

Kent Acquired Brain Injury Forum

www.kabif.org.uk

Minutes

Wednesday 9th September 2009 at 3.00 pm

Raphael Medical Centre, Coldharbour Lane, Hildenborough,
Tonbridge, Kent TN11 9LE

In attendance:

Mrs Lucy Barnes	Senior Occupational Therapist	East Kent Hospitals University Foundation NHS Trust
Ms Frances Beaumont	Independent Occupational Therapist	Occupational Therapy Services
Dr Bryan Bennett	Neuropsychologist	Strode Park Foundation
Mr Tanesh Bhugobaun	Registered Manager	Raphael Medical Centre
Mr Alex Brown	Trainee Solicitor	Rix & Kay Solicitors LLP
Ms Jan Cartmell	Service Manager	The Regard Partnership
Mrs Sophia Chung	Executive Director	S C Support & Care Services Ltd
Mr Matthew Collins	Occupational Therapist	South East Driveability
Ms Patricia Corbett	Private Occupational Therapist	Patricia Corbett Occupational Therapy Services
Ms Di Drummond	Manager	Headway Centre Tunbridge Wells & District
Ms Pattie Ducie	Independent Social Worker	
Dr Gerhard Florschutz	Director	Raphael Medical Centre
Dr Melanie George	Clinical Neuropsychologist	Kent & Medway NHS and Social Care Partnership Trust
Ms Kelly Hamer	Legal Executive	Brachers
Mr Tony Hart	Head of Vocational Rehabilitation	Queen Elizabeth's Foundation, Brain Injury Centre
Mr Keith Hawley	Director	Enable
Ms Jane Heath	Regional Manager	Independent Clinical Services
Ms Karen Heath	Team Leader	The Priory, The Vines
Mandy Heddle		Priory, Egerton Road
Ms Ruth Langridge	PA to Dr Gerhard Florschutz and Tanesh Bhugobaun	Raphael Medical Centre
Ms Julia Law	Partner	Brachers
Mrs Jenny Mazur	Parent of son with ABI	
Mr Tony Merriman	Solicitor	Rix & Kay Solicitors LLP
Ms Kate Parrin		Kent Supported Employment

Mr Mark Parrin		Kent Supported Employment
Ms Frances Pierce	Partner (KABIF Chairwoman)	Rix & Kay Solicitors LLP
Mrs Becca Porter	PA to Frances Pierce	Rix & Kay Solicitors LLP
Ms Mary Ryan	Vocational Assessment Manager / Occupational Psychologist	Royal British Legion Industries Vocational Assessment Centre
Ms Lisa Rye	Coordinator	Headway Tunbridge Wells
Mr Dennis Smith	President	Headway Tunbridge Wells and District
Ms Natalie Spurrier	Solicitor	Irwin Mitchell
Mrs Judy Taylor	Wife of husband with a severe brain injury	
Mrs Linda Theoff	Brain Injury Case Manager	East Kent Hospitals Trust / Head First
Ms Linda Touray		Priory, Egerton Road

Apologies:

Mrs Tracey Allport	Brain Injury Case Manager / Occupational Therapist	Independent Living Solutions Ltd
Mr Robert Aylott	Solicitor	ASB Aspire LLP
Ms Debbie Bateson	Lead Commissioner – Neurosciences and Adult Therapies	Eastern & Coastal Kent NHS
Mrs Liz Bray	Head of Nursing	The Children's Trust, Tadworth
Rt. Hon. Greg Clark MP	Member of Parliament and Shadow Minister for Charities and Volunteers	House of Commons
Ms Nicky Coffey	Associate Director	South East Coast Specialised Commissioning Group
Mrs Ros Eastwood	Head Teacher	East Kent Health Needs Education Service
Ms Hannah Farr	Trainee Clinical Psychologist	Salomons
Ms Rikki Gandolf	South East Regional Co-ordinator	Headway UK
Ms Sarah Greenland		Multimedia for Multiple Disabilities
Ms Tanya Hodnett	Centre Manager	Blackheath Brain Injury Rehabilitation Centre and Neurodisability Service
Mr Keith Hutchinson	Centre Manager	Hothfield Manor Centre
Ms Linda Kerley	C.E.O.	Headway East Kent
Mr Stephen Leidecker	Director of Operation	Kent Adult Social Services
Mr Edward Lewis	Solicitor	T G Baynes
Ms Kiri Mazur		
Mrs Wendy Morcom	Legal Executive	Rix & Kay Solicitors LLP

