# Welsh Pharmacy Review ISUE 60 - 2024

# CHRONIC KIDNEY DISEASE

Awareness and action in primary care

WELSH PHARMACY AWARDS

Entry is now open

#### ROYAL PHARMACEUTICAL SOCIETY

Advocating for the profession

PARKINSON'S

The impact of the workforce crisis

#### ALL WALES MEDICINES STRATEGY GROUP

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# WPR

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# WELCOME

## EDITOR'S LETTER

# Welcome to the latest edition of Welsh Pharmacy Review!

Those long-held memories of my school days are now increasingly shrouded in fog – with the exception of the day I undertook my A Level History exam. This isn't because the questions penned on the test paper triggered any particular poignancy, but because of the escalating pain pounding in my head throughout. By the time I blotted my final full stop and the exam co-ordinator commanded our departure from the hall, the pain was pulsating through the rest of my body. I backed out of the end-of-exam plans and instead spent the duration of the day resting in a dark room, interjected only with bouts of nausea.

When the doctor later informed me about migraines, I was eager to dismiss his diagnosis. I had spent years misunderstanding their impact – secretly dubbing anybody I knew who experienced one as dramatic, and as simply utilising their label to escape unwanted plans. To me, they were 'just a headache'. Although I soon corrected my course of thought, now when I in turn opt out of engagements due to the onset of migraines, I fear that others may view it as a flimsy excuse.

This is only a simple example, I know, however it still taught me about how easy it can be to slot into a mindset of preconception. In fact, as I began plotting this edition of WPR, the towering hurdle of misunderstanding – and the urgency in overcoming it – emerged time and time again in our expert articles. Misperception can breed a limited want for empathy, education and awareness, which subsequently can derail the drive for improvement in many health areas.

In fact, AMMF is eager for the population to 'Rethink Liver Cancer' – addressing some important misconceptions about cholangiocarcinoma, and why there's a need to improve the way this often lethal cancer is diagnosed and treated (page 40). Dr Michael Long additionally explains how migraine still remains quite a poorly-understood condition (page seven), while continued failure to recognise the impact of endometriosis is contributing to worsening diagnosis times for the condition (page 32).

Elsewhere in this issue, explore the NHS workforce crisis' severe impact on Parkinson's care (page 20), and find out about the All Wales Medicines Strategy Group's new five-year strategy for Wales (page six), as well as how the Royal Pharmaceutical Society have been amplifying the voices of the profession at the Senedd (page four).

Also – Zoe Kennerley delves into the workload aligned with her role as an antimicrobial pharmacist (page 18); and Simon Evans reflects on his experiences as a final year pharmacy student at Cardiff University (page 27).

Don't forget to check out the unveiling of this year's Welsh Pharmacy Awards categories too, and details on how you can enter for a chance to win (beginning on page 21).

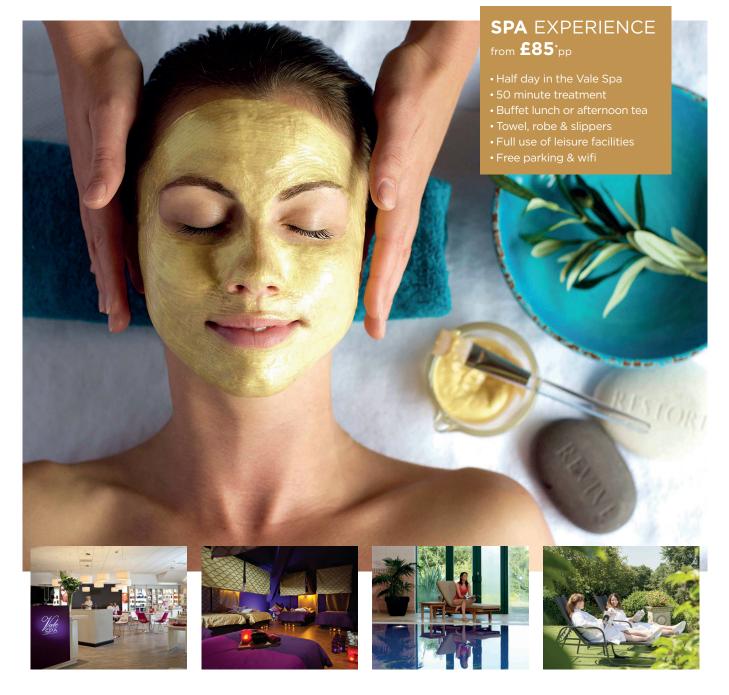
Happy reading!





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# ROYAL PHARMACEUTICAL SOCIETY

# A WORK IN PROGRESS

A big part of what we do at Royal Pharmaceutical Society (RPS) Wales is to be the voice for our members and the profession at the Senedd, explains RPS Wales Director, Elen Jones, in this issue's column, as she reflects on recent topics addressed, advocated for, in addition to the progress being paved.



With the NHS and healthcare being such a high-profile issue in the news and within political circles, it's so important that the politicians appreciate the amazing work of pharmacists and understand what support we need from them to provide the best care to our patients.

That's why we make sure to have a strong presence at the Senedd and regularly brief politicians on the issues that matter to you. The last few months have been particularly busy on this front.

### OUR EVIDENCE ON CHRONIC CONDITIONS AT THE SENEDD

Back in March we were invited to give oral evidence to the Senedd's Health and Social Care Committee as part of their inquiry into chronic conditions management.

If you're unfamiliar with this committee, they are made up of six Members of the Senedd (MSs) who scrutinise the work of the NHS and Welsh government on health matters. They do this by holding inquiries into specific topics. These inquiries usually follow three steps:

1. A public call for written evidence

2. Expert organisations or individuals to attend an evidence session with them to delve deeper into issues

3. A detailed report will be produced with recommendations to the Welsh government who usually take forward those recommendations

So this is a very influential committee! Therefore, we always make sure to build relationships with every committee member and engage with all of their inquiries. We find that getting them to advocate on our behalf and make positive recommendations for pharmacy in their reports can be incredibly powerful and far-reaching. Positive changes and initiatives that can be traced back to this engagement over recent years include:

• Funding for pharmacy's 10-year vision (Pharmacy: Delivering a Healthier Wales)

• Parity of support for community pharmacy staff with the rest of the NHS during the pandemic

• Increased role for pharmacists in care homes and reducing inappropriate antipsychotic medicines use

For this inquiry on chronic conditions, we had already provided written evidence last summer. We also held an event at the Senedd in October where MSs had a chance to meet us and RPS members with relevant expertise in Parkinson's and respiratory conditions; Sheridan Court from Swansea Bay University Health Board and Charlotte Pritchard from Cwm Taf Morgannwg University Health Board, who brought the pharmacy's expertise to life for the politicians. This prior engagement meant they were keen to hear more from us, and I was delighted to attend an evidence session at the Senedd to go into further detail. I was joined by RPS Fellow, Chris Brown, who was able to share his extensive experience in renal care and his role as a consultant pharmacist.

At the evidence session, a significant aspect of the discussion focused on how pharmacists can empower patients to optimise their medication management through:

• Collaborating with patients to streamline their medication regimen

Addressing polypharmacy concerns

• And engaging in appropriate prescribing or de-prescribing practices

Other topics addressed during the session included the role pharmacists and pharmacy teams across all sectors, health literacy and prevention efforts, facilitating self-management, the need for enhanced referral pathways, and addressing health inequalities.

In addition to explaining pharmacy's integral role in chronic condition management, we also stressed the necessary support required for the profession to effectively fulfil this role.

This included calling for:

• Consistent integration of pharmacy teams within broader multidisciplinary frameworks

• Job planning that allows adequate time for training

• Mitigation strategies for challenges like medicine shortages

A big thank you to Chris, Charlotte and Sheridan for their support with this work – your expertise and knowledge really resonated with the politicians! We're now looking forward to the committee's report.

#### ROYAL PHARMACEUTICAL SOCIETY Wales Cymru

## ROYAL PHARMACEUTICAL SOCIETY



Chris Brown and Elen Jones giving evidence to the Senedd's Health and Social Care Committee

### BACK AT THE SENEDD – ADVOCATING FOR THE WORKFORCE'S WELLBEING

A few weeks later, we were back in the Senedd, as a mixture of our staff and board members held an event where we invited MSs to join us to discuss the result of our recent workforce wellbeing survey.

The results show a worrying 86 per cent of pharmacists are at high risk of burnout with inadequate staffing, lack of worklife balance, absence of a colleague or senior support, and long working hours being cited as contributing factors. Meanwhile 61 per cent of respondents reported not being offered sufficient protected learning time to focus on their professional development and learning needs, despite the drive across pharmacy to provide more clinical and prescriber-led services.

In all we met with 22 MSs to firstly brief them on the results and, more importantly, to explain to them what solutions are needed:

- Adequate staffing and resource
- Protected learning time within work hours
- Embedding clear competency-based career pathways

• Increased public messaging on the role and pressures facing pharmacists

Thank you to every one of you who took the time to complete the wellbeing survey. I can't stress how powerful it was to be able to refer to the robust data and lived experiences that was provided. It was clearly a real eye-opener to the politicians that helped so much to get our messages across to them.



Mabon ap Gwynfor



Samuel Kurtz

### MOVING FORWARD WITH OUR 10-YEAR VISION

Away from our work at the Senedd, we've been continuing to support the work of the Pharmacy: Delivering a Healthier Wales (PDaHW) Delivery Board and working groups driving the profession forward towards our 2030 vision. We've also been busy raising awareness of PDaHW by visiting pharmacy teams across the country.

You can find out more about PDaHW and sign up to our Champions Network for regular updates at: www.rpharms.com/ wales/pharmacy-delivering-a-healthier-wales

We're also excited to be able to share details of the second annual PDaHW Conference. It will be taking place at the Park Gate Hotel in Cardiff on 19th September.

Look out for more details and registration through RPS member emails and our social media – www.facebook.com/ rpswales and www.twitter.com/RPS\_Wales.

It was fantastic to be joined by nearly 200 pharmacy professionals last year for such an inspiring and energetic day. Hopefully we'll see you there with us this year!







Above images: last year's PDaHW Conference



# LOOKING TO THE FUTURE

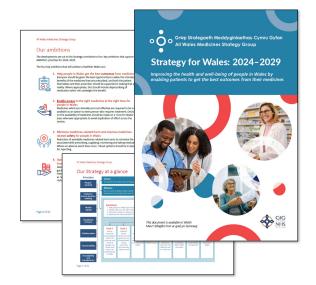
The All Wales Medicines Strategy Group has launched a new five-year strategy for Wales.

It is the role of the All Wales Medicines Strategy Group (AWMSG) to advise Welsh Ministers on strategic developments in prescribing, ensuring that patients living in Wales have access to the right medicines at the right time. AWMSG advises on the use, management and the prescribing of medicines alongside working collaboratively with healthcare professionals in the development of prescribing guidance as part of its medicines optimisation programme.

All of this work is directed by an AWMSG Strategy for Wales which focuses on the following four key ambitions:

- To improve outcomes for patients
- To ensure the right medicines are available at the right time
- · To minimise medicines-related harm and improve safety

• To optimise the value the NHS achieves from its investments in medicines



With the support of the All Wales Therapeutics and Toxicology Centre (AWTTC), AWMSG has been developing their next five-year strategy for 2024 – 2029 which aims to make significant progress in a broad range of objectives that have been grouped under eight goals: • Advice, resources and guidance reflect the priorities and needs of

- people and health and social care professionals in Wales
- AWMSG advice, resources and guidance are disseminated, widely promoted and routinely implemented
- Data and technology are used to improve value, patient outcomes and safety
- Medicines assessment processes are rigorous, timely and deliver value
- Health and social care professionals receive high-quality training in the safe and effective use of medicines
- People in Wales take their medicines in a way that maximises their health outcomes
- Waste associated with medicines use is reduced and sustainability is improved

• The benefits of genetic-informed precision medicines are realised in Wales

AWMSG has a part to play in ensuring all people in Wales can receive health services that meet their needs by defining a strategy which aligns to the priorities of both NHS Wales and the Welsh government, and its members want to see significant progress made across all eight of their goals. This will be achieved through a concerted effort from the group members to drive and promote their work, but also through close collaboration between AWMSG and the key partner organisations named throughout the document.

Through the approach of open and collaborative working, AWMSG seeks to make sure that their resources are always directed to those areas where they can have the greatest impact, so they can achieve their vision to improve the health and well being of people in Wales by enabling patients to get the best outcomes from their medicines.

To read more about the AWMSG Medicines Strategy 2024 – 2029 (available in both English and Welsh), visit the AWTTC website at www.awttc.nhs.wales.





## MIGRAINE

# GETTING A HEAD START

Migraine is a complex, genetic neurological disorder which affects approximately one-in-seven adults worldwide. Although it is more common than epilepsy, asthma and diabetes, it receives a fraction of the research budget of these other conditions. Dr Michael Long, GP with special interest in headache and migraine, IslandHealth, Guernsey, Education Fellow, and Headache Specialist, National Migraine Centre, breaks down the multifaceted elements of the condition, crucial strides in research and management – and the action warranted to bring about much-needed awareness.



Dr Michael Long

Despite the fact that there are approximately one billion people worldwide with migraine, it still remains quite a poorly-understood condition. I am currently studying at the Danish Headache Centre which is one of the world's leading centres in migraine research.

Migraine essentially gives you an easily irritated brain, one that likes routine. It is a whole-body disorder where headache is only one of the symptoms. Often people will experience nausea, vomiting, loss of balance, and want to lie down in a

dark room during an attack. One-third of people will also experience aura.

Migraine is also a threshold disorder, which is likely genetically linked. Things often described as triggers can raise a person's tolerance above their threshold. Many people endlessly search for a trigger – in my experience this can be a fruitless endeavour. Despite doing everything 'right', people can still experience attacks. If you are a person with migraine, it can already affect your life significantly, therefore I discourage people from trying to avoid specific things to avoid attacks. This often leads to a worse quality of life and often no improvement in attack frequency.

#### **COMMON REASONS**

The most common reasons for having an attack are hunger, dehydration, changes to sleep pattern (too much, or too little sleep) and stress. Some of these we can influence, but others are more difficult. I would suggest that those with migraine eat regularly (every three-to-four hours), maintain good hydration, and try to maintain as regular a sleep pattern as possible, including at the weekends. The Heads Up Podcast, which is produced by the National Migraine Centre, is an invaluable source of information for patients with migraine.

Women are three-times more likely than men to suffer from migraine. This can also be greatly affected by life-changing events, such as pregnancy and the menopause. I have had many patients whose migraine attacks have disappeared during pregnancy, although the first trimester can often be a very difficult time for those with migraine. On the flip side, migraine becomes much more common and frequent during the peri-menopause and menopause.

#### **BREAKING THE STIGMA**

I think the perception that migraine is 'just a headache' creates a lot of stigma around migraine. People often do not understand the severity of attacks. The effects can be very debilitating and the person is unable to function in the home or work environment. They are also much more likely to suffer from conditions, such as depression and anxiety. The WHO recognise migraine as the second leading cause of years lived with disability in the world. I see lots of people in my clinics, both at the National Migraine Centre and GP surgery, who are struggling to get support from their workplace and feel that their migraine attacks are poorlyunderstood and stigmatised.

#### **MEDICATION OVERUSE HEADACHE**

For someone with chronic migraine they will have attacks on more than 15 days per month, less than that it is usually called episodic migraine. Often those with a diagnosis of chronic migraine started with episodic but it has become more frequent over time. One of the main causes of this can be the overuse of acute medication, such as simple analgesia, opiates (such as codeine), or triptans. Use of any acute treatment for more than two-to-three days per week for three months can cause medication overuse headache (MOH). Usually happening slowly over time, it is thought that this condition can account for up to 50 per cent of people with chronic headache. It is important that patients are told about the risk of MOH when taking medicines for their headache. Once MOH is established, it can be very difficult to treat and prevention is almost certainly more effective.

#### **MEDICATION OPTIONS**

There are lots of preventative medications available for migraine – these include multiple easy tablet options, such as Candesartan, Propranolol or Amitriptyline. For those with chronic migraine who have tried three or more preventers they can also become eligible for other treatments, such as Botox or the newer anti-CGRP medications. CGRP is calcitonin gene-related peptide which was found to be higher in people during attacks. Some of the research for this medication was actually done at the Danish Headache Centre where a team won the Brain Prize for their work in the development of these drugs. The biggest benefit of the newer medications is that in general they are extremely well-tolerated with very few side-effects.

#### LOOKING TO THE FUTURE

Migraine is still a very under-diagnosed disorder. My advice is that anyone presenting in primary care with an episodic headache that impacts their ability to function, with a normal examination, has migraine until proven otherwise. Unfortunately at present migraine has no cure but what we aim to do at the National Migraine Centre is to work on a plan that allows people to feel in control of their attacks, rather than migraine controlling their life. We are also able to prescribe all the anti-CGRP medications which are often described as 'life-changing' by a lot of patients.

For more information about the National Migraine Centre, visit www.nationalmigrainecentre.org.uk.





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Prescribing Information and the adverse event reporting statement can be found on the opposite page.

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#### Recommended by NICE in eligible adult patients (restricted use)<sup>2,3</sup>

NICE, National Institute for Health and Care Excellence.

