2013 Carol Service at Trinity Methodist Church, Hull

Whichever way you look at it, the choir of St. Helen’s Welton did our Branch proud as they led our annual Carol Service on 8th December.

Our sincere thanks to Choir Director Helen Duffus working in partnership with Gareth Naidoo, organist at St Helen’s Welton, who planned the content of the service and to all the members of the choir young and old for their singing and musicianship.

2013 Christmas lunch at the Marina Holiday Inn, Hull

Branch Chairman Robert Watkinson receives a large cheque from the R.A.O.B. arising from the social event they ran in late October.

Toni Ellis, our professional entertainer, gets energetic support from talented members.

The main raffle made £139 and the hamper raffle made £158
When the last Newsletter was being ‘put to bed’ in October the Help Cards were still being designed.

They are now ready and available for use. If you are a PwP you should find a Help Card in with this Newsletter. If you are not a PwP but feel you would benefit from having one as a carer or you know of health professionals who might benefit, please contact me (details on page 1) and I will supply.

David Perry

We need your used stamps

REQUEST FOR YOUR USED STAMPS
Did you know there is a scheme for collecting used stamps to make money for Parkinson’s UK?

John and Carole Ward tell us why they organise this appeal on behalf of the charity.

“To be honest we were inspired by people who did so many charitable good works for a number of organisations including the Parkinson’s Disease Society, as it then was known and in the main, the late Professor Arthur Birley and his wife Joy, who many Parkinson’s UK members may still remember.

“All three of the inspirational men who in turn ran the stamp RE-cycling collection had Parkinson’s, yet gave of their time and effort to help others. Unfortunately, in time because of their failing health, I and my wife Carole took over the running of the stamp collection.

“Soon after we took on the responsibility, we faced a family tragedy of our own when our youngest son, Mark, died unexpectedly. At the time of his death Mark was a Senior paramedic and the father of three young children. It was Mark’s lifetime commitment to others, that prompted Carole and me to set up a Tribute Fund in his name at Parkinson’s UK. This is not only a fitting acknowledgement for our son, it’s a major comfort to both of us to know that his name lives on for the benefit of people with Parkinson’s.”

The process...

“When I receive the stamps, I soak, clean and dry them ready for pressing, as you can imagine this is very time consuming. The modern day stamps have a different type of glue from older stamps which is far more difficult to work with. When I have a sizeable amount I send them on for recycling. Other more collectable stamps are usually sold at locally held stamp fairs in Cambridgeshire.

“It’s impossible to thank everyone who kindly sends stamps to us, so when you send them to us, please include an email address if you have one and we can confirm we have received your stamps and pass on our very sincere thanks.”

Follow John and Carole’s tips for maximum fundraising appeal

• Ideally stamps sent to us should be in excellent condition.
• Stamps from around the world are ideal for recycling and resale.
• Any size of stamp is acceptable either in albums or loose.
• If you trim round a stamp, please leave a small edge. Also trimming the envelope paper will help reduce the cost of postage.
• Please have your packages of stamps weighed so the correct postage is used. Sending second class is fine.

If you would like to raise funds by sending postage stamps to John and Carole please send them to:
John and Carole Ward,
8, Glenariff Close,
Eynesbury, St Neots,
Cambridgeshire PH 9 2QW.

For further information about their work you can email john.ward6@sky.com
There will be significant changes made at the AGM. We are glad to announce that Cllr David Gemmell of Hull City Council has accepted our invitation to chair the AGM. He chaired the meeting three years ago when he was Lord Mayor of Hull. We remember well that he made Parkinson’sUK one of his mayor’s charities with an outstanding result of over £22,000 for our funds. Furthermore the committee has ascertained that David is willing to become President of our Branch, so the item in the AGM will be the formal approval of this appointment by members of the Branch.

Also at the AGM Robert Watkinson will be standing down as chair and treasurer of the Hull & East Yorkshire Branch. Robert and his late wife Christine have been outstanding supporters of the charity and at the centre of the Hull & East Yorkshire Branch’s operations. Robert hopes to continue as a member of the committee. Fortunately there is someone on the present committee who is willing to take on the position of treasurer. This is excellent news, seeing that a prime activity of the Branch is fund-raising.

About the choice of a new chairman - At present there is no one waiting in the wings. Perhaps by the time we reach the AGM there will be. Failing that, we may need to fall back on the new committee arranging who from among themselves should chair meetings of the committee. At present our committee comprises eight people. According to the rule book a committee’s size can range between a minimum of 6 and a maximum of 20, so there is scope for flexibility.