Mrs Pam Munro	Founder and Volunteer	Headway Tunbridge Wells and District
Dr Stephen O'Connor		Department of Health
Ms Lynn Park		DART Team
Ms Julia Ross	Director of Civic Engagement	West Kent Primary Care Trust
Ms Patti Simonson	Head of Social Work	Royal Hospital for Neuro-disability
Mrs Jenny Stockley	Consultant Paediatric Neuropsychologist / Director	Jennifer Stockley Limited
Mr Simon Truett	Head of Commissioning for Long Term Conditions	Medway Primary Care Trust
Mr Anuraj Varshney	Acting Co-Coordinator	DART Team
Miss Sue Ware	Independent Speech & Language Therapist	
Ms Jo Worby	Partner	Brachers

1. Welcome and Introductions

The Chair Frances Pierce welcomed all attending.

2. Approval of minutes of meeting held on 10th June 2009

The minutes of the meeting held on the 10th April 2009 were approved as drawn.

3. Matters Arising from the Minutes of 10th June 2009

Frances Pierce announced that Jan Cartmell of The Regard Partnership will become the Vice Chair of KABIF when Tanesh Bhugobaun becomes Chair, as from the first meeting of next year (February 2010) – there was applause.

There are only 2 speaker slots left for next year and the Steering Group are now looking at booking speakers for 2011, so if there are particular topics or speakers that KABIF members are interested in then please let Tanesh (tanesh@raphaelmedicalcentre.co.uk) know.

Frances welcomed and thanked the speakers for today's meeting – Mary Ryan (who had kindly stepped in for Sharon Patmore) and Mark Parrin.

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

Nicky Coffey, Associate Director of the South East Coast Specialised Commissioning Group, was unable to attend this meeting but had kindly sent a report.

On behalf of Nicky, Frances was able to report that NHS Medway have been working with CBIT on developing a business case for expansion to cover brain tumour.

NHS Medway have been working with the acute trust on information given to those with mild head injuries. Frances said that, as all around the KABIF table knew, mild head injuries often get missed.

NHS Eastern & Coastal Kent have been looking at a post acute rehabilitation pilot due to finish soon. The subsequent evaluation is to be shared with the group if it is relevant to ABI.

In addition, NHS Eastern & Coastal Kent have been working with district councils regarding housing for people with long-term conditions.

NHS Eastern & Coastal Kent are working with East Kent Hospital Trust to move more complex ABI back to Kent and Canterbury Hospital, including evaluating the challenge of appropriate skill mix.

Nicky's report confirmed that in NHS West Kent the Commissioners are carrying out patient interviews to find out about their experience of long-term conditions pathways.

The Community Neuro Team in Dartford now has a Neuropsychologist, which means that all community teams now have access to neuropsychology.

Dr Melanie George, Clinical Neuropsychologist at Kent & Medway PCT, was asked to give more information about the recent restructuring of the Kent Clinical Neuropsychology Services. Melanie confirmed that she started in her post about a week ago and she understands that there are around 7 or 8 new posts, so the service has expanded. Melanie confirmed there are psychologists based in Maidstone, Tonbridge, Dartford/Gravesend, Medway/Swale, Dover, Ashford, Canterbury and Thanet. On behalf of KABIF, Frances confirmed she was grateful to Julia Ross and the Commissioners for this increase in psychology services.

Tony Merriman of Rix & Kay Solicitors confirmed that he had recently met Dr Mohamed Sakel, Director of Neuro Rehabilitation Services East Kent and that a future meeting is planned with some of the KABIF Steering Group.

It is believed that the only Neuropsychiatrist within the PCTs in Kent is at the Sevenoaks unit.

The structure document for Kent Clinical Neuropsychology Services is to be circulated with the minutes and included on the KABIF website (www.kabif.org.uk) and those listed on the document will be added to the mapping on the website.

