

Kent Acquired Brain Injury Forum (KABIF)

MINUTES

of meeting held on 29 June at 4.00 p.m.

at the Spa Hotel, Tunbridge Wells, Kent

In attendance:

Liz Bray, Head of Nursing, The Children's Trust, Tadworth
Louise Brown, Legal Assistant, Thomson Snell & Passmore
Jan Cartmell, The Regard Partnership
Sophia Chung, Executive Director, S C Support and Care Services Ltd
Diane Cloke, Physiotherapist
Diane Drummond, Manager, Headway House Day Centre
Ros Eastwood, East Kent Hospitals Schools Service
Gerhardt Florschutz, Raphael Medical Centre
Tim Gilbert, Brain Injury Case Manager
Mike Hope, ABI Co-Ordinator for East Sussex, Brighton and Hove
Bhavna Jones, Service Development Manager, Unsted Park Hospital
Dr Lal Landham, Consultant in Rehabilitation Medicine
Roy Marcus, Case Manager, Harley Reed Consulting
Chris Merriman, website co-ordinator
Tony Merriman, Solicitor, asb law
Lorna Morris, West Kent Neuro-Rehabilitation Unit
Pam Munro, Founder and Volunteer of Tunbridge Wells and District Headway
Frances Pierce, Solicitor, Thomson Snell & Passmore (Chair)
Mary Ryan, Occupational Therapist, RBL
Patti Simonson, Principal Social Worker, Royal Hospital for Neurodisability
Sally Tester, Neuro-Rehab
Linda Theoff, Single Incident Brain Injury Service
Sue Ware, Independent Speech and Language Therapist

1. Apologies

Nicky Coffey, Head of Commissioning, Kent and Medway
Elizabeth Francis, Consultant Clinical Neuropsychologist
Mandy O'Brien, Brain Injury Case Manager
Dennis Smith, President of Tunbridge Wells and District Headway
Don Young, Case Manager

2. Approval of minutes of meeting held on 4 April 2006

The minutes were approved subject to removal of the reference in Martin Burke's talk to there being funding by Headway.

3. Matters arising from minutes of meeting held on 4 April 2006

Frances updated the Forum on the present position regarding the joint meeting on 18 August and passed round copies of the flyer for the meeting, encouraging everyone to book themselves onto it and pass copies of the flyers on to any other interested people they know of.

4. Introductions and information exchange

Sue handed round a voucher for Cerebra, a charity for brain-injured children and young people, who are starting a scheme for its members that will pay for a child to have an assessment, an agreed course of treatment and a report from a private physiotherapist. A copy of this voucher is attached to these minutes.

Patti said that she would like to mention that there is a legal seminar taking place at the Royal Hospital for Neurodisability, details of which she requested be placed on the KABIF website. These details were therefore passed to Chris so that he could do this.

Mike said that there was going to be a BIRT study day to be held on 7 July at Slinfold in West Sussex. Details of this were passed to Chris to put on the KABIF website.

5. PCT reorganisation and up: Nicky Coffey, Head of Specialist Commissioning, Kent and Medway

Nicky had sent her apologies for the meeting but had provided by email an update and this is set out below:

PCT Reconfiguration – Update June 2006

The boundaries of the new Ambulance Trusts and PCTs were formally announced by the DoH in mid May:

Kent Ambulance NHS Trust will merge with Surrey Ambulance and Sussex Ambulance to form **South East Coast Ambulance Service**.

The 9 PCTs within Kent and Medway will be reconfigured as follows:

Ashford PCT Canterbury and Coastal PCT East Kent Coastal Teaching PCT Shepway PCT	Eastern and Coastal Kent Teaching PCT
Medway Teaching PCT	Medway Teaching PCT
Maidstone Weald PCT South West Kent PCT Dartford, Gravesham & Swanley PCT	West Kent PCT

Transitional teams are now in place for the 3 new PCTs at Chief Executive and Director level.

Specialist Commissioning

A DoH independent review “Review of Commissioning Arrangements for Specialised Services” (the “Lord Warner Report”) was published in May 2006. The purpose of the report was to inform the thinking around future structures for specialist services in the future.

The paper recommends that collaborative arrangements continue for specialist services, with PCTs formally working together with centralised Specialist Commissioning Teams. By 2008, it is anticipated that there will be pooled budget arrangements for all specialist services – the funding will be devolved from the PCTs to these centralised teams. Currently, all neurology/neuroscience/neurorehab services *except Stroke* are deemed to be specialist, however, these definitions may change over time.