Our AGM is not only a business meeting. It also includes refreshments and a raffle, with music in the background so that people have time to meet and talk with each other. Tracy Westgarth, our regional manager, will also be present and be able to give us an idea of work going on in Yorkshire and Humberside.

Watch out for a motoring scam—warning passed on via Jane Merrills

Motorists are being warned that text messages or emails regarding a licence which is due for renewal have not been sent by the DVLA. The DVLA says that it does not send these types of reminders by text or email and these services are in no way affiliated with the DVLA.

It warns motorists that they may be charged more for using these services. By using the online driving licence transactions on GOV.UK motorists can be sure that they are dealing directly with the DVLA and they will not be charged any additional fees for their driving licence.

The application will be completed online without the need for a postal application in the majority of cases. The online driving licence services can be found in the driving licences section of GOV.UK.
I suggest that the primary goal of research is not to “find a cure” but to find how to prevent PD.

As PD is neither infectious nor contagious but is an array of negative symptoms brought on by the death or disruption of brain cells, it is not good enough to repeat the mantra that PD is an idiopathic disease with no known cause.

What is needed is co-ordinated research into toxicity in the human body, starting with mercury. Why is prevention of PD the target rather than a cure for PD?

Consider an analogous example – how to deal with cirrhosis of the liver. Is the goal to be cirrhosis cured or cirrhosis prevented? Surely prevention of cirrhosis is the more favourable result. We already know that excessive alcohol consumption is the mega factor that leads to cirrhosis of the liver. The obvious course is to drastically reduce alcohol abuse.

What would we make of a doctor who told his alcoholic patient to keep on drinking but he would prescribe a special remedy for his hangovers while research was continuing to discover a cure for cirrhosis? We would say that he had lost the plot. Instead of tackling the root cause of the cirrhosis the doctor was content to manage the symptoms with pharmaceutical treatments while scientists search for ways of reducing the impact of cirrhosis.

Yet that goal “find a cure” for Parkinson’s Disease follows the same illogical pattern. Mercury is more toxic than alcohol. Indeed it is the most toxic non-radioactive element known to mankind. It can cross over the blood/brain barrier and also the placenta. As long as it is permitted to enter the human body, especially the brain, it will continue its destructive effects. Just as a drastic reduction in alcohol consumption will have a beneficial effect on the liver so, I believe, would the elimination of mercury from the human intake have a profound effect on the whole gamut of neurological diseases.

Is eliminating mercury from the environment and from human consumption a realistic goal? The answer is a resounding YES.

On 10th October 2013 many years of hard work came to fruition with the signing of the Minamata Convention by over 140 nations. The convention’s goal is precisely the elimination of mercury in the environment and in the human body.

Alongside phasing out the use of mercury in industrial processes the Convention also requires nations to phase down the use of dental amalgam fillings, of which mercury is a component, over an appropriate period of time. The signing of the treaty follows years of discussion by the United Nations’ Environmental Programme’s Intergovernmental Negotiating Committee (UNEPINC).

Norway, Sweden and Denmark have shown the way to the future. From 2009 they have already banned the use of dental amalgam.

Could it be that the neurological diseases are not distinct entities each with their own distinct causes but rather all the result of mercury getting to a variety of sites within the brain?

I prophesy that the quest for a mercury free human body in a mercury free environment will follow the same pattern as the quest for unleaded petrol—denial by industry of the harm that mercury inflicts until the amount of evidence is utterly incontrovertible and leads to a world-wide ban.

In the meantime I have found it instructive to surf the net and see what information is readily available about Parkinson’s and its likely causes.

Continued on page 5
Over a year ago Nathan began work on his training project. He chose to examine the extent to which PwPs receive palliative care. An important part of his study was a face to face meeting with a group of PwPs and carers from our Branch. There he was able to gain insight into what life as a PwP or carer involves. Now with the project well under way he writes:

“Although medication can have benefits for many of the symptoms of Parkinson’s Disease, the psychological and social impact of the disease may persist for both patients and carers. These additional difficulties beyond the motor symptoms of Parkinson’s Disease are not dissimilar to the challenges faced by patients with terminal cancer and their families, such as a loss of control and social isolation, yet in contrast to this group of patients, those with Parkinson’s Disease rarely access Specialist Palliative Care services.

