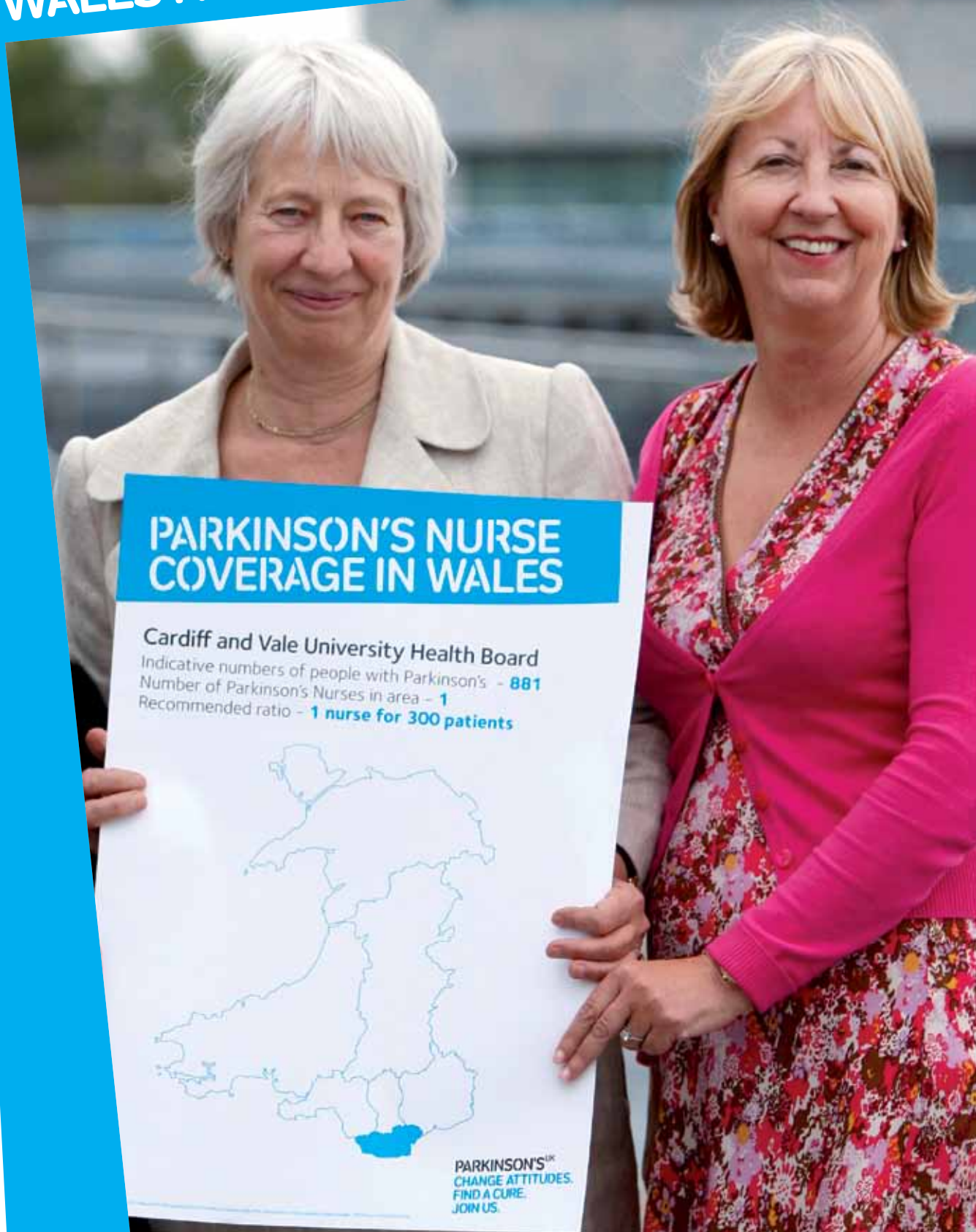


PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.

