

# The Big Virtual Cycle Fundraiser!



On 30 May Renal Youth Worker, **Shaun Thomas**, led a team of patients and healthcare professionals to cycle virtually (using exercise bikes at their homes) the 120 miles between the dialysis units in South Wales in order to raise awareness of kidney disease.

The heroic team of renal warriors raised **£1525** for Kidney Wales, Kidney Care UK and Paul Popham Fund. **Well done and thank you!**

## Recipe of the week!

Kidney Care UK have launched new recipes as part of the Kidney Kitchen initiative. These have been specially put together for people to make using store cupboard ingredients during the lockdown. Try this tasty lockdown version of Indian spiced baked beans!



### Indian Spiced Baked Beans:

#### INGREDIENTS

- 1 teaspoon cumin seeds
- 1 teaspoon curry powder
- 1 tablespoon olive oil
- 1 red onion, finely chopped
- 2 garlic cloves, finely chopped
- 1 red chilli finely chopped (or ? teaspoon chilli flakes)
- 2 x 400g tins of baked beans
- 4 slices of thick sourdough toast (or just your normal bread)
- 1 handful of fresh coriander (optional)
- 10g unsalted butter
- Black pepper



#### METHOD

1. Heat the oil in a frying pan, once hot add the cumin seeds and curry powder cooking for 1 minute being careful not to burn the spices.
2. Add the onion, garlic and chilli and cook until soft.
3. Then add the baked beans and stir to combine.
4. Toast and butter the bread.
5. Serve the beans on top of the buttered toast.
6. Top with the chopped coriander and black pepper to taste.

For more kidney-friendly recipes visit [www.kidneykitchen.org](http://www.kidneykitchen.org)

## We can help!

The Paul Popham Fund, Renal Support Wales has a team of volunteers available to deliver essentials and prescriptions to people with kidney disease under Swansea Bay University Health Board.

If you are a person who is currently having to shield until the 16th August, the charities volunteer team are available to collect essentials from your local supermarket and will arrange for your prescription to be collected from the Renal Pharmacy Team. This service is currently only available under Swansea University Health Board and covers from Llantrisant to Aberystwyth.



If you are a shielding and have no one to help collect essentials, then please call us now for support on **0800 038 8989** or email: [support@paulpophamfund.co.uk](mailto:support@paulpophamfund.co.uk)

### The Journey of the Kidney Community in Wales during the Coronavirus Breakout and Lockdown

The Paul Popham Fund, are creating a daily journal of the journey and challenges that the Kidney World in Wales faces and overcomes during the Coronavirus lockdown.

They want to record what happened, how the Kidney Community in Wales dealt with it and how we lived through it - the Charity want to be able to look back on this, reflect and share for future generations. The Charity would like anyone from Wales' Kidney Community to contribute in whichever way they would like: it could be a diary journal you would like to share, an activity you did, something you have learnt, how you felt, how you overcame the lockdown ,how you overcame the virus.

All photos, videos, poems and stories are welcome. The Charity will co-ordinate the journal entries, send them with the date created too: [hayley@paulpophamfund.co.uk](mailto:hayley@paulpophamfund.co.uk)

### For information & support

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Head Office: 01420 541424  
Wales Advocacy Officer: 01656 514776  
E: [Linzi.Isaac@kidneycareuk.org](mailto:Linzi.Isaac@kidneycareuk.org)

**Team from Kidney Wales**  
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E: [team@kidneywales.cymru](mailto:team@kidneywales.cymru)

**Team from Paul Popham Fund**  
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# Kidney patient Covid-19 update



Welcome to the fourth edition of your kidney patient newsletter. As the first steps towards lifting the Coronavirus lock down measures have begun, this issue highlights the changes that affect people with kidney disease and looks at some of the key issues as we move forwards.

This newsletter has been compiled by Kidney Care UK, Kidney Wales, Paul Popham Fund, the Welsh Clinical Renal Network which oversees services for adult kidney patients in Wales and the Wales Kidney Research Unit (an All-Wales strategy for the study of diagnosis, prevention, treatment and social context of kidney disease) and the All Wales Health and Wellbeing Reference Group (an initiative to support professionals allied to medicine in their important role in delivering kidney patient health and social care).

We value your opinion and would welcome your feedback on the content, what you would like to see now and in the future. This is your newsletter and it is important that it works for you. You can feedback through your kidney care team or by contacting any of the charity providers on the details below.

Please help us in continuing to thank our renal health and social care workers by sharing your stories, photos, artworks, poems with us. Specially designed certificates of thanks are available from us - send one to someone who deserves a special mention today. We will publish them online and on our social media.

