

Analysis of PSG Questionnaires- Cavernoma Alliance UK

Over the past six months, the Genetic Interest Group (GIG) and Cavernoma Alliance UK have been working on a Department of Health Funded Project which will facilitate the formation of a network of professionals with expertise in the care and management of individuals affected by cavernous angiomas.

In our effort to ensure patients, service users and carers' needs inform and guide the network's activities, we collected an account of your experiences accessing support and healthcare services for your condition.

Out of 110 questionnaires sent to the members of Cavernoma Alliance UK, we received 25% back. From these responses, GIG has produced a summary which illustrates the individual and collective experiences shared.

Section A: INFORMATION, COMMUNICATION AND EDUCATION

When asked whether individuals thought they would benefit from more information about their genetic condition? (In cases where a genetic disposition is applicable)

- 85% responded YES,
- 11% NO
- 4% stated this was not applicable as their cavernous malformation was idiopathic.

Respondents were given the option to elaborate on 'what aspects of their genetic condition they would like to learn more about'.

- 83% wanted to access more information pertaining to genetic tests,
- 87% wanted more information on medication and treatments
- 100% wanting to be kept up to date on clinical research.

Note these options were not mutually exclusive.

The section allocated for individuals to elaborate on what 'other' information they would find useful elicited the following responses;

- 'Follow-up from genetic test'
- 'Anything available, I have had to find everything myself via the internet'
- 'Any information!'
- 'Impact on dependants'

Examining what modes of communication individuals preferred to receive this information found;

- 52% opted for paper based text information (e.g. monthly newsletters and journals),
- 52% Computer based text information (e.g. using the internet, e-journals),
- 61% through attending discussion meetings with professionals who are knowledgeable about the condition, and
- 30% joining on-line forums and sharing information electronically.

Note these options were not mutually exclusive.

When asked if there were any other modes of communication (not specified in the pre-recorded options) which individuals would find useful, respondents listed;

- 'a combination of all',
- 'attending meetings with other members to exchange experience and information', and a recommendation
- 'I download USA news letters four times a year'

Section B: THE COORDINATION AND INTEGRATION OF YOUR CARE

We enquired about *where* members went for the 'treatment' of their condition? The results are detailed below.

- 14% attended a local clinic
- 29% attended a regionally based clinic
- 20% attended **more than one**. Annotations included: 'Regional clinic and referred to London hospital'; 'local paediatrician; tertiary referral to neurosurgeon and paediatric neurologist'; 'I have been to Queen's Square London - Mr. Kitchen RBH MRI scan'; 'QMC Nottingham'
- 32% confirmed **none of the options detailed above** applied to them and commented; 'No support in my area that we know of' 'my Cavernoma was treated in April 2006 in Torbay &... Hospital. I haven't had any treatment since then'; 'G.P. prescribes Tegretol- no one actually 'looks after' my condition'; 'Had my Cavernoma removed from my brainstem in 2006 when I left hospital there was no follow-up offered other than six monthly appointments with my specialist, some useless', 'Don't get any treatment', 'I was told at the Western Edinburgh there was nothing they could do- no follow up' , 'a neurologist but without special interest', 'I am no longer monitored as my MRI scans have been the same for three years', ' I go to my local G.P. and she will refer me back to the hospital when needed which is not very often. 'it is benign/asymptomatic at the moment so no treatment'
- 5% did not respond

Individuals were then asked whether they felt there was enough communication between the professionals involved in the care and management of their genetic condition.

- 32% felt that there was
- 57% stated there was not
- 11% chose not to respond;

Additional commentary included the following:

'Most neurologists seem to know very little about Angiomas especially in the brainstem', 'my case is being dealt with by a surgeon despite the fact surgery is not an option in my case', 'I don't know', 'What communication!', 'there is no care and management', 'my condition is not fully diagnosed/not common', 'neurologist was too rushed, uninformed and heartless. He did not know much about the condition which initially exacerbated anxiety', 'the condition is not well known yet amongst the medical fraternity', 'I do not have a regular professional involved in my care;', 'we got conflicting information', 'The NHS is at breaking point and my condition seems to be relatively unknown', 'Four years of problems at Ulster Hospital with very little information, just increasing medication', 'Because they do not explain it very well I found out much more on my own house computer. And hearing other stories.' 'Limited experience/ information' 'Consultant obviously knowledgeable@

When respondents were asked whether they had ever been under the care of a multi-disciplinary team

- 32% said they had and commented that the benefits included;

'Excellent treatment plan- good level of skill and knowledge', 'joined up thinking communication and skill share', 'coordinated approach of specialists in different but complimentary fields', 'I was examined by a eye/ear specialist and neurological consultant and felt the level of care was excellent', 'more knowledge and expertise'.

One of the more salient comments made by a person who had also been under the supervision of a MDT remarked, 'I was worse off for the experience, misdiagnosed and prescribed medication I did not need'

- 61% had never been under the care of a MDT
- 7% did not respond

Section C: CLINICAL NETWORKS

When given the working definition of Clinical Networks (i.e. linked groups of health professionals from across all sectors of health care e.g. neurology, dermatology who work in a coordinated manner, to ensure equitable provision of high quality and clinically effective services) we then asked individuals whether they thought such a

network of clinicians with interest in their particular disease group would be a good idea;

- 93% of respondents were in favour and
- 7% were unsure (supplementary annotations revealed these 4% of these individuals were undecided as a result of the questionnaire's 'genetic assumption').
- **Named clinicians included:** Mr. Kitchen at Queen Sq (1)