YDDRAIG

WALES NEWS Autumn 2011



PARKINSON'S NURSE COVERAGE IN WALES

Cardiff and Vale University Health Board
Indicative numbers of people with Parkinson's - **881**
Number of Parkinson's Nurses in area - **1**
Recommended ratio - **1 nurse for 300 patients**



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

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HELLO

Welcome – croeso!
I hope you enjoy
this issue of the
**Parkinson's UK Wales
newsletter. So much has been
happening across the country
and there's plenty to look
forward to.**



We're working closely with community pharmacists and staff in local pharmacies to arrange training for them about Parkinson's. We're also looking at how we can work more closely with pharmacists to deliver the best possible local support for people affected by the condition.

In the Hywel Dda Health Board area, we're planning a long-term partnership to enable health and social care professionals to learn more about Parkinson's. We want to implement effective medicines management programmes to ensure that

people with Parkinson's receive the best possible care when they're in hospital. We'll be inviting local groups in the area to discuss this work in more detail.

We're working hard to increase Parkinson's nurse coverage in Wales. In July, we launched our new guide on the benefits of Parkinson's nurses. The guide, which is targeted at NHS planners in Wales, was unveiled at the Welsh Assembly building in Cardiff. As a result, we're already talking with decision-makers from the Aneurin Bevan and Cardiff and Vale Health Boards to campaign for more Parkinson's nurses in these areas. We'll keep you updated on our progress. Our other hot-spot area is Neath Port Talbot, which is part of the Abertawe Bro Morgannwg University Health Board.

Following our successful event last year, we're hosting another Learn and Share day on Tuesday 1 November at the Royal Oak Hotel in Welshpool. This will be a great opportunity to meet members from across Wales and discuss our plans for Parkinson's Awareness Week 2012. And for those of you who were involved in our two-day branch event, I would like to take this opportunity to thank you for your help and commitment to making the event such a success. We're using your valued comments in our planning for 2012 – which we know will be another busy year.

A huge thank you to all – together we are making a difference.

Diolch yn fawr,

Aileen Napier

CAMPAIGNING FOR PARKINSON'S NURSES IN WALES

In July, as part of a UK-wide campaign, we launched our new guide for NHS planners in Wales: 'Parkinson's nurses – affordable, local, accessible and expert care'.



The guide provides evidence of the significant contribution that Parkinson's nurses make to the local delivery of care for people with Parkinson's and their carers.

We launched the publication at a reception at the National Assembly for Wales. It gave us an opportunity to celebrate the role of Parkinson's nurses and to highlight the need for more nurses.

We want to ensure that everyone with Parkinson's in Wales can have access to one. The event was attended by 50 of our members, along with 17 assembly members and support staff, as well as representatives from other organisations.

The event was opened by Jeff Cuthbert, Assembly Member for Caerphilly. John and Sue Day from Montgomeryshire Branch spoke about the benefits of having access to their Parkinson's nurse. Assembly members met with their constituents to hear about their experiences and receive copies of the guide. We're asking them to support us by taking specific actions, including sending a letter to the chief executive of their local health board and signing a statement of opinion.

The statement was laid down by Christine Chapman, Assembly Member for Cynon Valley, who is a keen supporter of Parkinson's UK.

How you can help

We need your help with the campaign, too. You can contact your assembly member, health board and the Health Minister to tell them how important Parkinson's



John and Sue Day of Montgomeryshire Branch

nurses are and to highlight the need for everyone in Wales to have access to one. You can email your assembly member direct from our website and there are example letters you can use to write to your health board and the Health Minister at parkinsons.org.uk/walescampaigning

It will really help us if you can let us know of any actions you take and any responses you receive.

You can also help us by telling us about your experiences with a Parkinson's nurse by using the interactive map at parkinsons.org.uk/nursemap

Follow the instructions on the webpage to add your comment to the map. If you have a Parkinson's nurse, please tell us what your nurse means to you. If you don't have access to a Parkinson's nurse, please tell us why you need one.

