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Scottish Association of Neurological Sciences

BW/JCC

Dr Rustam Al-Shahi Salman
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Dear Dr Salman

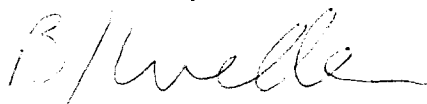
Re: Scottish Intracranial Vascular Malformation Study (SIVMS)

We discussed SIVMS at the recent business meeting of the Scottish Association of Neurological Sciences in November 2007. It was the view of all present at the meeting that Scotland-wide disease registers such as this are vital for clinical audit, service evaluation, and observational research. SIVMS is the only ongoing nationwide disease register in the neurosciences, and its unbiased data have great value for the work on the Neurosciences Implementation Group, by informing clinical care and comparing practice at the four neuroscience centres. Furthermore, SIVMS emulates the design of other ongoing disease registers which have similar dual purposes, and it is an ideal model for up-coming disease registers in the neurosciences (such as the MS Society's register). In Scotland, there is an almost unique opportunity to perform very high quality, truly population-based audit and epidemiology, so SANS believes it is crucial to preserve SIVMS in its truly population-based format by giving an all-inclusive picture of current clinical care.

SANS appreciates the difficulties in obtaining consent from the neurosciences patient communities, and has long known that SIVMS does its best to gain informed consent from as large a proportion of the participants as possible. We note that the register and its methods are endorsed by all the relevant patient organisations. SANS will value the unbiased, all-inclusive picture gained from this audit, and will closely watch the result of the evaluations of the SIVMS audit standards, so as to achieve high standards of clinical practice in Scotland for these patients.

The objectives and methods of SIVMS have the complete endorsement of SANS, as the national professional organisation that is the key stakeholder for multidisciplinary neuroscience projects.

Yours sincerely



Belinda Weller
Secretary SANS

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