This newsletter is available in Welsh. Ask a member of your kidney care team if you would like a copy in Welsh.

## Shielding up-date

On Sunday 31 May Welsh Government announced a relaxation of the lockdown measures for people who have been shielding during the pandemic.

The new advice says:

- Outdoor exercise is unlimited, as long as individuals strictly follow social distancing rules and hygiene practices
- Those who are shielding can meet outside with people from another household - but should not go into another person's house or share food with them

All people who are shielding will receive a letter from the Chief Medical Officer for Wales before 15 June setting out the next steps to confirm that shielding will be extended to 16 August.

The change in advice for Welsh patients who are shielding has understandably caused concern for some. It's important to remember that the government is trying to find the right balance between keeping you safe from coronavirus and allowing a quality of life that is manageable. There isn't a lot of scientific evidence to guide them as the disease is very new and not like ones we've seen before, and therefore the changes being suggested are only small at the moment.

On 9 June Kidney Wales hosted a Facebook Live Q&A with Dr Mike Stephens, Consultant Transplant Surgeon <https://www.kidneywales.cymru/news/2020/06/01/shielding-people-kidney-disease-nextsteps/>, to help understand the changes and what they mean for kidney patients and families.

The key messages from Dr Mike were:

- Until there is a vaccine or an effective treatment, the only thing we can do is to avoid getting Coronavirus. The priority is to prevent transplanted patients, older patients, and older transplanted patients picking up the virus.
- The advice for shielding is clear: stay at home, with the exception of keeping a social distance of 2m for exercising outdoors and meeting another family outside. You must not go into other people's houses.
- Following advice on shielding and hand hygiene can keep your risk of Coronavirus really low. However shielding is difficult to do in practice and so a balance must be found with what is achievable and gives you an acceptable quality of life. Stick at it - this won't last forever.
- You are advised to wear a mask when you are out of the house and in any area where a social distance cannot be maintained. Request your mask from Kidney Wales here!
- The decision on whether your child(ren) return to school must be your decision, based on what you know about your child, yourself and your circumstances. If you are shielding and there is a realistic option to not send your children back to school at this stage, that would be reasonable.
- Most transplant units across the UK are looking at how to re-open in a phased way, with priority given to the lowest risk patients. For Welsh patients, transplants are either done in Cardiff or Liverpool.



ISSUE 4  
JUNE 2020



Here's a picture of one of our weekly meetings to produce the newsletter!

## Q&A

**Q&A with Dr Mike Stephens**  
Consultant Transplant Surgeon

**Tuesday 9 June at 7pm**  
'Kidney Wales Community' Facebook Group

*Email questions by 9am Monday 8 June to [judith@kidneywales.cymru](mailto:judith@kidneywales.cymru)*

- The vaccines that are being tested at the moment are not live vaccines and so would be safe for transplant patients.
- If you're asked to come to hospital, please be assured that effective measures are in place to ensure it is safe to do so.

If you have doubts or questions, ask your kidney team who know you, your condition and your personal circumstances and will be able to give you the best individualised advice. Also take a look at the Kidney Care UK guidance on Coronavirus for people with kidney disease.

The kidney charities have also written to the Welsh Government Minister for Health and Social Services to ask for clarification on what the shielding changes mean for with regards to continued access to food boxes, support for mental health, changes to employment and the furlough scheme, and children and young people returning to school from 29 June. More information will be provided as soon as a response has been received.

## Welfare, benefits and advice

**Linzi Isaac**, Wales Advocacy Officer for Kidney Care UK, offers the benefit of her experience of supporting many kidney patients with Personal Independence Payment (PIP) applications:

If you are due for a review or reassessment of Personal Independence Payment (PIP), or any other benefit, between 24th March and 24th June 2020; your award will be automatically extended to receive support at your current rate.

People making a new claim for PIP can still do so in the usual way by phoning the DWP on 0800 917 2222 to request an application form.

Once you have completed your application form and sent off supplementary evidence, you will be given a date for your health assessment. For the time being, face-to-face assessments for sickness and disability have been suspended. Many people who have made a new claim for PIP have been receiving their assessment in the form of a phone call to prevent further delay to much needed financial support. You will receive your decision letter 4-6 weeks after the assessment. If you do not agree with this decision, you are still able to appeal in the usual way, which will be detailed in the letter.

The first stage of appealing is called a Mandatory Reconsideration (MR), which can be requested over the phone. It is strongly recommended that you send further information as to why you disagree with their decision, a letter of support from a clinician or member of your renal team is an excellent example. The MR process is paper-based and will not require a further health assessment. If you are still not satisfied after the second decision letter, there is the option to progress your claim to tribunal.