1. Vydura (rimegepant) Summary of Product characteristics for Great Britain; Vydura (rimegepant) Summary of Product characteristics for Northern Ireland; 2. NICE. Rimegepant for treating migraine. October 2023. https://www.nice.org.uk/Accessed April 2024; 3. NICE. Rimegepant for preventing migraine. July 2023. https://www.nice.org.uk/Accessed April 2024; 3. NICE. Rimegepant for preventing migraine. July 2023. https://www.nice.org.uk/Accessed April 2024; 3. NICE. Rimegepant for preventing migraine. July 2023. https://www.nice.org.uk/Accessed April 2024; 3. NICE. Rimegepant for preventing migraine. July 2023. https://www.nice.org.uk/Accessed April 2024; 3. NICE. Rimegepant for preventing migraine. July 2023. https://www.nice.org.uk/Accessed April 2024; 3. NICE. Rimegepant for preventing migraine. July 2023. https://www.nice.org.uk/Accessed April 2024; 3. NICE. Rimegepant for preventing migraine. July 2023. https://www.nice.org.uk/Accessed April 2024; 3. NICE. Rimegepant for preventing migraine. July 2023. https://www.nice.org.uk/Accessed April 2024; 3. NICE. Rimegepant for preventing migraine. July 2023. https://www.nice.org.uk/Accessed April 2024; 3. NICE. Rimegepant for preventing migraine. July 2023. https://www.nice.org.uk/Accessed April 2024; 3. NICE. Rimegepant for preventing migraine. July 2023. https://www.nice.org.uk/Accessed April 2024; 3. NICE. Rimegepant for preventing migraine. July 2023. https://www.nice.org.uk/Accessed April 2024; 3. NICE. Rimegepant for preventing migraine. July 2023. https://www.nice.org.uk/Accessed April 2024; 3. NICE. Rimegepant for preventing migraine. July 2023. https://www.nice.org.uk/Accessed April 2024; 3. NICE. Rimegepant for preventing migraine. July 2023. https://www.nice.org.uk/Accessed April 2024; 3. NICE. Rimegepant for preventing migraine. July 2023. https://www.nice.org.uk/Accessed April 2024; 3. NICE. Rimegepant for preventing migraine. July 2023. https://www.nice.org.uk/Accessed April 2024; 3. NICE. Rimegepant for preventing migraine. July 2024; 3. NICE. Rimegepa

### ACUTE

#### NICE recommendation published October 2023:<sup>2</sup>

- 1.1 Rimegepant is recommended as an option for the acute treatment of migraine with or without aura in adults, only if for previous migraines:
  - at least 2 triptans were tried and they did not work well enough or
  - triptans were contraindicated or not tolerated, and nonsteroidal anti-inflammatory drugs (NSAIDs) and paracetamol were tried but did not work well enough.
- 1.2 This recommendation is not intended to affect treatment with rimegepant that was started in the NHS before this guidance was published. People having treatment outside this recommendation may continue without change to the funding arrangements in place for them before this guidance was published, until they and their NHS clinician consider it appropriate to stop.





# PREVENTION

#### NICE recommendation published July 2023:<sup>3</sup>

- 1.1 Rimegepant is recommended as an option for preventing episodic migraine in adults who have at least 4 and fewer than 15 migraine attacks per month, only if at least 3 preventative treatments have not worked.
- 1.2 Stop rimegepant after 12 weeks of treatment if the frequency of migraine attacks does not reduce by at least 50%.
- 1.3 If people with the condition and their clinicians consider rimegepant to be 1 of a range of suitable treatments, after discussing the advantages and disadvantages of all the options, use the least expensive. Take account of administration costs, dosage, price per dose and commercial arrangements.
- 1.4 These recommendations are not intended to affect treatment with rimegepant that was started in the NHS before this guidance was published. People having treatment outside these recommendations may continue without change to the funding arrangements in place for them before this guidance was published, until they and their NHS clinician consider it appropriate to stop.

#### Prescribing information for Great Britain and Northern Ireland

, This medicinal product is subject to additional monitoring. This will allow quick identification of new safety information. Healthcare professionals are asked to report any suspected adverse reactions. See section 4.8 of the SmPC for how to report adverse reactions. VYDURA\* 🛡 (rimegepant) Prescribing Information: Please refer to the Summary of Product Characteristics (SmPC) before prescribing VYDURA 75 mg oral lyophilisate. Presentation: Oral lyophilisates containing 75 mg rimegepant. Indications: Acute treatment of migraine with or without aura in adults. Preventive treatment of episodic migraine in adults who have at least 4 migraine attacks per month. **Dosage**: For acute treatment of migraine, the recommended dose is 75 mg rimegepant, as needed, once daily. For prophylaxis of migraine, the recommended dose is 75 mg rimegepant every other day. The maximum dose per day is 75 mg rimegepant. Another dose of rimegepant should be avoided within 48 hours when it is concomitantly administered with moderate inhibitors of CYP3A4 or with strong inhibitors of P-gp (see SmPC section 4.5). VYDURA can be taken with or without meals. The oral lyophilisate should be placed on the tongue or under the tongue. It will disintegrate in the mouth and can be taken without liquid. Patients should be advised to use dry hands when opening the blister and referred to the package leaflet for complete instructions. No dose adjustment is required in patients aged 65 and over as the pharmacokinetics of rimegepant are not affected by age (see SmPC section 5.2). No dose adjustment is required in patients with mild, moderate, or severe renal impairment. Caution should be exercised during frequent use in patients with severe renal impairment. Use of rimegepant in patients with end-stage renal disease (CLcr < 15 ml/min) should be avoided. No dose adjustment is required in patients with mild (Child-Pugh A) or moderate (Child-Pugh B) hepatic impairment. The use of rimegepant in patients with severe hepatic impairment should be avoided. The safety and efficacy of VYDURA in paediatric patients (< 18 years of age) have not been established. Contraindications: Hypersensitivity to the active substance or to any of the excipients listed in SmPC section 6.1. Warnings and Precautions: Hypersensitivity reactions, including dyspnoea and rash, have occurred in less than 1% of patients treated with rimegepant in clinical studies (see SmPC section 4.8). Hypersensitivity reactions, including serious hypersensitivity, can occur days after administration. If a hypersensitivity reaction occurs, rimegepant should be discontinued and appropriate therapy should be initiated. VYDURA is not recommended in patients with severe hepatic impairment (see SmPC section 4.2), in patients with end-stage renal disease (CLcr < 15 ml/min) (see SmPC section 4.2), for concomitant use with strong inhibitors of CYP3A4 (see SmPC section 4.5) or for concomitant use with strong or moderate inducers of CYP3A4 (see SmPC section 4.5). If overuse is experienced or suspected, medical advice should be obtained, and treatment should be discontinued. The diagnosis of medication overuse headache (MOH) should be suspected in patients who have frequent or daily headaches despite (or because of) the regular use of medicinal products for acute headache. Drug Interactions: Rimegepant is a substrate of CYP3A4, P-glycoprotein (P-gp) and breast cancer resistance protein (BCRP) efflux transporters (see SmPC section 5.2). Concomitant administration of rimegepant with strong CYP3A4 inhibitors (e.g., clarithromycin, itraconazole, ritonavir) is not recommended (see SmPC section 4.4). Concomitant administration of rimegepant with itraconazole resulted in a significant increase in rimegepant exposure (AUC by 4-fold and C\_ 1.5-fold). Concomitant administration of rimegepant with medicinal products that moderately inhibit CYP3A4 (e.g., diltiazem, erythromycin, fluconazole) may increase exposure to rimegepant. Concomitant administration of rimegepant with fluconazole resulted in increased exposures of rimegepant (AUC by 1.8-fold) with no relevant effect on C<sub>max</sub>. Another dose of rimegepant within 48 hours should be avoided when it is concomitantly administered with moderate inhibitors of CYP3A4 (e.g., fluconazole) (see SmPC section 4.2). Concomitant administration of VYDURA with strong CYP3A4 inducers (e.g., phenobarbital, rifampicin, St John's wort (Hypericum perforatum)) or moderate CYP3A4 inducers (e.g., bosentan, efavirenz, modafinil) is not recommended (see SmPC section 4.4). The effect of CYP3A4 induction may last for up to 2 weeks after discontinuation of the strong or moderate CYP3A4 inducer. Concomitant administration of rimegepant with rifampicin resulted in a significant decrease (AUC reduced by 80% and C<sub>my</sub> by 64%) in rimegepant exposure, which may lead to loss of efficacy. Inhibitors of P-gp and BCRP efflux transporters may increase plasma concentrations of rimegepant. Another dose of VYDURA within 48 hours should be avoided when it is concomitantly administered with strong inhibitors of P-gp (e.g., cyclosporine, verapamil, quinidine) (see SmPC section 4.2 and 4.5). Concomitant administration of rimegepant with cyclosporine (a potent P-gp and BCRP inhibitor) or with quinidine (a selective P-gp inhibitor) resulted in a significant increase of similar magnitude in rimegepant exposure (AUC and C<sub>max</sub> by > 50%, but less than two-fold). **Pregnancy & Lactation:** There are limited data from the use of rimegepant in pregnant women. Animal studies demonstrate that rimegepant is not embryocidal, and no teratogenic potential has been observed at clinically relevant exposures. As a precautionary measure, it is preferable to avoid the use of VYDURA during pregnancy. The relative percentage of a maternal dose estimated to reach the infant is less than 1%. There are no data on the effects on milk production. The developmental and health benefits of breast-feeding should be considered along with the mother's clinical need for VYDURA and any potential adverse reactions on the breastfed infant from rimegepant or from the underlying maternal condition. Driving and Operating Machinery: VYDURA has no or negligible influence on the ability to drive and use machines. Side Effects: The most common adverse reaction was nausea for acute treatment (1.2%) and for migraine prophylaxis (1.4%). Most of the reactions were mild or moderate in severity. Hypersensitivity, including dyspnoea and severe rash were uncommon side effects observed in the acute treatment and occurred in less than 1% of patients treated. Hypersensitivity reactions can occur days after administration, and delayed serious hypersensitivity has occurred. Legal Category: POM. Marketing Authorisation Holder Northern Ireland (NI): Pfizer Europe MA EEIG, Boulevard de la Plaine 17, 1050 Bruxelles, Belgium. Marketing Authorisation Numbers for NI: EU/1/22/1645/001, EU/1/22/1645/002 Marketing Authorisation Holder Great Britain (GB): Pfizer Limited, Ramsgate Road, Sandwich, Kent, CT13 9NJ, United Kingdom Marketing Authorisation Number for GB: PLGB 00057/1717 Local Representative: Pfizer Limited, Walton Oaks, Dorking Road, Tadworth, Surrey, KT20 7NS, UK. Package quantities, Basic NHS Price: VYDURA 75 mg, 2 x 1 oral lyophilisates, £25.80; 8 x 1 oral lyophilisates, £103.20;

PP-NNT-GBR-0700; July 2023

Adverse events should be reported. Reporting forms and information can be found at <u>www.mhra.gov.uk/yellowcard</u> or search for MHRA Yellow Card in the Google Play or Apple App Store. Adverse events should also be reported to Pfizer Medical Information on 01304 616161.

## THE PHARMACISTS' DEFENCE ASSOCIATION

### PDA EDUCATION OFFERS A FREE SUPPORT PROGRAMME TO TRAINEE PHARMACISTS

The PDA supports members in every stage of their career. To help trainee pharmacists with their assessment in June, the PDA has developed a number of programmes that are completely free to trainee members. Those that are not yet PDA trainee members can register for free today.

PDA Education's programme will provide trainee pharmacists with access to FREE resources and support ahead of the upcoming summer assessment.

The PDA wants to ensure that trainee pharmacist members have the guidance they need as the summer assessment approaches, including revision support, help with managing stress, and a clear understanding of the assessment process.

Those sitting the June 2024 assessment will now be able to access this series of free resources and events designed to support them in their preparation for the assessment.

#### **REVISION ASSESSMENT PROGRAMME**

Created by experienced pharmacists with backgrounds in writing assessment questions, the PDA's FREE programme will help to prepare trainee pharmacists for their assessment.

- This self-directed online programme includes:
- Over 100 practice questions
- Multiple practice case studies
- Two timed mock 'exams'
- Revision tips
- Guidance on the process for sitting the assessment
- Guidance on what to do if you do not pass
- And more!

Register for the revision programme here: www.the-pda.org/ supportfortraineepharmacists2024.

#### LIVE CALCULATIONS EVENTS

These live, online sessions will give trainee pharmacists the chance to practice calculations with immediate support provided by experienced pharmacists. The identical events will focus on dilutions, displacement values, and the common calculation errors made in the part one paper.

Trainees will also be able to ask questions to ensure that they understand each calculation. The sessions are ideal for those who are struggling with calculations or need a refresher.

As there is a limit of 25 people per session, members who are interested in attending one are encouraged to register as soon as possible.

- Session One will take place on Thursday 16th May from 7pm 8.15pm
- Session Two will take place on Thursday 13th June from 7pm 8.15pm

Register for a live calculation session at: www.the-pda.org/supportfortraineepharmacists2024.





## GET MENTALLY PREPARED FOR THE ASSESSMENT

Date: Wednesday 22nd May Time: 7pm – 8.15pm Place: Online via Microsoft Teams

The PDA and Pharmacist Support are hosting an online Get Mentally Prepared Workshop to support trainee pharmacists who are feeling stressed or anxious about the upcoming assessment. The live session will cover:

- Strategies trainees can implement to help them look after their wellbeing and explore relaxation and meditation
- The science behind visualisation and how to use it
- How our thoughts can impact how we feel
- The importance of sleep
- Other areas related to exam preparation.

This session is part of Pharmacist Support's upcoming trainee ACTNow wellbeing campaign.

Register for the session here: www.the-pda.org/ supportfortraineepharmacists2024.

If members have any questions about the above, they should email pdaeduaction@pda-union.org.

## NOT YET A PDA MEMBER?

These courses are exclusively available to PDA members. Membership of the PDA is free to pharmacy students, trainee pharmacists, and for the first three months of being newly-qualified.

Join the PDA at: www.the-pda.org/join.

# **Trainee Pharmacists**

The PDA provides FREE comprehensive membership for all the work of a trainee pharmacist; supporting you on your career journey.

## Membership of the PDA gives you:

- Professional indemnity insurance whilst working as a pharmacist\*
- Representation and advice for fitness to practise hearings
- A dedicated team of pharmacists and legal experts on hand to provide support and advice
- A PDA Plus benefits package of discounts and special offers
- Membership of the PDA Union the only independent trade union in the UK exclusively for pharmacists
- Each year you are a member, we will donate £1 to the charity that helps pharmacists



## Join the PDA today at: the-pda.org/join



### Let's stay connected! Follow us on social media



\*The insurance included with PDA membership is arranged and administered by The Pharmacy Insurance Agency (PIA) Ltd who are authorised and regulated by the Financial Conduct Authority (Register No 307063).



|supporting **your** career |



## TRAUMA

# THE ROAD TO RECOVERY

Healthcare professionals from Wales are being encouraged to share their experiences of working with major trauma patients as a UK charity brings together professionals for the first time. Day One Trauma Support explain further, and delve into the necessity of support for those who have experienced life-changing catastrophic injuries, in addition to the importance of amplifying their voices.

Day One Trauma Support is organising Major Trauma Awareness Week to take place from 16th-to-22nd September 2024. The week will include a range of activities and opportunities for health professionals working in this space to shout out about the incredible work they do. This ranges from attending physical events and fundraising challenges, to supporting Day One's messaging online and sharing content on social media.

Each year thousands of people experience major trauma. Lifechanging injuries can have lots of causes, including road crashes, falls, industrial accidents, suicide attempts, and violence. Dedicated teams of professionals work around-the-clock to save and rebuild lives following the most horrendous injuries, with people relying on the work of healthcare professionals beyond the hospital ward too.

This year Day One will amplify the voices of those who have experienced life-changing injuries to discuss the real challenges people face after their injuries. The road to recovery can be long and difficult, often taking years. Most people who suffer major trauma will live with disabilities and experience mental health problems. The support available right now is often inadequate for their needs.

Day One is calling on professionals to champion the amazing

stories of recovery and the challenges people face after major trauma. The week will:

• Raise awareness so there is a greater understanding of the long-term impact catastrophic injuries have

• Celebrate the heroic professionals who work tirelessly to give people the best chance of recovery, from emergency care through to rehabilitation and beyond

• Bring together all the fantastic organisations, charities and industry leaders who give people the skills, courage and hope they need to rebuild their lives again

Surviving major trauma is just the start. Day One believes that noone should have to rebuild their life on their own.

For more information and to sign up to the week, visit www. dayonetrauma.org/mtaw.



EGIONAL MAJOR TRAUMA CENTRE

#### Day One Trauma Support

Support US so no one is left to rebuild their life on their own.

#### **MORE ABOUT DAY ONE**

Day One Trauma Support provides the emotional, practical and financial support people need after suffering life-changing catastrophic injuries. The charity provides bedside support alongside NHS colleagues in major trauma hospitals and through its national support to anyone in the UK. It also has a network of peer support volunteers who share their own experiences to bring hope and inspiration to others.

Day One was created in Leeds, West Yorkshire, by a trauma and orthopaedic surgeon and his patients. Now it supports people across England, Wales, Scotland and Northern Ireland, and works closely with healthcare professionals.

Day One provides emergency grants for items, such as clothes, accommodation and travel, so that families can remain close to their loved ones when the worst has happened. It also offers legal, welfare and benefits advice, counselling and peer support from volunteers who are further ahead on their recovery journey. More than half of major trauma cases in the UK are caused by road traffic collisions and falls, and trauma is recognised as the main cause of death for people under the age of 45 and is a major cause of debilitating long-term injuries.

Health professionals who work with patients and families following major trauma can refer people into the charity through its national offer. Counselling and emotional support is available for family members, as well as patients.

Dave Nichols, from Day One Trauma Support, said, 'In the briefest of moments, a catastrophic injury can shatter someone's life, with the impact on them and their loved ones hard to overstate. The amazing health professionals do a fantastic job putting people back together and we're here to help rebuild the rest of their life by helping with the emotional, practical and financial support they need.

'We're proud to be there for people when they need us, but unfortunately so many people miss out on the support they deserve. By working with professionals, we want to raise awareness of major trauma and reach more people so that no-one is left to cope on their own after a catastrophic injury.

'We would love to hear from professionals across the UK about the work they do and how we can help them provide the best possible care, and future for people.'

If you have someone who could benefit from Day One's services, you can call 0333 034 2107, email support@dayonetrauma.org or complete their self-referral form at www.dayonetrauma.org/ supporting-you. For more information, visit www.dayonetrauma.org.

## TRAUMA

#### **MAKING A DIFFERENCE IN WALES**

In Wales, Day One has provided support to a number of families following catastrophic injuries. Recently they supported a 10-yearold boy who was receiving life-saving treatment at The Childrens Hospital for Wales. He had been involved in a car crash with his entire family, including younger siblings. His mum, who was also injured, contacted Day One for emotional support for her, and her son.