Nicky's update on the South East Coast Specialised Commissioning Group confirmed that the PCTs are working closely with the SCG and the priority work stream has been agreed as post acute pathways for medically stable patients. Nicky Coffey will be co-ordinating a needs assessment with the Public Health Team. Each Commissioner is currently identifying local capacity for managing ABI from the end of the hyper-acute phase up to the point of discharge into the community. The PCT Commissioners are working together to look at information leaflets given to patients in A&E departments.

Di Drummond confirmed that Headway UK have an A4 leaflet about post acute brain injury, which is available on the leaflets page of the Headway UK website. Di agreed to send a copy of this to Nicky Coffey.

Members of the KABIF Steering Group are hoping to meet with Nicky Coffey and their aim is to have joint funding for brain injury throughout Kent between social services and health.

5. Coordinator for Kent Update – Simon Truett

Simon Truett had given his apologies for the meeting and confirmed he was relying on Nicky Coffey's update, he had nothing to add.

Simon subsequently submitted the following report on 24th September: -

1) I trust Nicky's note explained that she was planning to attend KABIF to give an overview of Kent and Medway's Commissioning work but was unable to attend at the last minute. As she explained her update was for the whole local health economy. I will endeavour to attend the next meeting.

2) The current leads for Adult Disability Services in Medway are Amanda Dean and Jackie Challis (job share) they are based at Medway Council, Gun Wharf, Dock Road, Chatham ME4 4TR. A representative from the council has been invited to attend the Long Term Conditions Strategic Change Programme Group.

3) The South East Coast Procurement Hub Programme Board took the decision in regards to the Continuing Healthcare Sourcing Group to have a single service specification to cover the four care categories that the Procurement Hub Programme is looking at (ABI, Elderly Frail, Older Peoples Mental Health and Palliative Care). Therefore the ABI specification which the ABI sourcing group developed has been incorporated into the larger residential care specification – there is a huge amount which is applicable across all care categories, anything specific to ABI is in a separate section. The specification is close to final sign off which will be done firstly by the residential care sourcing group and then by the Programme Board. It will then be available for viewing.

When the four individual sourcing groups were merged into a single sourcing group each PCT nominated a lead to represent their organisation (usually the Continuing Care Lead). In Kent, Janet Manuel represents Medway PCT, Angela Knight West Kent PCT and Naomi Snell Eastern and Coastal Kent PCT. These members are expected to consult with whoever they deem it necessary to within their PCT to ensure that their organisation is adequately represented and that specialists/subject experts are consulted. I have let Janet know that I will be happy to assist in this area but she has is the continuing care lead for the PCT and as such has significant experience in this area.

Once the specification and associated schedules have been completed the sourcing group will be launching a provider engagement programme to ensure that all providers understand what we are trying to achieve and what is required of them.

6. Mapping Exercise/Website Update – Tony Merriman

Tony Merriman confirmed that the Website Steering Group had met this month.

Tony had received lots of useful feedback on the website from UKABIF members.

The mapping questionnaire has been re-jigged and the Mapping Steering Group will be asking all KABIF members to fill out a new questionnaire, it will be possible to fill it in online via the website. The information will go through the Steering Group before it is published on the website.

The hosting of the KABIF website had been changed to deal with the modern updates being made by Chris Merriman.

Frances thanked the Website Committee for all their hard work.

7. Headway (Kent) – Di Drummond

Di Drummond reported that Headway Tunbridge Wells are currently reviewing and assessing their services. Their garden development is due to start in a couple of weeks. They are hoping that next year the garden and the centre can be used by the community, for example for meeting rooms, for a small fee.

Headway Tunbridge Wells are selling raffle tickets. If the tickets are purchased through Headway Tunbridge Wells then half the money goes to Headway Tunbridge Wells and the rest goes to Headway UK.

The Friday drop in has dropped off a bit. Headway Tunbridge Wells are rethinking their strategy for this, how it is advertised, etc.

Di reported that sadly she had come into contact with a number of families of brain injured people who have fallen through the net / dropped of the list, where the GPs are perhaps not doing all they should to assist. These families had found Headway by chance. Di had received communication today from the Probation Service about someone they believe suffers from a head injury. Di asked KABIF members to let her know if they have examples they can share with her of people falling through the net, Di is planning to put together a report. Di's email address is headwaytwells@hotmail.com.