Specialist Palliative Care services aim to improve quality of life for patients with life threatening illnesses and their families, rather than focusing on curing the illness. They may provide additional support and advice, training and activities for patients and carers, advance care planning and respite, amongst other services, aiming to provide help with physical, psychological, social and spiritual challenges. Research has suggested that there are palliative needs in Parkinson’s. However, palliative care is often seen as end-of-life care and as being exclusively for cancer patients. In reality the Department of Health suggests palliative care can be beneficial and appropriate throughout the disease process dependent on patient need, and NICE guidelines recommend palliative needs be considered throughout.

Continued from page 4
An easy place to begin would be with Parkinson’s UK’s videos at: http://www.youtube.com/user/parkinsonsUK/videos

The current GDNF trial is arousing much interest: http://www.parkinsons.org.uk/content/clinical-trial-test-drug-gdnf-people-parkinsons

Correlation between mercury burden and number of amalgam surfaces

Worth a look
http://www.nature.com/cited/cited.html?doi=10.1038/sj.bdj.4808325 click on item 2 about East German children and that will give you the page with the abstract on. The project was trying to find whether there was a correlation between heavy metal pollution in the environment and the amount of mercury in the children’s bodies. They checked those from a heavily polluted area against those from a non-polluted area. There was no such correlation. But—there was a good correlation with the number of amalgam fillings each child had!

To my Parkinson world - you’re welcome
It seems rather odd, it’s really very strange
That with the on-set of Parkinson’s the world began to change
Clothes for example which once I easily could don
Must have been re-fashioned for they’re nigh impossible to put on
Trousers legs are surely now bonded with glue
If not why is it so difficult for my foot to pass through?
Likewise coat sleeves are no longer positioned the same
Else why can’t my arms locate them however oft I aim?
And why do jumpers when ever I get dressed
Form into a roll then only pull half way down my chest?
Then there are shoe laces which won’t tie into a knot
Hooks which don’t and buttons too large for their allotted slot
New bags and purses are of quality’s so poor
Whenever I try to use them my goods slide to the floor
(As I try to retrieve them I get into a stew
For I find behind me I am causing a long impatient queue)
But it’s wobbly knives and forks I particularly hate
For they make my food jump off an equally wobbly plate
So if I seem to struggle with what’s to you an easy task
Should you wish to help me - please don’t hesitate—just ask

GW - member of the Hull & East Yorkshire Branch
This picture shows Tracy Westgarth, Manager for Parkinson’s UK in Yorkshire and North Humberside, passing on a cheque for £12,000 from our Branch to Steve Ford, CEO of Parkinson’s UK, at Kings Cross station.

It reminds us of the basic purpose of fund-raising. Fundraising is not an end in itself. Money is raised or donated so that it can be spent on the purposes of the charity. For Parkinson’s UK this means spending money on research to find a cure and spending on ways to help PwPs to enjoy the best possible quality of life in the here and now.

Though the £12,000 has gone down to “them in London” it has done so to directly benefit “us in Hull and East Yorkshire”. It will be spent supporting and improving the deployment of Parkinson’s Specialist Nurses in Hull and East Yorkshire. This follows the pattern in other areas of work such as the deployment and funding of Information & Support Workers like Corinne. They work locally, are managed regionally and paid centrally. As a general principle it is vital that charities spend the money they receive because, if they don’t but just sit on it, people will rapidly turn away from them and give to those who obviously need the support and make prompt use of what they receive.

SOROPTIMIST GENEROSITY

Our Chairman receiving the cheque

The Hull Branch of the Soroptimists awarded our branch of Parkinson’s UK £1,500, made up on £900 from the Soroptimists and £600 from their Bar None Bridge Club.

Soroptimists like to decide to whom to give their money for themselves rather than respond to begging letters. We deeply appreciate their choice of Parkinson’s UK as the charity they wished to support.

RETURN OF THANKS

to Mrs Judith Wetherell and the Skidby Lakes Golf Club Ladies for raising a further donation of £100.

PARACHUTE GIRL

Rebecca Hancock, seen here in the comfort of her home holding an envelope with a big cheque—a far cry from falling through the air from several thousand feet. Her sponsorship brought in £1,274.

RETURN OF THANKS

To Margaret and Bob Banks of 4 Wentworth Grove, Aldbrough, and some friends who arranged a very successful Vintage Tea Party on 7th December 2013. The proceeds were split 50/50 with Macmillan and Parkinson’s UK Hull & East Yorkshire received the fine amount of £250.