Day One was able to support the mum. A caseworker from the charity was there to listen and understand. They provided practical support for the immediate future, but also got free counselling for mum so she could talk to a professional about the challenges she faced following an horrific incident.

The family are continuing to recover, but have Day One by their side for as long as it takes.

#### **LUCIE'S STORY**



Lucie Maguire and her family were supported by Day One Trauma Support when she spent 17 months (518 days) in a major trauma hospital recovering from bomb-like injuries after being hit by a tractor.

Lucie suffered life-changing injuries when she was hit by a tractor and dragged along the road under its 10-tonne trailer in January 2021. She had been trying to help her mum out of their smoke-filled car at the time. Her injuries, compared to those suffered by bombblast victims in wars, included full amputation of her right leg and pelvis, broken back and internal damage to key organs, including her bladder.

Lucie, who was 19 at the time, spent the first month in a coma fighting for her life. Her parents said 'goodbye' at her bedside as her internal bleeding was so severe, medics feared she would die. They also never knew whether she would be able to sit up or stand again.

Lucie spent more than a year on the hospital's major trauma ward confined to her bed, while specialist teams liaised with military medics to rebuild her body. By the time she left hospital on 28th June 2022 (518 days later), she could sit up and even walked on one leg while using supports. Throughout her stay in hospital, Lucie and her mum, Sue, were supported by Day One Trauma Support. Lucie was often scared, depressed, and at one stage pleaded with her mum to smother her with a pillow as she could not see an end to the pain and misery she felt.

Thankfully, Day One Trauma Support, along with psychologists and NHS staff, gave Lucie and Sue hope for the future and provided the emotional and practical support they needed to readjust to their new life, including Sue becoming Lucie's carer alongside running their village pub.

Lucie, 22, said, 'Day One Trauma Support was amazing. I feel like they saved my life. They were one of my constants, providing that emotional support that the busy NHS staff just don't have the time to give. They were with me at the start and they've been with me ever since. The emotional support my mum and I received from Day One was massive. Someone to talk to. Someone to offload to. Someone who doesn't judge and knows the bad days will get better.

'I had no idea how I was going to live and pay for things outside of hospital if I wasn't working. I had never thought about benefits as I'm a young woman and expected to work all my life. I didn't know how it all worked and what I needed to put in place when I left hospital. I remember speaking to someone from Day One about what I was entitled to, which was a massive relief for me as I wouldn't have known where to start.'

Samantha Monkman, Major Trauma Ward Manager, commented, 'All the staff involved with Lucie's care are delighted she's made such an amazing recovery and is working towards living independently at home. Lucie was our longest serving patient on the trauma ward and we became like family as we worked through all the challenges she faced together. It was the first time many of us had cared for a patient with the extent of injuries Lucie had, but by learning and working together we were able to give Lucie the best possible chance of recovery.

'As health professionals we could focus on Lucie's physical recovery, knowing Day One Trauma Support was there for her and her mum by giving them the emotional and practical support they needed, both in hospital and once they continued their recovery journey at home.'

Lucy Nickson, CEO of Day One Trauma Support, added, 'People are struggling financially during a cost-of-living crisis, and the impact is only compounded when a family member suffers a sudden catastrophic injury and faces a long recovery journey, often with a disability and reduced income. Our caseworkers are seeing the reality of this every day in the major trauma centres we operate and through our national support service. That's why we continue to need support so we can reach everyone who needs our help – people like

Lucie. Lucie's story of recovery is truly inspiring and we're so grateful that she has shared her story to support our cause. Together we can ensure no-one is left to rebuild their life on their own.'



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# **A SHOW OF SUPPORT**

The MS Trust delves into treatment approaches for MS patients - from the options available and evolving considerations, to the important role adopted by healthcare professionals throughout the management process.

Managing MS often involves two different approaches: • Symptomatic treatments – to manage the individual symptoms of MS

• Disease-modifying drugs - to treat the underlying condition

For the individual, learning to manage their symptoms takes time and they may need to try several options to find out what works best for them. Reading up about the different options can be helpful, so they can talk them through with their GP or MS team.

Treatment for MS may include medication, therapies, such as physiotherapy, and self-management techniques. Some people explore the use of complementary or alternative medicines.

There are also disease-modifying drugs which can reduce the number and impact of relapses and reduce the build-up of disability which can occur if the individual doesn't recover completely from relapses. Most disease-modifying drugs are for people with relapsingremitting MS, but there are some that are licenced for use by people with progressive MS. MS Decisions, our interactive decision aid, can help if people are considering a disease-modifying drug.

#### TREATING MS SYMPTOMS

#### WHAT ARE SYMPTOMATIC TREATMENTS?

Symptomatic treatments help relieve the physical or mental symptoms of a condition. They don't treat the underlying cause, or change the course of the condition. There's a wide range of treatments which are used to manage MS symptoms, they include:

• Drug treatments – such as medication for pain or spasticity

• Therapies – like physiotherapy to help with muscle stiffness, or cognitive behavioural therapy for pain, anxiety or depression

Management techniques – for example, learning to pace themselves to minimise fatigue

• Rehabilitation – which can improve day-to-day living. Depending on their needs, this might include services, such as physiotherapy, speech and language therapy, cognitive rehabilitation therapy, or an occupational therapist may give the individual aids or equipment that can help • Complementary and alternative medicines – this includes treatments, such as acupuncture, Pilates and mindfulness, which fall outside conventional medicine, but are recognised as being helpful in improving physical and mental wellbeing

# WHAT ARE THE PATIENT'S TREATMENT OPTIONS?

Treatments are available for the symptoms of MS, regardless of whether the individual has relapsing-remitting MS or progressive MS. Often people with progressive MS are under the impression that there aren't any treatments for them.

Their options will depend on what symptoms they're experiencing, how much they're affecting their day-to-day life, and sometimes what specialist services are available in their area.

# WHEN SHOULD THEY SEEK TREATMENT?

It can be difficult to know when to seek treatment and when to sit things out, especially if they're still learning about their MS. There are a few things the individual can look out for which may explain why their symptoms are worse at the moment:

• Do they have an infection, such as a cold, flu, tummy bug or a bladder infection? If so, this can cause a flare-up of symptoms. Their symptoms will improve as they recover from the infection so they should look after themselves in the usual way for a cold, flu or tummy bug, or visit their GP or MS nurse to see if they need antibiotics for a bladder infection

• Are they too hot? Many people with MS are sensitive to heat. They may find that hot weather makes their symptoms worse and the same can happen if the central heating is too high. They should do what they can to get cool and symptoms should improve

• Are they too cold? Some people find that being too cold makes their symptoms flare up, although this is not as common as heat sensitivity



• Are they feeling under pressure? Stress can make symptoms harder to live with and, for this reason, finding a technique that makes the individual feel more in control can be helpful

When to seek support from a health professional is a personal decision. However, if none of the aforementioned apply, or the individual's symptoms don't improve after a few days, the individual might want to consider getting support from their GP or MS team.

If the individual has new symptoms, their symptoms are suddenly much worse, or if they are having serious difficulty walking, it's probably worth contacting their MS nurse straight away – especially if they experience relapses.

Sometimes symptoms creep up on them and suddenly a slow, gradual worsening over months or years might add up to a big change the individual can't ignore. The individual should have their MS reviewed about once a year but, if this isn't happening or their appointment is a long way off, they can ask for a review.

If their symptoms are worrying them, interfering with their quality of life, or impacting negatively on family or friends – they shouldn't suffer in silence.

Remember, new symptoms may not be due to MS, so the individual should speak to their GP or MS team if they're concerned. Also, they should make sure they keep up with any vaccinations, or health screening for conditions, such as diabetes, high blood pressure or cancer, where appropriate.

#### WHICH HEALTH PROFESSIONALS WILL SUPPORT THE INDIVIDUAL?

Although the individual will be in charge of managing many aspects of their MS, like taking medication as prescribed or keeping up with exercises recommended by a physiotherapist, sometimes they might need a bit of extra support to make sure they're on top of their symptoms, they've selected the best treatment option for themselves, or if things change.

MS services work differently in different areas, so it's a good idea for them to check with their team in advance who to contact, and how, if they're concerned about symptoms.

The individual's symptoms may be reviewed by their neurologist, their MS nurse, or they may be referred to someone who specialises in a particular therapy, such as a physiotherapist or speech and language therapist, or someone who specialises in the management of a particular symptom, for example, a pain specialist, continence nurse or a spasticity nurse. Their GP can help with some symptoms or refer them to other services if they need them.

#### WHAT IF THE TREATMENT ISN'T HELPING?

Many treatments don't start working immediately, it may take a few weeks or months before they see any benefit. Hopefully they'll be given an idea of when they might expect to see results or be offered an appointment to review how they're doing after an appropriate time. For some medicines, the dose might have to be increased gradually until the individual finds the best possible relief for them. Typically they would start on a low dose and be advised when to increase the dose and by how much, or have a review before any changes are made.

Not all treatments work for everyone, so if the treatment really isn't working, they can ask if there's an alternative they can try. Sometimes it can be a case of trying several options, or a combination of treatments, to find what works best for them.

Unfortunately, sometimes treatments don't get rid of symptoms completely. For instance, treatments for nerve pain may reduce the pain to a more manageable level, but they may still experience some pain in the background. The same is also true for fatigue.

#### ARE THERE NEW OR EXPERIMENTAL TREATMENTS THEY SHOULD CONSIDER?

#### **EXPERIMENTAL TREATMENTS**

There is no cure for MS, so people should beware of anyone claiming they're offering a cure. The most important thing is to use reliable sources of information to inform their decisions, such as the MS Trust. Other sources may sound convincing but they may just be opinion, marketing hype or personal experience presented as facts.

If the individual does find a treatment that interests them, they should do their research. If there's been a genuine breakthrough, the main MS charities will be reporting it too. They should look for different opinions on the research and consider what is being said. Often research reported in the press is at an early stage, so it might be a while before a treatment becomes widely-available or it may never get to that point at all.

It can be tempting to try an experimental or controversial treatment, but the individual needs to consider the risks of harm, potentially significant side-effects and the costs involved. If in doubt, they should have a chat with their MS team or GP.

#### HOW DO THEY FIND OUT ABOUT NEW TREATMENTS?

MS is a very active area of research and new treatments are coming through all the time. They can keep asking if there are any new options during appointments with their MS team, especially if they feel their symptoms aren't being managed as well as they would like.

It's worth keeping an eye on our news and stories pages or read the latest research to stay up-to-date.

For more information, visit www.mstrust.org.uk.





## LATCH - WELSH CHILDRENS CANCER CHARITY

<u>LATCH</u> Welsh Children's Cancer Charity was established in 1983. The charity supports children receiving treatment for cancer & leukaemia, along with their families at the Children's Hospital for Wales. The charity supports around 150 families each year, over the last year we have, however, seen an increase in diagnosis.

<u>LATCH</u> is most well-known for its on-site family accommodation at the University Hospital of Wales, Cardiff. This unit consists of eight hotel-standard bedrooms (six of which are en-suite) with televisions as well as kitchen facilities, a laundry room, a dining room & lounge so families can make themselves at home. The accommodation is offered to families free of charge & helps keep families together during their child's stay in hospital. <u>LATCH</u> issues free passes to use the hospital sports centre to keep families active.

Staying on site allows families to stay together during a really challenging time, especially considering many families travel from as far as Aberystwyth.

<u>LATCH</u> also provides a vital Social work service – specifically the funding for a dedicated team of three social workers who specialise in the issues facing the families of children receiving treatment for cancer and leukaemia. The <u>LATCH</u> Social work team is there to provide practical, emotional & financial support in a confidential & safe environment.

Emotional Support for parents is offered in the form of counselling & alternative therapies. Running various support groups for parents including one-to-one sessions, as well as organising treats & get-togethers. Being with people in a similar situation often helps & doing something different can act as a much-needed support.

LATCH also provides a range of financial support through grants – this can be for travel, food, even rent in some cases. When a child goes through cancer or leukaemia treatment, families often face higher heating bills for example, & many parents have to give up work to care for a sick child.

LATCH offers holiday grants or the option to use their three caravans, & provides a number of excursions for children to the likes of Lego Land, build a Bear & other venues to provide a touch of normality or a well needed escape from ongoing treatment.

LATCH needs to raise on average £800,000 per year to cover the costs of supporting families. With no paid fundraisers & no government funding, we rely heavily on the hard work of volunteers & remain proud to have one of the lowest management expenses for a charity in the whole of the UK.











9TH JUNE 2024

# RUN & RAISE FOR

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Welsh Children's Cancer Charity Elusen Canser Plant Cymru

**IG** 

EMAIL: FUNDRAISING@LATCHWALES.ORG For more information

# DAY IN THE LIFE Bevar

"Creating health

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THINK ... INNOV

# ALL IN A DAY'S WORK

Zoe Kennerley grants WPR a glimpse into the workload aligned with her roles as a Clinical Lead Pharmacist and Antimicrobial Pharmacist – from her first steps forged in pharmacy, to the clinical knowledge and commitment she has fused into her support and promotion of antimicrobial stewardship.



Zoe Kennerlev

200 Kenneriey Health Board in Prince Phillip Hospital, Llanelli. The wide range of experiences that year gave me an appreciation of the variety of opportunities available in West Wales – from mental health, to medicines information, medical and surgical wards, palliative care, and antimicrobial stewardship ward rounds. Personal circumstances led to me making my way back home to Aberystwyth during the second year of my clinical diploma, and shortly after that I became the antimicrobial pharmacist in Bronglais Hospital.

My pharmacy journey

the journey across the

of Bath. I graduated in

border to the University

2015 and started my pre-

registration year working

at Hywel Dda University

started in 2011 as I made

This was a steep learning curve for me (and a total surprise speciality – it wasn't my favourite topic at university) but the blend of clinical knowledge, strategy and influencing behaviour change led to me really enjoying my job. Changing prescribing practices within the hospital, and working with the other antimicrobial pharmacists across the health board to write guidelines, organise audits and run educational sessions, helped me grow in confidence. I was fortunate to be able to undertake my independent prescribing qualification supported by two very experienced consultants in the hospital.

As we were hit by the COVID-19 pandemic I split my time between Bronglais Hospital and as the primary care antimicrobial pharmacist responsible for the whole health board. This offered me the chance to gain experience in a different setting with very different challenges. Influencing prescribing remotely across a large geographical area was difficult and I soon realised that regular bite-sized teaching, tailored feedback on prescribing, and prompts on the electronic prescribing system were effective. I was able to provide teaching and support to a wide range of healthcare professionals, including GPs, acute response team nurses, and community and cluster pharmacists, and teach on the Swansea University independent prescriber course.

Part of antimicrobial stewardship was ensuring that these groups knew when antibiotics are needed, but also which are best and any self-care and antibiotic-sparing options that are available. I was an integral part of the Hywel Dda team who introduced a new service to community pharmacies across the health board to help with access to UTI treatment for non-pregnant women aged 16-to-64. This service was a huge success for both patients and pharmacists and is in the process of being rolled out across Wales. I also had the chance to conduct some research and supervised an MPharm student on a project around penicillin allergy de-labelling, with plans to publish the findings later this year.

There is a well-established network of antimicrobial pharmacists across Wales where I have had the privilege of working with some inspirational leaders in this field. As the current Vice Chair of the Welsh Antimicrobial Pharmacist Group, I have participated in journal clubs, presented projects at national meetings and conferences, and contributed to national workstreams with audits and guidelines.

A

In 2023 I became a core member of the Commonwealth Pharmacist Grant Partnership with the Pharmaceutical Society of Malawi, collaborating on a project to support pharmacists in hospitals in Malawi to become leaders in antimicrobial stewardship, and in June 2023 we visited hospitals in Malawi to help implement some of the training. In summer 2024 we will welcome them to Wales to experience how antimicrobial stewardship works in our healthcare settings.

Earlier this year I took on the role of clinical lead pharmacist and have changed some of the day-to-day processes, developing the role of pharmacy staff at ward level, educating and empowering technicians to counsel more patients on their medications as a routine, and helping the health board to achieve the recommendations set out in the Welsh government hospital review. I have continued with my work on antimicrobials and can really say that no work day is ever the same!



### **Testosterone Undecanoate** Intramuscular Injection A new addition to the Teva generics portfolio!



Testosterone Undecanoate is indicated for testosterone replacement therapy for male hypogonadism when testosterone deficiency has been confirmed.<sup>1</sup>

We know that low testosterone can cause a range of symptoms, such as fatigue, low sex drive, and muscle loss. That is why we are committed to providing this treatment option for patients.

#### Key features of Testosterone Undecanoate

#### Long-lasting Effects:

**Testosterone Undecanoate** 

extended release, reducing the

intramuscular injection is known for its

frequency of administration compared to other testosterone formulations.<sup>2</sup>

Patient convenience:

Longer dosing intervals may help patient adherence.<sup>2</sup>

> Testosterone Undecanoate

1000 mg/4 ml Solution for Injection Intramuscular use

1 vial

By prescribing generically,

**Testosterone Undecanoate** can help cost savings compared to the brand originator price.<sup>3\*</sup>

References:

- 1. Testosterone Undecanoate 1000 mg/4 ml Intramuscular Injection SmPC Teva UK Limited
- Hackett, G. et al. (2023) 'The British Society for Sexual Medicine guideline on male adult testosterone deficiency, with statements for practice', The World Journal of Men's Health, 41(3), p. 508. doi:10.5534/wjmh.221027.
- Joint Formulary Committee. British National Formulary (online) London: BMJ and Pharmaceutical Press - https://bnf.nice.org.uk/drugs/ testosterone-undecanoate/medicinal-forms/ [Last accessed March 2024]

\* claim accurate as of 08/03/2024

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Please refer to the Summary of Product Characteristics (SmPC) for full details of Prescribing Information.

