

Rustam Al-Shahi Salman MA PhD FRCP Edin MRC clinician scientist and honorary consultant neurologist Bramwell Dott Building Department of Clinical Neurosciences Western General Hospital Edinburgh. EH4 2XU

11 October 2007

Dear Dr Salman,

Re: Scottish Intracranial Vascular Malformation Study (SIVMS)

I wanted to write and express my appreciation for your contribution to the First Angioma Alliance UK International Forum sponsored, in part, by Awards for All.

Angioma Alliance in the USA, our parent organisation, has known about SIVMS since it started, and our members in the UK were glad to hear about the disease register you have established in Scotland. No one else in the world seems to be investigating and monitoring the whole population with cerebral cavernous malformations (CCMs).

Our main concerns as a patient organisation are that we are given a good standard of care throughout the NHS in the UK, and that further knowledge is gained about CCMs. On behalf of the organisation, as a key national stakeholder in your work, I would like to lend my support to the purposes of SIVMS: auditing the care people with CCMs receive, as well as investigating the prognosis and genetic influences on this condition.

I hope you can continue SIVMS for long enough to properly audit and investigate CCMs. For example, this year, I am "celebrating" twenty years of having been diagnosed – at first with MS and then, after a relatively short period, with a brainstem CCM.

Speaking as the co-ordinator of Angioma Alliance UK we will continue to lend moral support to the work of this important disease register.

Yours sincerely,

Ian Stuart BA (Hons.) MA Ph.D. Member and Co-ordinator

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