

Neurological Alliance of Scotland

Executive Meeting Tuesday 3rd November 2009
Tourette Scotland, Perth

Present:-

Andy Wynd (Chair) - Scottish Spina Bifida Association
Craig Stockton (Vice Chair) – MND Scotland
Peter Meager – The Dystonia Society
Tanith Muller - Parkinson's disease Society
Janice Mylan – Tourette Scotland
Jane McKerrow – CHSS
Ewan Dale – ME Association
Judy Barrow – Tourette Scotland
Candice Dillen – Neurological Alliance of Scotland Coordinator

Apologies: -

Maddy Halliday – Stroke Association
Craig Wilkie – MS Society Scotland
James Dornan – MS Revive
Pamela MacKenzie – Sue Ryder Care

1	<u>Minutes of last meeting</u> The minutes were approved with the clarification that the MSN Neurosurgery Operational Management Group is one group bringing together regional areas rather than four regional groups.	
2	<u>NHS QIS Clinical Standards</u> The clinical standards for Neurological Health Services have still to be launched with the NHS QIS website stating a publication date of end October. Andy, Craig Stockton and Tanith met with NHS QIS recently to discuss the prioritisation of the standards. At this meeting, concern was expressed to NHS QIS regarding implementation as there are no site visits scheduled in their work plan and there are changes in the structure and focus of the organisation. It was suggested that the Alliance should meet urgently with NHS QIS regarding implementation. Andy is awaiting a date for this proposed meeting. It was agreed it would be useful for this to be followed up with James Miller. Member organisations were also being asked by their members about the standards and when they would be coming out. It was felt therefore, it may also be useful to raise this at ministerial level. There was a discussion around the implementation of the standards with concern that NHS QIS have not clarified the role of the Alliance. Involvement of the Alliance in the standards implementation is a clear expectation of SGHD who are funding the Alliance. Tanith has had some	Andy to contact James Miller and Shona Robison, copied to Will Scott

	<p>contact with the CEO of NHS QIS who has clearly stated that the Alliance will take a role in the implementation of the standards. The Alliance already have representation via James Dornan on one of the implementation groups set up – Data and Audit – which have met once to date. It was felt that it may perhaps be beneficial for the Alliance to develop a proposal to NHS QIS on what we feel our role should be rather than wait to be approached.</p>	<p>Candice to develop proposal on what Alliance can provide</p>
<p>3</p>	<p><u>MSN Neurosurgery</u></p> <p>Peter gave feedback on the Operational Management Group for Neurosurgery. There have been two meetings held to date. Peter was the only Alliance representative at the most recent meeting. At the meeting Peter had presented a paper on Deep Brain Stimulation for Parkinson’s Disease and Dystonia using six patient stories to illustrate. There was some discussion around the importance of representatives attending the meetings of this group.</p> <p>Peter asked about the Neurosurgical standards. The standards which are currently being developed are qualifying equal access to services but this may be conditional on individual NHS board funding. This issue is likely to be taken back to the MSN strategic board at their next meeting in December. There was some discussion around the MSN for neurosurgery. Andy stated that the MSN has some funding but the neurosurgical service is not funded nationally. There may therefore be issues regarding clinical decisions not being met due to local NHS board funding.</p> <p>Andy stated that the MSN was still in its infancy. It is still expected that the draft neurosurgical standards will be presented to the Alliance at its January meeting.</p>	<p>Candice to check availability for next meeting with representatives</p> <p>Candice to circulate Papers for standards when available</p>
<p>4</p>	<p><u>Alliance Strategic Plan</u></p> <p>Andy suggested going through the strategic plan and making amendments where necessary. The plan has yet to go around the whole Alliance membership for comment but will do so following this meeting. The monitoring and evaluation framework is also still to be added. Andy stated that the suggestions made by SGHD in the response to the Alliance funding bid have been incorporated into this draft and thanked those who had provided comments on the suggestions.</p> <p>The group went through the plan page by page. There was a minor change made to the wording describing the Alliance and one of the aims. It was suggested that the constitutional aims should be checked against the aims in the plan. There was discussion regarding the objectives and key activities within the plan and with three additions or amendments made in relation to self management and MCNs, clarifying the role of the</p>	