Di introduced Judy Taylor who explained that her husband had been admitted to King's in July 2008 and was then transferred into the Royal Hospital for Neurodisability at Putney. Recently he had been transferred to a nursing home near to the family home. While Judy's husband was at Putney he had been diagnosed as being in a 'persistent vegetative state'. Judy had noted that there is not a lot of support for the families of those in a 'vegetative state' and there were many families at Putney in a similar position to hers who, once their injured family member is discharged, return home to various parts of the country. She explained the reason she had come to the KABIF meeting this afternoon was to ask if anyone knew of any support groups or indeed was interested in starting a support group for those in a similar position to her.

Gerhard Florschütz of The Raphael Medical Centre expressed a dislike for the term 'persistent vegetative state' and said that he and his colleagues at The Raphael Medical Centre were interested in setting up a support group for families in a situation similar to Judy's. Gerhard invited Judy to liaise with him about setting up a support group.

Di Drummond (headwaytwells@hotmail.com) said that if anyone knows anyone in similar circumstances to Judy who is interested in a support group she is happy to coordinate getting their details passed through to Judy Taylor.

Tony Merriman reported that he had met with Linda Kerley of Headway East Kent on 16th June. Linda plans to attend KABIF meetings whenever she can and to send a report in to Tony when she isn't able to make the KABIF meetings.

Tony outlined that Linda Kerley runs 5 day centres – Ashford, Dover, Canterbury, Folkestone and Margate. The centres are manned by staff based at the centres and

there are also specialised, mostly Canterbury based, staff who visit the various Headway centres. Many of Headway East Kent's clients are referred to them by the Local Authority. Those clients come in with case plans which often have to be redone as they are not appropriate.

Linda had reported to Tony that personal budgets are causing problems, some are being mal-administered. She had experienced a number of examples of individuals not paying for care services and saying, "I'll pay you the rest later". Linda is keen that the issue of personal budgets for those with brain injuries is taken up with the relevant authorities.

8. Towards Independence – Ros Eastwood & Mary Ryan

Mary Ryan confirmed that the Towards Independence booklet had been produced, aimed at those aged 18 – 35 with brain injuries. The Steering Group have a list of organisations to circulate the booklet to. The booklets were circulated at the meeting. If anyone would like further copies of the booklet, please let Mary Ryan know (mary.ryan@rbli.co.uk).

Frances Pierce mentioned that people within this age group often fall through the gap between services for children and services for adults. The research from this project clearly showed that people in this age group really want to be as normal as possible. Unfortunately, a lot of the equipment and services for those with head injuries tends to be more suitable for older clients and not so easily acceptable to those aged 18 – 35.

9. Health Network – Dennis Smith

Dennis Smith updated the meeting about CareCall – see the minutes of the KABIF meeting dated 10th June 2009 for further details.

Dennis reported that LINKs (Local Involvement Networks) seem to be getting their act together. Dennis proposed that he liaise with John Cunningham of LINKs to try and forge a relationship between LINKs and KABIF. Frances Pierce confirmed it would be useful to have communication with LINKs, John Cunningham could have an agenda item at a KABIF meeting. Dennis agreed to approach John Cunningham to enquire whether he was available for the next December meeting.

10. Joint Meeting Update – Stephen O'Connor

Stephen O'Connor had sent his apologies and an update. He was looking at the policy document for joint working.

Kent Adult Social Services had recently had a serious restructure. KABIF now has a list, which is to be circulated with the minutes.

Sophia Chung of S C Support & Care Services Ltd reported that approximately 30 senior managers had left Kent Adult Social Services, so the restructure has been chaotic, but the new people are starting to come into post. The first point of call for those with head injury is the Kent Contact and Assessment Team.

Frances Pierce thanked Sophia and said that it was very useful to have the named individuals at KASS. If anyone becomes aware of any changes of names or roles on the list into the future they are asked to let Frances know (francespierce@rixandkay.co.uk).

Dennis Smith and Ros Eastwood are looking at the policy document for joint working between social services and health.

