PARKINSON'S UK CHANGE ATTITUDES. FIND A CURE. JOIN US.

## HULL PARKINSON NEWSLETTER OF HULL & EAST YORKSHIRE BRANCH

Reg. Charity No. 258197

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# May 2014

## PARKINSON'SUK

## **Annual Meeting Report**

This year's AGM proved to be a creative and successful event. Our Branch now has a president in the person of Councillor David Gemmell OBE. It also proved possible to elect a new Chairperson and a new Treasurer. Robert Watkinson continues as a committee member, thus keeping available a fund of experience and knowledge of Parkinson's UK. Harold and Cathryn Brazier decided it was time to stand down after having served so many years in key positions within the Branch. Our AGM was not only a business meeting. It also included refreshments and a raffle, with music in the background so that people had time to meet and talk with each other. Tracy Westgarth, regional manager for Parkinson's UK, spoke about work going on in Yorkshire and Humberside while Corinne Kaye, our Information and Support Worker, gave a lively and upbeat account of her first year in the post. Next year we shall seek a new venue for our Annual General Meeting.



### **OUR CHAIRPERSON**

My name is Gillian
Jackson. I am retired and was diagnosed with Parkinson's in September 2012.
I joined the Hull and

East Riding support group shortly afterwards; in 2013 I decided I wanted to be more involved so offered to stand for the post of Chairperson. I live in Hull with my husband Graham. We both attend the Yoga for PWP and find it really helpful.

In my spare time I enjoy cake making and decorating, reading, knitting and gardening.

## **OUR TREASURER**

My name is John Hinson and I was diagnosed with Parkinson's 5 years ago when I was 46.

Married to Jo with 3 children aged 19-24 my diag-

nosis has raised many challenging issues. Since losing my job and finding it difficult to regain full employment I have been active in volunteering my services to Parkinson's UK as chair of the Yorkshire & Humber Younger Persons Support Group and as Treasurer for the Hull and FR Branch.

All items in this newsletter aim to provide as much information as possible but, since some information involves personal judgement, their publication does not mean that the Hull & East Yorkshire Branch of Parkinson's <sup>UK</sup> necessarily endorses them. While due care is taken to ensure that the contents of this Newsletter are accurate, the publisher and printer cannot accept liability for errors or omissions.

## What do our teeth teach us?

David Perry continues his investigation into the disputed link between amalgam and Parkinson's

Since the last newsletter where I suggested how the goal must be Parkinson's prevention and that mercury in amalgam fillings was a prime suspect for causing neurological damage, there have been two developments.

- 1. A few weeks ago I received a donation to the branch with an accompanying covering letter containing this:
  - "........... Incidentally, I was interested in your article (in February newsletter) on mercury poisoning. Years ago I read about mercury fillings affecting people with neurological problems. I mentioned this to my husband's dentist who dismissed it as not being enough to cause a problem and within safe limits. I disagreed, especially as my husband's teeth started to disintegrate due to his new found love of sweets, causing him to constantly need his teeth filling when his teeth started to crumble. I am sure he would occasionally swallow bits of filling.

I have had several elderly relatives who have lived to their late eighties or nineties and none of them suffered any great neurological problems. The main thing they all had in common was full dentures—therefore no chance of mercury poisoning, Food for thought.

Kind regards, Y T "

2. I have taken the step of asking for a copy of my dental records. Practices are required to keep dental records for eleven years. In my case I was able to retrieve records from the Hedon practice from 1999 to 2007 and from South Cave from 2007 up to the present. I found that in 1999 I had 20 teeth with fillings and 1 with a crown. I will have had 18 or more amalgam fillings since I was 22, i.e. for fifty years.

The old saying "one swallow does not make a spring" is very true. The fact that my dental record suggests there is a link between my fillings and the fact that I now have Parkinson's is not very compelling. However, if the issue is of interest, do please contact me and let us compare notes and see if evidence for the link may turn out to be stronger than is usually recognised.

David Perry (01430 421412 or perrydr@dsl.pipex.com)

## Is someone missing out?

If you or someone you care for has been affected by Parkinson's disease, you would be most welcome to join Parkinson's UK. This nationwide charity provides information and support plus quarterly magazines about activities and latest research developments.