	<p>Alliance. There was some discussion around the self management fund with Peter describing the work the Dystonia Society is involved with in Scotland, providing training to participants using the Stanford model of self management. Peter explained that the Long Term Conditions Alliance who is funding this project is also open to models of self management other than Stanford. Tanith added that PDS have received some funding from the self management fund to provide training to PD nurses regarding sleep therapies.</p> <p>There was some discussion regarding the provision of training to lay people as suggested by SGHD and which has already been developed for respiratory illness and stroke. Jayne gave an overview of CHSS 'Voices' work which she stated should be possible to transfer to neurological conditions. The 'voices' project has produced leaflets and encouraged MCNs to develop sub groups for patient involvement. It was suggested that due to limited capacity of the Alliance perhaps the development of a toolkit would be useful. This would set out a series of processes and ideas for member organisations to use to involve patients and carers in MCNs.</p> <p>There was an addition made regarding the ability to co-opt members onto the Executive throughout the year and some discussion on the focus of Executive meetings.</p> <p>It was agreed that this was a clear and useful document to guide the work of the Alliance and once these amendments had been made should be circulated to the rest of the membership for comment. The plan would then be finalised and forwarded to SGHD and other stakeholders.</p>	<p>Candice to make amendments and circulate to members for comment</p>
5	<p><u>Finance</u></p> <p>Peter went through the finances. There are reserves, some of which will be spent on resource development before the end of the financial year. Peter stated that there will need to be a note added to the end of year accounts to clarify reserves.</p> <p>Andy confirmed that Scottish Government had agreed to provide funding for an increase in staffing levels to respond to increased requirements of the organization. It was agreed to discuss this in more detail under AOCB.</p>	
6	<p><u>Parliamentary Event, DVD and Website</u></p> <p>Event. Candice stated that a Parliamentary event is confirmed for 17th March 2010. This is during Brain Awareness Week and will take place in the evening in Committee room 3 at the Scottish Parliament. A sub group has been established to take forward planning of the event. All members</p>	<p>Candice to send invitation with date of event to all</p>

	<p>will be invited; however there is a capacity of 60. There was discussion around what materials would be needed and it was agreed that the Alliance should have a banner stand and a large display board on which could be all member organisations logos.</p> <p>DVD Resource. Candice presented a project plan for the DVD and all agreed this could go ahead. Candice stated that the common themes must be agreed as soon as possible in order to develop the interview questions and that this must come from member organisations who know what the most relevant issues are. Filming would need to take place throughout January in order to ensure the final resource is ready for screening at the parliamentary event. The DVD was agreed to be a useful mechanism to get across the key messages of the Alliance and illustrate some of the often hidden, non obvious common issues patients and carers face. Once the themes are agreed all interested member organisations can recruit interested patient/carers to participate.</p> <p>Website. Candice has invited three web design agencies to pitch for the redesign and development of the Alliance website. All have sent in proposals with initial quotes for the work. One agency in particular has a good grasp of what is needed. All agreed that Candice and Andy should decide which agency to commission and a detailed brief could then be developed. It is hoped that the new website will be ready to launch in Brain Awareness Week.</p>	<p>member organisations</p> <p>Candice to commission production company</p> <p>All to email potential questions to Candice who will finalise themes and invite members</p> <p>Candice to commission agency and develop web brief</p>
7	<p><u>Requests</u></p> <p>Candice stated that there are occasionally issues brought to, or requests made of the Alliance which will require discussion at Executive meetings.</p> <p>Communication Forum Scotland have requested that the Alliance formally adopt their six principles and link with their online toolkit. They also have a proforma which is used in responses to consultations. It was agreed that complex communication issues were very relevant to neurological conditions and therefore the Alliance would adopt the principles and once the new website is launched will link with the toolkit.</p> <p>Breaking Bad News Research is a research project being undertaken by Glasgow University looking at diagnosis in progressive neurological conditions. Candice has agreed to become a member of the steering group for the project. The interview schedule for patients/carers had been circulated to relevant member organisations and some had provided very useful comments.</p> <p>New proposed Build at Royal Infirmary Edinburgh. Candice has been contacted by Susan Duncan, a Neurologist at the Western General Hospital in Edinburgh, who is concerned with the plans for the new build.</p>	<p>Candice to inform Amanda Bennett of outcome</p> <p>Craig to take information to patient group</p>

	<p>Issues were regarding unsuitable drop off points for patients & lack of private space for medical staff for both counselling and training. Craig stated he could bring the issues to a patient group he attends in Edinburgh for discussion.</p> <p>Disabled Persons Parking Spaces (Scotland) Act – Implementation Working Group</p> <p>Andy informed the group that he has been asked on behalf of the Alliance, to be involved in a working group. He will feed back to the Executive regarding this.</p>	
8	<p><u>Future Meetings</u></p> <p>The following meetings were confirmed:</p> <p>12th January 2010 – SSBA offices 4th March 2010 – MND Scotland 1st June – AGM (venue TBC)</p>	
	<p><u>AOCB</u></p> <p>Staff Terms and Conditions: In view of the imminent discussion regarding Terms and Conditions, Candice withdrew from the meeting at this stage.</p> <p>After discussion it was unanimously agreed to offer Candice an increase in hours to 24 per week from beginning January and Peter will adjust salary accordingly.</p> <p>Funding has also been agreed to recruit an admin worker (part time) and it is hoped that this person would also begin in January. It was also agreed that time should be set aside at least annually to look at regular review of terms and conditions for staff. Andy agreed to facilitate this. It was also noted that in order to appoint an additional worker there would need to be some planning work to develop job description etc. Andy to liaise with Peter and Craig Stockton on this particular issue.</p>	<p>Andy to organise</p>