

THE KILTIED KIDNEY

Together We Are Stronger

Renal Young Adult Support Newsletter

SUMMER 2025



Welcome to the first Renal Young Adult (YA) Newsletter, "The Kiltied Kidney". Brought to you by Jess and Victoria, we are volunteers for the RYASS, we hope you enjoy reading!

The Renal Young Adult Support Service (RYASS) is a brand-new service – The first of its kind for Scotland set up in May 2023 by Sharlene Taylor who is the Renal Young Adult Support worker (RYASW). It was noticed that there was a lack of support for the age range 16-35. The service helps young adults with any stage of Chronic Kidney Disease (CKD) whether this is pre-dialysis, during dialysis or post-transplant, the support is there for you. Also when setting up the service it was noted that most of all the YA mentioned that they didn't seem to know anyone with CKD at their age.

In August 2023 Sharlene set up the first peer support group with only 3 attendees. Everything that has happened for the service to run as it has is all thanks to Sharlene's wild enthusiasm and motivation. As we jump forward to April 2025, there have been 16 attendees who attended the peer support group meetings which are held every month. The support service covers Edinburgh City, the Lothians and the Borders. Services provided are home visits, hospital visits, a chit chat over a coffee or a friendly face to accompany you to clinic appointments or she can meet you in the community too.

Having someone like Sharlene helps to empower the young adult to have the confidence to ask questions when meeting with clinical staff. The service also provides follow-up chats after clinic appointments. The service provided by Sharlene also helps people to navigate other challenges in life.

Depending on the individual's needs, this can include areas such as education, employment, financial benefits for the young person and their family, housing, relationships and mental health. Sharlene can work individually and/or in groups to encourage young adults to adjust positively to their health conditions, taking responsibility for managing health and treatment through inevitable change.

Sharlene can help you to apply for KCUK grants to enable you to go on holiday, get an electrical appliance or even get driving lessons. If you are eligible, she can attend appointments to support with Adult Disability Payment through Social security Scotland.

Opportunities that have been created for the young adults ranging from art projects to nature projects to volunteering opportunities as well as the chance to travel to the Kidney Care UK Young Adult Residential Weekend at Mount Cook Adventure Centre. Over the coming months there will be more exciting events to add to your calendar, thanks to the RYASS.



NHS Lothian young adults heading to Mount Cook Adventure Centre

Credit - Sara McBurnie-Davies

Let's Bowl

In April 2025 a group of 14 young adults from across Edinburgh, the Lothians and the Borders came together to have a fun night of ten pin bowling. 2 games were played, and the 'tournament' consisted of 2 games. The winner of game 1 was Jess with 85 point and the winner of game 2 was Murray with 112 points. During the game everyone tucked into burger and fries along with a drink of choice. This was funded through the NHS Lothian Charity to celebrate 2 years of the Renal YA Support service being launched. Everyone who came along had a great time and were able to chat with people of a similar age and has been through health issues without being in a clinical setting or having to talk about their CKD. We look forward to more events like this in the future.



Above: The group on the bowling alley after the game.

Credit - Passerby



Left: The group at the arcade area after some time to socialise.

Credit - Passerby



The Kiltwalk is a large sponsored walk that takes place across Scottish cities. Edinburgh's Kiltwalk is taking place on Sunday 14th September 2025. There are 3 different lengths of walks you can sign up for, 20 miles (The Mighty Stride), 11 miles (The Big Stroll) or 5 miles (The Wee Wander). The NHS Lothian Charity is one of the many charities to choose from and you can enter as an individual or as part of a team. Entry fees per adult are £20 for the Mighty Stride and the Big Stroll and £13 for the Wee Wander.

In 2023 one of our young adults completed the Big Stroll which was 15 miles that year. She has said, "it was tough especially after the ninth mile when my hip gave way but I persisted as I was going to cross that finish line at Murrayfield stadium." She then continued to say "I would highly recommend doing it and I'll be taking part in the Wee Wander this year to raise money for the NHS Lothian Charity as they do amazing work and have helped out the Renal YA Service behind the scenes, so I want to say thank you."

In 2024 over £7 million was raised for over 1650 Scottish charities. If you would like to sign up, visit thekiltwalk.co.uk

Great Scottish Kidney Kitchen Bake Off!

