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WALES NEWS

Autumn 2019

WELCOME

In this issue

Welcome to the second 2019 edition of the Parkinson's UK Cymru bilingual newsletter.

This year has flown by - there is so much to celebrate it might not all fit between these pages!

Some really significant and innovative pieces of work, shaped by and with contributions from, people affected by Parkinson's, have been developed through the year including our 'strengthening our local work' project in north Wales and our Newly Diagnosed Days in south Wales. You can read more inside.

You can also read more about our campaign successes and one of the highlights of the year - the World Parkinson's Day Boccia tournament - as well as some amazing fundraising stories from across Wales.

If you're interested in fundraising, join us to help fund groundbreaking research and life-changing services for people with Parkinson's. We can support your fundraising activities every step of the way, from a bake sale to a sing-a-thon, our fundraising officers and fundraising pack are at hand, full of information and advice. Contact our Fundraising team on **020 7963 3912**, email **fundraising@parkinsons.org.uk** or download your free pack from our website: **www.parkinsons.org.uk/get-involved/order-fundraising-pack**

We always welcome your feedback on the newsletter so please do get in touch with Rachel Williams on **0344 225 3715** or email **rwilliams@parkinsons.org.uk** with your views.

Ana Palazon

Wales Director

SUCCESS! DRUG APPROVED FOR USE IN WALES

This year, Opicapone has been made available to all patients in Wales who need it. Previously, a lack of a clear policy for the use of Opicapone in Wales meant a postcode lottery of who could access the drug. There were also delays in making it available to those who had been granted access to it.

Opicapone is a Parkinson's drug known as a COMT inhibitor, these drugs are used alongside levodopa to help it work better.

COMT inhibitors do not help to manage the symptoms of Parkinson's on their own – they must be used with levodopa. They may be suitable for some people who find their dose of levodopa is not working for long enough.

Some people with Parkinson's find they cannot tolerate other types of COMT inhibitor, or they may not work so well for them. The approval of Opicapone for use in Wales means a further treatment option for people living with Parkinson's.

Raymond Cooper from south Wales who shared his experiences of using Opicapone

Parkinson's UK campaigned to make access to the drug easier. It will enable people living with Parkinson's to have greater choice in the treatment options available to them.

We shared the experiences of people with Parkinson's when their medication wears off and of the impact Opicapone has had for some already using it. This helped us to make a strong case to the NHS who agreed that Opicapone can be made available for use for 12 months initially, to gather more evidence about its effectiveness.

Rachel Williams, Policy, Campaigns and Communications Manager for Parkinson's UK Cymru, said: "We're really grateful to those people living with Parkinson's who shared their experiences of Opicapone and delighted it's now available as an option for those people who may benefit from it via the One Wales Interim commissioning process.

"However, the nature of the policy means this decision only applies until March 2020. We look forward to working further with people living with Parkinson's to campaign to make this a permanent decision."

If you are using Opicapone, or have used it in the recent past, and are willing to share your experiences, we'd really like to hear from you to help us make the case. Please get in touch with Rachel Williams, Policy, Campaigns and Communications Manager, Wales by email **rwilliam@parkinsons.org.uk** or telephone **0344 225 3715**.

PARKINSON’S OUTPATIENT CLINIC SAVED!

Working closely with local volunteers, Parkinson’s UK Cymru has successfully campaigned to save a Parkinson’s outpatient clinic on the brink of closure.

The clinic, in Neath Port Talbot, south Wales, had a question mark over its future due to a range of complicating factors - from the consultant specialising in Parkinson’s being due to retire and uncertainty over funding for administrative support.

Working with members of Neath Port Talbot local group, we gathered evidence, met with the local Assembly Member, David Rees, and wrote letters to the Chief Executive of the health board. Finally we had a face to face meeting with decision makers in a position to make changes and improvements.

Rachel Williams, Policy, Campaigns and Communications Manager for Parkinson’s UK Cymru said: “We are delighted action has now been taken by Swansea Bay University Health Board to ensure the future of the Parkinson’s outpatient clinic in Neath Port Talbot.”