Get involved at parkinsons.org.uk/walescampaigning or contact Carol Smith on **0844 225 3715** or email csmith@parkinsons.org.uk

Campaigning for
Parkinson's nurses at the
Welsh Assembly building

PUTTING A STOP TO DYSKINESIA

Jenni McCabe of Parkinson's UK Newport Branch reports on her visit to Professor Brambilla's research project at Cardiff University, which aims to put a stop to dyskinesia. The Newport Branch raised £2,000 to support the project.



I went to Cardiff University's Department of Life Sciences to hear Dr Riccardo Brambilla speak about his project to counteract dyskinesia. This is a side effect that some people who have been taking levodopa for a while may experience.

The talk was particularly interesting to me, because I experience dyskinesia myself. Dr Brambilla has identified pathways in the brain that allow dyskinesia to flourish, and has produced a substance that can close off the pathways to prevent dyskinesia.

He has tested this substance, a type of peptide, in mice that have been treated to display Parkinson's symptoms. The results are really encouraging, and he is now seeking further funding to set up a company to produce peptides more cheaply than they can currently be produced, and to obtain an international patent. Using these peptides, Dr Brambilla would like to take the prototype drug through further testing to clinical trials. He estimated that the timescale for this would be three to five years.

During his presentation, Dr Brambilla indicated that no medication is available to minimise the effects of dyskinesia – apart from a drug currently available, called amantadine. This drug is not widely used because it can cause adverse side effects.

I'm benefiting from amantadine with no apparent side effects, so I asked why we were developing a new drug when one already exists. Dr Kieran Breen, Director of Research and Innovation at Parkinson's UK confirmed that although amantadine is used to help a small number of people with dyskinesia, it can only be used to treat some people with Parkinson's who have this problem, as the drug can cause side effects.

That's why we need to find better treatments. There are a number of studies currently researching dyskinesia, all using slightly different approaches. Parkinson's UK wouldn't fund a project if the charity didn't consider it to be important. This research may lead to the development of better and more effective treatments.



RESEARCH UPDATE

Finding better treatments to improve the lives of everyone living with Parkinson's is a vital part of our work. We fund research studies across the UK, and we're currently funding more than £800,000 of research in Wales.

Some Parkinson's UK-funded projects in Wales:

- **£13,441 over 12 months to Dr Peter Hobson at Cardiff University.**
Dr Hobson is investigating a new test for people with Parkinson's to spot thinking and memory problems at the earliest stage. He hopes that his research will help to identify people with Parkinson's who need to be referred for more assessments of in-depth thinking and memory.
- **£34,939.63 over 12 months to Dr Jeff Davies at Swansea University.**
Dr Davies is investigating whether ghrelin (a hormone produced in the stomach) can

protect the dopamine-producing nerve cells that die in Parkinson's. This research could lead to the development of drugs that can slow or stop Parkinson's – something no current treatments can do.

- **£251,496 over three years to Professor Riccardo Brambilla at Cardiff University.**
Professor Brambilla is working on ways to tackle the uncontrollable movements (known as dyskinesia – see left) that some people develop as a side effect of Parkinson's drugs. Early results from his team have shown that blocking a key molecule inside nerve cells could significantly reduce these side effects.

For summaries of these projects and other research funded by Parkinson's UK, visit parkinsons.org.uk/currentresearch or call **020 7963 9326**.

To find out how you can actively support research through joining the Research Support Network, please email rsn@parkinsons.org.uk or call Emily Hughes on **020 7963 9376**.

LATEST NEWS

We couldn't achieve what we do without the support of the valued members of our local group network, community groups, local businesses and fundraisers. We're constantly amazed at the lengths people go to support us by raising money in their local communities – with friends, families and neighbours.

This year in Wales we've seen cycle rides, social nights, sales and shows that have helped to raise vital funds to improve the lives of people affected by Parkinson's. And there's more to come! Keep an eye on our website for events happening near you. If you're interested in getting involved, get in touch with our Wales Fundraiser on **0844 225 9835** or email rf.wales@parkinsons.org.uk



Ray Cooper of Pontyclun has been fundraising for us for three years. He's organised a variety of events, including an annual cream tea in his back garden for friends and neighbours, which has turned into a much anticipated annual occasion. He's also organised concerts with local male voice choirs, soloists and musicians. He has also approached his church, his local golf club and other local businesses for support. Ray was a great supporter of the campaign for a Parkinson's nurse in his area, and continues to support our work in Wales and Parkinson's research.