World Baking Day was the 18th of May so what better way to celebrate than to host The Kidney Kitchen's first ever Renal Bake-Off?! There was bunting, points and prizes, amongst the judges we welcomed Paul Ripley from Kidney Kitchen. Paul is a chef of 35+ years and helped set up Kidney Kitchen with a friend who had CKD dietary restrictions themselves. The latter stages of CKD can sometimes bring about limitations on certain foods, but no one enjoys missing out. Kidney Kitchen is a fantastic place to find recipes that are suitable for those navigating these adaptations, and it includes sweet treats too. These can be enjoyed by most, so no missing out on celebrations or special events and no requirement for separate preparation. Participants were encouraged to use a recipe from Kidney Kitchen which would score them points, as would texture, taste and creativity. The table was filled with the 11 entries of cakes, pastry tarts, cream desserts, biscuits and scones. Several participants were first time bakers too. A big thank you and well done to everyone who took part. We hope you feel proud of yourselves! Our first ever winner of the renal bake off came up roses with her carrot cupcake bouquet, Congratulations Jess! Her precarious but stunning design was super moist with attention to detail. Who wouldn't love to receive this edible topiary! This was a chance for them and newer group members to experiencing what the Young Adult Renal Service is about. It was a chance to break down barriers.

The remaining cakes were taken to the renal ward where their sale raised £225 for KidneyCareUK.

A special thanks go to them and NHS Lothian Charity for supporting the event.



Chef Paul Ripley, Winner Jess with her winning entry and Renal Youth Support Worker, Sharlene.

Credit - Lukaz Kuc



The young adults with their baked entries

Credit - Lukaz Kuc



The judges tasting the entered cakes and bakes.

Credit - Lukaz Kuc

Lived Experience

The Kilted Kidney caught up with one of the YA, Rikki, from the peer support group to find out his kidney journey

Can you tell us three things that go a little way to describe yourself?

"I love adventures in the outdoors, experimenting with cooking oftentimes combining the two, and I own a large collection of classic hats."

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What is the cause for your CKD?

“It’s called Atypical Haemolytic Uremic Syndrome or AHUS which is a rare genetic condition. Part of your immune system known as the Compliment, is designed to attack foreign bugs, and certain proteins prevent it from attacking the body. With AHUS those proteins are missing which causes blood clots to form in small blood vessels. It mostly targets the kidneys and eyes.”

Can you share how your diagnosis came about and what that was like for you?

“I had been feeling a bit off for a while but nothing I thought was serious. I’d had headaches and changes in vision for around a year but was managing with over-the-counter pain relief. When I eventually had my blood pressure and eyes checked. I was told I may be contacted by renal. I didn’t even know what renal referred to at that point, but it didn’t sound urgent. Whilst on holiday in England my chest felt really bad, so I went to A+E. Blood tests showed my kidneys weren’t good at all & I was transferred to another hospital with a renal unit & fitted with a chest line. After two weeks I was sent to a big London hospital where I continued Haemodialysis. Those Drs were certain I had AHUS, but genetic testing is required for a definitive diagnosis, and this takes months and is very expensive. The other financial concern was funding for the drugs I needed for AHUS. At the time, the treatment was only a few years old and so unimaginably expensive, special permission for funding was required for each case.”

Rikki continues “Going through such a life altering health issue in my mid-twenties, during the uncertainty of the pandemic was scary, very scary. Transplant lists even got closed for a period, from a flip side it was comforting that there was protection in place for vulnerable people such as myself. It was also during this time that I received ‘The Call’. My recovery was good. The donor kidney worked immediately & I felt great in comparison to before. The first-year post-transplant was a blur to me-like being on a caffeine buzz! I was a fire hose of energy and had a heck of a lot of an appetite! There was no semblance of normality. I do remember my first night of uninterrupted sleep with no pee break, that sticks in my mind!”

Have you ever met anyone else with AHUS?

“Yes, there are currently around 200 people in the UK who know they have it.”

Do you have any goals for your future?

Yes, when I woke up in an anaesthesia stupor after my transplant, I said I felt good enough to climb Ben Nevis. I’ll be 5 years post-transplant in September 2025 so that’s what I’m going to do. I’m proud that I got my driving licence too-it’s such a normal part of life for many but something I was too sick for before.”

Rikki finished with a bit of advice, “Don’t neglect symptoms. Even if they don’t seem serious-go and get them checked”.