Our local Hull & East Yorkshire Branch of Parkinson's UK has its own dedicated support worker and welfare officer. Activities include a monthly social event and a weekly yoga session. If interested please contact the Branch Secretary David Perry—contact details just above.



## Science on the job

# Parkinson's and the Genetic revolution

from genes to treatments
Wednesday 18 June, 7.30pm–9pm

The Ron Cooke Hub, University of York, Heslington, York YO10 5GE

Join us to hear Dr Patrick Lewis of University College London and Dr Flaviano Giorgini of the University of Leicester, discuss how their work on genetics is helping us develop treatments for Parkinson's.

The genetics revolution has had a massive impact on the way in which we approach the research of human conditions – including Parkinson's.

In this lecture, we will take you on a journey through the genetics of Parkinson's. We talk about how we as scientists are using genetics to learn about the causes of the condition – providing us with new potential targets in the hunt for better treatments.

Places are free but must be booked in advance via **parkinsons.org.uk/yorklecture** or by calling **020 7963 9309**.

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

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#### **MORE ABOUT SITran**

Our annual Open Days are always a great opportunity to catch up with our supporters and present our latest research. On 17th September last year SITraN welcomed over a 100 visitors: patients, carers, families as well as members of the public.

We had an exciting programme with talks, posters, lab tours, demonstrations, and many interactive workstations. Our researchers explained how animal models such as zebra fish are used in Parkinson's and NMD research; how drug screening technology is helping us to identify and develop new treatments and how we use viral vector technology for gene therapy for MND and SMA.

The dementia group offered memory tests and informative stands were hosted by the South Yorkshire MNDA branch, Alzheimer's Research UK and the Sheffield Motor Neuron Disorders Research Advisory Group (SMND-RAG) with plenty of advice for our visitors.

## SITran at Sheffield University invites . . . .

## Fundraising meerkats Mo LeCule and Mo MND wouldn't miss a SITraN Open Day!

You can follow what they are up to on Twitter:
Mo LeCule@Mo\_MND



## Our Next pen Day - 11 July 2014

We would be deligted to see you at our next Open Day!

To register please phone 0114 222 2230 or email: neuroscience @sheffield.ac.uk



## How to get around as a PwP

## MOTABILITY SCHEME—HOW IT WORKS

This information has been culled from the Motability website www.motability.co.uk

## How it works

The Motability Scheme enables disabled people to lease a new car, scooter or powered wheelchair by exchanging their Government funded mobility allowance. If you receive either the Higher Rate Mobility Component of Disability Living Allowance (HRMC DLA), the Enhanced Rate of the Mobility Component of Personal Independence Payment (ERMC PIP), the War Pensioners' Mobility Supplement (WPMS) or the Armed Forces Independence Payment (AFIP) you may be eligible to join the Motability Scheme.

We provide the vehicle and the support you need so you can simply enjoy worry-free mobility. As part of our worry-free package, you can receive:

- A new car, scooter or powered wheelchair every three years
- Insurance from RSA Motability (RSAM)
- Breakdown assistance
- Servicing, maintenance and repairs
- Adaptations, many at no extra cost

More about worry-free mobility
What our customers say about us Are you eligible?

Once you've decided that the Motability Scheme is right for you, there are a few steps you can take to get a new car, scooter or powered wheelchair.

## 1 Choose your vehicle

When choosing a new vehicle, there is a lot to consider, including cost, suitability and fuel consumption. To make it easier to find a vehicle that best meets your needs, we've outlined a few key areas in the 'Important things to consider' section that may help you decide.

Important things to consider when choosing a car Important things to consider when choosing a scooter or powered wheelchair

#### Financial help for car customers

If you need a specific car because of your disability and you are unable to afford the Advance Payment required, or if you need essential adaptations or a Wheelchair Accessible Vehicle (WAV) which can sometimes cost more, Motability may be able to provide financial help.

Financial help is only awarded towards the least expensive solution that meets your mobility needs and you should also expect to contribute as much as you can afford.

More about financial help What are Advance Payments?