Claiming for a welfare benefit can feel very daunting and you can ask for help at any stage of the process. Sometimes it can be as simple as talking it over with someone before you begin completing a form. Your renal social worker or youth worker can help you gather support letters and provide advice on the process. Your Kidney Care UK advocate can also advise on the process and provide practical support in filling out the forms, along with tools on how to provide all the information and evidence needed to support your claim or appeal.



**Here is Caron Jones, Renal Social Worker attached to Wrexham Maelor, describing her experience of supporting a patient with a PIP Tribunal:**

*"When a mandatory reconsideration is turned down, the claimant has the right to appeal and their application for PIP or Attendance Allowance be considered by an Independent Tribunal. Again, this must be done within one month of the date on the notification letter. At this stage the claimant can nominate a person*



*to represent them (friend, family member, renal social worker, kidney care advocate... whomever best placed to advocate for them).*

*Normally the Appeals Service requests claimants and representatives attend in person.*

*Currently, due to COVID-19, the process has changed. Appeals are being considered over the phone. Last week I represented a person whose claim had been turned down in 2018.*

*Unfortunately the claimant was unwell, unable to make the conference call. There were 3 people on the tribunal panel: GP (medical expert), Solicitor (legal expert) and a person with knowledge/experience of illness and disability. Due to COVID-19 each person on the panel was working remotely. A week prior to the tribunal I forwarded further supporting medical evidence, highlighting recurrent infections, hospital admissions and on going support provided by Medical Team, Renal Psychologist and Renal Social Worker.*

*Each member of the panel asked questions... why there were gaps in the data provided, how the claimant managed to work, how long I had known the claimant, clarification of medical procedures and treatment. As is the case for many people living with a chronic illness, I stressed the impact of on-going infections and fatigue and the psychological impact this has on a person.*

*As the claimant was not present, members of the Panel could not share their decision. They awarded the allowance, backdated to 2018, and informed the claimant by letter.*

*Please take advice and support if your claim is turned down".*



Kidney Wales recently held a Q&A session on welfare and benefits with **Julie Ann Riseborough** of **RCT Citizens Advice**, which you can read at:

<https://www.kidneywales.cymru/news/2020/05/15/benefits-financialsupport-entitled/>

<https://www.kidneywales.cymru/news/2020/04/21/qa-session-covid-19-welfare-advice/>

If you would like to find out what benefits and financial support is available to you, please contact **Kidney Care UK** about a financial health check.

## Tell us about your Covid-19 experience!

The Coronavirus pandemic has forced some changes to the services that people with kidney disease receive from renal services in Wales.

Kidney Care UK, Kidney Wales, Paul Popham Fund, Welsh Kidney Research Unit and the Welsh Clinical Renal network are keen to learn about the positive changes that have come out from the adaptation of services in Wales during this time such as outpatient appointments, dialysis treatment at unit or hospital, technical support, pharmacy and prescriptions, dieticians, social workers, psychologists, physiotherapists and so on. Considering your experience as a person with kidney disease, of the services you have had to or needed to access during the pandemic, please tell us in your own words:

- Which changes to your health care have worked well and should remain?
- What changes need adapting?
- What changes would you like to suggest?

Please feedback directly to either:

**Kidney Care UK**, Wales Advocacy Officer  
T: 01656 514776

E: [Linzi.Isaac@kidneycareuk.org](mailto:Linzi.Isaac@kidneycareuk.org)

**Team from Kidney Wales**

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**Team from Paul Popham Fund**

T: 01792 654182

E: [enquiries@paulpophamfund.co.uk](mailto:enquiries@paulpophamfund.co.uk)

## Coronavirus research study

HealthWise Wales is supporting a study by researchers at University College London (UCL) into the effects that COVID-19 is having on people's mental health.



The study will identify how the news about Coronavirus is affecting people, whether people are having to isolate, and their experiences of doing so.

The study is open to all adults in the UK and involves answering an initial 15-minute online survey, followed by a shorter 10-minute follow-up survey once a week whilst social isolation measures are in place.

For more information, see here:

<https://redcap.idhs.ucl.ac.uk/surveys/?s=TTXKN D8JMK>

## Volunteer's Week

"Volunteers don't get paid, not because they're worthless, but because they're **priceless**."

Volunteers' Week took place in the first week of June and was a chance for the kidney charities to celebrate and say thank you for the contribution of the volunteers who support our work. A massive diolch yn fawr from us to you!

