



# BRISTOL AREA KIDNEY PATIENTS ASSOCIATION

Registered charity No. 271775

## February 2024

Hello to all our readers

Already we are well into February, time is marching on. It has been a while since we created a news letter in this format, there are a few reasons for that, some of these items have already been posted as blogs on our website, also other items have only recently come to fruition, BUT we hope you find plenty of interest inside.

Don't forget you can join or renew your membership on our website. Under the new process, you will have your own account, enabling you to log in and renew next time. For ongoing memberships renewal will be automatic. You can also join or renew by contacting the Membership Secretary (see page 11).

We have been making improvements to the garden at McAllister house in Torquay, full information and photos on pages 6/7. We were awarded a grant from Costa foundation to help with the cost of this project, so if you are looking for a place to take a holiday please do consider McAllister House.

BAKPA celebrated 50 years working for the patients and renal department of Southmead hospital. Lots have happened in those 50 years with so many dedicated committee members and supporters who have raised funds and organised events on behalf of BAKPA, so a huge thank you to all.

BAKPA have collaborated with other KPA's in the southwest to bring the exercise and physio platform Kidney Beam to your living room, enabling you to take part in keeping fit and healthy with out the cost of an expensive gym membership. More details on page 2.

Finally please do keep an eye on our website and our facebook page where all of our latest updates are posted.

We wish you a very happy and healthy 2024, from all of the BAKPA team.  
Vicky Gardner, Chairman

## Notice of Our AGM - All Members Welcome

The BAKPA Annual General Meeting is to be held on Saturday 23rd March 2024 at St Stephens Church, Ullswater Road, Southmead, BS10 6TP. There will be hot drinks/biscuits etc. from approximately 3.00pm, the meeting is due to start at 4.00pm.



# BAKPA Coffee Morning & tombola

Uphill Victory Hall  
16, Old Church Road, Uphill  
Weston-super-Mare, BS23 4UH

(Parking available)

Saturday 6<sup>th</sup> April 2024

10:00 – 12:00 hrs



## John Lewis Cake Raffle

A huge Thank you to the partners at John Lewis Cribbs Causeway who held a Christmas Cake raffle in aid of BAKPA the prizes were 3 Cakes and two decorated Terry's Chocolate Oranges, one in the shape of Snapper to complement the Christmas advert and the other Santa Claus.

The money raised was £149.72 Thank you to all who bought tickets and a huge Thank you to Carol Small who organised this.



### Cake Raffle in aid of BAKPA



## AMD Solicitors Charity of the Year 2023

Every year AMD Solicitors nominate a charity of the year to raise as much money as they can for that chosen charity. Michelle Bird who works at AMD in Henleaze chose BAKPA, which received the most votes so became the charity for 2023. Below is Michelle's reason for supporting BAKPA in her own words.

During November 2011 at the age of 54, My Father Andrew Bird became very unwell and was taken to hospital. During the process of several tests and treatment, he was subsequently diagnosed with a very rare autoimmune disease known as Goodpastures Syndrome, this causes the immune system to mistakenly make antibodies that attack the lungs and kidneys. As a result, my Dad had to dialyse three times a week at the Richard Bright Renal unit.

Devastatingly, after 9 years my Dad lost his life on the 15th of January 2021 aged 63. We as a family were grateful to the Richard Bright Renal Unit for their support and treatment given to Dad which no doubt prolonged his life. I therefore looked into whether there was a charity that raised money for the unit where my Dad was treated which is how I became aware of BAKPA. I wanted to put forward this charity because of everything they did for my Dad and my family during such a difficult time and give something back.

This charity is very close to mine and my family's hearts and therefore, my family and I know my Dad would be extremely happy we have been able to raise funds for this unit, I will forever be in debt to this unit and what they did for my Dad.

AMD raised an amazing £1122.11, all done through cake sales and dress down days to name a few. BAKPA would like to thank Michelle for nominating the charity and Lauren Carley who was the contact for us for all the hard work raising such an amazing sum.

Pictured is Michelle Bird with Vicky Gardner, chairman of BAKPA



## **NKF Webinars**

The NKF webinar videos give information on a wealth of topics. Head over to <https://www.kidney.org.uk/Event/nkf-webinar-series> and you will find something of interest. These are some of the videos currently available:

- Matching for Transplant - A guide to compatibility and blood tests
- How can a Kidney Patient Association (KPA) support you and why you should be a member
- Patients Know Best - for accessing results previously available in Patient View. It integrates with the NHS app.
- Healthy eating with diabetes and kidney disease
- An insight into Renal Pharmacy.

## **Kidney Beam**

We are delighted to announce that Kidney Beam, an innovative online service that supports and encourages kidney patients in taking care of their physical and mental health, is now fully funded in all of England. This achievement was made possible through the NKF's coordination of the Southern Kidney Patient Associations, who successfully secured funding for the platform in their region. Kidney Beam has established various partnerships with renal networks for a region-by-region rollout, and with the help of the NKF coordinating the KPAs, funding has now been completed.

KPAs that came together to fund this are Wessex KPA, Sussex KPA, Bristol KPA, Exeter KPA and Gloucester KPA. Not all KPAs are in a position to financially support this, so those that are have stepped up to enable all kidney patients of the southwest to access Kidney Beam.