Testosterone Undecanoate Solution for Injection Abbreviated Prescribing Information. Presentation: Each vial with 4ml solution for injection contains 1000mg testosterone undecanoate corresponding to 631.5mg testosterone. Indications: Replacement therapy for male hypogonadism when testosterone deficiency has been confirmed by clinical features and biochemical tests. **Dosage and administration:** For intramuscular use only. Adults: One vial of testosterone undecanoate injection (corresponding to 1000mg testosterone undecanoate) is injected every 10 to 14 weeks. Serum testosterone levels should be measured before the start and during initiation of treatment. Depending on serum testosterone levels and clinical sumptoms, the first injection interval may be reduced to a minimum of 6 weeks as compared to the recommended range of 10 to 14 weeks for maintenance. With this loading dose, sufficient steady state testosterone levels may be achieved more rapidly. Children: Not indicated for use in children and adolescents. Elderly: Limited data do not suggest the need for a dosage adjustment in elderly patients. Renal impairment: No formal studies have been performed in patients with renal impairment. Hepatic impairment: No formal studies have been performed in patients with hepatic impairment. The use of testosterone undecanoate is contraindicated in men with past or present liver umours. **Contraindications**: Contraindicated in men with androgen-dependent carcinoma of the prostate or of the male mammary gland, past or present liver tumours, and hypersensitivity to the active substance or to any of the excipients. The use of Testosterone undecanoate injection in women is contraindicated. **Precautions and** warnings: Testosterone undecanoate injection should be used only if hypogonadism (hyper- and hypogonadotrophic) has been demonstrated and if other aetiology, responsible for the symptoms, has been excluded before treatment is started. Testosterone insufficiency should be clearly demonstrated by clinical features and confirmed by two separate blood testosterone measurements. There is limited experience on the safety and efficacy of the use of testosterone undecanoate injection in patients over 65 years of age. Currently, there is no consensus about age specific testosterone reference values, however, it should be taken into account that physiologically testosterone serum levels are lower with increasing age. Prior to testosterone initiation, all patients must undergo a detailed examination in order to exclude a risk of pre-existing prostatic cancer. Careful and regular monitoring of the prostate gland and breast must be performed in accordance with recommended methods in patients receiving testosterone therapy at least once yearly and twice yearly in elderly patients and at-risk patients. Testosterone level should be monitored at baseline and at regular intervals during treatment. In patients receiving long-term androgen therapy, the following laboratory parameters should also be monitored regularly: haemoglobin and haematocrit, liver function tests and lipid profile. Androgens may accelerate the progression of sub-clinical prostatic ancer and benign prostatic hyperplasia. Testosterone Undecanoate Injection should be used with caution in cancer patients at risk of hypercalcaemia (and associated hypercalciuria), due to bone metastases. Regular monitoring of serum calcium concentrations is recommended in these patients. Cases of benign and malignant liver tumours have been reported in users of hormonal substances such as androgen compounds. If severe upper abdominal complaints, liver enlargement or signs of intra-abdominal haemorrhage occur in men using testosterone undecanoate injection, a liver tumour should be included in the differential-diagnostic considerations. In patients suffering from severe cardiac, hepatic or renal insufficiency or is chaemic heart disease, treatment with testosterone may cause severe complications characterised by oedema with or without congestive cardiac failure. In such case, treatment must be stopped immediatelu. Caution should be exercised in patients predisposed to oedema. In case of severe complications characterized by oedema with or without congestive heart failure treatment must be stopped immediatelu. Testosterone may cause a rise in blood pressure. Testosterone undecanoate injection should be used with caution in patients with epilepsy and migraine, as the conditions may be aggravated. Improved insulin sensitivity may occur in patients treated with androgens who achieve normal testosterone plasma concentrations following replacement therapy. Pre-existing sleep apnoea may be potentiated. Testosterone undecanoate injection should be permanently withdrawn if symptoms of excessive androgen exposure persist or reappear during treatment with the recommended dosage regimen. Testosterone has been subject to abuse, typically at doses higher than recommended for the approved indication(s) and in combination with other anabolic

androgenic steroids. Abuse of testosterone and other anabolic androgenic steroids can lead to serious adverse reactions including cardiovascular (with fatal outcomes in some cases), hepatic and/or psychiatric events. Testosterone abuse may result in dependence and withdrawal symptoms upon significant dose reduction or abrupt discontinuation of use. Interactions: Testosterone and derivatives have been reported to increase the activity of coumarin derived oral anti-coagulants. Patients receiving oral anti-coagulants require close monitoring, especially at the beginning or end of androgen therapy. Increased monitoring of the prothrombin time, and INR determinations are recommended. The concurrent administration of testosterone with ACTH or corticosteroids may enhance oedema formation, therefore, these active substances should be administered cautiously, particularly in patients with cardiac or hepatic disease or in patients predisposed to oedema. Androgens may decrease levels of thyroxin-binding globulin resulting in decreased total T4 serum levels and increased resin uptake of T3 and T4. Free thyroid hormone levels remain unchanged, however, and there is no clinical evidence of thyroid dysfunction. **Pregnancy and** lactation: Testosterone undecanoate injection is not indicated for use in women and must not be used in pregnant or breast-feeding patients. Effects on ability to drive and use machines: No influence on the ability to drive and use machines. Adverse reactions: Polycythaemia, hypersensitivity, depression, bronchitis, dyspnoea, urinary retention, urinary tract disorder, prostatitis, pulmonary oil microembolism. Common: Haematocrit increased, red blood cell count increased, haemoglobin increased, weight increased, hot flush, acne, prostate specific antigen increased, prostate examination abnormal, benign prostate hyperplasia, injection site reactions (injection site pain, injection site discomfort, injection site pruritus, injection site erythema, injection site haematoma, injection site irritation, injection site reaction). Consult the Summary of Product Characteristics in relation to other side effects. Overdose: No special therapeutic measure apart from termination of the rapy with the medicinal product or dose reduction is necessary after over dose. List  $\mbox{Price}$  . Single 4ml vial, £74.04. Legal category: POM. Marketing Authorisation Number: PL 00289/2540. Marketing Authorisation Holder: Teva UK Limited, Ridings Point, Whistler Drive, Castleford, WF10 5HX. Job Code: MED-GB-00283 Date of Preparation: February 2024.

Adverse events should be reported. Reporting forms and information can be found at <u>www.mhra.gov.uk/yellowcard</u>. Adverse events should also be reported to Teva UK Limited on 0207 540 7117 or medinfo@tevauk.com.



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

# A MATTER OF TIME

Ana Palazon, **Director of** Parkinson's UK Cymru, reveals how the NHS workforce crisis is severely impacting care for people with Parkinson's - a condition that affects about 8,300 people in Wales.

# A FAILING SERVICE

Parkinson's is the fastest growing neurological condition in the world and currently there is no cure. There are over 40 symptoms associated with Parkinson's, which range from tremor and pain, to anxiety. Such a complex condition requires an integrated multidisciplinary approach to care, with expert input from a range of specialities.

Last year, we found that NHS staffing levels are so low that people with Parkinson's are often waiting years between appointments, which is causing their symptoms to deteriorate rapidly. The UK is bottom of the European league table for the number of neurologists and physiotherapists. In Wales, we estimate that about 1,700 people with Parkinson's are missing out on support from a Parkinson's specialist nurse.

## THE CURRENT LANDSCAPE

In 2022, we found that only 53 per cent of people with Parkinson's in Wales had access to a physiotherapist, 43 per cent had access to an occupational therapist, and 43 per cent to a speech and language therapist. The NICE guidelines on Parkinson's state that these therapies should be routinely offered to people with Parkinson's.

Growing and upskilling the Parkinson's workforce is vital to improving timely access to healthcare for people with the condition. Parkinson's is estimated to cost the UK economy £3 billion per year. This cost could be dramatically reduced through joined-up, proactive multidisciplinary care. For example, providing physiotherapy for people with the condition from diagnosis could save the UK economy up to £1 billion per year.

Through our campaigning, we are calling on the Welsh government to clarify how it will: • Address regional variations in workforce supply and demand across the country – stopping the postcode lottery and reducing shocking health inequalities

Incentivise and support nurses to train as Parkinson's specialists – an area the charity continues to support through funding
Give healthcare professionals protected time and space to learn more about Parkinson's so they can deliver the best possible care

## THE HUMAN IMPACT

Wendy, who is living with Parkinson's, was forced to adjust her own medication after struggling to get an appointment with her consultant. The retired nurse said she was unable to sleep and in pain after being told to change her medication. But after having a severe reaction and failing to speak to a medical expert or her Parkinson's nurse, she was so desperate that she made the drastic change herself.

Wendy says the consultants are 'wonderful', but a lack of healthcare professionals means that she is left waiting too long for appointments.

Wendy's situation is not unique. Sadly, we hear from so many people with Parkinson's who are upset and worried about not being seen regularly by health experts, which is essential to them staying well.

# WHAT YOU CAN DO

To learn more about Parkinson's, visit the charity's Excellence Network Learning Hub (www.parkinsons.org.uk/professionals/ learning-hub). It hosts bite-sized introduction courses and in-depth programmes for all levels of experience, across a range of disciplines.

## ABOUT PARKINSON'S And Parkinson's Uk

Parkinson's is what happens when the brain cells that make dopamine start to die. There are more than 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.

Parkinson's is the fastest growing neurological condition in the world. Around 153,000

people in the UK have Parkinson's.

We are Parkinson's UK. Here for everyone affected by the condition. Funding research into the most promising treatments, taking us closer to a cure every day. Fighting for fair treatment and better services.

For more information about Parkinson's UK, visit www.parkinsons.org.uk.

# Welsh Pharmacy Awards 2024

# Journey to Success

Returning for 2024, the Welsh Pharmacy Awards is striving to capture the heart and scope of the sector – and we need your help to do so!

Shouldering pressures while sculpting healthcare improvements; contending with present challenges while innovating future solutions – the strength and commitment of Wales' pharmacists only continues to soar. And once again, we are aspiring to showcase the sector's successes under the spotlight of the Welsh Pharmacy Awards.

This year the event will be taking place on 25th September at the Vale Resort, Glamorgan. Renowned host Andrea Byrne will be taking the reins of the celebration in which the winners of the multifaceted categories will be revealed.

The application process couldn't be easier so shrug off any reservations and allow us to take your team's achievements to the stage.

Turn the page for this year's categories and how you can enter. Good luck!



#### THE VALE RESORT, GLAMORGAN WEDNESDAY 25<sup>TH</sup> SEPTEMBER

## HOSPITAL PHARMACY TEAM OF THE YEAR

SPONSORED BY





Last year's winner, the Education and Training Team, Swansea Bay University Health Board, with Bruno Ultra Barcelos, Ethypharm UK, and Bethan Tranter, Chief Pharmacist, Velindre Cancer Centre

## PHARMACY STUDENT LEADERSHIP



Last year's winner, Caitlin Edwards, Cardiff University, with Helen Lewis, The Pharmacists' Defence Association, and Professor Andrew Morris, Swansea University **SPONSORED BY** 



## Welsh Pharmacy Awards 2024

#### THE VALE RESORT, GLAMORGAN

WEDNESDAY 25TH SEPTEMBER

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## SUSTAINABILITY IN HEALTHCARE

Welsh Pharmacy Awards 2023

Last year's winner, the JDS Evans Pharmacy Team, Newport, with Alasdair Mercer, Teva UK, and Paul Gimson, Assistant Director of

Improvement (Cwm Taf Morgannwg University Health Board)

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SPONSORED BY



INNOVATIONS IN SERVICE DELIVERY IN COMMUNITY PHARMACY (INDEPENDENT)



Last year's winner, HOW Pharm Ltd – The Llanidloes Pharmacy Team, Powys, with John Pignone, Numark, and Dave Thomas, Managing Director, Thomas Group (Newport) Ltd **SPONSORED BY** 





### THE VALE RESORT, GLAMORGAN

WEDNESDAY 25TH SEPTEMBER

## COMMUNITY PHARMACY PRACTICE OF THE YEAR (INDEPENDENT)







Last year's winner, the Caerau Pharmacy Team, Maesteg, with Leon Vincent, Cambrian Alliance Group, and Raj Aggarwal, the Aggarwal Group

## COMMUNITY PHARMACY PRACTICE OF THE YEAR (MULTIPLE)

NEW CATEGORY

SPONSORED BY



## Welsh Pharmacy Awards 2024

THE VALE RESORT, GLAMORGAN WEDNESDAY 25<sup>TH</sup> SEPTEMBER

MANAGEMENT OF SUBSTANCE DEPENDENCY



Last year's winner, the Pencoed Medical Centre and Brynawel House Partnership Team, with Ken Sutherland, Ethypharm UK, and Amy Jayham, Head of Pharmacy Operations (Swansea Bay University Health Board)

SPONSORED BY



## BUSINESS DEVELOPMENT OF THE YEAR



Last year's winner, the Hopwoods Pharmacy Team, Llanedeyrn, with Roddy McEwan, AAH Pharmaceuticals, and Rhodri Thomas, Community Pharmacy Wales

To apply, visit www.welshpharmacyawards.info.

SPONSORED BY





#### THE VALE RESORT, GLAMORGAN WEDNESDAY 25<sup>TH</sup> SEPTEMBER

**SPONSORED BY** 



# NEW CATEGORY COMING SOON

# SPECIAL RECOGNITION

The 2024 Special Recognition Award will be honouring one inspiring individual. The recipient will not only have forged a better path for the profession through their expertise and hard work, but throughout their years of working have identified the importance of collaborative team-working and communication. Against the challenges of the last few years, the impact of our pharmacy sector has never been as vital – and we are thrilled to be able to bestow this honour on one formidable representative.

#### WWW.WALESHEALTHCARE.COM

## EDUCATION

# **A LEARNING EXPERIENCE**

From the poignancy underscoring his pursuit of pharmacy as an educational pathway, to the endeavours he has taken on since to help the future footing of his fellow peers, Simon Evans reflects on his experiences as a final year pharmacy student at Cardiff University.



Simon Evans

My interest in pharmacy started with a personal observation in my family. My grandmother had a successful knee replacement but within a few days was showing irrational behaviour. This turned out to be caused by a withdrawal symptom due to the absence of medication that she had been taking for some time. The drug concerned was Seroxat (a selective serotonin reuptake inhibitors). Previously, I had thought that medication was always completely safe because all drugs are subjected to extensive toxicity testing. I began researching the topic and was intrigued by the view of Paracelsus - 'the dose alone determines the poison'. No drug is without hazard, but the public expect all drugs to have no detrimental effects.

As a final year pharmacy student at Cardiff University, the past three years have been incredibly rewarding. Beyond academics, I've formed deep and lasting friendships that have enriched my experience. Together, we've supported each other through challenges and celebrated successes, creating memories that will stay with me forever. Cardiff University has been more than just an educational institution; it's been a nurturing environment where I've grown both personally and professionally. The experiences gained here have been invaluable, shaping me for the future. I'm especially grateful for the supportive lecturers who have guided and encouraged me every step of the way, creating an environment where learning thrives, and students feel empowered to succeed. As I near the end of my journey, I'm thankful for the friendships, growth, and experiences Cardiff University has provided.

Throughout my academic journey, spanning within and beyond the confines of Cardiff University, I've been fortunate to embrace remarkable opportunities. One memorable occasion was my participation in the 2023 Welsh Pharmacy Awards. At this event, I had the privilege of immersing myself in inspiring narratives that shed light on the profound contributions pharmacists make daily. I was honoured to be there as a nominee for the Pharmacists' Defence Association Student Leadership Award.

As a committee member of the Welsh Pharmaceutical Association Society and the Football Captain of the Welsh School of Pharmacy, I've had the privilege of collaborating with esteemed entities, such as Kyron Media and the Welsh Pharmacy Trade Show. One of my proudest achievements has been spearheading the inaugural Welsh Pharmacy Varsity event this year, uniting Cardiff University and Swansea University. This event not only served as a platform for pharmacy students to showcase their talents among peers and faculty, but also forged a lasting bond between the two institutions. Its success ensures that this tradition will endure, forming stronger ties between the pharmacy schools for years to come.

Over the past year, I've had the privilege of serving as the Pharmacy Officer for

Future Frontline, a not-for-profit community interest company comprised of a dedicated team of UK healthcare students and professional volunteers. In my role, I've taken on multifaceted responsibilities aimed at both raising awareness of the pharmacy degree and supporting current pharmacy students throughout their academic journey. This entails the development of informative articles, hosting engaging webinars, and organising insightful conferences. Through these initiatives, I've strived to provide valuable resources and guidance to aspiring pharmacists while also fostering a sense of community and support within the pharmacy student body. It has been a fulfilling experience to contribute to the growth and empowerment of future pharmacy professionals, and I look forward to continuing this meaningful work.

I am incredibly grateful for the invaluable education I've received at Cardiff University. It has provided me with a solid foundation in pharmacy that I am excited to build upon during my upcoming pre-registration year. As I look forward to this next step in my journey, I am eager to continue learning and growing in a clinical setting. While I'm uncertain about the exact path I'll take after pre-registration, whether it involves specialising in areas such as oncology or hepatology, pursuing additional qualifications, or even considering further studies with a PhD, I am committed to making a positive impact in healthcare. I believe in the importance of life-long learning and am enthusiastic about the opportunities that lie ahead to contribute to the field of pharmacy and improve patient care.

## NEWS

### VITAL FUNDING TO SUPPORT WELSH HOSPICES

Welsh hospices will receive £4 million in government funding to continue their crucial work.

The funding will ensure that people across Wales continue to receive palliative and end-of-life care from the network of hospices, which traditionally rely on fundraising and charitable donations. But the cost-of-living crisis has made fundraising increasingly difficult, making it harder for hospices to retain and recruit staff – some have had to consider whether they can continue to maintain services.

The £4 million, which will be shared by Wales' 12 commissioned hospices, will help them maintain services, meet staffing costs, and improve the quality of end-of-life care provided to individuals and families.

More than £770,000 will go to the two children's hospices – Ty Gobaith and Ty Hafan – which support children and young people living with a life-limiting condition.

Chair of Hospices Cymru and Chief Executive for City Hospice, Liz Booyse, commented, 'Every year, thousands of adults and

### LATEST DATA ON SUBSTANCE MISUSE IN WALES PUBLISHED

There were a total of 869 school exclusions as a result of alcohol or drugs among school-aged children in 2022-to-2023 – that's an increase of 119 per cent from 2020-to-2021 and up 16.5 per cent from 2018-to-2019. This is the highest number of exclusions since 2011-to-2012.