Warburtons Bakery has awarded the South West Wales Younger Parkinson's Network a donation of £250. Thanks to this gift, members of the group enjoyed a field trip to the small market town of Narberth in Pembrokeshire.



Earlier this year, Tom Walker of Newport, along with 15 colleagues and members from the Celtic Manor Resort, organised a 54-mile walk over three days. The team followed the Taff Trail from Brecon to Cardiff Bay. Tom has a family member with Parkinson's, so wanted to raise money to support the work we're doing to help families like his.



The Machynlleth Support Group was set up in 2007 by members of the local community health board who were aware of the need for local support for people with Parkinson's. Their main objective was to campaign for a Parkinson's nurse for North Powys to provide the care that was needed. Over the years the group has organised coffee mornings and other events to raise funds, and earlier this year, member John Watkins ran the London Marathon at the age of 74, raising £2,715 for Parkinson's UK. A Parkinson's nurse was appointed to North Powys in November 2009, and in July 2010, Fiona Edwards joined Parkinson's UK as information and support worker for Powys. Unfortunately, the group has now decided to disband as its numbers have dwindled due to ill health.

Thanks to all of the Machynlleth Support Group members for their invaluable work and support over the last four years. We wish them well for the future.



Stephen Pilbeam of Holyhead, his son Wil and his daughter's partner Mike, walked the Anglesey coastal footpath from Amlwch to raise funds for Parkinson's UK. He has a family member with Parkinson's and is well aware of the effect it has on the whole family. Stephen wanted to support the work of the charity across the UK, as well as his local branch.

If you have any local news, please email cymru@parkinsons.org.uk

JOIN US: AUTUMN EVENTS

LEARN AND SHARE DAY

Tuesday 1 November



The Royal Oak Hotel, Welshpool

Back by popular demand, this will be a great opportunity to meet members from across Wales.

DANCE THE NIGHT AWAY – PENPERLLEN

Saturday 19 November



7.30pm

Goytre Sports and Social Club,
Penperlleni

Tickets are £10 each and available from the village hall nightly or by calling Derek Curtis on **01873 880000** or **07968 691314**.

WALES WINTER WARMER CONCERT

Saturday 19 November



2.30pm

All Hallows Church, Miskin, near Cardiff

Join us for an afternoon of music with a Christmas twist as we welcome winter in Wales.

Every ticket sold helps us to find a cure and improve life for people affected by Parkinson's in Wales.

Tickets £8. See our main events section for more information or contact Philippa Davies, Wales Fundraiser, on **0844 225 9835** or email rf.wales@parkinsons.org.uk

LIVING WITH PARKINSON'S

A poem written by Hywel Griffiths, member of the South West Wales Younger Parkinson's Network.

If you wake up each morning feeling quite low or quite sad,
I'd like you to think that life's not quite that bad –
Because the first thing I think of – the question that begs –
Is whether my brain will talk to my legs.

And if it appears that different languages they are talking,
I know that for sure that I'll have difficulty walking.
But I never stop and wonder – 'Why me?'
I've just come to accept that's the way things will be.

So before you complain – just think how lucky you are,
And how you take things for granted – like driving a car,
Then instead of a frown wear a smile on your face –
You'll find that it might even brighten the place!

Do this for yourself, for your friends far and near,
For your family and everyone else you hold most dear.
And if after all you still find that you really can't cope,
Then the thing to remember is that there is always some hope.

For this hope allows us our troubles to share,
And a positive attitude helps the people who care.