Adaptations and adjustments Wheelchair Accessible
Vehicles (WAVs)

#### 2 Search for dealers

Once you've worked out what's important to you in a vehicle, the next step is to visit a dealer. With nearly 5,000 dealerships offering Motability across the UK there's bound to be one local to you. You can discuss your preferred options with a fully trained Motability specialist and arrange a test drive. Your dealer can also discuss whether optional extras or adaptations might help make driving easier or more comfortable. If you're a scooter or powered wheelchair customer, a specially trained dealer will be happy to come to your home with a selection of products for you to try. Alternatively, you can visit a dealer showroom to see a range of models.

Search online for dealers and cars Search online for dealers and scooters and powered wheelchairs

## 3 Order your vehicle

Once you have decided which vehicle is right for you, your Motability specialist will complete your order with you using our simple online system. We will then send you an acceptance letter containing your Personal Identification Number (keep this safe as you need it to collect your vehicle). Before making your final decision it's worth asking the dealer the expected delivery time for your new car as this can vary from model to model. It could take a few weeks, but please stay in touch with your dealer in case there are delays.

More about ordering a car More about ordering a scooter or powered wheelchair

## Watch our video on getting started with the Motability Scheme

Our customers share how easy it is to lease a car with us. Click on the play button to view.

<u>Watch the full</u>

range of videos in our Car Scheme series

Watch our scooter and powered wheelchair video series

#### SCOPE FOR A NEW SORT OF CARER?

Time to recruit a tableteer.

No. I don't mean a pill. I mean a helpful person ( a grandson or good neighbour?) who can call with their tablet to provide quick answers on any subject.

Intelligent access to the internet can make a huge difference to our standard of living.

## Forthcoming major fundraising events



DARREN HOULT SPEAKS ABOUT EARLY ONSET PARKINSON'S

Darren, a father of two and stepfather of three, said: "I know a

dozen people that have been diagnosed with it when they were younger but it isn't well known to other people. "I went to a support group when I was first diagnosed and it scared me because they were all old and I was only 35. I didn't want to be like that.

"Now, I want to raise awareness and support for the people who are younger. "Knowing other people your own age are going through the same thing helps a lot, just being able to relate to them, have a coffee, see what they are going through and swap ideas about how to cope.

"Being diagnosed this young is a hammer blow, but being able to fundraise is such a joy. I will never be able to climb a mountain for Parkinson's UK but I can do this for them."

Picture and extract of interview from Hull Daily Mail coverage of Parkinson's Awareness Week.

YOU ARE INVITED TO SUPPORT DARREN THROUGH
THE CHARITY FUNDRAISER EVENT

# Charity Fundraiser

In aid of

PARKINSON'S CHANGE ATTITUDES FIND A CURE.

13th June 2014 at the Goodfellowship Inn, Cottingham Road, Hull Kenilworth Suite from 7pm.

ALL WELCOME
There is a DJ and Disco—Charity
Auction—Raffle—Karaoke—Quizzes

**Please** 

search for DARREN HOULT PARKINSONS on www.justgiving.com to donate

contact: darrenhoult@hotmail.com for further information or auction donations

## Handy hints

#### **PROBLEM SLEEPING?**

If you Google Northumberlandnhstrust self help a range of subjects will come up. Click on Sleeping Problems and a very useful booklet appears. I printed it off and keep it handy because it covers a wide range of sleep problems and although a lot of it is "common sense" I ask myself "but do I do it??". The answer, now, is "yes" because I have found that it works and is a big help to me. I hope it helps you too. If you do not have access to a computer and would like a copy please let me know and I'll send you one. I think it goes without saying that if you can manage to sleep without more medication it is worth a try.

David Gamble Tel Hull 667799.

