

Kent Acquired Brain Injury Forum

Minutes

Friday 14th December 2007 at 3.00 pm

Thomson Snell & Passmore, 3 Lonsdale Gardens, Tunbridge Wells, Kent, TN1 1NX

In attendance:

Rebecca Allen
Liz Bray
Jan Cartmell
Sophia Chung
Greg Clark MP
Becca Coffey
Delia Elliman
Gerhard Florschutz
Tim Gilbert
Mike Hope
Roy Marcus
Catherine McDonagh
Chris Merriman
Tony Merriman
Pam Munro
Julien Payne
Frances Pierce
Sandra Rafferty
Dennis Smith
Linda Theoff
Heather Thomson
Susan Ware
Kath Wilkinson -Carr

Apologies:

Bruce Aitken
Frances Beaumont
Margaret Bentley
Claire Carter
Sally Collins
Di Drummond
Rikki Gandolf
Kelly Hamer
Denise McKeown
Aggie Moreno-Lopez
Patti Simonson
Jennifer Stockley
Juliette Stuart

1. Welcome and introductions

Frances Pierce welcomed all attending and again reminded people of the need to complete the Data Protection forms.

Frances Pierce proposed circulating a petition to try to save the position that Mike Hope currently holds in Sussex. Mike Hope is a founder member of KABIF and SABIF and has helped many people all over the country. His position is currently funded jointly by health and social services (two local authorities and three primary care trusts), but it is thought the post may not remain into the future. It is understood that social services are happy to continue to fund their portion. The petition was circulated at the meeting. It was agreed that Frances Pierce would draft a letter on behalf of KABIF to support the campaign.

2. Approval of minutes of meeting held on 11th October 2007

Dennis Smith proposed some minor amendments to the Minutes of the meeting held on the 11th October 2007. The Minutes were approved as amended.

3. Matters arising from minutes of meeting held on 11th October 2007

There were no matters arising.

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

Nicky Coffey was not present to give an update and had not provided a report.

5. Mapping exercise/website update

Tony Merriman felt the headings in the mapping website emphasise rehab to the exclusion of other services. He proposed the category headings be reviewed and either amended or further categories added. Further headings of 'housing', 'children's services' and 'therapists' were proposed.

It was suggested that a questionnaire could be sent to KABIF members to ask if their organisations fit into those headings as well as those existing. The website committee agreed to discuss this.

6. Talk by The Rt Hon Greg Clark, MP for Tunbridge Wells, about his role as Shadow Minister for Charities and Volunteers

Greg Clark said he was grateful for the opportunity to come to speak to KABIF. He said that, whilst he is not an expert in brain injury, he has picked up a lot from Pam Munro and Dennis Smith of Headway. He confirmed that his role in parliament was as Shadow Cabinet Minister for Charities and Volunteers.

Whilst KABIF is not a registered charity, he confirmed it is a voluntary organisation, so he was keen to discover KABIF members' views on what the government could do better. He said that head injury is multi faceted, there are a number of government agencies involved, and difficulties arise when structures change and budgets move on. Greg Clark said that there is a real danger when the government gets involved with

voluntary organisations that the relationship often starts positive but further down the line budgets get so specified and over-engineered that this can smother any creativity that existed within the voluntary organisation.

Greg Clark said the tradition of grant giving may be being usurped by a culture of contract funding, so he was keen to hear KABIF's thoughts on accessing public sector funding. He feels that traditionally there has not been enough choice and discretion, but in the future it may be possible to break down services to allow people to exercise their rights to use their discretion.

He said that he would like to take away some marching orders to take back to his party.

Greg Clark confirmed he was aware of the All Party Parliamentary Group on Acquired Brain Injury, although confirmed the group does not have a big profile. He explained there are nearly a thousand all party groups and he will only join one if he will take a specialist interest in it. He does receive newsletters and asked KABIF to let him know if there is anything in particular that he should be aware of.

Dennis Smith said that Headway is concerned that the government will not continue to support the National Service Framework for Long-term Neurological Conditions and asked Greg Clark whether he would consider putting a question to the Minister in Parliament asking him about this and seeking reassurance that it remains government policy to ensure that PCTs act upon the requirements of that framework. Greg Clark said that certainly he would put down a question. Dennis Smith offered to help Greg Clark in phrasing the question, and Greg Clark said that would be helpful.

Greg Clark said that a study of stroke by the National Audit Committee showed a reality shockingly short of best practice. He thought it should not be a question of resources, as the Australian model costs less. England has a much higher death rate, so the Department of Health has an important role to say what is regarded as best practice. He said that progress since the report seems to be slow.

