

## Kent Acquired Brain Injury Forum

### Minutes

Wednesday 11<sup>th</sup> June 2008 at 7.00 pm

Royal British Legion Industries, Hall Road, Aylesford, Kent ME20 7NL

#### In attendance:

Mr Tanesh Bhugobaun	Registered Manager	Raphael Medical Centre
Mrs Liz Bray	Head of Nursing	The Children's Trust, Tadworth
Ms Jan Cartmell	Service Manager	The Regard Partnership
Miss Becca Coffey	PA to Frances Pierce	Rix & Kay Solicitors LLP
Ms Jo-Ann Davis	Manager, The Vines	Priory Healthcare
Ms Di Drummond	Manager	Headway Centre Tunbridge Wells & District
Ms Pattie Ducie		Kent Social Services
Dr Gerhard Florschutz	Director	Raphael Medical Centre
Mr Tony Hart	Head of Vocational Rehabilitation	Queen Elizabeth's Foundation, Brain Injury Centre
Mrs Jenny Mazur	Parent of son with ABI	
Ms Tanya Hodnett	Centre Manager	Blackheath BIRU
Mr Keith Hutchinson	Centre Manager	Hothfield Manor Centre Acquired Brain Injury Home
Mr Tony Merriman	Solicitor	asb Law
Mrs Wendy Morcom	Paralegal	Rix & Kay LLP
Mrs Pam Munro	Founder and Volunteer	Headway Tunbridge Wells and District
Ms Frances Pierce	Partner (KABIF Chairwoman)	Rix & Kay Solicitors
Ms Robyn Noonan	Physical and Sensory Impairment (PSI) Programme SE Lead	Care Services Improvement Partnership (CSIP)
Ms Mary Ryan	Vocational Assessment Manager / Occupational Psychologist	Royal British Legion Industries Vocational Assessment Centre
Mr Dennis Smith	President	Headway Tunbridge Wells and District
Ms Joanne Stovold	Group Care Homes Manager	Priory Neuro-rehabilitation Services
Mrs Linda Theoff	Brain Injury Case Manager	East Kent Hospitals Trust
Miss Victoria Toy	Trainee Solicitor	Rix & Kay Solicitors LLP

## Apologies:

Mr Bruce Aitken	Principal Physiotherapist	Strode Park Foundation
Ms Claire Carter	Occupational Therapist	Strode Park Foundation
Mrs Sophia Chung	Executive Director	S C Support & Care Services Ltd
Ms Sally Collins	Speech & Language Therapist	Strode Park Foundation
Ms Rita Eagles	Commissioning Manager for Gillingham and Rainham	Medway Primary Care Trust
Mrs Ros Eastwood	Head Teacher	East Kent Health Needs Education Service
Ms Delia Elliman	Independent Case Manager	Case Management Services
Ms Elizabeth Francis	Consultant Clinical Neuropsychologist	Community Brain Injury Team, Medway Maritime Hospital
Ms Rikki Gandolf	South East Regional Co-ordinator	Headway UK
Ms Kelly Hamer	Legal Executive	Brachers
Ms Jenny Hogg	Senior Work Psychologist	Jobcentre Plus
Mr Roy Marcus	Brain Injury Case Manager	ABI Services UK Ltd
Ms Denise McKeown	Partner	McMillan-Williams
Ms Mandy O'Brien	Brain Injury Case Manager	
Ms Patti Simonson	Head of Social Work	Royal Hospital for Neuro-disability
Mrs Jenny Stockley	Consultant Paediatric Neuropsychologist / Director	Jennifer Stockley Limited
Mr Richard Tutt	Registered Manager	Everycare Medway/Swale
Ms Julie Vanruyckevelt	Assistant Director of Patient Experience	West Kent PCT
Miss Sue Ware	Independent Speech & Language Therapist	
Miss Katie White	Paralegal	Rix & Kay Solicitors LLP
Ms Katherine Wilkinson-Carr	Unit Coordinator	Kent & Medway NHS Social Care Partnership Trust

### 1. Welcome and Introductions

The Chair Frances Pierce welcomed all attending.

### 2. Approval of Minutes of Meeting Held on 9<sup>th</sup> April 2008

Minutes of the meeting held on the 9<sup>th</sup> April were approved as drafted.

### 3. Matters Arising from the Minutes of 9<sup>th</sup> April 2008

Pam Munro of Headway Tunbridge Wells & District confirmed that the flat vacancy at Headway Court had now been filled, but there may soon be another. It was agreed that the advertisement on the KABIF website would remain, in anticipation of the further vacancy.

