

Black Country Neurological Alliance (BCNA)

Annual Report 2017

BCNA continues to be managed by a small but enthusiastic committee, often beset by personal difficulties. Even so we have continued to meet monthly and communicate frequently by email, and have had several successes this year.

At our last AGM we set out our eight key objectives, and we are pleased to report that we have achieved six of those, four fully and two partially, with two remaining as unachieved.

Achievements during 2016/17

We held a successful **Annual General Meeting** in November 2016, attended by ten members and supporters, with apologies received from ten others. We presented our annual report and elected a new committee; minutes are available.

We agreed to **Explore opportunities for bringing people together with neurological and neuromuscular conditions who can offer peer support.** This is how we achieved this.

This year we held our first two **“Question Time” events**, in Dudley in April and in Wolverhampton in September. These were well attended and well received by all who participated. A panel of Service providers was given a short time to introduce themselves and their work, and then took challenging questions from the audience. BCNA is aware that there have been some positive developments in service provision as a result.

Dudley QT was honoured with the presence of The High Sheriff of the West Midlands, and the Mayor and Mayoress of Dudley. The event was organised in conjunction with Parkinson’s UK to coincide with Parkinson’s Awareness Week; on behalf of Parkinson’s UK the High Sheriff presented one of their volunteers with his “Inspiring Others Award”. BCNA was delighted to learn that this special person was our own Stephen Williams.

Wolverhampton QT was honoured with the presence of the Mayor and Mayoress of the City of Wolverhampton. It was organised in conjunction with Staffordshire Neurological Alliance, who had recently conducted a qualitative survey of the experiences of people in Staffordshire with some neurological conditions which had shown very low levels of satisfaction. Their report “Not NICE enough” was launched at the event. Michele Paduano, the BBC’s Health Correspondence also attended and his feature appeared twice on BBC Midlands Today during the following weeks. One of his reports included an interview with Bryan Gould, which drew attention to the lack of Neurological Consultants in our area, especially in Walsall, an issue that BCNA has been working on for several months, as reported in last year’s Annual Report.

We launched our latest project, **Café Neuro**, in Dudley in August this year. Café Neuro set out to provide an opportunity for anyone with an interest in “neuro” conditions, whether personal or professional, to meet over a cuppa for informal conversation and advice. To date three Cafes have been held, attracting nearly 40 attendees who have heard brief presentations from

service providers and been able to chat to them and to other people with similar conditions. Plans are also in place for a Walsall Café Neuro, supported by Parkinson's UK, to be launched in February 2018, and Wolverhampton Café Neuro, supported by Compton Hospice and Wolverhampton Healthwatch is expected to follow shortly afterwards. It seems likely that Sandwell Café Neuro will be launched during 2018.

A further aim was **to Investigate various funding streams to support activities**. During this year we received funding for our "Question Time" Forums from Awards for All, and we continue to seek funding from various sources. Currently we have reached Stage Two of ITVs "People's Project", the finals of which will be decided by viewers. Further opportunities for fundraising are ongoing.

We hoped to be able **to discuss opportunities for networking and collaborative working with other organisations**. This work is ongoing; we work closely with representatives of many charities which support people with various neurological and neuromuscular conditions, and their support for us is very much appreciated. We are in contact with Healthwatch in all four Boroughs, as well as the Councils for Voluntary Services or their equivalent. We have been having discussions with Clinical Commissioning Groups in both Dudley and Walsall and will continue to try to develop similar relationships with other CCGs.

A key aim was **to Attract and recruit additional volunteers and committee members**. We have been pleased to welcome Teresa to recent committee meetings and hope she will join the committee in an official capacity. We have been lucky enough to have the support of Richard at several committee meetings as well as in the capacity of Chair for both of our Question Time events. Member Bill has increased his participation with us considerably, and it is thanks to him that Café Neuro is proving to be such a success.

A year ago we expected **to plan, arrange and produce three 'Question Time' type events**; in fact, as reported above, we completed two and are currently planning two more, so that by the end of this financial year there will have been one in each of our four Boroughs.

Our hope **to Recruit and train more neurological champions** was not achieved; as a committee we feel that all committee members act as Neuro Supporters, since our raison d'être is to support and campaign on behalf of people who know what it is like to live with neurological and neuromuscular conditions.

Finally, we planned **to produce a minimum of two newsletters**, but this was not achieved. It was an idea that fell by the wayside due to pressure of other work; furthermore it had not been easy to produce, there was a cost in having it printed and with previous editions we had not been able to distribute them as we'd hoped.

Other

As we reported last year, the clinical situation in Walsall continues to give us concern. Sue Worrall and Bryan Gould continue to attend meetings with the CCG and discussions with colleagues from the MS society and MND Association, but things are moving very slowly, if at

all. We will continue to campaign until the situation is resolved.

Additional support from charities: we continue to work closely with local representatives of several charities, including, but not only, the Motor Neurone Disease Association, Parkinson's UK, the Multiple Sclerosis Society, and Headway Black Country. Their advice and assistance has been invaluable and we extend sincere thanks to all.

Website: We continue to send updates when we can, but fear there is always out of date information on our website. However from time to time we receive enquiries from people who need help and we offer what advice we can. We also receive commercial information and spam via that email address, which is somewhat annoying. As before, if you happen to spot out of date information, or can suggest news and other items that perhaps should be there, this would be much appreciated!

It is our intention to continue working as we are at present.

BCNA Committee November 2017