Frances Pierce mentioned that a central, national Pathway for ABI is being launched at the UKABIF conference on 11th November. The stakeholders of this Pathway are the Commissioners, Members of Parliament, Temple-head had been very much involved. Details of the UKABIF conference were distributed. It is possible that this Pathway could be used as the framework for the joint policy document Dennis and Ros will be working towards with health and social services.

Frances reported that Putney and King's are often not trusting Kent to support those with serious ABI, which may have an effect on community based rehab providers within the county. Putney had also voiced their concerns about the quality of rehab in the county and had been reluctant to move patients across.

Mark Parrin of Kent Supported Employment mentioned that Job Centre Plus had worked on the vocational part of the Pathway. He said that a number of people with ABI come from outside the county, which throws up funding issues.

Dennis hopes to be in a position to update at the December KABIF meeting about the joint meeting agenda.

11. Department of Health & Health Commission Update – Mary Ryan

Mary Ryan of Royal British Legion Industries has agreed to liaise with Barbara Young of the Care Quality Commission.

Over the past months letters have been sent by KABIF; now Commissioners are engaging, the CSIP/Long Term Conditions Team have given KABIF some tools to push the agenda forward to ensure that ABI and the NSF are up there in the priorities. There is a lot of letter writing going on in the background and parties are starting to talk together.

Tanesh Bhugobaun of The Raphael Medical Centre has agreed to take on the work with the Department of Health to see if they can assist with pushing the agenda in this county.

Gerhard Florschutz, also of The Raphael Medical Centre, confirmed that there would be a mid term review of the NSF in 2010. He mentioned that Chris Clough, a Neurologist at King's, and David Tommi of the Primary Care Trust had a special interest in the NSF. Gerhard agreed to email their contact details to Frances Pierce so that she can update them both on what KABIF are doing.

Gerhard Florschutz said that at a local level KABIF could look for an opportunity to join forces with the Neurological Alliance. Frances Pierce said she would be interested to know who attends the Neurological Alliance so that KABIF can make contact with them and link in. He agreed to send the steering group the contact details.

Tony Merriman mentioned Phase 1 of the Head Injury Survey that UKABIF had referred to, involving Kent & Medway Accident & Emergency Units.

Frances Pierce said that the numbers in the Bexley Audit are enlightening.

Tony said that 3184 patients attended with head injuries in 6 weeks. 12% (373 / 3184) were admitted to hospital or transferred to a neurosurgical centre – of those 88% (330 / 373) had their Glasgow Coma Score measured at triage: -
93% had Glasgow Coma Scores of 13 – 15 (307)
5% had GCS of 9 – 12 (15)
2% had GCS of 3 – 8 (8)

Frances said that Sevenoaks and Canterbury are keen to ensure the matters improve so that King's and Putney start to trust Kent with ABI and the funds then stay in the county.

12. Tea & Coffee Break

There then followed a break for tea and coffee.

13. Speakers

a. Mary Ryan on behalf of Sharon Patmore of Royal British Legion Industries on the topic of the Pathway Scheme

Please see attached PowerPoint presentation.

b. Mark Parrin from Kent Supported Employment – ‘How Supported Employment Can Help People Towards Employment Goals’

Mark Parrin confirmed that Kent Supported Employment is part of Kent County Council. KSE are half funded by Care Management within Kent County Council and half funded by the Department for Work and Pensions. The service is free for the service users.

Mark confirmed that he had not yet come across service users with personal budgets trying to buy into the KSE service.

An aim of the Department for Work and Pensions is to deliver Work Step (which Mark confirmed, if delivered in the right way, is good for people with long-term conditions) / Work Preparation (an opportunity to gain work experience).

Kent Supported Employment offer a person centred service – they start with the person, they need to get to know the individual, profiling them to get to know their background. Mark said this was particularly important with those with acquired brain injuries as what you see is not what you get.

This is a county-wide service with 6 bases – Folkestone, Whitstable, Ashford, Tunbridge Wells, Sevenoaks and Maidstone. 40 team members support 500 service users, most of whom are in employment.