Find out more about AHUS at www.atypicalhus.co.uk and www.kidneyresearchuk.org

The Sun Has Got It's Hat On!

Scotland may have had its two weeks of warm weather for our summer, let's hope we get a little more. Even if you are not going abroad in the sun it's important to remember that the sun doesn't need to be blazing to be at risk of sun damage. The sun produces rays of radiation which penetrate our skin if we are exposed and unprotected. We know them as UVA & UVB. But what's the difference & why should you care? UVA penetrates our skin deeply and causes DNA changes in the skin-normally this will show as a tan however UVA is the wavelength that is most responsible for skin cancers. UVB doesn't affect our dermis quite so deeply, it's the one that causes premature aging of the skin and wrinkles.

Skin cancer is referred to as Non-Melanoma or Melanoma, depending on the type. Treatment rate for non-Melanoma is very good according to Cancer Research UK website where you can familiarise yourself with risks, what skin changes to be aware of and more in-depth information. It's not much of a secret nowadays that sun protection is important, it's more present than ever in facial creams, and a multitude of fake tans have replaced sunbeds but how does this relate to renal patients? Those who are post-transplant have to take Anti-Rejection medications to suppress our own immune system from attacking the new organ(s). This makes our bodies less efficient at detecting and eliminating mutated cells that may be cancerous. Some of these medications also react directly with UV light and people with a suppressed immune system can find recovering from sun burns more difficult. Being in the sun has many benefits from Vit D absorption for strong bones to boosting our mood. It's important to maintain these benefits and to be able to enjoy the outdoors just because it feels nice.

Prevention and Protection.

- Avoiding sun when at it's strongest (11am-3pm in the UK) by staying in the shade
- Wearing a sunscreen with a minimum 4* UVA rating and Sun Protection Factor SPF of 50 and learning how to apply it effectively.
- Wearing tight woven clothing, wide brimmed hats and UV protective sunglasses.
- Staying hydrated.

There is a of sunscreens on the market now, creams, gels, sprays, sticks, sweat proof, matte, shimmery, chemical, mineral...It may take a few trials to find one that suits your skin and lifestyle. It can be helpful to have a few different ones or a specific facial one. Just remember to check for the 4*UVA rating and SPF50. A lot of younger people turn to social media influencers for information, there are some good channels that give their thoughts on sunscreens, however, please be very mindful to check that they are board certified doctors or dermatologists and that any products meet NHS recommended criteria before trying them yourself. Sometimes it can be annoying or impractical to reapply sunscreen for a quick outdoor errand, or whilst doing outdoor sports. A good option is tight woven material that blocks UV reaching the skin. It's now possible to buy clothing that has a rating system just like sunscreens, Ultraviolet Protective Factor means that the material has proven capabilities of blocking UV reaching the skin. Again, make sure to choose UPF50+ from a reputable company.

NHS Tayside has a comprehensive list of suppliers. Search for "sun protective clothing" on www.nhstayside.scot.nhs.uk for more information and links.



L: Sunglasses, sun hat and sunscreen.

Credit – Matucha
iStock images

R: Sun cartoon with sunglasses on

Credit – Freepix



Sip and Slurp

Staying hydrated doesn't help prevent sunburn but it can help our skin be more resilient & is essential to keep new organs happily sloshing around. Warmer weather can increase exertion leading to more sweating and faster breathing, both of which increase loss of fluids. This is true for everyone, pre- and post-transplant. Taking in enough hydration can have its challenges, it's the complete flip of fluid restriction so remember that all fluids count towards meeting or staying within your personal goals.

Replacing fluids can be problematic if you are on a fluid restriction and the thirst is REAL! It's a basic bodily instinct.

Some tips to stay within your personal fluid limits are:

- Sipping small amounts frequently instead of chugging a full glass.
- Swilling your mouth out with water can moisten it before you do enjoy a drink
- Replacing sugary drinks with lower sugar or sugar free options. Sugar can cling to the mouth creating a furry feeling & an urge to drink more.
- Sugar free gums or boiled sweets/hard mints that can be sucked slowly
- Flavoured ice cubes. Measure how many millilitres each cube holds to make keeping track easy. Try popping in fruit chunks or juice.
- Frozen fruit-berries, melon, grapes are a healthy snack too. Try mixing with a little yogurt.
- Measuring your daily allowance into one jug or bottle.
- Using the same cup & glass at home. Different cups can vary in volume.
- Although it can be tempting to enjoy some alcohol in sun, one beer or cocktail can eat into a fluid limit and may cause a bigger thirst later. Speak to your consultant if this is something you are keen to enjoy.
- Noting down fluid volumes each time you drink something with a running total.
- Keeping cool can help control thirst. A personal, portable fan, facial spritz or mist, cool packs & cooling pulse point products can be good options to try.
- Breathable natural fibre clothing.