6. Neuro-Rehab Stakeholders Group and NSF update - Lorna Morris

Debbie was unable to attend the meeting and so this update was kindly given by Lorna Morris who had attended on her behalf.

Laura said that there had recently been appointed a neuropsychologist for the long-term condition strategy group and brain injury will be looked at jointly with MS.

With regard to the neuro-rehab unit, this is now called Heads Together and the patients are involved in all interviews for staff.

They have begun having quarterly socials and Yippee are doing a presentation for them shortly.

A garden party is due to be held next Friday at which about 150 people will be attending.

With regard to the Patient Forum, they are currently revising their information pack.

The buddy system is now up and running.

7. Mapping exercise/website update - Mary Ryan

Mary gave an update to the Forum following a meeting of the mapping exercise committee which had met earlier.

She said that Chris was still having difficulty finding a map of Kent which would be suitable for him to put on the website. Various offers had been made to try and find a suitable one and hopefully there will be one in place shortly. Chris has arranged the data from the mapping questionnaires into

two tables, personal and business contacts. However, he is finding lots of inconsistencies which is making the task much more difficult for him than anticipated. Also, following a discussion about the categorisation of the services, it was apparent that Chris did not have access to all the information he needs and Louise and Frances arranged to meet with him the following week to go through with him the problems he was encountering and see where we could assist with additional information and general input from them.

A further meeting of the mapping exercise committee had been arranged for 13 September and hopefully by then the task will be well under way so that it will not be too much longer before the information will appear on the KABIF website.

Frances thanked him for all the work he had kindly put in to this project.

8. Headway (Kent) - Di Drummond

Di was unable to provide any information about East Kent this time so confined her talk to Headway Tunbridge Wells. She said that the day centre was becoming quite full up, particularly with younger folk who are coming straight from neuro-rehab to them.

She said that there is an exciting new focus taking place in which they have joined forces with CBIT and will launch Headway Junior, which will provide mainly carer support. A project is therefore under way to find out what it is that carers want, and a form will be produced over the summer to initiate the project.

With regard to the move, Di said that the house purchase was still going through the legal formalities and the cost of renovations was still being worked out. There is still lots to do with e.g. lifts, and the move will probably not now take place until the New Year.

Fundraising events for the house purchasing are continuing, the next one being a bric-a-brac sale on 15 July at Oakley School, Pembury Road, Tunbridge Wells, and a garden party on 5 August at 2.00 p.m. at Pembury Hospital. Full details are on the KABIF website. The amount raised so far for the house is £112,000. Any contributions will be gratefully received.

9. Focus on Young Adults with ABI - Ros Eastwood

Ros has not had an opportunity to progress this project due to pressure of work. However she said that she should have more time over the summer holidays and gave the Forum a brief synopsis of what the project is all about. Frances asked if we could assist her given her work pressures and she said that she and Mary would email people to see if they want to be part of the group. A further report on the project will hopefully be available by the October meeting and Ros and Mary will let people know in the interim if they need any help.

10. Talk by Dr Lal Landham, FRCS FRCP, Consultant in Rehabilitative Medicine at the Medway Maritime Hospital

Dr Landham said that rehabilitative medicine is a sub-speciality of general medicine. He himself looks after people who have suffered head injuries and other traumas, such as limb trauma but it might also be someone suffering from MS or Parkinson's Disease; the remit is wide and he focus is very much upon rehabilitation.

Dr Landham gave some background to the present situation regarding the organisation of the PCTs. He said that the East Kent PCTs had merged to form a single trust to which Swale, Gillingham and Sheppey had joined. Medway and West Kent are separate trusts. Kent and Medway NHS and Social Care Partnership Trust was formed on 1 April 2006 following the merger of East Kent NHS and Social Care Partnership Trust and West Kent NHS and Social Care Trust.

The trust provides a wide range of services across Kent and Medway. The main focus is on mental health services, but other services provided include forensic mental health, learning disability and substance misuse, as well as a range of specialist services such as neurology rehabilitation and eating disorders.

On the neurological side, the hospital provides a single incident centre. A psychiatrist has been appointed to start on 1 September who will provide neuropsychiatry services and advising hospitals in West Kent and Medway, visiting acute hospitals. The plan is to have inpatient facilities as well but no date has yet been set for this. Neurorehabilitation is provided for patients although not those with very severe disorders, only moderate to severe.