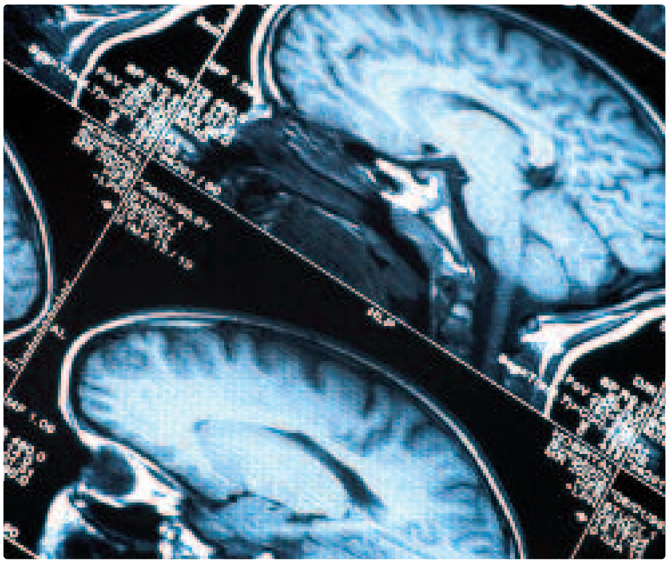
Tony Hillier, coordinator of the Neath Port Talbot local group and patient representative on the partnership group told us: “As people with Parkinson’s often struggle when it comes to travel, it’s vital to have a clinic 'on our doorstep' where both newly diagnosed and people who have lived with Parkinson’s can be seen by a specialist.”

DEEP BRAIN STIMULATION - SHARE YOUR EXPERIENCES

Deep Brain Stimulation (DBS) is the main type of surgery used to treat the motor symptoms of Parkinson’s. People in Wales who are suitable for DBS have to travel to England for the surgery as it is not available in Wales.

The Welsh Health Specialised Services Committee (WHSSC) is responsible for commissioning DBS for Welsh patients at hospitals in England. Currently, people in north Wales go to the Walton Centre in Liverpool, those in south Wales travel to Southmead Hospital in Bristol and people in mid Wales to the Queen Elizabeth Hospital in Birmingham. People also have to travel to these hospitals for their pre and post surgical care.

We want to understand the experiences of people affected by Parkinson’s who have had, or are awaiting, DBS surgery so we can share this with WHSSC as they look at the best way of delivering DBS care (both before and after surgery.)



If you would be willing to chat about your experience, please get in touch with Rachel, Policy, Campaigns and Communications Manager, Parkinson’s UK Cymru **rwilliams@parkinsons.org.uk** or telephone **0344 225 3715**.

LIVE LOUD! A PROJECT TO SHOUT ABOUT

Live Loud! has proved a hugely successful volunteer led initiative for people with Parkinson's related speech difficulties. The popularity of the scheme continues to grow and we've been working on ways to reach more people affected by Parkinson's.

People have told us they would like to join in but find it difficult to commit to another activity outside of their local group or to travel to one of the locations where Live Loud! is already set up.

In response we've piloted the inclusion of Live Loud! directly into some of our south Wales groups so that it becomes embedded within the activities the group offers. We have developed a comprehensive toolkit and training for volunteers so that they can offer Live Loud! sessions true to the original model of the scheme but within their group setting.

Swansea Live Loud! in action

This approach is working well with two new schemes successfully set up in Bridgend and Swansea and training for another two groups in Monmouth and Chepstow recently completed.

If you'd like to find out more about Live Loud! Please contact Karin Chandler, Live Loud! Project Worker **kchandler@parkinsons.org.uk** or telephone **07966 827887**.

NEWLY DIAGNOSED DAYS PROVING POPULAR

People often tell us they wish they had been signposted to Parkinson's UK when first diagnosed, to benefit from the information and support on offer.