#### **HOW ABOUT YOU?**

Do you have any "handy hints" to share with others? Please send them to David Perry, Branch Secretary & Editor

## Golfing for Parkinson's

The John Harrison
Charity Pro Am
at Hull Golf Club
Friday 22nd August 2014

Teams of 3 amateurs and a professional (Hull GC and John Harrison to provide the pros if needed)
Team event, bacon rolls and coffee on arrival,
two course meal after play, fantastic evening
party with live entertainment and prizes!
Wonderful Prizes! £250 Per Team

Contact: John Harrison 07747 036879 johnharrisonagencies@hotmail.com Aaron Pheasant 01482 660972 pro@hullgc.com

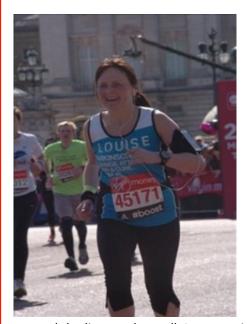


Hull Golf Club (1921) Ltd, The Hall, Packman Lane, Kirk Ella, Hull, HU10 7TJ All in aid of

PARKINSON'S<sup>UK</sup> CHANGE ATTITUDES. FIND A CURE. JOIN US.

## A London Marathon for PARKINSON'S





In September 2012 my husband and I ran the Great North Run for Parkinson's UK. I half thought about hanging up my running shoes after that but something inside me was telling me to try a marathon. In October 2013, I was given a bond place for Parkinson's UK and shortly after, my 5 months of training started for the biggest ever challenge of my life. It wasn't just the training that was a challenge - with the bond place I had to pledge to raise at least £1900.

The training programme was tough. From the word go I was plagued with injury niggles and had a delayed start to my programme. However, come April 13<sup>th</sup> 2014, having run a total of 250 miles through all weathers, I was ready for the marathon. I had also smashed my fundraising target with the overwhelming support and generosity of my friends and family.

The day was glorious. It was so hot and at times very painful but I kept on 'eating up the miles' and after 4 hours and 40 minutes I

crossed the line on the mall. It was an incredible feeling, and although it hurt for a lot of the run, I had my Dad as my inspiration along with the motivation to keep going for everyone who has Parkinson's and everyone who had believed in me and sponsored me to raise money for Parkinson's UK.

A once in a lifetime experience that raised over £3700 for Parkinson's UK. As I have gone way over the minimum pledge to raise £1900, Parkinson's UK are kindly allowing some of this money to be channelled to my Dad's local Hull group, which I am so pleased about! My Father in law also has Parkinson's but has no access to a nurse or a local group so I plan to run the Great North Run again in October this year as part of Parkinson's UK 'Team Nurse'. Then I think these little 43 year old legs will definitely need a rest ......

The photograph was taken on the mall with Buckingham Palace in the background, and 200 metres to go to the finish .... And the tears! Louise Bisset

The Branch congratulates Louise on her wonderful achievement both as an athletic triumph and as a superb exercise in moneyraising.

We await with gratitude the £500 from Parkinson's UK office which has been agreed.

## THANKS FOR IN MEMORIAM/ **FUNERAL DONATIONS**

In the past three months the Branch has received funeral collections or donations in memory of V Holdsworth; K Ives; R Grantham; P Newton; J Bloomfield; E Cappleman; J Townend

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

## How to keep a happy treasurer

#### IMPORTANT NOTICE

If you find yourself in the position of having money, whether cash or cheques, to pass on to our treasurer John, please can you put on an accompanying note clearly stating the source of the money, the reason it was raised, the amount and your own name, address and phone number, so that he can contact you if there are any queries?

It makes life very difficult if such information is lacking. . It also makes sending out "thank you"s very difficult

#### John Hinson's contact details:

37 Marine Avenue, NORTH FERRIBY, HU14 3DS 01482 632284

## Opportunities to meet

#### **BEVERLEY MEETINGS AND MORE**

Following the successful start to the programme of meetings in Preston we are pleased to announce that arrangements have been made to have monthly meetings at the TIGER INN, Lairgate, Beverley on the first Thursday of the month starting on Thursday 5th June at 2pm to 4pm.

The Tiger Inn is well known for its food and hospitality and has proved a popular venue for the meetings of various groups who do their shopping in the mornings, have lunch in the meeting room and carry on with their meeting in the afternoon.

This completes for the time being our new venues for meetings. We hope that having meetings in Preston and Beverley, in addition to the regular Sunday meetings in Hull will mean that more people with Parkinson's and their families will be able to meet and have a chat and swap notes etc.

Here is a list of meetings planned for the next few months - We hope to see you!