Greg Clark said it is striking that, compared with heart disease and cancer, stroke and brain injury seem to have a much lower profile. He said that KABIF had done a good job of raising awareness amongst people involved in brain injury. Head injury has similarities with Alzheimer's in that the injuries are long-term and not necessarily visibly apparent. He said the way the Alzheimer's Society raised the profile of their condition is very instructive. They have a particular and personal style, which manages to cut through the mass of printed information that MPs receive. The members write handwritten letters as individual constituents, not using standard letters or forms. For example, the Alzheimer's Society pre-printed postcards on which individual sufferers or carers wrote personal recollections of a loved one. This was a touching approach. The Society had engaged with people to encourage them to write individually, so had found a way to go beyond official correspondence and had raised their profile.

Greg Clark found the idea put forward by KABIF that speeding and drunk driving fines be credited to a separate national account to be used to support groups like Headway, on the grounds that such drivers are responsible for road accident brain injuries, very interesting and one he had not come across before. Tim Gilbert asked where the money does currently go and Greg Clark explained the speeding fines go towards buying more

speed cameras or funding road safety partnerships, but the drink driving fines go back to the treasury. He thought a campaign to ring-fence the drink driving fines would be popular, he could see the logic in it. Dennis Smith asked whether there were precedents for this type of idea. Greg Clark said that KABIF could present the idea and ask the government to consider it. If the government say no, KABIF should ask them why not and keep going at it.

Sue Ware pointed out that a lot of accidents are caused when drivers are talking on the phone. Frances Pierce pointed out that as there is precedent for speeding fines to be ring-fenced, and ring-fencing is commonplace in the police, statistics would need to be gathered supporting the link with individual ABI sufferers. Problems due to brain injury though are often not picked up and there is no follow up after the impact. She explained that the government claim back over £37,000 of health service expenses if an accident is someone else's fault, but this money does not go back to specific PCTs, but into a Compensation Recovery Unit pot – central government. Even the ambulance fee did not go back into the emergency services' coffers.

Greg Clark was asked whether he would consider using his influence to help reduce the incidents of traumatic brain injury through preventative measures, such as the compulsory wearing of cycle helmets; constraints for young drivers; doing more to come down hard on drink driving; and a reconsideration of the twenty-four hour opening of public houses; freeing up police bureaucracy to enable more street patrols, especially at night, to reduce assaults. He responded by saying that he is not personally persuaded that measures such as banning or making things compulsory are the way to go.

Greg Clark mentioned that his children wear cycle helmets but he doesn't!

With regards constraints on young drivers, Greg Clark said that this could mean a conflict of interest with insurers. Young drivers cost insurance companies a lot, but those young people who, for example, live out in the sticks may need to drive to get to work. He wouldn't want to raise the driving age because of those young people who need to drive to get to work. Greg Clark said that the use of technology may assist in a scheme such as paying by the mile with cost dependant on the type of road and the time of day. A policy could be written specifically for young people to restrain them at the more dangerous times, such as at night, but not on the way to and from work.

Sue Ware pointed out that Norway and Sweden have a no drink and drive policy, which she was in favour of. Greg Clark said that he had travelled in Sweden and Norway and this policy didn't cause him difficulties. He said it would be interesting to see evidence as to whether this made a successful impact on the problems KABIF is concerned with.

Greg Clark said that a year before the smoking ban the majority within parliament were against a smoking ban, but the evidence, particularly with regard to passive smoking, was very persuasive, hence the smoking ban outcome. He said that this had required advanced planning to ensure a good solid case.

Jan Cartmell pointed out that in accidents caused by young, inexperienced drivers, drink is not always an issue. Frances Pierce raised the point that nothing is done to keep inexperienced drivers into smaller, less powerful vehicles. Tony Merriman proposed a

policy that if young people offend they should have to re-take their test and / or they should have a test to drive on motorways. Catherine McDonagh suggested that insurers could do more to encourage drivers to take the pass plus test.

Mike Hope said that the All Party Parliamentary Group is key to raising the profile of brain injury, to gain critical mass and to raise the right questions at the right time in the right place, quoting particular examples as and when they happen. He said the National Service Framework for Long-term Neurological Conditions had been really good in setting standards but there had been a lack of coherence and follow up. He said that most KABIF members have been drawn towards brain injury because of the injustice of it all and the huge numbers of people it affects. He urged Greg Clark to join the All Party Parliamentary Group and Greg Clark said he would.

Catherine McDonagh raised an issue with regard to the Department of Work and Pensions. She said the symptoms of acquired brain injury are often hidden, so as a result it is very difficult for sufferers to succeed with claiming benefits. Greg Clark said that this type of situation is going to get worse as there is a bill going through parliament forcing more people to get back to work. He suggested that specific examples need to be put to the government. He said that the voluntary sector tends to be very good at mobilising people to mount effective campaigns. Arguments in policy papers tend to be abstract and compelling examples of manifested injustice should be presented to counter these. With specific examples that are in the public eye, perhaps changing the names of clients to protect confidentiality, the MPs are more likely to be engaged and will want to make a difference to these people and could help.