There are presently eight beds for the neurological service. Some of the patients have multidisciplinary needs as well although not those with traumatic spinal cord injuries.

There is a slow-track rehabilitation service at Dartford which has a 12 bed unit and opened about a month ago. The new philosophy of the trust is to do the commissioning themselves and so it will be necessary to see how the providers go.

There are plans to take patients with a minimum or low conscious state who currently go to Putney as this is obviously quite far away for patients and their families.

With regard to musculo-skeletal rehabilitation, the hospital is a regional service for people with limb deficiencies and covers the whole of Kent and parts of London. They are able to offer advance prostheses and a specialist orthotic service. Other services include such things as special seating for those with complex needs, e.g. cerebral palsy and spinal cord damage; environmental control systems for those who are profoundly disabled to enable them to live in their own home and take control of their lives, e.g. it enables to carry out simple, everyday tasks such as opening and closing doors and changing the TV channel. This service covers the whole of Kent and Sussex as well as parts of London such as Bromley and Lewisham.

Questions were to put Dr Landham as follows:

What about funding for the environmental control systems? Dr Landham said that the budget for the whole region is £½m.

How many referrals are there? Dr Landham said that there were about 100 referrals per year and about 60 units are provided per year.

Frances asked Dr Landham how rehabilitation is managed with all the different types of injury which a patient can have. Dr Landham said that rehabilitation is a comprehensive discipline and there is an excellent team at the hospital; he will see the patient himself first and then the team with all their different disciplines will continue - it is very much a teamwork effort.

Dr Landham said that one of the problems was that once the patient leaves the hospital you tend to lose touch and therefore there is no follow-up to see how they are getting on. However, if there is a particular patient about whom he is concerned then he will keep them under his wing for a bit longer than normal. Fortunately there is a very good community rehabilitation team to whom he can refer patients.

Dr Landham was asked if neuropsychological problems could also be dealt with in his unit and he said that they depended upon a psychologist to provide help in this area and they had also been able to call on the assistance of Simon Fleminger in the past who has always been very helpful.

Di asked if it was useful to refer people back to his team or to the community rehab team and Dr Landham said that if the community team felt that a patient should be referred back to him or to his colleague that that was perfectly alright.

Dr Landham was thanked for taking the time today and to come and give the Forum this valuable talk.

11. Any other business

Frances said that she had been sent a document called "Proposals to develop an integrated network for neurosciences in the North East of England and North Cumbria". A copy will be made available on the website.

Frances also reminded the Forum about the forthcoming BSWIG Annual Brain Injury Legal Seminar on 21 September.

With regard to forthcoming meetings, Frances said that the next meeting on 18 August was at the Clarion Hotel, on 11 October Pam Wells and Don Young would be talking. On 8 December Liz Bray and Di Drummond would be talking.

She then went through the dates for 2007 meetings which are as follows:

8 February	7.00 p.m. at asb law, Maidstone
5 April	2.30 p.m. at East Kent School Service, Canterbury
7 June	7.30 p.m. at RBLI Capel Morris Hall, Aylesford

9 August 2.30 p.m. at Thomson Snell & Passmore, Tunbridge Wells

11 October 7.00 p.m. at asb law, Maidstone

7 December 2.30 p.m. at Thomson Snell & Passmore, Tunbridge Wells

Any suggestions for speakers for next year are welcome.

Roy said that a young woman working in the Brain Injury Foundation in Australia is coming here for a year and looking for a job. If anyone can assist her then please send him an email (roymarcus@harleyreed.com) and he will let her know.

With regard to speakers, Patti offered to provide a speaker from the Royal Hospital.

Bhavna told that Forum about a new unit which has just opened at Unsted Park. It is a 9 bed unit for patients with complex needs. There will be a series of open days for those interested in looking at the unit.

Sue said that Professor Lindsay McLellan from there would be happy to do a talk next year.

Liz asked if it would be possible to put the Children's Trust on the KABIF website and Frances confirmed that they were on the mapping information so a link to them on the website would be possible..

The meeting ended at 5.10. p.m.

Next meeting:

The next KABIF meeting is the special joint KABIF/SABIF meeting and seminar with Chris Wall on 18 August at Gatwick.

The next regular meeting will be on 11 October at 7.00 p.m. at East Kent Hospitals School Service, City Way, Canterbury, Kent. An agenda and directions will be sent in due course.