These figures are highlighted in the Data Mining Wales report – an annual statistical report summarising substance misuse data for Wales. It aims to better explore the evidence of substance misuse over the life course, starting with prenatal, moving through childhood, and incorporating youth and older adults.

There were 4,960 children in Wales receiving care and support due to parental substance misuse in 2022-to-2023. The number of children receiving care and support for their own substance abuse was 630. Meanwhile, alcohol conditions accounted for lower numbers of young people under-25 admitted to hospital.

For adults aged 25-to-49 years, the number of hospital admissions for illicit drug poisonings decreased by 10.6 per cent in the last year, from 4,859 in 2021-to-2022 to 4,342 in 2022-to-2023. Compared to 2018-to-2019 there has been a 27.6 per cent decrease in illicit drug admissions. When hospital admissions for illicit drugs do occur, opioids continue to account for substantially more admissions than any other illicit substance group. 38.3 per cent of hospital admissions for illicit drugs in Wales in 2022-to-2023 were due to opioids.

Cannabinoids were the second highest substance group, with 1,097 hospital admissions in 2022-to-2023 relating to 917 individuals admitted.

Drug misuse deaths were the highest in the 40-to-49 age category, accounting for 33.7 per cent of all drug misuse deaths registered last year. Betsi Cadwaladr University Health Board area has the highest admissions related to illicit drugs (152.1 per 100,000 population) and along with all health boards (other than Cardiff & Vale and Powys Health Board areas) had rates above the Wales average in 2022-to-2023. children facing life-limiting illnesses turn to charitable hospices in Wales for expert care and trusted support, for them and their families.

'Members of Hospices Cymru welcome the Welsh government's recognition and support of the essential role Welsh hospices play in delivering palliative care and end-of-life services, in collaboration with the NHS.

'As the demand for our services continues to grow, we also welcome the Welsh government's commitment to develop a sustainable funding arrangement with Welsh hospices. This commitment is vital for ensuring the ongoing continuity of the critical services we provide to communities across Wales.'

The funding is part of phase three of the Welsh government's endof-life care review; £4 million was provided to support hospices in 2023-to-2024.

#### £2.3 MILLION FOR BREAKTHROUGH ACUTE MYELOID LEUKAEMIA TREATMENT

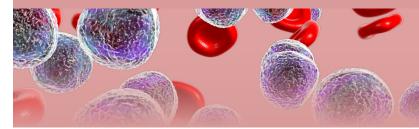
Cardiff University researchers have been awarded a £2.3 million Development Pathway Funding Scheme grant from the Medical Research Council to advance the development of an innovative approach to treating acute myeloid leukaemia.

The award will fund a project that aims to develop new therapies for acute myeloid leukaemia by targeting blast and leukemic stem cells. The therapies being developed will use new technologies that hijack the body's own mechanisms to stop the growth of cancer cells. This novel medicine, called PROTAC, will be highly specific to blood cancers.

Dr Darren Le Grand, Senior Research Fellow at Cardiff University's Medicines Discovery Institute and project lead, said, 'Acute myeloid leukaemia is a potentially fatal blood and bone marrow cancer that increases in incidence above the age of 60 years. Current aggressive chemotherapy drugs used to treat this form of cancer can be less well tolerated by older patients and, for all patients, relapse is commonly seen within two-to-three years.'

This project brings together the expertise of Cardiff University's medical research community, uniting Cardiff University with NHS collaborators in Velindre University NHS Trust and Cardiff & Vale University Health Board. The collaborations between the Medicines Discovery Institute, School of Medicine and University Hospital of Wales' Cardiff Experimental Cancer Medicine Centre aims to translate medical science research into drug development, accelerating the progress of novel therapeutics into the clinic for patients.

Professor Steve Knapper, from the Division of Cancer and Genetics at Cardiff University School of Medicine and Honorary Consultant Haematologist at the University Hospital of Wales, added, 'The collaboration between drug discovery and clinical expertise positions us well to make significant strides in improving acute myeloid leukaemia treatment. If successful, this therapeutic approach promises to bridge a significant current area of unmet treatment need.'





CHRONIC KIDNEY DISEASE

# DAMAGE CONTROL

What role can healthcare professionals play in reducing the number of lives being put at risk by the failure to recognise the seriousness of chronic kidney disease?

Chronic kidney disease (CKD) affects one-in-every-10 people, equivalent to more than seven million people in the UK. Despite this, around one million people with the condition don't even realise they have it.

With diabetes and high blood pressure being the two leading causes of CKD, it's vital that there is more awareness and more action in primary care to help identify those at risk, screen for possible kidney problems, and help people with early-stage kidney disease know what they can do to maintain their kidney health.

The number of people with CKD in the UK is expected to grow significantly over the coming decade because of an ageing population, increasing prevalence of type 2 diabetes and hypertension. So, this is an issue that is not going to go away. But the approval of new drugs, including SGLT-2 inhibitors, means that there are new treatment options and even more incentive to identify and intervene early.

Kidney Care UK, the UK's leading kidney patient support charity, found in their Let's Talk Kidneys report that 65 per cent of people with diabetes and high blood pressure who went on to be diagnosed with CKD were not made aware of their risk of CKD before diagnosis. As part of the report, Kidney Care UK spoke to over 1,000 GPs and they found that more than four-in-10 GPs would not routinely share CKD risk with highest-risk patients. Raising awareness of risk can help to engage patients in annual monitoring.

People with kidney disease have told Kidney Care UK that they want to be able to access information, support and advice about kidney disease. Despite the fact that patient charities have a wealth of accredited information, only three-in-10 respondents to Kidney Care UK's patient survey were told how to contact charities for further support.

Consistent coding of CKD in primary care can support regular monitoring and follow-up. The 2023 CVDPrevent audit found that 300,000 people with CKD didn't have a coded diagnosis of their condition despite recorded readings which indicated that they had CKD. Fiona Loud, Policy Director of Kidney Care UK, explained, 'There are huge opportunities to improve support for people in the early stages of CKD to maintain their health and delay the risk of kidney failure for as long as possible.

'People must be told about their CKD and have regular checks to measure any changes in kidney function. When we asked them, people with kidney disease told us clearly that they want to take control of their kidney health. It is time to change the dynamic on kidney health and take simple steps to save lives, and it's time to talk kidneys'.

Patients at risk of kidney disease or in the early stage of diagnosis must be actively supported and involved in the management of their disease, including lifestyle modification support in line with the Welsh government CKD Quality Statement.

To find out how you can help, visit www.kidneycareuk.org/ health-professionals.

# **ABOUT KIDNEY CARE UK**

Kidney Care UK is the UK's leading kidney patient support charity, providing practical, financial and emotional assistance for kidney patients and their families throughout the UK. The charity also provides support to units, hospitals and trusts across the UK through a hospital grants programme; investing more than £9.5 million in funding for innovative projects, equipment and staff posts in over 70 hospitals over the last decade.

Kidney Care UK also offers a wide range of free accredited patient information resources that can be ordered by healthcare staff as well as by people with kidney disease themselves. The charity believes that no-one should face kidney disease alone.

## LYME DISEASE

# TICKED OFF

Julia Knight, RN Child (Retired), BSc (Nursing), BMedSci (Specialist Community Nursing and Healthcare Practice), Press and Community Outreach Manager and Trustee, Lyme Disease UK, presents tips for recognising, diagnosing and treating Lyme disease.

## WHAT IS LYME DISEASE?

Lyme disease is a bacterial infection caused by the spirochete Borrelia Burgdorferi. The infection is spread by ticks infected with the bacteria. Lyme disease is increasing in incidence and is the most common tick-borne disease in the northern hemisphere. Infected ticks can be found throughout the UK. Some areas are known to be higher risk, including the Highlands of Scotland, South and Southwest England, and parts of East Anglia but infection can occur in any area. Ticks are mainly found in grassy areas and woodlands but have also been found in urban parks and gardens.



Ticks live in grassy areas and look for food by an activity known as questing. A tick waits on a blade of grass for a host to brush by it, transfers onto the host, and then crawls to find a warm spot to embed itself into. The tick will feed and eventually fall off if the host does not realise the tick is there. Ticks can feed for between three-to-six days. Ticks are usually most active from early spring-to-late autumn, and this was traditionally thought to be peak time for tick bites. However, with our changing climate and the UK now having milder winters with more rainfall, ticks appear to be now active in some areas throughout the year.

### HOW TO REMOVE A TICK



Photo credit: H3D

If a person presents with an embedded tick, it must be removed correctly and not with anything not designed for the job. Never stress the tick by covering it by anything to make it fall off (i.e., Vaseline). A stressed tick can respond by regurgitating the contents of its stomach into the host's bloodstream. A tick should be removed with a tick tool or a pair of fine-tipped tweezers. If a tick tool is available, slide the fork-like part of the tool underneath the tick, twist the tool which will loosen the grip of the tick and pull upwards (see instructions for the tool that you use). If using fine-tipped tweezers, grasp the tick as close to the skin as possible and pull straight upwards. Clean the area with an antiseptic wipe and give advice about type of symptoms to observe for over the next few weeks. If the tick is not removed cleanly and the mouthparts remain embedded, the body will dispel them like any other foreign body, but the person should be advised to observe for any signs of localised infection that might need treatment. Retained mouthparts do not increase the risk of contracting Lyme disease.



Prophylactic treatment after a tick bite is not usually recommended by the NHS but the Royal College of GP Lyme disease toolkit does suggest that it can sometimes be considered for certain high-risk cases. It is estimated that only about 10 per cent of ticks carry the bacteria that causes Lyme disease which can be reassuring when a person seeks advice after a tick bite.

## LYME DISEASE

### EARLY SYMPTOMS OF LYME DISEASE

#### THE ERYTHEMA MIGRANS RASH

The most obvious sign of Lyme disease is an erythema migrans rash, sometimes referred to as a bull's eye rash. However, it is estimated that about 30 per cent of people infected with Lyme disease do not develop a rash. As well as the typical bull's eye presentation, the rash can have a solid or bruise-like appearance. It can appear very differently on darker skins and be harder to spot. The behaviour of the rash is very important when considering diagnosis. It is always delayed in appearance (from three days after a bite, up to three months), is generally not itchy or painful, and slowly spreads outwards as its name indicates. The spreading is the tell-tale sign of an erythema migrans rash. In some cases, erythema migrans rashes can become huge. Any redness, itchiness or swelling immediately after a bite is likely to be a histamine reaction.

#### **OTHER SYMPTOMS**

Other symptoms to look out for are flu-like symptoms, headache, neck ache, sore muscles and joint pain, fatigue and feeling generally very unwell. Good history-taking is essential.

#### TREATMENT

If an erythema migrans rash is diagnosed, treatment with antibiotics should begin straight away with no need for a blood test as an erythema migrans rash is diagnostic for Lyme disease. Antibiotics should be prescribed as per the NICE guideline for treating Lyme disease. It is important to note that antibiotic dosages for children with Lyme disease are much higher than for other infections and are based on the child's age and weight. The guideline should always be consulted if the clinician is not familiar with prescribing for Lyme disease.



Photo credit: LDUK



Photo credit: Brown Skin Matters

## SEROLOGY TESTING

If Lyme disease is suspected but there is no erythema migrans rash present, serology testing should be carried out. Testing for Lyme disease in the UK is a two-tier system. The first tier is an Elisa test and if this returns a positive or equivocal result, it should be followed by the second tier of testing, an Immunoblot. The Immunoblot is carried out by the National Reference laboratories at Porton Down in England and Wales and Raigmore in Scotland. Both are antibody tests, first tier is an Elisa test, and if this returns a positive or equivocal result, it should be followed by the second tier. It is important to remember that the immune system can take some time to make antibodies to the bacteria that causes Lyme disease, possibly up to four weeks or more. Therefore, testing straight after a bite is likely to return a negative result even if the person has been infected. If a test is carried out during this early window testing should be repeated. The NICE guideline states to consider starting treatment while waiting for the results of testing if there is high clinical suspicion of Lyme disease and also for clinicians to be aware that testing can produce both false positive and negative results.

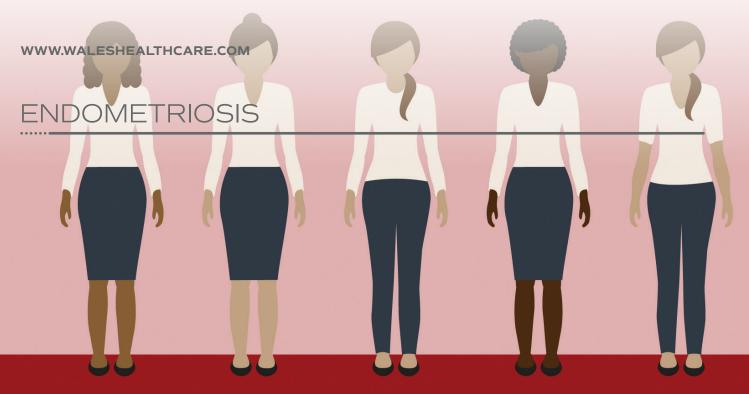
### CONCLUSION

Early recognition and treatment of Lyme disease are essential for a complete resolution of symptoms. Lack of an erythema migrans rash or delay after a bite of an erythema migrans rash appearing and / or symptoms can be confusing and many people who contract Lyme have no recollection of being bitten. This is because at certain times in the tick life cycle, ticks can be as small as a poppy seed. It is essential if there is no erythema migrans rash, diagnosis is based on a combination of careful history, clinical presentation and, if necessary, serology testing. Lyme disease should not be ruled out based on a negative testing alone due to the reasons mentioned previously of the unreliability of testing. Late diagnosis or misdiagnosis can lead to long-term debilitating symptoms that can be difficult to treat, and it is very important that clinicians who are presented with a patient with a possible Lyme disease infection are aware of the complexities of the disease.

#### RESOURCES

- NICE Lyme Disease Guideline: www.nice.org.uk/guidance/ng95
- RCGP Lyme Disease Toolkit: www.elearning.rcgp.org.uk/mod/
- bok/view.php?id=12535
- Lyme Disease UK Clinicians Hub: www.lymediseaseuk.com/ clinicians
- Key Points on Diagnosis, Testing and Treatment (short animation): www.vimeo.com/936371793





# A LONG TIME COMING

The lengthy road to an endometriosis diagnosis in the UK is leading to too many individuals spending years feeling dismissed, ignored, and belittled. How can sufficient support mechanisms be put in place to improve deteriorating diagnosis times and empower those struggling?

Getting a diagnosis for endometriosis now takes almost a year longer than before the pandemic, according to new research published by Endometriosis UK during Endometriosis Action Month 2024.

The new study demonstrates that diagnosis times in the UK have significantly worsened over the last three years, increasing to an average of eight years-and-10 months – an increase of 10 months since 2020.

This lengthy wait means a delay in accessing treatment, during which the disease may progress, leading to worsening physical symptoms and a risk of permanent organ damage.

Endometriosis impacts the physical and mental health of onein-10 women and those assigned female at birth in the UK from puberty to menopause, although the impact may be felt for life.

The new report, which is based on a survey of 4,371 people who have received a diagnosis of endometriosis, indicates:

• A rise in diagnosis times in all four nations since 2020, to eight years-and-10 months in both England and Scotland, to nine yearsand-five months in Northern Ireland, and nine years-and-11 months in Wales

• Almost half of all respondents (47 per cent) had visited their GP 10 or more times with symptoms prior to receiving a diagnosis, and 70 per cent had visited five times or more

• Only 10 per cent of respondents reported that GPs mentioned they suspected endometriosis at either their first or second appointment where symptoms were discussed

• 52 per cent had visited A&E at least once, and fewer than a fifth of those (17 per cent) were referred to gynaecology at their first visit. 26 per cent of respondents visited A&E three or more times with

symptoms prior to diagnosis

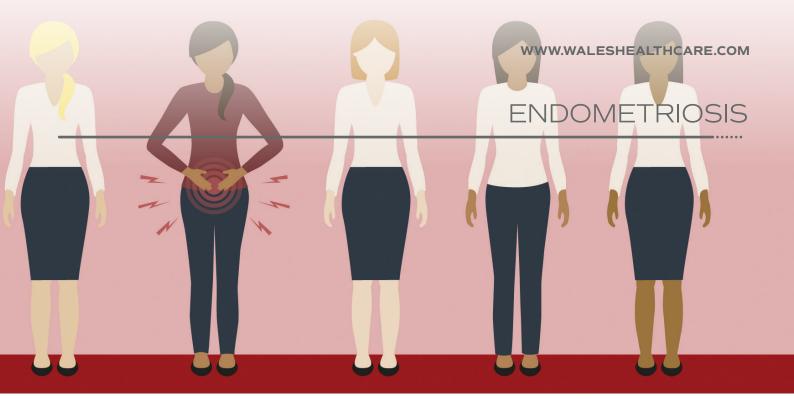
• 20 per cent reported seeing a gynaecologist 10 or more times before being diagnosed

• 78 per cent of people who later went on to receive a diagnosis of endometriosis had experienced one or more doctor telling them they were making a 'fuss about nothing' or similar comments and many had the severity of their symptoms questioned by healthcare practitioners. The number of people reporting this experience has increased from 69 per cent in the 2020 survey

Despite impacting 1.5 million across the UK, governments are failing to recognise the impact of endometriosis or allocate sufficient resources to diagnose it, with many healthcare practitioners lacking understanding of the disease.

Emma Cox, CEO of Endometriosis UK, explained, 'Taking almost nine years to get a diagnosis of endometriosis is unacceptable. The theme of Endometriosis Action Month 2024 is 'Could it be Endometriosis?' Raising awareness of the symptoms of endometriosis with the general public, along with healthcare practitioners and those in charge of health services, will be a step towards shortening very lengthy waits.

'Our finding that it now takes even longer to get a diagnosis of endometriosis must be a wake-up call to decision-makers to stop minimising or ignoring the significant impact endometriosis can have on both physical and mental health. Now is the time to reverse the trend and make commitments to drive down diagnosis time for endometriosis and other menstrual health conditions.'



