

Black Country Neurological Alliance (BCNA)

Annual Report 2019

BCNA Trustees and Committee have continued to meet each month and members communicate frequently by email. Since the last AGM there have been several changes which have made our work more difficult, and we have not been able to achieve all that we should have done.

Trustees and Committee

The Trustees were pleased to welcome Sue Worrall to their number; we still have six Trustees:

- Peter Cornell
- David Napier
- Pam Archer
- Tim Miller
- Sue Worrall
- Bryan Gould.

However we have said farewell to some former committee members: Richard Beamish, Teresa Brown, Bill Weston, and Jackie Dornford-May. Daniel Preston's paid work has considerably increased this year and he has not attended any meetings. Bill continues his work as a key Co-ordinator of Dudley Café Neuro. The Trustees convey their sincere thanks to all the volunteers for the work they do.

Currently the committee consists of six Trustees plus Stephen Williams, and we have recently been pleased to welcome Clare Whittaker from Compton Care who has been co-opted to our committee; we hope to accept her as a full member at this AGM.

Several Trustees and members of the committee have been experiencing increasing difficulties due to health and personal problems.

In short, it has been something of a struggle to keep BCNA going and we have not been able to complete much of what is expected.

Administration

We have done quite a lot of work to better organise how we administrate our work. Sue is in the process of introducing Office 365 as our management tool, and it is on the verge of being ready to proceed.

Tim now locally manages the website, <http://www.bcna.org.uk/>, with the help of our website manager Jackie, and we take it in turns to arrange and chair our meetings, also to take and distribute minutes.

There is much more that we wish to do, or are obliged to do, but we don't have sufficient resources between us, so much that needs to be done, or must be done, just doesn't get done. Our two main needs are finances and help from volunteers, without which we fear we will not be able to continue for much longer, but we don't even have the human resources to work on seeking funding or volunteers.

We are aware that the GDPR regulations came into force last May and we held a workshop to familiarise ourselves with this. Prior to this we were communicating with our contacts fairly frequently, but since then these have been much less frequent. We hope to remedy this when Office 365 is fully functional for us, but we will need to reassemble our contacts list.

On the positive side

1. Our work with **Walsall CCG** has had results, notably the work that Sue and Bryan have done to enable the recruitment of 1.8 Neurological consultants, thanks to the new Commissioner, Louise Jones.
2. Our main project is our **Cafés Neuro** in Dudley, Walsall and Wolverhampton.
 - a. Dudley and Walsall have continued to meet monthly on the first Thursday (Dudley) and Friday (Walsall) of each month.
 - b. Wolverhampton took a short break in order to identify a new venue and relaunched on the third Thursday in September.
 - c. Sadly Sandwell was unsuccessful for various reasons and it closed in February. We have had discussions with Sandwell CVO about setting it up again, but we have not been able to progress this due to the lack of personnel and funding to follow this through.
 - d. The Café Neuro Co-ordinators have begun to have quarterly meetings to discuss progress and share ideas. From this group a new poster was designed and will be adopted by the three Cafés
3. In Spring a meeting was called inviting neurological **charity representatives** from across the West Midlands to discuss ways of working together. It was called by Jackie Dornford-May and Ian Chandler from the MND Association and attended by 14 representatives from BCNA, Headway UK, the Multiple Systems Atrophy Trust, the MS Society, MyAware, Parkinson's UK and Staffordshire NA. Unfortunately the hoped-for follow-up meetings have not yet taken place, but BCNA would like to try to take this forward.
4. Committee member Bryan has prepared a **survey for service users** which we hope to be able to circulate in Walsall shortly.

Conclusion

In conclusion, this year has been something of a challenge for BCNA, with a diminishing committee struggling to do even the basic tasks necessary, against many difficulties, not least personnel and finances.

We find it difficult to see how we can continue without more external assistance to bring more people in to help us.

*Pam Archer
BCNA Trustee and Committee member
October 2019*