Mark Parrin told the group that 20 years ago he sustained an acquired spinal injury. Since then he became a volunteer with Headway for 9 years and that experience at Headway opened his eyes. He noticed that, other than Headway, there is not a lot of support for those with brain injuries. He said that for those with a brain injury keeping a job can be very hard.

Pam Munro asked whether there were examples of people with brain injury who were in employment and Mark Parrin confirmed that he works with service users with brain injuries, many of them had remained in a job for a number of years with the support of KSE.

Mark explained that KSE support the individual employee and also support the employer. A lot of work is done with the employers and much support is given early on. Work trials can be useful to get the service user into a job. A lot of support work is done on the ground with the employers. KSE don't usually use legislation as a lever but sometimes it can be useful to remind employers of the legislation.

Mark introduced his colleague Kate Parrin who is a Job Coach with KSE. He explained that Job Coaches break a job role down to the basics and re-teach the role to the individual broken down into small sections. Once a service user has been assessed and profiled, the Job Coaches work one-to-one in a job with the service user for up to 6 months, offering encouragement and support in the workplace. The Job Coaches are trained in teaching automatic instructions – natural cues and prompts to empower the individual to do the role. Mark said that often people within the workplace dis-empower whereas it is important to empower individuals.

Approximately 40% of the KSE team have disabilities themselves, including those with brain injury.

KSE's methodology includes repetition, colour coding, being inventive and trying different ways to support their clients. Mark gave an example of someone in a job who started going downhill to the extent that they may have been dismissed. Mark's team considered the situation and realised that the client had forgotten the training he had been given, so KSE ensured the client was retrained and therefore improved and kept his job.

Mark highlighted that for those with brain injuries it is very difficult to get through the interview and selection process, so often is it useful to look at alternatives such as work trials.

One of Mark's bugbears for those with ABI is that assistance is often not sought early enough. If someone with ABI and their employer are given the appropriate support early on after an accident, companies are more likely to be persuaded to keep a job open and to make adjustments for the employee with the ABI. Supported Employment can make the transition smoother for the employee and employer and Mark has known employers to keep a job open for a couple of years while their employee recovers from their injuries.

14. Any Other Business

- a. The brain injury seminar on 8th October 2009 run by BISWG in association with Field Fisher Waterhouse Solicitors includes a section by Andy Tyreman on vocational rehabilitation – information about this event is on the KABIF website.
- b. Linda Theoff, Case Manager, has resigned from East Kent Hospitals Trust. She will join Head First on 21st September. Linda doesn't know at the moment about a replacement in her post. Frances Pierce reminded the meeting that Linda had the most extraordinary caseload and KABIF had petitioned in the past to keep Linda's post. Frances thanked Linda on behalf of KABIF for all she had done and confirmed it is very sad to know Linda is going from her post and wished her well in her new role.

- c. Tony Merriman will soon be meeting with representatives from the East Kent Neurological Unit that has moved to Canterbury. Tony had recently met with Dr Sakel.
- d. Dr Gerhard Florschutz confirmed that The Raphael Medical Centre are holding two workshops by Barbara Wilson. The topic for 5th October 2009 will be Memory and the workshop on 6th October 2009 will be on Research for Clinicians. Details of these are on The Raphael Medical Centre website.
- e. To celebrate its anniversary, The Raphael Medical Centre will next year be holding a conference towards the end of May. Dr Florschutz will let KABIF know as soon as further details are available.
- f. Dr Florschutz announced that The Raphael Medical Centre has a Neuropsychiatrist in post providing 4 sessions a week. He is a consultant from Cambridge (he is a researcher in brain tissue at the university) and he is available for private referrals.
- g. Frances Pierce thanked Gerhard Florschutz and Tanesh Bhugobaun for allowing KABIF to hold the meeting at The Raphael Medical Centre and thanked everyone present for coming to the meeting.

15. Next Meeting

The next meeting will be held on 2nd December 2009 at 7 pm at The Headway Centre, Milestones, 3 Culverden Park, Tunbridge Wells, TN4 9QT. Di Drummond, Manager of Headway Tunbridge Wells & District, will be presenting 'A personal account from an ABI sufferer' and Dr Aggie Moreno-Lopes, Clinical Psychologist, will be presenting her research project on How Young People Cope with a Parent with ABI.