Garlick, John Walker, Helen Atkin, Steve McAleese, Evelyn Sanderson, Paul Saxon, Des O'Meara, Helen Hastie, Alister Berry, Neil Brownlee.

#### 1. Apologies

Ruth Cooper, Janice Thomson.

#### 2. Minutes from the last meeting

Approved.

Matters arising:

- i). Website: A website designer has been instructed and is preparing the website. The costs are being underwritten by Blackett Hart & Pratt, pending collection of voluntary contributions.
- ii). Regional Neurosciences Review/NSF: It was agreed these should remain a regular agenda item.
- iii). Neurological Alliance: Des O'Meara has agreed to be the point of liaison between NABIF and the Neurological Alliance.

#### 3. UKABIF Meeting 02.11.2006

Des O'Meara, Paul Saxon and Steve McAleese reported back from the above meeting. In attendance were representatives from UKABIF, Kent (KABIF), Sussex (SABIF), West Surrey (SABIN), East Region (ERABIF), NABIF, Scottish Head Injury Forum (SHIF) and representatives from London who were interested in setting up one or more ABIF's.

Each organisation gave a short presentation regarding its aims, mode of operation and achievements. KABIF, SABIF and SHIF are well established. The others are, like NABIF, getting off the ground.

Most ABIF's have a meeting every two or three months, in the afternoon or evening (usually alternating), at which there is a presentation on a topic of interest, followed by a business meeting and informal discussion. Of particular interest:

- i). KABIF have carried out a mapping exercise that allows users of the KABIF website to access information about ABI specialist services in the County.
- ii). KABIF are currently undertaking a research project on the needs of young people with ABI in Kent.
- iii). SABIF organised a conference on the ABI Pathway, with another planned (possibly jointly with KABIF).
- iv). SABIF are assisting in the development of a Neuro-Rehab Commissioning Strategy with local PCTs.
- v). SABIF have also assisted the West Sussex ABI Network to develop a mapping survey of services available in Sussex, Brighton and Hove, which again will be accessed on their website.
- vi). SABIF has been invited to provide training to GP's regarding ABI.
- vii). SHIF's main aim is to develop standards of working practice and services for those with ABI in Scotland. They achieve this by having working groups and local fora.
- viii). SHIF wish to do more political lobbying, which is one of the principle functions of UKABIF.

Generally speaking, therefore, the aims of the other ABIF's are similar to those of NABIF, and it was felt that given we have only be in existence for a year we have made good progress.

There was agreement amongst the ABIF's that they wanted close links with UKABIF, but without any formal affiliation. It was agreed in the first instance that UKABIF would set up an e-mail network with the Chairs of the various ABIF's. In particular, when UKABIF intend to lobby parliament on a particular issue, they will provide information to the ABIF's, who can then hopefully provide UKABIF with evidence to support their lobbying.

#### 4. Services in Carlisle

Jenny Locke explained her new role in Carlisle, developing and generating services for people with ABI, and improving training to those providing services to people with ABI.

#### 5. Training Day 29.01.2007

John Walker and Helen Hastie provided details of the training day to take place on 29<sup>th</sup> January 2007. Topics would include:

- Cognitive rehabilitation.

- How to set up a program development officer.
- Mapping services in the North.
- Service users perspective.
- Managing a medico-legal claim.
- Capacity and consent.
- Public Law: Boundary areas between Public and Private Agencies.

## 6. Service Mapping Project

Simon Easton and Steve McAleese reported on the current proposals for the service mapping project.

Steve has agreed to be the “*Lead Officer*”, and together with John Walker and Simon Easton he will be responsible for administration and co-ordinating information.

A sub-group has been set up to plan and implement the project: Simon Easton, Neil Brownlee, John Walker, Helen Atkin, Steve McAleese and Alister Berry.

At this stage the area to be covered by the project is from the Scottish Border in the North, down to Teesside and including Cumbria in the West (but not Morecambe Bay).

There was a discussion emphasising the importance of obtaining input from service users as well as service providers.

Penny Davison indicated that her group were already developing a resource directory for Sunderland. This was being done by people on the ground carrying out assessments, with Sunderland Social Services putting in place a database.

John Walker believed the same exercise had been carried out in North Cumbria.

Neil Brownlee has already indicated that Northumberland Head Injury Services carried out an exercise in Northumberland, matching the services available against the requirements of the NSF.

The proposed format at the moment is for a questionnaire or proforma to be sent out to all interested parties, at the same time inviting those parties to attend a “*roadshow*” in their region. In this way we can obtain information from the questionnaires and from a meeting at which people will be able to provide their views on the services available and those they would like to see.

Alistair White has suggested that, as part of the exercise, it may be possible to map clinical pathways in the different regions. It was generally agreed this would be very useful, and hopefully would not create too much additional work.

It was also hoped the service mapping would include matters such as the accessibility of services to those with head injuries e.g. restaurants, cinemas, etc. This is essentially an information sharing exercise.

The aim is that the results of the service mapping exercise should be:

- i). Made available on the NABIF website;
- ii). Made available to the SHA and PCT's to identify those areas where services need to be improved.

Des O'Meara raised the possibility of obtaining funding and/or support from local universities, who may have an interest in such a research project.

An alternative source of funding and IT support is the Strategic Health Authority.

The key to the project will be identifying as many service users and service providers as possible. The NABIF network is the key to this, but if the project is to succeed all members of NABIF will have to assist, and use their own individual networks to extend the project into all areas of the community.

In particular NABIF needs to extend its links with the service user network and suggestions are invited for organisations which may be able to assist (such as Disability North East, Newcastle Special Needs Network and Newcastle Children and Adult Services).

There was a discussion as to whether the service mapping project should be limited to adults or should extend to children's services. For the majority of members of NABIF this is outside their area of expertise (the emphasis being on provision of services to adults) and is covered by a different legislative framework.

This matter was left for consideration by the Working Group.

It was left for the Working Group to consider the scope and implementation of the service mapping project, and to report back to the group with its proposals.

## 7. The year ahead

There was discussion about the format and frequency of NABIF meetings.

Those present were content with the present formats.

The possibility of a presentation (of perhaps 30 – 40 minutes) at each meeting followed by an informal discussion was discussed. The general feeling was that it would be good to do this occasionally.

It was agreed that 10 minute presentations about the services available in the region were useful and the following volunteer (all were volunteered in their absence):

Cognitive Therapy Services (Helen Atkin/Anne Hunter).

Psychiatric Services (William Barker).

Whickham Villas (Boda Gallon).

Partners in Specialist Care Limited (Viv Watson).

Strategic Property Solutions (Alistair McDonald).

Rehab UK (Alister Berry).

Penpals (Millie Parker).

Sunderland Model for ABI (Penny Davison).

Overseas Brain Injury (Barbara Chandler).

Leonard Cheshire ABI Services (Helen Spellman).

The following dates were agreed for the quarterly NABIF meetings for this year:

Friday 2<sup>nd</sup> March 2007 – 12 noon – Hunters Moor/SHA.

Tuesday 5<sup>th</sup> June 2007 – 7pm – venue tba.

Friday 28<sup>th</sup> September 2007 – 12 noon – Carlisle – venue tba.

Friday 14<sup>th</sup> December 2007 – 12 noon – Walkergate.

8. Any other business

None

9. Next meeting

Friday 2<sup>nd</sup> March 12 noon – 2pm. Likely to be Hunters Moor or Strategic Health Authority Building.