PE1179/Y

Public Petitions Committee TG.01 The Scottish parliament Edinburgh EH99 1SP

17th November 2011

Dear Committee Members,

Open Petition PE1179 - Brain Injury Awareness Campaign (BrainIAC)

(a) BrainIAC's Response to Scottish Government's letter of 6th October 2011 (PE1179/X)

With regard to the above letter emanating from the Planning Division of the Healthcare Improvement Directorate, **BrainIAC** is pleased to see that the work of the ABI Managed Clinical Network (ABI MCN) has been progressing in a generally positive direction from our perspective, as evidenced by the very recent Sabin Mid-year Report, October 2011.

BrainIAC notes that, on the "**Standards Implementation**" strand of the MCN"s activity, they have been trying to ensure that individual Health Boards and their departments put these standards into effect. BrainIAC awaits to see (in their report expected to be published at the end of 2011) the degree of compliance that has been achieved by then.

With regard to the MCN's "**Data collection and management - National strategy**" strand, **BrainIAC** were pleased to hear that a conference involving a wide range of interested groupings has been held recently. **BrainIAC** considers that within any agreed data collection/management system, it will be crucial to be able to identify and follow ABI patients" routes through their clinical (and social, etc) care so as to support better planning of relevant services.

BrainIAC sees the **development of educational videos and other types of media packages** related to the acute care of ABI patients **being circulated to medical professional training organisations** as a **very positive step**. It sounds very relevant to include auxiliary nurses and patients" carers in this educational resource.

As far as information availability and education for interested parties of the general public are concerned, **BrainIAC** agrees with the MCN that this area is also important: **BrainIAC** remains willing to report and advise on the suitability/propriety of materials proposed to be made available.

BrainIAC strongly supports the setting up a paediatric ,arm" of the network to help support the specific needs of children and young people affected by the ABI problem. We are also sure that getting involved in a programme of public awareness, carer resources and public education on ABI for these particularly vulnerable groups is most appropriate.

BrainIAC is particularly interested in the MCN's work looking at the evolution from a "**Clinical**' network into a "**Care**' network; **BrainIAC** believes this to be another crucial area where the **ABI** patient experience and their resultant outcome can be improved very significantly. We acknowledge the intention of the MCN's sub-group to progress this aspect of the longstanding and current problems over the next few years. We also note that sub-group's proposed action to write to all Directors of Social Work requesting information relevant to ABI patients' care; given the Petitions Committee failure to get any response from this body's Association in relation to this petition (see (b) below), it will be of great interest for **BrainIAC** to see if the MCN can make any progress with the engagement of these bodies.

(b) BrainIAC's Response to input invited from the Association of Directors of Social Work

It has been **BrainIAC's** understanding that the Association of Directors of Social Work had been asked by the Petitions Committee over a year ago to indicate at this time what, if any, progress has been made by this time in improving their services for ABI clients.

However, with no response having been received from the Association, we are no further forward in this respect.

(c) Conclusion

Whereas **BrainIAC** originally launched Petition PE1179 calling on the Scottish Parliament to urge the government to introduce a separate and distinct health and community care client category of "acquired brain injury", **BrainIAC** acknowledges that the ABI MCN are in the process of making improvements (not involving the introduction of our proposed distinct ABI category) which should nevertheless feed through into the provision of better clinical care for people who experience an ABI.

As far as ABI community care provisions are concerned, **BrainIAC** supports the transformation of the ABI M<u>Clinical</u>N to evolve to a Managed <u>Care</u> Network for ABI. However, since only a very few small steps on what a care network would look like and how it might function have been made, and particularly where the main state providers have not as yet been prepared to provide any input to the exercise, **BrainIAC** strongly requests that Petition PE1179 should remain open until similar improvements can be demonstrated as with the clinical side of ABI healthcare. At that stage, **BrainIAC** would then be satisfied to see our petition being closed as our objectives will have been partly achieved.

Yours truly,

Helen Moran, Chairperson

For, and on behalf of, the Brain Injury Awareness Campaign (BrainIAC) November 2011

[Via email from Helen Moran, BrainIAC Chairperson]