#### **4. Neuro-Rehab Stakeholders Group and NSF Update – Nicky Coffey**

Nicky Coffey was unable to attend the meeting.

Frances Pierce confirmed that she and Dennis Smith had met with Julia Ross (Director of Civic Engagement at West Kent Primary Care Trust), Bob Deans (Director of Commissioning at West Kent PCT) and the commissioners from the rest of Kent PCTs as well as a representative for social services for Kent. As a result of this meeting, Frances announced that a new post responsible solely for neurosciences in Kent had been agreed, funded jointly by health and social services (Dennis and Frances had aimed for one person dedicated to acquired brain injury). KABIF would have an input into the job description – a subcommittee will work on this over the next few weeks. The job will include MND, MS, ME, Parkinson, Stroke as well as brain injury. At this stage funding has been agreed for the role for three years.

In addition, there will be a further person appointed at commissioning level to cover Kent, Sussex and Surrey so the three counties will have a more coordinated approach. Nicky Coffey will be involved in setting up this role.

Frances expressed thanks to Julia Ross who was instrumental in achieving these two roles. Dennis and Frances had put forward to Julia Ross a shopping list that included (1) the lack of information given to families and sufferers of ABI at the point of injury; (2) specialist follow up plus care at the earliest opportunity; (3) the implementation of the NSF through properly costed plans with an appropriate interface with Social Services; (4) the consideration of case management and / or coordination of ABI services through a single body; (5) education of GPs and other frontline workers; and (6) maximising the experience of the members of KABIF and those willing to assist and train and / or give time to make a difference to the outcome of care pathways.

#### **5. Mapping Exercise/Website Update – Tony Merriman**

Tony Merriman explained that the mapping exercise was on hold at the moment as he was not able to continue work on this in his current job. However, he would soon be moving to work at the same firm as Frances and there he would be able to dedicate more time to looking into the gaps in information in the entries on the mapping facility.

Tony said that his son Chris Merriman would be happy to receive any suggestions for amendments or updates for the KABIF website (his email address is [chris@imperfections.freeseve.co.uk](mailto:chris@imperfections.freeseve.co.uk)).

#### **6. Headway (Kent) – Di Drummond**

Di Drummond said she had no news from Headway East Kent.

She confirmed that Headway Tunbridge Wells was getting close to its maximum numbers at the Day Centre as since their move new attendees had joined. The Day Centre is currently open Monday to Thursday.

Di mentioned Headway's Way Ahead Conference that will be held in the first week of July – this would be an opportunity for carers and others involved in the ABI field to attend workshops and network.

On 20<sup>th</sup> October Headway UK are holding a conference in Stratford-Upon-Avon.

Dennis Smith mentioned the Members Meeting to be held at Headway Tunbridge Wells & District at 7.30 on 7<sup>th</sup> July where Anuraj Varshney of West Kent PCT will be talking on the topic of 'Could You Drive Again' – all are welcome to attend.

Di said she would email a list of events to Chris Merriman to update the forthcoming events page of the KABIF website.

## **7. Towards Independence – Ros Eastwood & Mary Ryan**

Mary Ryan confirmed that she and Ros had received feedback on the leaflet and had produced a framework. They met last week to get the document into its final format so it could be produced over the next few weeks. Di Drummond offered to assist with the design of the leaflet.

Mary said that the feedback she had been getting was that it would be useful if KABIF could produce a leaflet to assist in signposting.

Frances Pierce thanked Mary Ryan and Ros Eastwood for their hard work and also Jenny Mazur's son for his input on the leaflet.

## **8. PPI Forum and Report on London Commissioning Conference – Dennis Smith**

Dennis Smith confirmed that the PPI Forum had been abolished on 31<sup>st</sup> March.

He mentioned the report he had circulated to the KABIF membership following the London Commissioning Conference on 12<sup>th</sup> May regarding neurological conditions. Dennis said that, although KABIF had identified that it would be better for ABI to be dealt with as a separate stream to neurosciences, it appears that commissioning seems to be based around neurosciences as a whole, to include ABI.

Dennis confirmed he was involved in the Health Network, which is headed by Julia Ross (Director of Civic Engagement at West Kent PCT). There is currently a drive to recruit volunteers who would like to input on the various services provided by the PCT. Dennis has some leaflets for those interested in becoming a volunteer. Dennis confirmed he has signed up for 'community services' and 'long-term conditions'.

As part of Dennis' involvement, he is keen to ensure that the Adult Health Consultation Advisory Group covers neurosciences / neurological conditions and the PCT's community therapy service.

Dennis mentioned that Di Drummond is part of the West Kent Neurosciences Group and Dennis also wishes to join. Dennis and Di will put ideas about ABI forward at the West Kent Neurosciences Meetings.