Consultants are aware that warmer weather can require temporary adjustments so please let them know if you are having difficulty with your prescribed fluids.

Kidney Kitchen recipes like the one here can be found at - [kidneycareuk.org/get-support/healthy-diet-support/kidney-kitchen/recipe-index](https://www.kidneycareuk.org/get-support/healthy-diet-support/kidney-kitchen/recipe-index)

Each issue of the newsletter will feature a different Kidney Kitchen recipe for you to try at home.

Kidney Care UK 1975-2025: 50 years of changing lives

For half a century, Kidney Care UK has stood alongside and supported kidney patients and their families. What started as one mother's mission – Elizabeth Ward's fight for her son Timbo and others like him – has become the UK's leading kidney patient support charity.



Credit – [kidneycareuk.org](https://www.kidneycareuk.org)



Charlie's lentil pizza with chicken and sweetcorn

Prep: 20 minutes + 1 hour soaking • Cook: 20 minutes • Serves: 4



Ingredients

Lentil base
250g red lentils, soaked for 1 hour then drained and rinsed
100ml cold water
1 teaspoon garlic, crushed
1 teaspoon dried oregano or basil
1 teaspoon cornflour

Sauce
1 dessertspoon olive oil
1 onion, peeled & finely chopped
2 garlic cloves, peeled & finely chopped
1 teaspoon dried oregano or basil
1 tablespoon tomato purée
200g tin chopped tomatoes

Toppings
150g cooked chicken breast, shredded
100g sweetcorn, frozen (defrosted) or tinned (drained)
150g mozzarella, ripped into pieces

Salad
100g gem lettuce
50g cucumber, diced
½ red pepper, deseeded and sliced

Dressing
100ml olive oil
1 tablespoon Dijon mustard
1 tablespoon white wine vinegar

- 1 Preheat the oven to 200°C / 180°C fan / gas mark 5. Add all the base ingredients to a food processor and blend until smooth.
- 2 Line a baking tray with greaseproof paper. Pour the lentil base mix onto the tray, smooth out into a pizza base of approximately 25cm in diameter or on a rectangular tray (approximately 25cm x 18cm). Cook for 15 minutes, remove from the oven, flip over and return to oven for a further 5 minutes.
- 3 Once the lentil base is cooked, spread the tomato sauce over the base and add the toppings. Put back into the oven for a further 5 to 10 minutes until the cheese has melted and turned golden.
- 4 Combine the salad dressing ingredients and stir or whisk together. Pour the dressing over the salad.
- 5 Remove the pizza from the oven and serve with the prepared salad.

Nutritional info

Low phosphate ✓
Low potassium ✓
Carbohydrate **44g**
Low protein ✓
Low salt ✓
Cost per portion (March 2025) **£2.00**
Energy in kcal **683**

www.kidneykitchen.org

Key Events/Dates Coming Up

30th July – Peer Support Group OPD4 Royal Infirmary 5.30pm (Lived Experience)

3rd September – Art Project Showcase OPD4 Royal Infirmary 5.30pm-7pm (Drop In)

1st October - Peer Support Group OPD4 Royal Infirmary 5.30pm (Fun and Games)

29th October – Nature Ranger Halloween Project OPD4 Royal Infirmary 5.30pm

Key Websites/E-Mail Addresses

Renal Young Adult Support Service (Sharlene Taylor) - sharlene.taylor@nhs.scot

Kidney Care UK – www.kidneycareuk.org

National Kidney Foundation – www.kidney.org

Kidney Research - www.kidneyresearchuk.org

REACH Transplant Team (Alison Sharry) - loth.reachtransplant@nhs.scot

Kidney Care Patient Advocacy Officer (Annette Cliffe) - annette.cliffe@kidneycareuk.org