The South Wales Local Development Team (LDT) felt strongly it was important to try to reach out to newly diagnosed people. The first 'Newly Diagnosed Day' was held in September 2018, developed in partnership with people living with Parkinson's and Adam Lewis, Parkinson's Nurse Specialist in Neath Port Talbot.

Neil Ranft, who lives with Parkinson's and is a member of the LDT hosted the event and people with Parkinson's contributed enormously with their personal stories, as well as hints and tips for living better with Parkinson's.

36 people with Parkinson's and their families attended the event and the feedback was excellent.

Participants at the recent Cwm Taf Newly Diagnosed Day getting involved

We continue to develop these days across south Wales and the north and mid Wales LDT has also recently held its first newly diagnosed event at Glyndwr University in Wrexham.

For more information about future Newly Diagnosed Days in south Wales contact Suzanne Marchment on **0300 123 3671** or email **smarchment@parkinsons.org.uk**. For north and mid Wales, contact Dawn McGuinness on **0344 225 3713** or email **dmcguinness@parkinsons.org.uk**

PARKINSON'S UK CYMRU GOES BOCCIA BONKERS IN BALA!

To celebrate World Parkinson's Day on 11 April, 22 teams made up of people affected by Parkinson's from across north and mid Wales, joined by Mark Isherwood, Assembly Member for north Wales (and Chair of the Cross Party Group on Neurological Conditions at the National Assembly) and ITV Wales News, gathered at Penllyn Leisure Centre in Bala for an eagerly anticipated boccia tournament.

Boccia (pronounced 'Bot-cha') is an indoor precision ball sport, similar to bowls and has been a Paralympic sport since 1984, there is no Olympic equivalent. Athletes throw, kick or use a ramp to propel a ball onto the court with the aim of getting closest to a 'jack' ball.

The Boccia Tournament has evolved from humble beginnings, when a couple of years ago we joined forces with other charities such as Dementia Go and MS Society to set up informal, fun sessions, in Porthmadog and Bala. As these are rural areas, setting up a Parkinson's specific group would have been unsustainable, but working with other charities means we can have more people attending, making the groups more viable. The Porthmadog group quickly evolved into the first Gwynedd Boccia League, which has just completed its first season, where our Parkinson's team took second place.

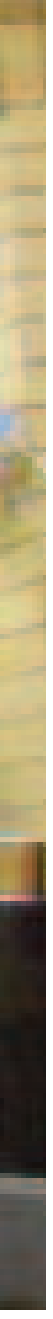
There are now monthly sessions in several Parkinson's groups across north Wales. Our long-term aim is to have a Boccia League in each county, with the winners of each county coming together for an all Wales final.

Elaine Evans was diagnosed with Parkinson's at the age of 47 and has been living with the condition for 18 years.

Elaine said: "I got involved with Boccia as I felt it was a fantastic way for people living with a disability to engage with sport. I am the coordinator for the South Snowdonia Parkinson's Support Group, as a group we applied and received a grant from Disability Sport Wales to purchase Boccia equipment. Part of the grant conditions was to set up a Boccia tournament. With the help of Parkinson's UK Cymru we decided to hold a Boccia tournament made up of teams from across mid and north Wales area."

If you'd like to find out more about the boccia activities on offer, please contact Dawn McGuinness on **0344 225 3713** or email **dmcguinness@parkinsons.org.uk**

Pictured above: left to right - Mark Isherwood AM, Rob Williams, Linda Rhys, Ruth Williams, Del Rhys (members of the winning Arfon and Môn Group team) and Dawn McGuinness, Area Development Manager for north and mid Wales



STRENGTHENING OUR LOCAL WORK IN NORTH WALES

In 2018 the charity embarked on an ambitious project to find different ways to best support people with Parkinson's locally. North Wales was one of the pilot areas for this work.

Members of the Local Development Team (LDT), local groups and people affected by Parkinson's came together to discuss and agree what they wanted to achieve:-

- share knowledge, resources and good practice
- reduce inequality throughout North Wales
- try to reach more people affected by Parkinson's
- bring everyone together to achieve better joint outcome
- make sure plans fit with Parkinson's links to deliver Parkinson's links quicker
- work to provide efficient use of money and resources.