## RECOMMENDATIONS FOR IMPROVING DIAGNOSIS TIMES

Endometriosis UK's report contains several recommendations for improving diagnosis times, including:

• Calling on the four governments of the UK to commit to a target of an average diagnosis time for endometriosis of one year or less by 2030

• Urging NHS commissioners and providers to urgently drive down gynaecology waiting times

• Making sure that all healthcare

practitioners receive training on menstrual health and endometriosis awareness • Asking governments across the UK to invest in public health education campaigns helping people to recognise the most common endometriosis symptoms

• More investment into research to find the cause of endometriosis, improve treatments, and find better ways to diagnose the disease

## RESPONDENT COMMENTS

The report includes a range of comments from respondents to the survey, such as: • 'I was constantly dismissed, ignored and belittled by medical professionals telling me that my symptoms were simply due to stress and tiredness. I persevered for over 10 years desperate for help'

'When I first went to the GP as a teenager, I was told I was being dramatic and would get used to the period pain I was having'
'A&E nurses told me that everyone has

period pain so take paracetamol and go home'

• 'The first gynaecologist I was referred to was exceptionally dismissive – he denied my experience and told me I was 'probably not in that much pain' and 'just having normal periods"

### **MORE MUST BE DONE**

In response to the report, Ranee Thakar, President of the Royal College of Obstetricians and Gynaecologists, said, 'Endometriosis can have significant impacts on every aspect of womens' lives – and timely diagnosis is crucial to ensuring that treatment and wider support can be in place to limit the progression of disease and manage symptoms.

'The barriers to timely diagnosis of endometriosis and other gynaecological health conditions are complex, but it is clear that more action is desperately needed. We need education and national communications campaigns to support women and girls to recognise their symptoms and feel confident seeking help; we need clinicians across the health service who listen to women and have the skills and expertise to diagnose and treat gynaecological conditions; and we need investment in services to ensure that we have the right equipment and training for healthcare professionals to achieve timely diagnosis.

'The length of waiting lists in gynaecology services grew significantly during the COVID-19 pandemic, and grew disproportionately faster than other elective specialties. As a college, we are calling on the government and the NHS to continue dedicated actions to address waiting lists and ensure fair and equitable recovery of services.' In response to the report, the Minister for the Women's Health Strategy, Maria Caulfield, explained, 'More must be done to improve women's experiences of the healthcare system, and for those women suffering from endometriosis, we have a long way to go. From getting an initial diagnosis to getting the right care and treatment, we must learn from this report.

'We launched our Women's Health Strategy to do just this – listen to women. Endometriosis is a priority area within our strategy, so expect to see more in this space. In addition, we are rolling our Women's Health Hubs across the country to support more women with specialist care required with this condition.

'Through the Women's Health Strategy, we are working to turn dismissed, ignored and belittled into listened to, understood and empowered.'

## **METHODOLOGY**

In 2023, Endometriosis UK undertook an online survey to determine the average length of time to secure a diagnosis of endometriosis, and to better understand the experiences of people seeking a diagnosis in the UK.

They gathered data from 4,371 participants who had previously received a diagnosis from a healthcare practitioner in the UK. Comparator data comes from a similar survey undertaken in December 2019 / January 2020 providing comparable data from just before the COVID pandemic, and the All Party Parliamentary Group on Endometriosis report with date from March / April 2020 and published in October 2020.

For more information, visit www. endometriosis-uk.org.

## MYELOMA

## PUTTING IT ON THE MAP

More than half of people with myeloma face a wait of over five months to receive the right diagnosis, with onein-four contending with a longer than 10-month wait – some of the longest delays out of any cancer in the UK. Now, a pioneering update that maps out the order in which patients' symptoms arise is helping to promote earlier diagnosis and spare thousands of patients from undue pain and lifethreatening complications.

One-in-four people with the incurable blood cancer, myeloma, are waiting more than 10 months for a diagnosis – and by that point, many of them are experiencing severe or life-threatening symptoms, like broken spines and kidney damage.

Despite being the third most common type of blood cancer, myeloma is especially difficult to detect as symptoms, including back pain, easily broken bones, fatigue, and recurring infection, are often linked to general ageing or minor conditions. But pioneering research by blood cancer charity, Myeloma UK, has now mapped out the order in which patients' symptoms emerge and the pattern of symptoms more common in people with a delayed diagnosis.

Based on two surveys carried out by the charity, the study found that, overall, patients with a timely diagnosis experience three symptoms before their cancer is picked up, compared to five symptoms for people with a delayed diagnosis.

It also revealed that while the majority of patients tend to experience the same first two symptoms to begin with – namely, pain and fatigue – there is a difference in the subsequent three symptoms suffered by people with a timely diagnosis and those with a delayed diagnosis.

Indeed, people with a timely diagnosis go on to suffer spinal fractures, recurrent infections and a general decline in health, meaning they fit the more typical profile of a myeloma patient. Those with a delayed diagnosis go on to experience more vague symptoms, namely a general decline in health, depression, and shortness of breath.

The findings, which were recently presented at the annual meeting of the American Society of Hematology, could be key to earlier diagnosis and sparing patients from undue pain and avoidable life-threatening complications.

Lead researcher at Myeloma UK, Dr Sandra Quinn, explained, 'This research could be a game-changer for patients and help us to understand why delays in diagnosis take place in myeloma.

'The next stage is to unpack why myeloma patients' symptoms unfold in the way they do and to uncover what the underlying issues might be, which will help our research move forward and bring us closer to a time when myeloma can be diagnosed earlier.

'We don't have all the answers yet, but we are really excited about the findings so far. This research gives us a framework to draw upon and we will use the patterns we have identified to solve the next part of the puzzle.'

The findings are based on feedback from more than 1,000 myeloma patients and carers.



Dr Sandra Quinn

#### **PAVING A BETTER PATH**

Myeloma occurs in the bone marrow and currently affects over 24,000 people in the UK. On average, 5,900 people are diagnosed every year, while it claims the lives of more than 3,000 patients in the UK each year. It is a relapsing-remitting cancer, meaning that although many patients will experience periods of remission following treatment, the disease will inevitably return.

While it is incurable, myeloma is treatable in the majority of cases. Treatment is aimed at controlling the disease, relieving the complications and symptoms it causes, and extending and improving patients' quality of life. 40 per cent of myeloma patients visit their GP practice at least three times before getting a diagnosis, and almost a third of patients are diagnosed through an emergency route, like A&E.

Just 25 years ago, myeloma was nothing short of a death sentence. There was no treatment for the incurable blood cancer and most patients could only hope to survive the disease for up to two years.

More than two decades on, thanks to Myeloma UK's tireless campaigning and £19 million poured into vital research towards much-needed drugs, and ultimately a cure, patients' life-expectancy has quadrupled and there are now over 13 treatment combinations available across the UK. But tackling delays in diagnosis and making sure the cancer is caught before any avoidable, life-limiting complications occur remains a major challenge.

## MYELOMA

Myeloma UK Chief Executive, Dr Sophie Castell, commented, "This vital new research is key to understanding why delays in diagnosis happen and could pave the way for a better future for the myeloma community. We have achieved so much over the past 25 years: life-expectancy and treatment options have improved dramatically. But these new treatments can only go so far if harmful and unacceptable delays in diagnosis leave patients with life-limiting complications and mobility issues before they've even had a chance to get treated. It is imperative we catch myeloma as early as possible and give patients the best chance to enjoy a good quality of life.



#### JANE'S MYELOMA STORY

Patient Jane Finbow discovered that she had myeloma by chance, back in May 2018, after trying to donate blood. By the time her myeloma was caught, the mother-of-two had suffered some kidney damage.

Six years on from her diagnosis, and after four-and-a-half years in remission, her cancer has now sadly returned, and she had to start chemotherapy again.

In hindsight Jane had been feeling unusually tired for months prior to her diagnosis. She found gardening especially draining and had started to neglect her beloved garden, but she just chalked it up to feeling 'a bit lazy'.

Things came to a head when Jane went to donate blood and was told she was anaemic. She visited her GP who said her symptoms were so severe she 'could be dead within two or three months.'

'The GP I went to see led me to believe I could be dead within two-to-three months, it

was extremely shocking,' Jane reflected.

'Initially I had mixed feelings about having gone to donate blood, but in hindsight I'm aware of just how lucky I was to have done so, and then to be seen by that particular GP and to be diagnosed at that point. I'm sure that my quality of life has been markedly better than it would have been. Ultimately I will live longer for having been diagnosed before much damage was done.'

She added, 'Being told it was 'incurable but treatable' was a shock. I was under the misapprehension that I was on a downward spiral, that it would get worse and worse. But of course, I know now that's not what it means. It's not a slow and painful death. You can be treated back to a better quality of life.'

Jane, 65, was unable to go back to work as a social worker post-treatment, but she has put her experience supporting the most vulnerable to good use by volunteering as a Peer Buddy with Myeloma UK and offering a listening ear to fellow patients struggling with their diagnosis. She also runs a myeloma support group.

'I try to offer hope and reassurance to other people with myeloma,' she explained.

'I find it mutually beneficial. Other patients get the psychological and physical impact of myeloma without having to be told. I know how reassuring that can be.'

Although her cancer has returned, she hopes to be in remission again soon.

'I'm still here,' said Jane. 'Relapsing hasn't fundamentally changed my approach. There are more treatments than ever before so there has never been a better time to have myeloma.

'I'm hoping that this treatment will keep the myeloma at bay and that I'll be able to get back to a place where it doesn't dominate my life.'



Jane Finbow

#### 10 MYELOMA RED-FLAG SYMPTOMS

• Persistent or unexplained pain for more than four-to-six weeks, particularly in the back or ribs

- Easily broken bones or unexpected fractures
- Experiencing either frequent urination or minimal to no urination
- Frequent or hard-to-clear infections
- Swollen legs or abdomen
- Tiredness that doesn't improve with rest (fatigue)

 Nosebleeds or unexplained bleeding or bruising

- Unexplained shortness of breath
- Unexplained weight loss
- Numbness in the feet, hands, or legs

#### **ABOUT MYELOMA UK**

Myeloma UK are the only organisation in the UK exclusively dedicated to myeloma and related conditions. They receive no core government funding and rely almost entirely on voluntary donations and fundraising.

Their ultimate goal is to find a cure and make myeloma history. Until then, Myeloma UK's mission is to help every patient live well with myeloma for as long as possible. They are committed to diagnosing myeloma earlier, discovering and sharing knowledge, transforming the patient experience, and influencing positive change in care.

Myeloma UK provide a range of crucial information and support services for patients, their family and friends.

For more information about myeloma or to get in touch with Myeloma UK, visit www.myeloma.org.uk. Myeloma UK run an infoline on 0800 980 3332.



## ASTHMA

# **AN EDUCATION**

Asthma is one of the most common chronic noncommunicable diseases that affects over 260 million people and is responsible for over 450,000 deaths each year worldwide, most of which are preventable. In a bid to tackle its prevalence and impact, the Global Initiative for Asthma is emphasising the need to empower people with the condition with the appropriate education to manage their disease, and to recognise when to seek medical help.

Asthma is a common and potentially serious chronic disease that imposes a substantial burden on patients, their families and the community. It causes respiratory symptoms, limitation of activity, and flare-ups (attacks) that sometimes require urgent healthcare and may be fatal.

Fortunately, asthma can be effectively treated and most patients can achieve good control of their asthma.

When asthma is under good control, patients can:

• Avoid troublesome symptoms during day and night

- Need little or no reliever medication
- Have productive, physically active lives
- Have normal or near normal lung function
- Avoid serious asthma flare-ups

#### SYMPTOMS AND Flare-UPS

Asthma causes symptoms, such as wheezing, shortness of breath, chest tightness, and cough that vary over time in their occurrence, frequency and intensity.

These symptoms are associated with variable expiratory airflow, i.e., difficulty breathing air out of the lungs due to bronchoconstriction (airway narrowing), airway wall thickening, and increased mucus. Some variation in airflow can also occur in people without asthma, but it is greater in asthma.

Factors that may trigger or worsen asthma symptoms include viral infections, domestic or occupational allergens (e.g., house dust mite, pollens, cockroach), tobacco smoke, exercise and stress. These responses are more likely when asthma is uncontrolled. Some drugs can induce or trigger asthma, e.g., beta-blockers, and (in some patients) aspirin or other NSAIDs.

Asthma flare-ups may occur, even in people taking asthma treatment. When asthma is uncontrolled, or in some high-risk patients, these episodes are more frequent and more severe, and may be fatal.

#### MANAGEMENT APPROACHES

A stepwise approach to treatment takes into account the effectiveness of available medications, their safety, and their cost to the payer or patient.

Regular controller treatment, particularly with inhaled corticosteroid-containing medications, markedly reduces the frequency and severity of asthma symptoms and the risk of having a flare-up.

Asthma is a common condition, affecting all levels of society. Olympic athletes, famous leaders and celebrities, and ordinary people live successful and active lives with asthma.

#### **WORLD ASTHMA DAY 2024**

World Asthma Day is organised by the Global Initiative for Asthma, a World Health Organisation-collaborative organisation founded in 1993. World Asthma Day is held each May to raise awareness of asthma worldwide. In celebration of World Asthma Day 2024, the Global Initiative for Asthma has selected the theme of 'Asthma Education Empowers'. The Global Initiative for Asthma is highlighting the need to empower people with asthma with education to manage their disease. Healthcare professionals are called upon to increase their awareness of the continuing avoidable morbidity and mortality from asthma, and the published evidence on effective management of asthma, so they are equipped to provide reliable information and optimal treatment for their patients.

Key universal issues on which education is required are under- or inaccurate diagnosis, underuse of anti-inflammatory inhaled corticosteroid inhalers, overuse, and overreliance on short-acting beta2–agonist (SABA) inhalers, and poor recognition of patients requiring specialist assessment and further management. In low-middleincome countries, lack of availability of inhaled medicines and especially inhaled corticosteroid-containing inhalers is a major contributor to the fact that more than 90 per cent of asthma deaths occur in these countries.

Policy-makers and the pharmaceutical industry are called upon to increase their awareness of the continuing preventable morbidity associated with this common disease in spite of the existence of highly effective controller treatments, and to increase their efforts to ensure that environmentally-friendly inhaled medications are made available in all countries, 'leaving no-one behind'.

For more information, visit www. ginasthma.org/reports.

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#### Adverse events should be reported. Reporting forms and information can be found at https://yellowcard.mhra.gov.uk or search for MHRA Yellow Card in the Google Play or Apple App store. Adverse events should also be reported to Lupin Healthcare UK Limited on +44 (0)1565 751 378 or EU-PV@lupin.com

Ref. 1. NHS BSA. Drug Tariff. https://www.nhsbsa.nhs.uk/pharmacies.gp-practices.and-applancecontractors/drug-tariff. Accessed. November 2023. 2. Certifications of carbon neutrality for Luforbec 100/6 and 200/6 SMDL 3. Carbon Footprint Limited, Luforbec Lif Gyclek Assessment Report 2022. Data on File. 4. MIMS: Inhaler Carbon Emissions. https://www.mims.co.uk/inhaler-carbon-emissions/ respiratory-system/article/1739635. Accessed: November 2023. 5. Luforbec 100/6 pMDI. Summary of Product Characteristics (SPC) Lupin Healthcare UK Limited 6. Luforbec 2006/pMDI. Summary of Product Characteristics (SPC). Lupin Healthcare UK Limited 6. Luforbec 2006/pMDI. Summary of Product Characteristics (SPC). Lupin Healthcare UK Limited 6. Luforbec 2016. PMDI. Summary of Product Characteristics (SPC). Lupin Healthcare UK Limited. Fostair is a registered trademark of Chiesi Ltd



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### NEWS

### NEW CLINICAL LEAD TO HELP DRIVE IMPROVEMENTS IN WOMEN'S HEALTH

A new clinical lead for women's health has been appointed, who will help drive improvements in women's health services across Wales.

Dr Helen Munro, a consultant in sexual and reproductive healthcare, will take up the role of Wales' first ever clinical lead for women's health. Together with Alex Hicks, the new strategic network manager, she will lead the National Clinical Strategic Network for Women's Health in developing the Women's Health Plan for Wales.

The development of the plan will be underpinned by the results of a wide-ranging survey completed by almost 4,000 women and girls who shared their health experiences.

### POSITIVE CHANGES TO EATING DISORDER CARE ACROSS WALES

The vast majority of people who need treatment for an eating disorder are seen in Wales and treated in their local communities. A new team and clinical lead for eating disorders is helping to drive positive changes to eating disorder care, with a focus on early intervention.

Over the coming year, a number of health boards will be working with the clinical lead to explore the introduction of the First Episode and Rapid Early Intervention in Eating Disorders (FREED) model, which is targeted at young people aged 16-to-25. Health boards are already providing early intervention models of care – support aimed at preventing people from requiring specialist care and for people waiting for treatment to start.

Waiting times for assessment and treatment have also been reduced to four weeks in some health boards.

Examples of the new models of care include:

• Cardiff & Vale University Health Board is piloting the Beat Synergy programme – an early intervention model for people who don't meet the diagnostic criteria for treatment

• Aneurin Bevan University Health Board is arranging for initial telephone assessments to be carried out on the day a referral is received; speeding up the referral process and time to treatment and support; this service is also accepting and providing referrals and intervention for people suffering from avoidant restrictive food intake disorder

• By providing earlier intervention, Betsi Cadwaladr University Health Board's specialist eating disorder team have reduced the number of people with anorexia who need to be admitted onto general units for care and treatment and reduced the use of feeding tubes in the community; it is also the first in Wales to embed paediatrics at the start of a patient's journey and the first in the UK to recruit a specialist cardiologist to provide dedicated paediatric cardiology to all eating disorder patients

A review of eating disorder provision, including the provision of a specialist unit in Wales, is currently being carried out. Eight adult eating disorder beds have been made available in Wales at a private facility in Ebbw Vale. This will help more people to be treated in Wales instead of being sent to units in England. £750,000 to commission research, from April 2025, focused entirely on women's health has also been announced.

Work to improve women's health services has included the publication of the Quality Statement for Women's and Girls' Health and the Women's Health Implementation Group, which has been looking at issues like pelvic health, use of mesh, endometriosis and faecal incontinence. Pelvic health co-ordinators and dedicated endometriosis nurses are now working in every health board in Wales.

