

NEWS

Barnsley & District Branch

**HAPPY
EASTER
TO ALL OUR
READERS**

April 2019

Fantastic News



Courtesy of the Barnsley Chronicle



Philip in jubilant mood after receiving £10,000 from the National Lottery to fund our Respite Care service for a year.

Well done Philip - another successful bid for funding.

TEAM PARKINSON'S

As many of you will already know, Parkinson's UK has revamped the membership offer to encourage more people to join and become involved.

For more information please visit the website at:-
parkinsons.org.uk

Coming up soon...

- 16 April - Meeting, Ian McMillan
- 30 April - Walk, Locke Park
- 21 May - Meeting, Tai Chi with Bronia
- 22 May - (Wednesday) Walk, Elsecar Park & Heritage Centre
- 27 May - Coffee morning - Mapplewell Methodist Church
- 18 June - Visit to Bradford Media Museum
- 25 June - Walk, Cannon Hall Park
- 16 July - Natalie Murray - Cannon Hall

Find us online

Barnsley Branch WEB:
barnsleyparkinsons.org.uk

EMAIL:
info@barnsleyparkinsons.org.uk

Spring and Summer Walks

All walks start at 10.30am and end near a café.

30th April Tuesday - Locke Park - Meet in car park

May 22nd Wednesday - Elsecar Park and Heritage Centre - meet in main car park

June 25th Tuesday - Cannon Hall Park - park at the end near the farm shop.

July 23rd Tuesday - Bretton Sculpture Park - meet in pay car park accessed from the roundabout.

August 27th Tuesday - Dearne Valley Park. Parking opposite the Indian restaurant.

September 24th Tuesday - National Trust Wentworth Gardens (if open)

You take part entirely at your own risk. All walks are suitable for mobility aids and led by a volunteer. Volunteers are not allowed to give care. Bring a friend if you may need help.

Chair's Chatter

I am writing this between the two episodes of the TV programme about Parkinson's and the use of an entirely new method of treatment, the so-called GDNF trial. This Thursday will see the report on the result of the trial and I can't wait. Apart from any other considerations, the programme was an example of film-making at its best in the sensitivity and clarity with which some extremely difficult issues were dealt. The newspaper I read gave the programme six stars out of six in its review column. Which brings me to the recent AGM and one of the stars of that programme. I am referring of course to our own research champion Susan Grant and her contribution to the meeting. It was both interesting and satisfying to hear that one of our members is involved in the vital work being carried out. I hope you might be inclined to take up Susan's offer of supplying information on any topic of interest to you and we all look forward to the description of her clinical trial experiences in the next newsletter.

Quite out of the blue and in no way associated with my pleas at the same AGM, I have received an expression of interest from two people who might be willing to serve on the committee, people whose background would appear very relevant. I have already set in motion our informal 'selection procedure' which is largely a matter of whether the candidates select us rather than the other way round.

We have now provided Rose, our volunteer support worker, whom you all met at the AGM, with the necessary facts on the implications of raising money from grant making trusts, foundations and charities rather than doing it ourselves, which has been very much the case in 2018. The effect on our bank balance is already apparent, it's rapidly going down! We await comments from on high.

Although this winter has been nothing like 'The Beast from the East' of yesteryear we shall all be glad when Spring arrives and our programme of summer walks starts. The flyers will be out shortly.

Happy Easter to everyone,

Philip

What You Thought

Thank you to everyone who filled in the recent survey to find out what you thought of last year's talks and events.

The U3A Choir acquired most votes (or should I say 'Likes' in these days of social media), closely followed by Ian McMillan and the Ten-pin bowling. Sarah McHale and Heather Mortiboys were also popular. On this occasion, every item on the list had at least three marks against 'Not Sure' which could mean that members were absent from some of the meetings.

When deciding on future speakers or entertainments, it is very helpful to know your preferences, so thank you again for your co-operation.



A Sense of Satisfaction: Taking Part in Research Trials

As your research champion I had thought for some time about getting involved in a research project. I looked at the Research section of the Parkinson's website and eventually found a clinical trial where I fitted the criteria. The aim of this stage 2 trial was to test a drug that might be able to control dyskinesia, a side effect that is common in those who have been on levodopa medication for some years. These involuntary movements can be distressing and very tiring. A successful drug would make an enormous difference to everyday life of people with Parkinson's. The only drawback to this trial was its location; the nearest centre was Nottingham SMC and I needed to attend once a week for 6 weeks.

The trial consisted of taking tablets for 4 weeks with tests before, during and after this key period. After an initial screening visit the second visit lasted over 4 hours for blood tests, an ECG, questionnaires and to be the star of a video showing my quality of movement. (Definitely NOT available on general release). I also had to complete 4 separate 24 hour diaries recording every half hour (when I was awake) my level of dyskinesia. It was a double-blind trial so neither I, nor the research team at the hospital, knew whether I was given a placebo or the real drug. I certainly felt well-tested.

During the first week I was convinced I was taking the active drug, but after that I didn't notice much difference. On the positive side I found it interesting to be involved and have the opportunity to discuss issues with the research nurse and the neurologist. They were enthusiastic and caring so I felt totally relaxed as they were explaining what was happening in a way that I, as a non-scientist, could understand. I felt as though I was taking some control of my symptoms. Another plus point about visiting Nottingham was that it gave me a few opportunities for retail therapy!

Over the years I have been acutely aware of the cost of the many tablets I take for Parkinson's and this is a way to give something back. You may not be interested in this kind of trial but there are always questionnaires and other opportunities that can be completed to help with research. Just take a look at the Parkinson UK website. Researchers need our help.

Susan Grant, August 2018

Fund-raising Collections

Thank you to everyone who helped with our recent collections at Tesco and Barnsley FC. We received £1000 from the two collections at Tesco Penistone and Wombwell Lane, while the bucket collection at the football club raised a fantastic £710. This was a big increase on last year's collection, probably partially accounted for by the fact that Barnsley FC is having a successful season with more spectators but, also, donors could have been prompted by the two recent programmes on BBC about research into Parkinson's. The programmes were very informative and would have widened public understanding of the condition.

Happy Retirement



After 17 years of loyal service, Rona has decided to retire from the committee, although she has agreed to remain as the 'meeter and greeter' at the general meetings. Over the years, Rona has filled virtually every position on the committee and has always been on hand to remind Philip of anything he might have forgotten. We will all miss her knowledge and enthusiasm but hope that she enjoys having a slightly more restful life than previously.

At the recent AGM, George presented Rona with a certificate acknowledging her contribution to the organisation, along with a cheque and a rose tree. George was also kind enough to offer to plant the tree for her and had thoughtfully provided the necessary manure, though fortunately he left it in his car. The pictures tell the story!

Thank you for everything, Rona

BARNSELEY AND DISTRICT BRANCH

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Many thanks to the contributors to this issue.
If you wish to contribute in future, please send items to [Sheila Ireland](mailto:sheilaireland@hotmail.com) at sheilaireland@hotmail.com

Parkinson's UK

WE'RE the Parkinson's support and research charity. Help us find a cure and improve life for everyone affected by Parkinson's.

Free confidential helpline:
0808 800 0303

Interpreting available;
Textphone 0800 111 4204

Visit us online at parkinsons.org.uk

A charity registered in England and Wales (258197) and in Scotland (SC037554).

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