Hywel Griffiths at work as a police constable in Wales

IMPROVING LIFE FOR EVERYONE AFFECTED BY PARKINSON'S

Social services

Earlier this year, the Welsh Government published a white paper called Sustainable Social Services for Wales – a Framework for Action. This outlined a wide range of priorities including:

- focusing on citizen-centred services with more opportunities for user involvement
- developing a model of self-directed support

As a result of the March referendum, the Welsh Government has now increased powers to make legislation in various areas, including health and social care. The Welsh Government is planning to introduce a Social Services (Wales) Bill that will provide, for the first time, a legal framework for social services in that. Consultation on the Bill will take place this winter (with the Bill being introduced

in October 2012) and we'd like people affected by Parkinson's to get involved in this consultation.

Carers

The Carers Strategies (Wales) Measure 2010 places a new duty on health boards and local authorities in Wales to work, on their own or in partnership, to prepare and publish a carers' strategy. Regulations and guidance on implementing the measure is being developed and will be in place early 2012.

A carers strategy should outline the ways that health boards and local authorities will:

- provide information for carers
- engage with carers as partners – on i) assessments and ii) the provision and evaluation of care services
- train staff to better assist carers



Call our helpline for the latest information on services and benefits

As part of their planning for Carers Week 2012 (18–24 June) Carers UK are researching the Olympics. They're keen to find out about carers and their families in the UK who may have an Olympic link of any kind – either past or present.

Were you ever an Olympic contender? Did you ever travel with the Great Britain team? Do the Olympics mean something special for you as a carer? Whatever your link is with the Olympics, Carers UK would be really keen to hear from you. Please send your details to the Carers Week Media Officer, Rebecca Couper, at rebecca.couper@carersuk.org

Benefits

We know that many people with Parkinson's find the support of the benefits system a lifeline. A major part of our work this year has focused on benefits, because a Bill before Parliament proposes massive cuts to the welfare state. We are determined that people with Parkinson's should not lose out.

Two benefits being targeted under the Bill are Disability Living Allowance (DLA) and Employment and Support Allowance (ESA).

Disability Living Allowance

The DLA helps towards extra costs of living with a condition such as Parkinson's.

Under the Bill, everyone of working age currently receiving DLA will be reassessed for a new benefit called Personal Independence Payment (PIP), from spring 2013. The aim is to cut the bill for DLA by £2billion (or 20%) in the coming years.

The savings will come from having a new assessment, regular re-testing of eligibility, one less care rate for PIP than for DLA, and removing the mobility component of DLA from people of working age in state funded-residential care.

The idea of a new assessment is particularly troubling. There is no guarantee assessors will understand Parkinson's and its fluctuations properly. We think people with a progressive condition such as Parkinson's should be exempt from the stress of face-to-face assessments and periodic reviews. Written medical and other evidence could be relied on instead, and would actually save money.

DLA also provides an important passport to other benefits, such as the Blue Badge Scheme, and can be the difference between a carer getting Carer's Allowance or not. However, the plans to retain these links are vague.

Elaine Evans from Gwynedd has been helping us call on MPs to reject these proposals:

“
As a younger person with Parkinson's, I'm alarmed at the way disability benefits for people of this age group are being targeted for cuts. When you have a fluctuating condition such as Parkinson's, this financial support is a lifeline to help you live an independent life.”

Employment and Support Allowance

Employment and Support Allowance (ESA) is a benefit for people of working age who are unable to work due to illness or disability. We're unhappy with the way people with Parkinson's are tested for this benefit and that some are declared fit to work and refused support, despite the way their Parkinson's affects them.

Unfortunately, the Bill adds insult to injury. It will withdraw ESA from some claimants after only twelve months, irrespective of their national insurance contributions.

Steve Parker, from Monmouthshire, is someone who has been helping us call on MPs to reject this measure.

“People with Parkinson's have paid into the system, in the expectation that in the event of illness then they would be supported,” Steve says. “It feels as if the government is breaking a contract.”

“Can the government promise that they will fund research into conditions such as Parkinson's to a level that's sufficient to ensure claimants would be cured within the twelve-month period?”

How can I help?