THANKS FOR IN MEMORIAM DONATIONS

In the past three months the Branch has received funeral collections or donations in memory of Mrs Avann, E Grantham, S Pryde, E Briggs, S Duffy and Mr Shepherdson totalling £1,027.

We offer our condolences to all who have lost loved ones in recent months.

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- Money Going out

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Exercise Opportunities

**HULL CITY CENTRE**

**Monthly Drop In**

Jane Curran and colleagues from Hull Royal Infirmary’s physiotherapy department do a session for people with Parkinson’s. There is no charge—its free. It is held on the second Monday in the month from 1.30 pm to 2.30 pm at the AgeUK building on the corner of Porter Street and St Luke Street. ISW Corinne Kaye attends and is available for consultation.

The end of the year saw the AgeUK premises flooded, so the December session had to be cancelled. In January the Drop In met again though the lift was out of order, which excluded members who are not good at climbing staircases.

Let’s hope all goes well on February 10, March 10, April 14, May 12, Jun 9, July 14, August 11, September 8, October 13, November 10 & December 8

**BRANTINGHAM VILLAGE**

**Chair Exercises**

Held on Mondays (except bank holidays) 1.30 pm—2.30 pm at Brantingham Village Hall

This is a “keep fit” which gives even those with much reduced mobility the chance to give their limbs and joints a very useful workout. It is all done sitting down with musical accompaniment to keep things cheerful.

After about 45 minutes of the exercises tables are set among the chairs and everyone has a drink and a chat before going home. Everyone pays £1.50 per session.

Many PwPs could benefit greatly.

For more info please phone Linda on 01482 666881 or Cathie on 01482 667823 or to let them know you are coming.

The tri-fold leaflet about our Hull & East Yorkshire Branch is to be revised and reprinted after the AGM. If you know of people or places where these leaflets can be passed on to advantage, please ask the Secretary David Perry for a supply and he will be glad to meet your request.

From page 5 the course of the illness.

There are few providers of Specialist Palliative Care in the UK for people with Parkinson’s Disease and their families. Our research is looking at how a small group of patients with Parkinson’s Disease and their carers, who have had access to a Specialist Palliative Care service which provides community, day hospice and inpatient services, have experienced being a part of that service. In particular we are asking people about how the Specialist Palliative Care service has affected their ability to cope with the changes that have occurred since diagnosis of Parkinson’s Disease.

So far we have interviewed five participants, with plans to interview a further five. To date participants have described a range of benefits for their coping as a result of being able to access the service. It is hoped this study can contribute to the discussion regarding the appropriateness of Specialist Palliative Care provision in Parkinson’s.

If you would like to know more about this study or any of the information mentioned above, please don’t hesitate to get in touch via email at Nathan.badger@nhs.net or telephone on 07847099534.”
2014 is well on the way and the committee is anxious that this year we will add a few new venues and times to our Branch Meetings. We appreciate that our current arrangements do not suit everyone and want this to change. However finding new meeting places is not easy, so we are asking for your assistance, because you will have the local knowledge. If you know of a suitable place, anywhere in the East Riding would you please ring David Gamble on 01482 667799 with details and we will check it out. The vision behind this development is that PwPs and carers will have the chance to sit and chat together in relaxed tea party style. Perhaps more — a local group might develop any of a wide range of possible shared interests.

We have already booked our first such meeting. This is at Preston Community Hall on a second Wednesday in the month—12th MARCH. Helpers will arrive just after 1pm to prepare for the meeting which will be from 1.30pm to 3.00pm. The hall is well equipped and warm and there is adequate parking. If you can get there, please come.

**NB THIS NEW STYLE OF MEETING DOES NOT REPLACE THE SUNDAY MEETINGS. THEY WILL CONTINUE AS CENTRAL MEETINGS OF THE HULL AND E.YORKS BRANCH. THE BRANCH WILL CONTINUE TO ENGAGE A WIDE VARIETY OF SUNDAY SPEAKERS.**
From Nathan Badger, trainee clinical psychologist at the Hull Medical School.

Over a year ago Nathan began work on his training project. He chose to examine the extent to which PwPs receive palliative care. An important part of his study was a face to face meeting with a group of PwPs and carers from our Branch. There he was able to gain insight into what life as a PwP or carer involves. Now with the project well under way he writes:

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