## **9. Any Other Business**

### **a. South East London Head Injury Audit**

Frances Pierce mentioned the South East London Audit. Julia Ross had confirmed the Primary Care Trusts need numbers before commissioning effectively. Frances had given Julia Ross the details of the audit in Bexley prepared by the NHS Audit & Analysis Unit. Frances had asked Helen Lew, one of the people involved in this audit, to speak to KABIF.

The findings of the audit showed that 2,500 went through King's College Hospital in the six-week period and then fell off the map with no follow up. Frances added a caution that King's take referrals from all over the country, so these figures did not necessarily relate to Kent.

A follow up audit is now being carried out over a longer period to gather more precise figures.

Liz Bray asked whether the figures included children and Dennis Smith said some of the hospitals didn't deal with children. It wasn't clear whether children had been included in all of the hospitals within the audit.

Please let Frances know if you would like a copy of the audit (email francespierce@rixandkay.co.uk).

Jan Cartmell mentioned that a question had been raised at UKABIF as to whether statistics could be made more readily available.

Dennis Smith mentioned the statistics produced by the study of head injury patients in A&E, which showed that a significant number of patients were admitted to A&E with head injuries and only a very few were referred on to specialist hospitals.

Frances mentioned that the South East London Head Injury Audit report had come to her attention from a contact out of the county, the people she had been meeting with in Kent hadn't mentioned it.

#### **b. Speakers for 2009**

Frances mentioned there were now only a few speaker slots left for 2009. Members should let her know of any particular speakers they would like to be invited.

#### **c. Life Expectancy**

Pam Munro mentioned that with brain injury there is not necessarily a reduction in life-expectancy. Gerwyn Samuel said that for those who suffer uncontrolled epilepsy following a brain injury there is a reduction in life-expectancy, but for those who do not suffer epilepsy or who suffer controlled epilepsy there should not be a reduction in life-expectancy.

### **10. Tea & coffee break**

There then followed a break for tea and coffee.

### **11. Speakers**

#### **a. Getting the NSF Moving**

Robyn Noonan, Physical and Sensory Impairment (PSI) Programme SE Lead, Care Services Improvement Partnership (CSIP) gave a talk on the topic of "Getting the NSF Moving" (please see PowerPoint slides on the website).

Robyn mentioned direct payments within her talk and Dennis Smith said he was uncomfortable about direct payments for brain injury sufferers. Di Drummond shared these concerns and mentioned that Social Services carried out a pilot in her area and people she has spoken to are concerned about direct payments.

Pam Munro said a key difficulty is lack of awareness of the problems caused by brain injury and the impact on such schemes as direct payments.

Robyn Noonan said she can see how service providers may feel uncomfortable about direct payments. She said individual budgets only work if the right support systems are in place; if they are not then systems such as direct payments fail.

Gerwyn Samuel said that, following the Mental Capacity Act 2007, if the government is forcing direct payments on people, it seems sensible to suggest that the government has a responsibility to make resources available so that deputies can be appointed for those who lack capacity to handle their financial affairs so direct payments can be administered appropriately.

Azeem Suterwalla mentioned that User Independent Trusts can be set up so that a board of trustees – made up of stakeholders such as family members and medical representatives – take decisions of how the direct payment money or settlement awards are used for rehabilitation, equipment, etc.

Linda Theoff said she noticed it often causes stress and conflict when family members take on the role of dealing with financial affairs such as direct payments.

As Robyn Noonan had confirmed CSIP's role was to help to make national policies work locally, Frances Pierce asked whether CSIP could assist KABIF, who had lots of people round the table, to get their views heard to encourage further progress for ABI with the implementation of the NSF. Robyn Noonan said that certainly CSIP could help and she was currently interviewing someone for the South East region who would cover Kent, so either Robyn or the person she recruited could assist.

## **b. Judicial Review and Patients' Rights**

There then followed a talk by Azeem Suterwalla and Gerwyn Samuel of Doughty Street Chambers on the topic of "Judicial Review and Patients' Rights" (please see handout on the website).

Pam Munro asked how Judicial Review cases are funded. Gerwyn Samuel and Azeem Suterwalla confirmed that Legal Aid is often available, this is assessed based on the financial situation of the applicant. Frances Pierce clarified that, although Legal Aid is available for Judicial Review cases, it is not available for personal injury claims that involve negligence.

## **12. Next Meeting**

The next meeting will be held on 11th September 2008 at 3 pm at Headway Canterbury, The Sustain Centre, Kent & Canterbury Hospital, Ethelbert Road, Canterbury, Kent, CT1 3NG