If you feel strongly or would like to help us defeat some of the measures in the Bill, please get in touch with Donna O'Brien, Social Policy and Campaigns Officer, on **020 7963 9307** or dobrien@parkinsons.org.uk

COMMUNITY PHARMACISTS ARE VITAL TO OUR WORK

We're currently discussing some exciting opportunities with the Wales Centre for Pharmacy Professional Education (WCPPE) – the body responsible for providing continuing learning support to community pharmacists in Wales.



Whenever you pick up prescriptions at your local pharmacy, it's the community pharmacists that make sure you have the correct medication. They are the people we can approach to discuss side effects and other issues about medication.

We need to make sure that all community pharmacists have up-to-date information about Parkinson's and are able to signpost people to valuable support services such as Parkinson's UK's free confidential helpline.

Between January and March 2012, community pharmacists will be offered educational sessions on Parkinson's as part of their continuing professional development. These sessions will be run by WCPPE, with some parts delivered by Parkinson's UK.

So that we can give a full and clear picture of Parkinson's in these sessions, we're looking for volunteers across

Wales who have Parkinson's who would be able to speak to community pharmacists about living with the condition. We want volunteers to talk about how Parkinson's impacts on their daily living and the importance of medication in managing their symptoms.

If you're interested in helping us, we're not expecting you to do this alone. You would be supported by our Education Training Officer, Tracey Anderson, before, during and after the session. We'll work with you on what you want to say and help you get across your experiences. These sessions will run in the evenings in locations across Wales, so we're looking for volunteers from all parts of the country. We're also looking for stories about your local pharmacy – whether people have been helpful on the subject of Parkinson's, or whether you've experienced any problems or anxiety.

If you think you might be interested in talking to people about Parkinson's and the work of Parkinson's UK, you can also become a volunteer educator. We are looking for more volunteer educators to go into care and nursing homes to deliver a standard one-hour session. You will be fully supported in this role and can choose how much time you give to the project.

If you are interested in taking on any of these volunteer opportunities and would like some more information, please call Tracey Anderson on **0844 225 3711** or email tanderson@parkinsons.org.uk

CONTACTS

Parkinson's UK Wales

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Dawn McGuinness, Branch and Volunteer Support Officer (North and Mid Wales)	0844 225 3713
Andrew Penny, Branch and Volunteer Support Officer (South Wales)	0844 225 3714
Philippa Davies , Wales Fundraiser	0844 225 9835
Cathy Probyn, Information and Support Manager	0844 225 3712
Alyson Smith, Administrator for Wales	0844 225 3784

Information and support workers

Karen Miles (Blaenau Gwent, Torfaen, Monmouth and Newport)	0844 225 3789
Anne Marie Hawkins (Cardiff and Vale of Glamorgan)	0844 225 3718
Vicky Riddle (Camarthenshire, Ceredigion and Pembrokeshire)	0844 225 3716
Sara Owen (Flintshire, Denbighshire and Wrexham)	0844 225 3719
Gillian Wills (Gwynedd, Anglesey and Conwy)	0844 225 3787
Fiona Edwards (Powys)	0844 225 9841
Kaye Emberlin (Rhondda Cynon Taff, Merthyr Tydfil and Caerphilly)	0844 225 3717
Kathleen Hierons (Swansea, Neath Port Talbot and Bridgend)	0844 225 3774

Trustee

Alun Morgan, Wales Trustee	01656 663384
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Every hour, someone in the UK is told they have Parkinson's. Because we're here, no one has to face Parkinson's alone.

We bring people with Parkinson's, their carers and families together via our network of local groups, our website and free confidential helpline. Specialist nurses, our supporters and staff provide information and training on every aspect of Parkinson's.

As the UK's Parkinson's support and research charity we're leading the work to find a cure, and we're closer than ever. We also campaign to change attitudes and demand better services.

Our work is totally dependent on donations. Help us to find a cure and improve life for everyone affected by Parkinson's.

Parkinson's UK Cymru

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Free* confidential helpline **0808 800 0303**

Monday to Friday 9am – 8pm

Saturday 10am – 2pm. Interpreting available.

Text relay **18001 0808 800 0303**

(for textphone users only)

*calls are free from UK landlines and most mobile networks.