A small project group was formed with representatives from four of the seven local groups in North Wales. Everyone shared their plans and budgets for the year and were able to challenge each other on what each planned activity would achieve for people affected by Parkinson's and whether it was good use of charity money. It also helped identify where resources could be shared and savings made.

In a bold new step for the way groups work across an area, as well as sharing their annual budgets they agreed to share their surpluses - if there was an activity that one group would like to set up but couldn't afford to, it would be funded through shared surpluses - this is how this year's Boccia Tournament in Bala was funded.

The project group learnt how to improve their approach to raising awareness and marketing through a workshop, exploring options for a welcome pack for new members and agreeing to produce a promotional video showcasing the range of support available locally. You can watch the finished video on the Parkinson's UK Wales Facebook page.

To encourage the other north Wales local groups to become involved and share the benefits of doing so, a get together was organised showcasing the video and with project group members telling the story so far.

Alison Underwood from the Llandudno Support Group said: "By working together, we have generated more ideas, bounced them off each other and thought "outside the box" to solve more challenging problems."

Dawn McGuinness, Area Development Manager for north and mid Wales, said: "Hearing the group representatives sharing their experiences and seeing their commitment to growing this way of working, is heartwarming. The way they work will continue to evolve but those original co-produced aims will continue to be the driving force.

Celebrating Torfaen

As many of you will know, the Torfaen Support Group went all the way last Christmas with its Bazar Extravaganza.

The hall was packed with local traders, crafts people and supporters from the area. Local MP, Nick Thomas-Symonds opened the event and lots of funds were raised through sales of Christmas goodies and incredible raffle prizes. A huge amount of organisation went into the event and it was a tremendous success.

And, if this was not enough, the tireless volunteers from the group were also celebrated during the early summer at the awards ceremony held by Torfaen Voluntary Alliance. Len, Dianne, Annie, Mike and Lynda were recognised for their contribution to the local Parkinson's community. We very much look forward to what the Torfaen Support Group may have in store this Christmas!

FABULOUS FUNDRAISERS!

1042 MILES IN 13 DAYS!

This summer, 54-year old, David Knight, from Buckley, Flintshire took on the cycling event in memory of his late father-in-law, Derrick Harding, who lived with Parkinson's for fifteen years. David cycled 1042 miles from Land's End to John O'Groats over 13 days, to raise £4,000.

David said: "I am delighted to have completed this charity cycle in memory of my father-in-law Derrick who had Parkinson's. I have been overwhelmed by people's interest and the support which I have received whilst undertaking the event.

"It's a wonderful feeling and I am so happy to have raised awareness of the condition and raised a huge amount for Parkinson's UK."

Thank you to David's employers Airbus who generously donated to his challenge.

David is pictured here with his uncle Gordon Knight, who supported him throughout the journey.

Mayor's charity cheque

Former Mayor of Bridgend County Borough, Councillor John McCarthy, chose to support Parkinson's UK during his year of office and has presented Parkinson's UK Cymru with a cheque for £2200.

A total of £6,600 was split equally between Parkinson's UK, Tenovus Cancer Care, and the Stroke Association after being raised at various events organised by the Mayor.

Councillor McCarthy, who is the ward member for Hendre, said: "All three organisations do wonderful work to support local people so I'm thrilled to present these cheques. I'd like to thank everyone who supported my fundraising events."

Pictured here are Ian Lewis (Stroke Ambassador), Carys Jenkins (Regional Fundraising Manager for Tenovus Cancer Care), Bethan Palfrey (Regional Fundraising Manager for Parkinson's UK) and David Burt (Parkinson's UK Cymru volunteer) were presented with cheques from last year's Mayor of Bridgend County Borough, Councillor John McCarthy, and his wife, Judy.