Here are just a few of the volunteer heroes for our charities:



Paul Popham Fund Peer Support Service - thanks to our volunteer befrienders!



At the Paul Popham Fund, Renal Support Wales the charity recognises the support they and their beneficiaries receive from their volunteers, they could not carry out our work during this time if it were not for them who themselves are also shielding.

The Charity runs a Peer Support Service (Befriending Service) where people with kidney disease or family members volunteer to become Peer Mentors (Befrienders) where they are trained to offer advice and support to people like them.

The Charities' Peer Mentors are matched to people with kidney disease seeking advice based on having similar circumstances as each other so that the Peer Mentor is best able to understand the situation of the person with kidney failure and able to offer support based on their lived experience. They would normally meet up to offer support however during this time that is not possible and so the charities volunteers are:

- Manning the charities Careline, a telephone service for people with kidney disease managed by people with kidney disease,

anyone wanting support can be guaranteed to speak to someone who understands, will listen, and offer their guidance during this time

- Providing Peer Support over the telephone, where people with kidney disease are referred to the service, they are matched to a Peer Mentor with similar circumstances, the Peer Mentor will then call the person to offer their support
- Facilitating the Charities' on-line support groups, where people with kidney disease can discuss burning questions in an on-line confidential setting and get feedback and morale support from their peers!

If you would like to train to become a **Paul Popham Befriender** please contact: [enquiries@paulpophamfund.co.uk](mailto:enquiries@paulpophamfund.co.uk)



## Peer Support Services - North Wales

The **Paul Popham Peer Support Service** is currently in operation within Swansea University Health Board and Cardiff and Vale Health Board.

Our aim over the coming months/year is to develop the service to support patients in North Wales.

As part of this process, we are looking to patients in North Wales to join our service by becoming **Volunteer Peer Mentors (befrienders)**. We are looking for people who understand what it is like to live with kidney disease, be on dialysis or have a transplant, who can help (and/or support) others.

Training is provided and volunteers are well supported by the Team. If this is you, please contact [support@paulpophamfund.co.uk](mailto:support@paulpophamfund.co.uk) or call **0800 038 8989** for further information.

**We look forward to hearing from you!**

## Kidney Wales face masks for patients

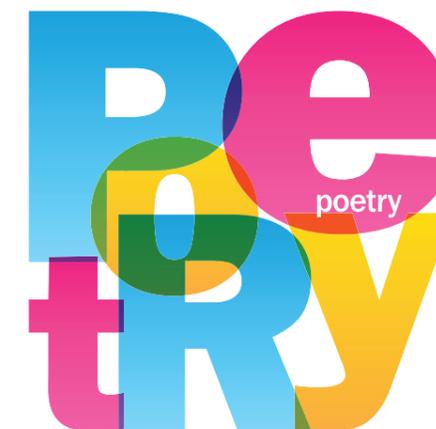
Welsh Government's latest guidance is for the public to wear face coverings whilst using public transport, or visiting areas where social distancing is difficult.

The use of face masks whilst travelling to/from and whilst dialysing is encouraged by the Welsh Renal Network. Transplant patients are also advised to wear a mask if going outside.

Kidney Wales will purchase re-usable face coverings for our Kidney community, for use during the pandemic. This type of mask is a face covering, rather than a medical grade surgical mask and it will therefore not negatively affect the supply of PPE to healthcare settings.

Masks are provided free of charge for all kidney patients who are under hospital care. Additional masks can be requested (limited to an additional 3 per household), but for these we ask that you consider a donation of £4.50 per additional mask to cover the cost of the mask and postage.

To order your mask, get in touch with Kidney Wales on **029 20 343 940** or email: [team@kidneywales.cymru](mailto:team@kidneywales.cymru)



## Kidney Wales Poetry Competition

In May, Kidney Wales launched a poetry competition within our private Kidney Wales Community Facebook group offering the opportunity for patients and families to express the impact the Coronavirus Pandemic has had on their lives in the form of a poem.

The first poem that stood out from the crowd was written by **Julie Jenkins**:

*What can we say about Covid, the worry it brings to our family.*

*Two of my boys work for the NHS, Mum's very proud but worried and stressed.*

*I listen to the news update everyday, wishing this virus would go away.*

*Missing my grandchildren my heart is breaking, how much longer is this taking?*

*Good job I can rely on Kidney Wales, for lots of updates and lots of news.*

*Nothing is too much trouble, no emails not answered.*

*They are never too busy or can't be bothered.*

*Thank you for being there for us. Kidney Wales you are the best.*

(<https://www.kidneywales.cymru/news/2020/06/02/poetry-competition-winners/>)