TACKLE DEPENDENCY, VISIBILITY, AND AVAILABILITY TO ADDRESS RAPID RISE IN YOUTH VAPING, SAY PUBLIC HEALTH EXPERTS



Support should be prioritised over punishment when helping young people who want to quit vaping, according to public health experts.

The recommendation is just one of the best practices identified by the Incident Response Group (IRG) convened by Public Health Wales to investigate the concerning rise in vaping among children and young people. Other recommendations include policy measures to restrict vape visibility, appeal and availability to young people, such as a ban on disposable devices, the introduction of plain packaging, and restrictions on vape flavour names.

In its final report published, the IRG recommends that vaping should be regarded as a dependency issue, rather than an act of deliberate misconduct and support services should reflect that. In addition to this, the IRG also recommends that young people who have a particular need in relation to their dependency should be given access to nicotine replacement therapies (NRT). Replacement therapies are already available for anyone over-12 who is smoking. NRTs may include chewing gum, skin patches, or inhalators.

The IRG makes further recommendations for policy control measures to restrict vape visibility, appeal and availability to children and young people:

• Denormalise vaping – vaping should not be permitted in spaces that are intended primarily for children and young people. This should be done by encouraging settings working with young people to develop vape-free policies

• Packaging and display – restricting the advertising, packaging and the display of vapes is likely to be one of the most effective measures to address vaping among children and young people in Wales

• Disposables – the sale and supply of disposable (single-use) devices should be banned

• Flavours – flavour names should be legally restricted to a specified list of basic descriptors, such as tobacco, mint, menthol and fruit

# POSTNATAL DEPRESSION

# BETTER DAYS AHEAD

**Despite its** prevalence, and the broad range of signs associated with its occurrence. postnatal depression often lingers startlingly low on the recognition radar. Here, the Association for Postnatal Illness casts a light on its impact, and the importance of attaining help.

Most people today have heard the term 'baby blues' used to describe a mild short period of depression which many women have after childbirth. Mothers may find that it is difficult to cheer up and they may feel very anxious and tense.

Minor problems may cause new mothers to worry a great deal. They will most likely feel very tired and lethargic. When a baby is born there are very sudden changes in the mother's hormone levels. Some, required during pregnancy, drop rapidly, while others, like those which start the production of milk, rise. These rapid changes may act to trigger the blues.

In most cases, the blues last for only a few days and then the feelings start to fade. If the blues do continue and seem to be getting worse, then the mother should see her doctor.

Fewer people are aware that as many as 10 per cent of all recently-delivered women develop postnatal depression. Sadly, many women experience severe postnatal depression without recognising it as a treatable illness. This can mean that the woman suffers her distressing symptoms for longer and the strain of the illness can affect her family and friends. The earlier a woman recognises that she is ill, the sooner she will seek medical help for her illness, and the sooner she will recover.

Slowly developing postnatal depression can take two forms. One type occurs when a patch of 'baby blues' which started soon after the baby's birth becomes worse and more distressing as time passes. The second type develops more slowly and is not noticeable until several weeks after the birth.

#### **RECOGNISING THE SIGNS**

Postnatal depression has many symptoms. Most mothers who have the illness find that they are less able to cope with the demands of a baby and of the home. Some mothers feel very despondent and cry frequently. They may worry about their own health and that of the baby. They may suffer from panic attacks and feel tense most of the time.

Some mothers experience pains for which there is no cause (other than tension and anxiety). Many suffer from poor sleep and a lack of appetite.

Postnatal depression can be treated successfully with antidepressant drugs and counselling. Both can have considerable benefit to the sufferer. It's important to remember that all mothers recover from postnatal depression and as the recovery proceeds, the bad days get fewer, and the good days become more numerous.

# ABOUT THE ASSOCIATION FOR POSTNATAL ILLNESS

The Association for Postnatal Illness (APNI) provides a telephone helpline for anyone affected by postnatal illness and can also support via email or instant chat. Our opening hours are Monday-to-Friday from 10am-to-2pm.

APNI has produced a leaflet which is available to maternity units, antenatal clinics, etc. The leaflet describes the baby blues and postnatal depression. It seeks to make women more aware of this illness without alarming them. It is hoped that women who do suffer from postnatal depression will seek medical advice at an earlier time in the course of the illness if they are educated about it.

We also have a country-wide network of phone and email volunteers, who have had, and recovered from, postnatal illness. The volunteers are carefully vetted to ensure that they are completely well. Postnatallydepressed women may feel unable to go out of their house, and meeting people may cause them a great deal of stress, therefore contact made on the phone or by email can be ideal.

For more information, visit www.apni.org.

CHOLANGIOCARCINOMA

# ALL FOR THE BETTER A step forward has been secured for rising cases of liver

cancer, cholangiocarcinoma, as findings highlight treatment and mortality inequalities - and how the help of people and systems is required to shift the dial towards a more equal playing field for the often misunderstood condition.

Senior doctors within the NHS are joining AMMF, the Cholangiocarcinoma Charity, in welcoming the first improvement in first-line treatment in 12 years for NHS patients with cholangiocarcinoma – a primary liver cancer with one of the worst survival rates of all cancers that is often missed, misdiagnosed, or managed too late.

# **FRESH HOPE**

As the first immunotherapy offered to NHS patients with cholangiocarcinoma, durvalumab is offering enormous new hope for those cases not considered suitable for surgery – the only current 'cure' for this cancer. Used in combination with chemotherapy, the drug has been shown to shrink or slow the growth of tumours. Clinical trials show that there were approximately twice as many patients with advanced biliary tract cancers (including bile duct cancer) alive two years after taking durvalumab with chemotherapy, compared to those who received only chemotherapy.

While access to durvalumab is a huge step forward, more needs to be done to improve the treatment of cholangiocarcinoma within the NHS, according to AMMF, who have funded a first-of-its-kind study of NHS patient data, carried out by teams at NHS England and Health Data Insight CIC, in collaboration with partners at Imperial College, London.

## **RETHINK LIVER CANCER**

AMMF's Cholangiocarcinoma Data Project has uncovered a number of worrying findings, now shared in three published papers. The latest, published in the World Journal of Gastrointestinal Oncology, highlights significant regional variation and inequalities in treatment and survival rates of patients diagnosed with cholangiocarcinoma.

The research found that the numbers of patients who were given access to surgery and chemotherapy varied significantly between NHS England's 21 cancer alliances, with access decreasing sharply based on a patient's age and deprivation status.

Mortality rates were found to be almost 40 per cent higher for the most deprived patients compared to the least deprived; and there was significant geographical variation in incidence exists, with northern cancer alliances showing the highest rates of cholangiocarcinoma, and London alliances among the lowest.

In response, AMMF representatives met with NICE to make the case for NHS patient access to durvalumab and are now calling on health service leaders to 'Rethink Liver Cancer' as AMMF's Chief Executive, Helen Morement, explained, 'With widespread inconsistencies in the diagnosis and management of cholangiocarcinoma occurring across the country, and new treatments evolving all the time, it is essential that GPs and teams working on the NHS frontline know how to better recognise, diagnose, and treat cholangiocarcinoma. That's why AMMF have published recommendations for policy-makers and health professionals in our Rethink Liver Cancer White Paper.'

### **ADDRESSING THE**

## CHOLANGIOCARCINOMA

## **MISCONCEPTIONS**

AMMF's Rethink Liver Cancer White Paper addresses some important misconceptions about cholangiocarcinoma and provides evidence from the Cholangiocarcinoma Data Project on why there is an urgent need to improve the way this often lethal cancer is diagnosed and treated.

Historically, the term 'liver cancer' has been mostly used and understood by the public and in our health services to mean only one type of the disease – hepatocellular carcinoma (HCC) – when there are, in fact, two quite different main forms of primary liver cancer. Cholangiocarcinoma is less well-known, harder to diagnose, has significantly worse survival rates, and receives less focus and investment.

Unlike HCC, where nine-out-of-10 patients also have a history of cirrhosis and the cancer can be screened for, many people with cholangiocarcinoma do not have a history of liver disease at all, or any other obvious cause of disease, and their cancer often presents without any clearly identifiable symptoms until it is advanced.

'This is why AMMF is asking people to 'Rethink Liver Cancer', so that it is no longer a term that applies only to HCC,' said Helen Morement.

'Recognising that cholangiocarcinoma is also a liver cancer will help more people to spot and diagnose cases earlier and improve what is currently one of the worst mortality rates of any cancer. Unlike most other cancers, there has been no improvement in survival rates for decades.'

Even when cholangiocarcinoma is talked about, misinformation is common. It is not a rare liver cancer – figures recently published by the NHS show the number of cases diagnosed in England to be almost the same as HCC. It is also not the case that 'nothing can be done' – the advice that many patients tell AMMF they have received from their GP or hospital consultant.

If caught early, it is potentially curable via surgery, and can be treated by a growing number of therapies that may make surgery possible further down the line, as globally-leading cholangiocarcinoma expert, Professor John Bridgewater, a Consultant Oncologist at University College Hospital London, explained, 'Cholangiocarcinoma should no longer be considered a rare and mysterious cancer as was once thought. It is a common liver cancer and the numbers of people getting it are increasing. NICE approval of the immunotherapy durvalumab with chemotherapy affirms how treatable this cancer is and, in addition, there are now two approved molecular therapies on the back of a growing revolution in targeted molecular therapy. The treatment landscape has never looked so promising for these very needy patients – but awareness needs to be raised at all levels if patients are to benefit from these improvements.' Professor Bridgewater was among the guests at AMMF's Rethink Liver Cancer reception at the House of Commons. The event was hosted by the Chair of the All Party Parliamentary Group for Cancer, Elliot Colburn MP, and brought NHS leaders and clinicians together with MPs, cholangiocarcinoma patients and representatives from the pharmaceutical industry, to inform future policy change and treatment innovation.

'AMMF needs the help of people and systems to shift the dial towards a more equal playing field for cholangiocarcinoma patients, to encourage earlier diagnosis and access to more cutting-edge treatments, so that ultimately we can reduce the number of lives being cut short by this devastating cancer,' said Helen Morement.

For more information on AMMF's Rethink Liver Cancer Campaign and to download a copy of the white paper, visit www. ammf.org.uk/rethink-liver-cancer.

# SIGNS AND SYMPTOMS OF Cholangiocarcinoma

• In its early stages, there are few obvious signs and symptoms and those that do occur (malaise, fatigue and weight loss, pale stools, dark urine and itching) are non-specific to the disease and can occur from other cancerous, as well as non-cancerous, causes in that area, such as gallstones and inflammation of the bile ducts

• In advanced stages, jaundice is the most common symptom (yellowing of the eyes and skin – although skin yellowing may be less obvious in people with darker skin types), dark urine, pale stools, and sometimes itching due to the cancer blocking the flow of bile. Jaundice is the most obvious and visible symptom associated with <u>liver disease, both cancerous and benign</u>

# ABOUT AMMF – The cholangiocarcinoma Charity

AMMF is the only UK charity dedicated solely to supporting people diagnosed with cholangiocarcinoma and research to improve its diagnosis and treatment. When AMMF was set up in 2002 by Helen Morement, it was the world's first charity dedicated solely to cholangiocarcinoma. Today, the charity is a registered charitable incorporated organisation that works across the UK, Europe and globally with medical and scientific experts and patient groups.

For more information, visit www.ammf.org.uk.

PHARMACIST SUPPORT



# MARKING A MILESTONE

Pharmacist Support is celebrating 183 years of supporting the pharmacy profession.

Pharmacist Support, the profession's independent charity, is thrilled to announce its 183rd anniversary. For well over a century, Pharmacist Support has been dedicated to helping pharmacists and their families navigate life's challenges with essential support services.

To commemorate this significant milestone, Pharmacist Support is launching a series of fundraising activities aimed at helping them achieve their ambitious target of raising £1 million over the next four years to further their mission of supporting the wellbeing of their pharmacy family.

These initiatives include:

#### **A DONATIONS APPEAL**

A non-membership organisation, Pharmacist Support relies on the support of individuals and organisations to continue their important work. Every contribution, regardless of size, can make a profound difference in transforming the lives of individuals facing difficult circumstances.

To make a one-off or regular donation, visit www.pharmacistsupport.org/supportour-work/donate.

#### TEAMGREEN FUNDRAISING

Individuals and groups are invited to join TEAMGreen and organise their own fundraising activities to support Pharmacist Support's mission. Whether it's hosting a bake sale, running a marathon, or organising a community event, every effort counts.

For fundraising inspiration and to download a fundraising toolkit, visit www. pharmacistsupport.org/support-our-work/ fundraise-for-us.

#### **LEGACY GIVING**

Wills are not just legal documents; they are vital tools for safeguarding your family's future while offering an opportunity to champion a cause dear to your heart. Pharmacist Support encourages individuals to consider leaving a gift in their will to support future generations of pharmacists. Legacy gifts play a crucial role in ensuring the sustainability of Pharmacist Support's vital services.

To find out more about leaving a gift in your will to Pharmacist Support, visit www. pharmacistsupport.org/support-our-work/ gifts-in-wills.

#### **CHARITY PARTNERSHIPS**

Partnerships enable the charity to expand its reach and enhance its support services.

'We have already established successful and mutually-beneficial partnerships with organisations across the sector, including AAH, Alliance Healthcare, the Pharmacists' Defence Association and Teva UK,' commented Chief Executive of Pharmacist Support, Danielle Hunt.

'We would like to highlight in particular the ongoing support of the Pharmacists' Defence Association, whose  $\pounds 1$  per member initiative, as well as member donations, has this year topped  $\pounds 250,000$ .

'On this anniversary of our creation, we are delighted that we enter into a formal partnership with the Royal Pharmaceutical Society which will see the Royal Pharmaceutical Society support the charity with a range of initiatives and fundraising activity, further strengthening our commitment to supporting the pharmacy profession.'

#### To find out more about charity partnerships, visit www.pharmacistsupport. org/support-our-work/partner-with-us.

To kick off its birthday fundraising activities, the Pharmacist Support team, comprising staff and trustees, has set themselves a Wellbeing Miles Challenge! By collectively covering 26.2 miles (the length of a full marathon) through running, dog walking, and cycling, they aim to emphasise the importance of physical activity and nature in promoting mental and physical wellbeing.

#### To find out more and make a donation, visit www.justgiving.com/page/pharmacistsupport-team-birthday-challenge.

Danielle Hunt stated, 'As demands upon the profession increase, it's likely that demand for the charity's assistance will also grow. As a charity we aspire to grow our financial resilience to give pharmacists the support to thrive throughout their career (and beyond into retirement).

'We are immensely proud to celebrate 183 years of serving the pharmacy profession and our anniversary initiatives reflect our ongoing commitment to supporting the wellbeing of pharmacists and their families. We invite everyone to join us in marking this special occasion and support our vital work to ensure that no-one in our pharmacy

family has to face challenging times alone.

For more information on how to get involved or make a donation, visit www. pharmacistsupport.org/news/charitycelebrates-183-years-of-supporting-thepharmacy-profession.



# Our vision is for no one in our pharmacy family to face challenging times without us by their side.

Pharmacist Support is an independent, trusted charity, providing a range of free and confidential services to pharmacists and their families, former pharmacists, trainees and pharmacy students.

We need your help to continue making an impact. Please scan the QR code to make a donation and help us to support our pharmacy family. Thank you.



#### pharmacistsupport.org

Pharmacist Support is a charitable company limited by guarantee registered in England and Wales with company number 9237609 and charity number 1158974.

Registered with FUNDRAISING **REGULATOR** 

# BOWEL RESEARCH UK



# A GUT REACTION

Over 42,000 people are diagnosed with bowel cancer every year in the UK and one million live with other life-changing and long-standing bowel conditions, such as the inflammatory bowel diseases, Crohn's disease and ulcerative colitis, and the incontinence sometimes induced in childbirth. The need to understand the risk factors and potential causes, as well as identifying new ways to diagnose, treat and manage them, has never been more urgent. Bowel Research UK highlight some of their new research being rolled out to help people with bowel diseases to live longer and improve their quality of life.

#### RISK OF GUT DISEASES DUE TO LACK OF DIET VARIETY

Nearly three-quarters of people in the UK buy the same foods in their weekly shop, limiting the diversity and health of their gut microbiome, according to a survey from Bowel Research UK.

The gut microbiome is the collection of bacteria, fungi and viruses that naturally live inside us. Diversity in an individual's diet is linked to diversity of healthy bacteria in their gut, which is strongly associated with better overall health and protection from bowel diseases.

Bowel Research UK asked 2,000 people how often they buy the same ingredients in their grocery shop. 74 per cent said they always or often buy the same ingredients. Across all ages, 12 per cent of people said that they always buy the same ingredients, rising to 25 per cent among people aged 18-to-25.

Reasons for the lack of variety included knowing what they like (61 per cent), convenience (37 per cent), and budget (31 per cent). Younger people were less likely to cite knowing what they like (46 per cent) when compared with all ages, but were similarly concerned about convenience and budget as reasons for buying the same ingredients.

Dr Saliha Mahmood-Ahmed, NHS doctor and chef, reflected, 'Studies have shown that rather than focussing on 'superfoods', one of the best things you can do for your gut health is to eat a variety of plants, such as fruits, vegetables and grains. Research also shows that varying your choice of fruit and vegetables weekly, or seasonally, has an even more positive effect on your gut microbiome.

'It's worrying to see that people are more likely to always buy the same ingredients due to convenience and budget – there are simple and cheap ways to enjoy different fruit and vegetables to help protect you from developing bowel diseases?

Lynn Dunne, CEO of Bowel Research UK, added, 'Having a healthy gut microbiome has positive effects on so many aspects of health – from helping maintain a healthy weight and mental health, to reducing the risk of bowel cancer and managing symptoms of irritable bowel syndrome. It's concerning that so many people are unaware of it, and it's particularly worrying that people are less likely to have heard of it if they are over-65, which is when they are at higher risk of bowel diseases.

'We've created some top tips on affordable and easy ways to get variety into your diet to encourage good gut health, which we hope will encourage people to think about the importance of their gut microbiome'.

#### THE ROLE OF THE GUT MICROBIOME

Research has shown that the gut microbiome has a role in many different conditions, and this also means it potentially offers new ways to treat diseases. It is a fast-growing but still underresearched area.