FLYING HIGH FOR PARKINSON'S

A nurse from Rhydargaeau, Carmarthen, turned daredevil to raise over £1,000 for Parkinson's UK Cymru. 60-year-old, Gillian Edwards, faced her fears to undertake the Titan Zip Wire Challenge at Blaenau Ffestiniog, north Wales. Gillian flew at over 70 miles per hour on the alpha, bravo and charlie zip lines, travelling 1,890 metres.

Gillian, pictured right, has worked as a registered nurse for over 40 years, Ten of which she spent as a district nurse in the Carmarthen area, providing care and support to people living with Parkinson's and become closely involved with a number of families.

Gillian said:"I am delighted to have completed this zip wire challenge to raise money for Parkinson's UK Cymru. It means so much to me. I feel proud and privileged to be able to support such a worthy cause and to contribute to the continuing research into treatment and a cure for Parkinson's."

Robert Bates legacy

We'd like to acknowledge the incredibly generous donation made to the charity on behalf of the late Mr Robert Bates.

Mr Bates' brother, Stephen Bates told us: "My brother Robert Bates of Neath, South Wales passed away in October of last year after living with Parkinson's for 17 years. Rob was a man of great character, energy and humour who remained undaunted and never complained.

A great source of comfort to Rob was the support he received from Parkinson's UK, both from the regular publications that came through the post and the contact he made with the staff and others living with the condition.

As a token of his appreciation he asked me to make a substantial donation to the charity, a pledge I made and was finally able to fulfill last month. I sincerely hope the £10,000 (plus gift aid) will help to facilitate the support Parkinson's UK offer to people in south Wales."

Liz Morgan with the new Welsh Language web page

CROESO I PARKINSON'S UK CYMRU!

In 2017, after working with the Welsh Language Commissioner's office, our Welsh language policy was approved by the Senior Leadership Team cementing the charity's commitment to the Welsh language and enabling people to increasingly engage with us through Welsh.

As part of this work we're excited to share with you a couple of new developments. Firstly, within Wales, the charity will be known as Parkinson's UK Cymru. We are still very much part of Parkinson's UK but our new name, along with our new bilingual logo for Wales, gives us a much stronger Welsh identity as an organisation working within Wales, something that is very important when working with decision makers such as the Welsh Government.

We're working hard to improve our bilingual communication channels and you'll see that we now produce our Wales newsletter bilingually. We are increasingly sending out our press releases within Wales bilingually meaning we can reach more people and raise more awareness of Parkinson's by being seen by both Welsh and English speaking audiences.

We're also pleased to let you know that the Wales pages on the Parkinson's UK website are now available in both Welsh and English. Liz Morgan, Country Content Officer for Wales and Northern Ireland, who has been working on the website pages told us: "We know how important it is to be able to access information bilingually, and I am delighted we now have a Welsh language page. It is a work in progress, and we hope to gradually have more pages available. I'd love to hear what you like about it, and also which pages you would like to see bilingually in future."

If you have any suggestions, or feedback on the page, email Liz on **lmorgan@parkinsons.org.uk** or telephone **0300 123 3685**. You can find the page through the following link. Or go to the main website, and click on About Us, then Parkinson's UK in Wales.

www.parkinsons.org.uk/cy/about-us/parkinsons-uk-cymru

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Your mum, son or neighbour. Anyone can get Parkinson’s, young or old. Every hour, two more people are diagnosed.

Parkinson’s is what happens when the brain cells that make dopamine start to die. There are over 40 symptoms, from tremor and pain to anxiety. Some are treatable, but the drugs can have serious side effects. It gets worse over time and there’s no cure. Yet.

But we know we’re close to major breakthroughs. By funding the right research into the most promising treatments, we get closer to a cure every day.

Until then, we're here for everyone affected by Parkinson’s. Fighting for fair treatment and better services. Making everyone see its real impact.

People with Parkinson’s, scientists and supporters, fundraisers and families, carers and clinicians, all working side by side. Impatient for change, we’re taking a stand, speaking out, chipping in, and playing our part.

We are Parkinson's UK. Powered by people. Funded by you. Together we'll find a cure.

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