Physio Drop In at AgeUK Hull 2nd Mondays in the month 1.30—2.30pm	Local Meeting at Preston Community Hall 2nd Wednesdays in the month 1.30—3.30pm	Local meeting at Tiger Inn Beverley 1st Thursdays in the month 2.00—4.00pm	Weekly yoga sessions Unitarian	Branch meeting at Trinity Methodist Church, 3rd Sunday in the month (usually) 1.45—3.45pm
12th May	14th May		Church in Park Street, Hull	18th May
9th June	11th June	5th June	Fridays 2.00 — 3.30pm	22nd June
14th July	9th July	3rd July		20th July

Branch Committee members will be involved with the Preston and Beverley meetings as they get themselves established.

However, for these meetings to flourish, each meeting will need to form a small committee to run and oversee the life of the group whether it be organising the content of meetings or acting as a local contact, who is able to handle enquiries.

#### YOGA FOR PARKINSON'S

Bryan Bayley runs a weekly session for PwPs and carers on Fridays 2.00pm to 3.30pm at Hull Unitarian Church, Park Street. £3 per session.

Please contact him before attending for first time.

mobile 07764 683838 e-mail bayleytb@gmail.com

Bryan will be our speaker at the August Sunday meeting.

## Announcements

#### R.I.P. Roy Grantham

It is with regret that in early April Roy passed away after a short illness. He was a loyal member of our Branch and did a great job on the bookstall for a number of years.

He was a fine gentleman and will be greatly missed.

#### Florrie Glasby—an update

Florrie is in hospital recovering after surgery. We all wish her well and hope that she will have a successful convalescence.

#### ANNUAL CAROL CONCERT

We hope to hold a Carol Concert again this December but so far we have not yet succeeded in landing a choir to make one possible.

This means we are unable to settle the date, i.e. as to whether it will be on 7th December, which is our preference or on 14th.

Hopefully by the time of the next newsletter we shall have made progress.

DP

## For your diary—Forthcoming Events

## **BRANCH CALENDAR 2014 Sunday Meetings**

Monthly Sunday Meetings in Trinity Methodist Church Hall (corner of Newland Avenue and Cottingham Road, Hull). 1.45pm for 2.00pm start

## Programme for the rest of the year

18th May Clive and Kath Richardson— Antiques QUIZ (bring antique items to show everyone)

\* 22nd June Philip Walker—"Laughing all over the world" Funny incidents during his many travels overseas

20th July— to be arranged

17th August—Bryan Bayley will speak about yoga for people with Parkinson's.

21st September—to be arranged

26th October—to be arranged

16th November— The speaker will be a Parkinson's UK expert from London...

21st December—Christmas Dinner at Marina Holiday Inn.

July, September and October meetings will include a quiz (pub style) and a talk about the wide-ranging work of Dove House

## **Changes to our Sunday meeting format**

With Harold and Cathryn retiring from the committee and with the death of Roy Grantham it was agreed at committee that the bookstall would now be run on an unattended self-service basis where people "bring books and buy" and also "bring books and take them home if unsold". Also, the bric-a-brac stall would cease forthwith, thus releasing Mike and Sheila to be able to welcome and chat to people. It was agreed that a bowl be put out for those who would like to give a little towards the cost of tea and coffee. Jane will also act as a welcomer and Graham Jackson (husband of Gillian our chairperson) is taking over selling the raffle tickets. We hope that giving up the bric-a-brac it may encourage people to think more about bringing a worthwhile prize for the raffle.

## A form you may find helpful

If you are on our Newsletter mailing list, have not yet joined Parkinson's UK and would like to do so, please tick the box for item 1, fill in your details and send to the Secretary.

If you know of someone affected by or interested in supporting Parkinson's UK, cut this form off and give it to them. They may then tick the box of item 2 to get on the newsletter mailing list (and item 1 if so minded) and send off to the Secretary, David Perry. His phone number is 01430 421412.

REPLY SLIP - to be sent to The Secretary, 11 Middle Garth Drive, South Cave, BROUGH, E. Yorkshire HU15 2AY

1	I wish to join PARKINSON'S Please send me a Membership Application			
2	I wish to receive the <b>HULL PARKINSON</b> newsletter			
NAME email				
ADDRESS				