Sophia Chung pointed out that there is a lack of funding for advocacy for those with brain injuries. Sandra Rafferty of ICAS said there is a huge gap for statutory advocacy. Greg Clark said that to address that huge gap KABIF could look at how to make things personal to appeal to MPs. He explained that he deals with the health and ambulance services quite a bit and that evening was going on an all-night shift with the local ambulance service. He said he will know a lot more after tonight than he would have done reading documents. He said that MPs and policy makers don't have the access to see what KABIF professionals see every day. He recommended that KABIF should think about how to step outside the conventional letter writing and get these individual factual examples across in a new way.

Mary Ryan highlighted that a number of service personnel are returning from war with brain injuries. It would help if MPs were able to sit down with the families so the family can talk the MP through from incident and through the recovery process.

Frances Pierce asked Greg Clark whether he would become a KABIF member and Greg Clark said he would love to become a member of KABIF. She thanked him for kindly giving up his time and for his support going forward.

7. Headway (Kent) – Di Drummond

Di Drummond was unable to attend the KABIF meeting as this was a big day for Headway in that it was the start of their move to a new property. Dennis Smith explained that adaptations had been taking place to the property that had been bought in

Tunbridge Wells and that volunteers and staff were in preparation for the opening proper on 2 January 2008.

Pam Munro welcomed KABIF members to come and see the new set up for Headway Tunbridge Wells. Headway are hoping that Anne Robinson will attend the official opening in March.

Frances Pierce presented a card signed by KABIF members to Pam Munro and Dennis Smith to wish Headway good luck in their new home.

On 21st January Headway Tunbridge Wells would be celebrating twenty years since formation.

8. Focus on Young Adults with ABI – Ros Eastwood

Ros Eastwood and Mary Ryan were half way there in producing the leaflet. They hope to have a working copy of the leaflet by February. Next year consideration will be given to where the leaflet will be distributed. If there is sufficient interest, there is the potential for it to become national.

Mary Ryan said that it came across very clearly that there is a need for more leaflets directed at young people about specific topics such as being safe. She would like to tap into the expertise of KABIF members in this respect.

9. PPI Forum – Dennis Smith

Dennis confirmed that the PPI Forum closes down at the end of March. It will be replaced by LINKs (Local Involvement Network). He explained the concept was very amorphous as no one knows how it will turn out. Dennis is more interested in the Patient Advisory Network (PAN) set up by West Kent PCT and would like to get involved with this. Key issues included long-term conditions and community and Julia Ross is keen for Dennis to be involved.

Dennis is hopeful that Julia Ross will come to talk to KABIF.

10. Any other business

Pam Munro confirmed there was a vacancy at Headway Court. It was suggested that a page for current vacancies could be added to the KABIF website.

KABIF members present were encouraged to look at the KABIF website to check their service is represented correctly on the mapping website.

Jan Cartmell fed back following the UKABIF conference in November. Mike Hope and Tim Gilbert had spoken about SABIF and Jan Cartmell and Frances Pierce had spoken about KABIF. North London ABI and the North East Acquired Brain Injury Forum had spoken and there was a talk from Temple-head. The talk about KABIF had included many positive outcomes including the setting up of the mapping exercise, the website, the project for young persons, the benefit of networking and the holding of joint conferences. The UKABIF conference had enabled Jan and Frances to see how far

KABIF had come over the past three years. There had been questions from the floor about how KABIF was set up and a lot of positive feedback. Frances Pierce said that if anyone would like a copy of the slides they should contact her.

The KABIF leaflets had been updated with the new post office box address.

Frances Pierce asked KABIF members to feedback as to what they would like next year. It was hoped that a representative from Disabled Go would come to speak to KABIF. Professor Mike Oddy had agreed to speak at the meeting in February. The April meeting was proposed as a networking event where each KABIF member could be given five minutes to speak about their organisation. Members were encouraged to bring leaflets about their services. It would be helpful to establish where KABIF has gaps in membership so efforts could be made to involve those people with KABIF. A barrister was being asked to speak at the June meeting about judicial review and patient rights – Tony Merriman was arranging this. Sue Ware would be speaking in September about speech and language therapy and it was hoped that the December meeting would offer the opportunity for KABIF members to see the new Headway premises and have Temple-head visit as speakers.