Bowel Research UK has launched an appeal for major donations to create a ringfenced pot of £250,000 for researchers to apply for PhDs or small grants for research on the gut microbiome.

Dr James Kinross, Bowel Research UK's microbiome clinical expert, said, '10 years ago, research on the gut microbiome was seen as in its infancy and, despite it now being a hot topic in research, it is still a neglected niche when it comes to science funding. It's great to see Bowel Research UK launching an appeal to fund microbiome research, particularly as the funding is targeted at researchers who are starting their careers who will bring fresh approaches to this exciting field.'

#### NEW STEM CELL RESEARCH PROJECT AIMS TO UNDERSTAND POTENTIALLY FATAL NEWBORN BOWEL CONDITION

Bowel Research UK has begun a new research project aiming to understand the causes and potential treatments for Hirschsprung's Disease – a rare condition which causes a blockage of the bowel and can lead to life-long issues with bowel control and, in a small number of children, death.

When an embryo forms, nerves in the rectum develop that enable the bowel to relax so that babies can poo. Hirschsprung's Disease is a rare, inherited condition affecting 170 babies every year in the UK, where nerves do not develop properly, and poo builds up in the abdomen. This can sometimes cause infection, called enterocolitis, which may be fatal.

When Hirschsprung's Disease is diagnosed, babies have surgery to remove part of their large intestine, which is then reconstructed. This leaves about 30 per cent of children with chronic bowel problems, including constipation, incontinence or inflammation, and 10 per cent require a long-term stoma.

Dr Rachel Harwood, researcher and Paediatric Surgeon based at Alder Hey Children's NHS Foundation Trust Hospital, commented, 'No new parent wants to hear that their newborn baby has a condition that needs surgery and will likely affect them for life. While it's good news that better awareness of this disease has meant that it's usually picked up and treated early, the significant long-term effects of being born with Hirschsprung's Disease means that looking for new treatments is important to affected children and families. Our research aims to understand Hirschsprung's Disease better so that we can develop smarter treatments which improve their outcomes and quality of life.'

Nerves that control bowel function grow from specific stem cells. Researchers were surprised to find these stem cells were still present in babies with Hirschsprung's Disease, indicating they had the potential for normal nerve development, but something went wrong.

This new project aims to understand what stopped those stem cells forming functioning nerves and whether those cells can be 'switched on' to grow functioning nerves in the patient retrospectively.

### DIABETES

# NOW WE'RE TALKING

Collaboration between the healthcare professional and patient plays a pivotal role in strengthening the provision of. and adherence to, diabetes care. Which areas in their interaction can be homed in on to further elevate the patient's diabetes experience?

Healthcare providers who treat diabetes need to think beyond the clinical numbers, such as solely focusing on a person's glucose goals. Taking the patient experience into account can improve the quality of care and facilitate attainment of treatment goals, according to a new position statement published in the Endocrine Society's Journal of Clinical Endocrinology & Metabolism.

More than 500 million people worldwide have diabetes, which occurs when the pancreas doesn't make enough insulin or when the body isn't able to respond to insulin properly, resulting in high levels of glucose in the blood (blood glucose).

Managing this chronic disease requires making lifestyle changes throughout life, which can be burdensome for people living with diabetes and their caregivers. Daily tasks, such as blood glucose monitoring, dietary and exercise management, routine preventive care scheduling, and medication management must be overseen by people living with diabetes themselves.

# TWO-WAY Communication

Effective two-way communication between people with diabetes and their healthcare providers helps establish a shared understanding of the treatment plan and goals.

Healthcare providers who take the time to explain treatment options and discuss potential barriers can improve patient satisfaction and clinical outcomes.

In addition, healthcare providers need to consider each individual patient's level of health literacy and cultural background when discussing treatment options.

'Many existing educational resources are available to help healthcare providers think through ways they can discuss diabetes treatment in a neutral and non-judgmental way and practice using those strategies,' explained Rita R Kalyani, MD, MHS, Professor of Medicine in the Division of Endocrinology, Diabetes, & Metabolism at John Hopkins University School of Medicine, who chaired the position statement and represented the Endocrine Society during the consensus roundtables.

'However, in the ever-changing landscape of diabetes and its management, both healthcare providers and people with diabetes will continue to need new and evolving tools to help address the common challenges they face.' People with diabetes face an elevated risk of developing depression, anxiety, and other mental disorders. This makes understanding the psychosocial impact of diabetes important. Addressing stressors in the healthcare setting and ensuring timely mental health referrals, when appropriate, can help individuals with diabetes feel more comfortable and help them participate more fully in their appointments and care.

# AREAS FOR OPTIMISING HEALTH OUTCOMES

Each section in the position statement begins with a common clinical scenario that illustrates key gaps in diabetes care. Readilyaccessible graphics and tools that can be used by healthcare providers to deliver patientcentered care in practice are also included.

The position statement offers a framework for leveraging the experiences of people with diabetes to optimise health outcomes in several important areas, including:

• Use of person-centered language in the healthcare setting

• Ensuring that referrals to diabetes

self-management and support service programmes are timely and accessible to all people with diabetes

• Effectively navigating available therapeutic options together and explaining complex regimens to people with diabetes to encourage them to take medication as prescribed

• Considering ways to adjust an individual's treatment plan in a timely manner if they aren't meeting therapeutic goals to prevent therapeutic inertia

• Discussing strategies for assessment of hypoglycaemia – low blood glucose episodes that can be dangerous – as well as prevention and treatment of hypoglycaemia

Improving cardiovascular and renal

outcomes using newer therapeutic options • Using telehealth in the appropriate clinical setting

• Using and incorporating diabetes technologies, such as insulin pumps and continuous glucose monitoring systems into the diabetes management plan, when appropriate

# URINARY TRACT INFECTION

# **COMMON KNOWLEDGE**

Compelling new urinary tract infection insights have been ignited – revealing that numerous bacterial strains are capable of hiding in the human bladder wall, contributing to the condition's persistence following treatment. WPR finds out more.

New research recently published in Science Advances is the first to use a sophisticated human tissue model to explore the interaction between host and pathogen for six common species that cause urinary tract infections (UTI). The findings suggest that the 'one-size-fits-all' approach to diagnosis and treatment currently used in most healthcare systems is inadequate.

#### **UTI: A GROWING ISSUE**

UTI is a rising problem, with around 400 million global cases per year and an estimated 250,000 UTI-related deaths associated with antimicrobial resistance. Although UTI is often perceived as a simple bacterial infection, 25-to-30 per cent of UTIs recur within six months despite antibiotic therapy for reasons that are poorly-understood.

A condition that primarily affects women, UTI has been historically understudied and underfunded, with no improved anti-infective treatments introduced since Alexander Fleming discovered antibiotics nearly a century ago. Diagnosis primarily rests on the midstream urine culture method (dipstick test), an early 20th Century technique that is known to miss many infections.

#### SHEDDING NEW LIGHT

In the study, researchers from University College London (UCL) developed three-dimensional cell models capable of mimicking the biological environment and function of human bladder tissue, in order to observe the interactions between host and pathogen in conditions as close to the human body as possible. These 'mini bladders' were exposed to six bacterial species commonly found in the human bladder: Escherichia coli, Enterococcus faecalis, Pseudomonas aeruginosa, Proteus mirabilis, Streptococcus agalactiae and Klebsiella pneumoniae. Professor Jennifer Rohn, senior author of the study from UCL Division of Medicine, detailed, 'We put a variety of UTI bacteria species and strains through their paces and discovered a battleground of diversity. One of the key observations was the importance of persistence. If you want to be a successful pathogen, you have to have strategies that help you to survive treatment and hide from patrolling immune cells, which means you live to fight another day.

'Some species of both 'good' and 'bad' bugs formed pods within the bladder wall, most likely as a way of surviving in this harsh environment. If this happens with a friendly bug, this isn't a problem. But if the bug is causing an infection, this poses a serious problem for diagnosis and treatment because the bacteria aren't necessarily going to be detected in a urine sample or be in a position where oral antibiotics can reach them.'

The study also found that human cells were very good at distinguishing friendly from not-so-friendly bacteria, regardless of whether they could invade the bladder wall or not. All the 'bad' bugs tested triggered the production of immune molecules, called cytokines, and the shedding of the top layer of the bladder wall, whereas the 'good' bacteria could colonise the bladder wall without triggering an immune response.

Dr Carlos Flores, first author of the study from UCL Division of Medicine, said, 'Based on our results, next-generation diagnostics for UTIs could focus on identifying 'bad' bugs based on how the body responds, rather than trying to spot the presence of problem bacteria among the background noise of the microbiome. There are so many species and strains of bacteria in the human bladder that we don't fully understand, but the body seems to be pretty good at telling friend from foe.'



#### THE FUTURE OF TREATMENTS

The findings indicate that effective treatments for persistent UTIs may require the ability to penetrate human tissues, in order to reach bacterial populations dwelling in the bladder wall. A UCL spin-out, AtoCap, is currently developing ways to deliver drugs inside cells to target pathogens hiding there.

Professor Rohn concluded, 'This study confirms what many women who've struggled with persistent UTIs already know, which is that the current methods of diagnosing and treating these infections are inadequate.

'Urine dipstick tests are too likely to miss infections hiding in the bladder wall, especially when a patient's first response to discomfort is to drink lots of water, which dilutes the test. Not all bugs can be cultured in the lab, and even if they could be that doesn't tell us if this strain is the cause of an infection or if its position in the bladder wall would make the standard three-day course of antibiotics unlikely to eradicate it.'

#### **A PATIENT PERSPECTIVE**

Helen Lucas, who has struggled with chronic UTIs for several years, reflected, 'Before my UTI problem started, I just assumed that living in the UK you could go to your doctor, be prescribed treatment, and get better. It's been a shock to find that the testing and treatment of UTIs, even the perceptions of what this disease can be, are so antiquated.

'If I wasn't outspoken, I think I might have been left with an undiagnosed chronic UTI, unable to fully live my life. I know other people are struggling to overcome the same hurdles that I had to. It's fantastic that research is being done into why UTIs persist, which will hopefully lead to better testing and treatment.'



# IN A NEW LIGHT

The NHS is 'completely in the dark' about the scale of obsessive compulsive disorder (OCD) in the UK due to a failure to collect patient data on the condition, according to a leading charity.

New research by OCD Action has found that NHS planning bodies across the UK are failing to collect data on people treated for OCD, meaning that they have no clear understanding of the condition's prevalence, population treatment needs, waiting times, or treatment outcomes.

The charity has said that the data gap reflects a system that 'dismisses and trivialises OCD' and its impact on individuals and their families. It is calling on the next government, following a General Election this year, to put an end to this failure by committing to improving data collection and ensuring timely access to treatment.

### **DATA COLLECTION CONCERNS**

Freedom of Information requests sent by OCD Action found that none of NHS England's 42 local integrated care boards collect any data on the treatment of patients for OCD. Similarly, there is no data collected on OCD by Northern Ireland's five local Health & Social Care Trusts.

Only one-of-seven health boards in Wales and one-of-14 NHS boards in Scotland collect any data on OCD treatment in the community. These are Swansea Bay University Health Board and NHS Greater Glasgow & Clyde respectively.

Ahead of a General Election this year, OCD Action has launched a manifesto with a number of recommendations for the next government focused around three key priorities:

• End trivialisation and increase understanding of OCD

- Recognise and count people with OCD
- Guarantee timely access to clinically-recommended treatments

# A POWERFUL MENTAL HEALTH CONDITION

OCD is understood to affect one-to-two per cent of people in the UK. It is a powerful and destructive mental health condition. Despite its severity, OCD is treatable with the right support and evidence-based treatment.

On average, people living with OCD face an unacceptable delay of six-to-seven years from symptom onset to seeking help, largely due to the pervasive lack of understanding and trivialisation surrounding the condition.

Once help is eventually sought, the path to effective treatment, specifically cognitive behavioural therapy with exposure and response prevention, is riddled with obstacles.

These delays inflict unnecessary suffering and prolonged periods of illness, exacerbating the condition into a chronic cycle of relapse and remission. The societal impact is profound, with delays in treatment for OCD costing the UK an estimated £5.1 billion annually. This highlights a critical need for immediate reform in how OCD is perceived and treated at both healthcare and policy levels.

Leigh Wallbank, CEO of OCD Action, emphasised, 'People with OCD in the UK are being failed by a crisis of neglect – OCD is invisible in our healthcare system. Data is the bedrock of effective healthcare, yet our findings reveal a stark absence of OCD-specific data in secondary care.

'This data gap indicates a healthcare system completely in the dark about the scale of OCD, with no clear understanding of the prevalence, treatment needs, waiting times, or treatment outcomes for those with OCD.

'To count is to acknowledge. The government's failure to collect and analyse data on people living with OCD is tantamount to accepting that those suffering from the condition may not receive the care they need. This oversight reflects a system dismissive of OCD, trivialising the condition and its impact on individuals and their families.

'This must change. We must count every person living with OCD – because every person living with OCD matters. OCD Action is calling on the next government to end trivialisation and increase understanding of OCD, recognise and count people with OCD and guarantee timely access to clinically-recommended treatments.'



# A significant progress in the **treatment of endometriosis**, in a **once daily tablet**<sup>1,2</sup>



Dienogest is a 4<sup>th</sup> gen<mark>eration selective progestin having anovulatory and anti-pro</mark>liferative effect in endometrial cells, as well as anti-inflammatory and anti-angiogenic actions.<sup>5</sup>

Reduces endometrioma volume by 75%<sup>6</sup>

Preserves the ovarian reserve<sup>7</sup>

As effective as GnRH agonists in relieving endometriosis-associated pain<sup>8</sup>
 Presents a favourable adverse events profile vs GnRH agonists<sup>8</sup>

Women treated with Zalkya<sup>®</sup> 2mg experienced hypoestrogenic symptoms less frequently than women treated with Leuprolide acetate.<sup>8</sup>

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#### **Prescribing information**

Please refer to the Summary of Product Characteristics (SmPC) before prescribing. Name and active ingredient: Zalkya<sup>®</sup> 2mg film-coated tablets. Each tablet contains 2mg dienogest. Indications: Treatment of endometriois. Posology and method of administration: One tablet daily without any break, taken preferably at the same time each day with some liquid as needed. The tablet can be taken with or without food. Tablets must be taken continuously without regard to vaginal bleeding. When a pack is finished the next one should be started without interruption. Treatment can be started on any day of the mestrucal cycle. Any hormonal contraception needs to be stopped prior to initiation of Zalkya<sup>®</sup> If contraception is required, non-hormonal methods of contraception should be used (e.g. barrier method). Isee SmPC section 4.2). Contraindications: Zalkya<sup>®</sup> should not be used in the presence of any of the conditions listed and should any of the conditions appear during the use of Zalkya<sup>®</sup> treatment nust be discontinued immediately: active venous thromboembolic disorder, arterial and cardiovascular disease. past or present (e.g. myocardial infarction, cerebrovascular accident, ischemic heart disease), diabetes mellitus with vascular involvement, presence or history of severe hepatic disease as long as liver function values have on terturne (see section 6.1 of the SmPC). Special warnings and precautions for use: Procutions should be taken regarding serious uterine bleeding is heavy and continuous over time, this may lead to anemia (severe in some case). In the event of anemia, discontinuation of Zalkya<sup>®</sup> should be stopped at once if there are symptoms of an arterial or venous thrombotic event or suspicion thereof, tumours: The risk of having breast cancer diagnosed in users of forgestogen-only preparations is possibly of similar magnitude to that associated with combined oral contraceptives (COC). However, for progestogen-only preparations, the evidene is based on much smaller populations of users and s

the progestogen drug metabolism. An increased clearance of sex hormones due to enzyme induction may reduce the therapeutic effect of Zalkya<sup>a</sup> and may result in undesirable effects e.g. changes in the uterine bleeding profile. A reduced clearance of sex hormones due to enzyme inhibition may increase the exposure to dienogest and may result in undesirable effects. Substances increasing the clearance of sex hormones (diminished efficacy by enzyme-induction), e.g.: phenytoin, barbiturates, primidone, carbamazepine, rifampicin, and possibly also oxarbazepine, topicamate, felamate, griseofulvin, and products containing St. John's wort (Hypericum perforatum). (see SmPC section 4.5) Fertility pregnancy and lactation: Zalkya<sup>a</sup> must not be administered to pregnant women because there is no near to treat endometriosis during pregnancy. Treatment with Zalkya<sup>a</sup> all induce recommended. Based on the available data, ovulation is inhibited in the majority of patients during treatment with Zalkya<sup>a</sup>. Honewer, Zalkya<sup>a</sup> is not a contraceptik. Based on the available data, the menstrual cycle returns to normal within 2 months after cessation of Zalkya<sup>a</sup> are (±1/100 to 1/10): weight increase, depressed mood, sleep disorder, nervoursness, loss of libido, altered mood, headache, migraine, nausea, abdominal pain, flatulence, abdominal disorder, nervoursness, loss do libido, altered mood, headache, migraine, nausea, abdominal pain, flatulence, adominal disroder, lorreast discomfort, ovarian cyst, hot flushse, uterine / vaginal bleeding including spotting, asthenic circulatory system disorder palpitations. hypotension, dyspnee, alorarhoe, constipation, adominal disconfort, gastrointestinal inflammation, gingivitis, dry skin, hyperhidrosis, puritus, hirsuitism, onychoclasis, genitaldischarge, pelvicipani, atophic vulvovagnitis, breast mass, fibrocystic hreas the sati duvorginal drynes, genitaldischarge, pelvicipani, attophic vulvovagnitis, breast mass, fibrocystic hreas the sati duvorginal drynes, genitaldischarge, pelvicipani, theyph

Adverse events should be reported: Reporting forms and information can be found at: www.mhra.gov.uk/yellowcard or search for MHRA Yellow Card in the Google Play or Apple App Store. Adverse events should also be reported to Kent Pharma UK Ltd on 01233 506574 or medical@kent-athlone.com. For a copy of the SmPC or further medical information, please contact: medical@kent-athlone.com. Additional information available on request.

For further information on this product, please contact your Kent Pharma Hospital Key Account Manager or our customer service team.



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