Future topics for speakers suggested included an update on the Mental Capacity Act by an IMCA representative. Mary Ryan agreed to let Frances Pierce have the contact details of occupational work psychiatrists Sharon Patmore and Pam North. Mary had proposed KABIF ask an occupational psychologist from the Department of Work and Pensions to talk about what people returning to work can and can't do. Sandra Rafferty suggested asking someone from the Alzheimer's Society to come to talk. Dennis Smith said he knew Tina Stirling and he agreed to follow this up. Sue Ware said that the Royal British Legion had been running campaigns based on individual cases, perhaps they could be asked to speak to KABIF. Liz Bray mentioned she would like to invite one of her marketing and campaigns team to look at raising the profile of brain injury. Frances Pierce said that KABIF may like to try and get a group of MPs together to present case studies to them.

Pam Munro pointed out that the All Party Parliamentary Group on Acquired Brain Injury is based at the House of Commons and Headway and KABIF don't get notice of their meetings. UKABIF have a direct link into the All Party Group, so KABIF could feed examples to UKABIF.

Liz Bray agreed to drop Frances Pierce a note outlining her concerns so she could talk to UKABIF, as education is not just a Kent issue, it is nationwide and they may like to follow up on this.

Tony Merriman said that with organisation KABIF could prepare a campaign involving individual letter writing. Frances Pierce proposed combining the sending of letters from individual constituents to MPs and then organising a conference of MPs to get together, using evidence and statistics such as the example from the Royal British Legion that thirty per cent of those coming back from war have a brain injury.

Catherine McDonagh said that she had become concerned about legal advice within a personal injury case and her client had felt that information about solicitors should have been made available to them earlier after the injuries were sustained so they could have

made a more informed choice about choosing their solicitor. Pam Munro confirmed that Headway have a published list of solicitors available and Tony Merriman and Frances Pierce confirmed that the most experienced in this area in the legal profession had tended to avoid marketing within hospitals or contacting potential claimants too soon. Pam Munro said that if anyone has concerns about a particular solicitor then they should let Headway UK know, as they don't want sub-standard solicitors, they hold an expert list. It was confirmed that choosing the right solicitor is an important decision as if a claimant under settles their case they won't necessary know that they have, so they may have been happy with their solicitor but had they chosen a different solicitor they may have achieved a better settlement. Frances Pierce confirmed she has often offered a friendly call to less experienced solicitors and often took cases over where the solicitor lacked the necessary experience.

Sandra Rafferty said that perhaps organisations that can sign post to a solicitor with appropriate experience should get involved at an earlier stage. Mike Hope said that some of the solicitors that come in earliest may be ambulance chasers or tied in with insurers. They may be fine with bangs on cars but are not necessarily good at bangs on brains.

Temple-head, who have set up in East Anglia with Neil Cawthorn at the helm, are interested in rolling out a similar ABI service on the South Coast, including Kent. They had lobbied in Suffolk to get a brain injury co-ordinator involved at acute hospital stage. Frances Pierce will invite them to speak next year.

Jan Cartmell mentioned an article in Cosmopolitan published in November, which raised awareness in young people. Jan Cartmell agreed to let Frances Pierce borrow the original article so this could be scanned and attached to the KABIF minutes (please see attached).

Aggie Moreno-Lopez had asked that KABIF members be thanked for their help with her study. She had a good number of potential interviewees.

Roy Marcus suggested that corporate firms should pay a membership fee of say £25 to £50 per year to KABIF. Sue Ware said it could be difficult collecting and administering. Pam Munro invited Roy Marcus to give a donation. Frances Pierce said that if there was something specific KABIF needed funds for then at that stage it might be considered how to raise those funds. She pointed out that the Raphael Medical Centre had generously sponsored the lunch for a course run for carers and Tony Merriman's firm asb law and her firm Rix & Kay had kindly offered funding for previous and current KABIF projects. Chris Merriman was thanked for all the work he very kindly does for the KABIF website. Tony Merriman said there would be no objections if organisations would like to sponsor the project leaflet in return for their logo appearing.

Mike Hope proposes to organise a SABIF conference on 26th June 2008 at Brighton Race Course regarding the "Risks of Choice", looking at the ethical dimension of access to rehab and support. Speakers include Denzil Lush and Trevor Powell. Mike Hope said that conferences are something that a corporate can sponsor.

Pam Munro mentioned an article in the Sun regarding the benefits of a Nintendo Wii in rehabilitation. She also mentioned that Kit Malia has been asked to write a leaflet about mild brain injury for the M.O.D. regarding service people returning from Iraq and Afghanistan.

Headway have a one bedroom flat available in Rustall available to someone who has suffered a traumatic injury. The applicant must currently live in Tunbridge Wells, Tonbridge or Sevenoaks.

Pam Munro was thanked for providing the mince pies that had been enjoyed by the KABIF members at the meeting.

KABIF members were wished a happy Christmas and a safe 2008.

The meeting concluded at 5.20 pm.