Kidney Beam is an online platform that hosts live and on-demand exercise, education and well-being classes aimed at anyone over the age of 16, with any ability, any kidney condition and at any stage of kidney disease.

All classes have a fitness rating so you can choose the right one for you, activities include yoga, pilates, dance, strength training and cardio fitness. The platform provides a range of tools to help kidney patients manage their condition and improve their quality of life.

For more information on Kidney Beam visit:

[www.kidney.org.uk/kidney-beam](https://www.kidney.org.uk/kidney-beam)

## Remembering Frank Howarth

We wanted to mark the passing of Frank Howarth, who had a long association with BAKPA, and who passed away last year.

Frank was a delightful man – a true gentleman and always a champion of renal patients and their families and always looking to do good and be of benefit to the renal community, which he certainly was.

Frank was diagnosed with kidney failure in 1965 when he was 30, and as neither he nor his wife Jean knew anything about kidney failure, it was a steep learning curve for them.

Frank dialysed for a number of years, using a home dialysis machine in their spare bedroom, which Southmead Hospital had kitted out perfectly. Frank first became involved with BAKPA when he attended a day long member's meeting in South Wales. At the time, Neoral (Ciclosporin) was a new drug, and some patients had volunteered to be guinea pigs in the trials, reporting back on reactions and side effects.

This was the beginning of Frank's long association with BAKPA, and he was also the President of the NKF (National Kidney Federation) for a number of years.

Frank received a cadaveric transplant in 1991 which proved to be a perfect match.

Frank was delighted when the dialysis unit at the Royal United Hospital in Bath was established, as it was just five minutes from where he and Jean were living so they were both able to visit regularly.

Frank's enthusiasm for BAKPA never waned and he considered the good relationship that BAKPA enjoyed with the Southmead Renal Unit to be a bonus of great value to all the patients.

He continues to be missed by us all.



## McAllister House - Torquay



McAllister House is available for holiday bookings, we look forward to welcoming you to it!

The House is named after our former chairman of many years, Mike McAllister, who we sadly lost in 2022. Mike was an enthusiastic supporter of providing holidays for renal patients and their families.

The house is about 6 years old and is located in a lovely private estate on the outskirts of Torquay. It's easily reached from Bristol via the M5, and offers the ideal base for touring round the English Riviera!

It's a semi detached property with parking and garage at the rear, so offers easy access on one level via the back patio doors.

The house has a cloakroom, lounge and large kitchen diner on the ground floor, with three bedrooms (two doubles and one small bedroom with two stacking single beds) and bathroom upstairs. All rooms are fully furnished and the kitchen is fitted out with everything needed to provide a self catering holiday.

You will need to be a full member of BAKPA to book the use of the house, and for legal reasons all those age 16 or over who accompany you will also need to join BAKPA.

*Unfortunately there is a strict NO PETS policy*

Please contact our Membership Secretary to book.

Stephen Nicholls on 01454 417864, evenings between 6pm & 9pm or email [secretary@bakpa.org.uk](mailto:secretary@bakpa.org.uk). Bookings are for up to one week.

Update - We have had the front and the back gardens newly landscaped. We intend to put a small patio table, chairs and parasol on the upper patio out the back so anyone staying can enjoy the sunshine in the summer.

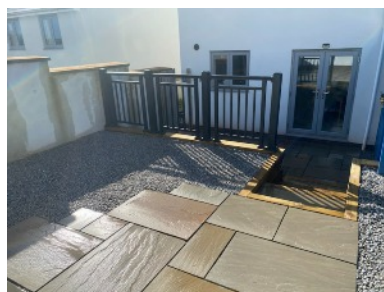
Thanks to Costa charity foundation for the grant towards the landscaping project.



**Back garden - Before**



**and After**



### **Weekly Charges**

There is a £50 booking deposit (to be paid by return)

Season	High Season (Jun-Aug)	Mid Season (Sept-Oct & Mar- May)	Low Season (Nov-Feb)
Patient and Carer	£200	£180	£160
Each Associate Member	£100	£90	£80
Accompanied children under 16	Free	Free	Free



## Our 50th Anniversary Party

BAKPA held its 50th Anniversary celebration on the 9th of September 2023 at the civil servicemen's club in Filton, we had lots of raffle prizes including hampers and a coffee machine, Anne and Andy Strange held their tombola table that was a massive hit with everyone who attended the night. There was plenty of food and an anniversary cake along with a disco so plenty of dancing.

We would like to thank everyone who supported Bakpa by buying raffle tickets for the cash prize draw and everyone who came and helped us celebrate to make the event a great success.



## BAKPA Merchandise

Support us by buying a BAKPA branded pen, lanyard, trolley token, or get all 3 items. You can purchase them online at <https://bakpa.org.uk/bakpa-merchandise/> or contact Anne at [events@bakpa.org.uk](mailto:events@bakpa.org.uk).





## **Changes to the Bristol Transplant Team**

by Catharine Hall - Team Manager

There are big changes to the team this year, I have decided after 14 years in the role that it is time to greatly reduce my involvement and step back into a remote admin only position. Running the team is a lot of work, most of it totally unseen and I have a lot of other commitments which take up increasing amounts of my limited time. Like all of us I am not getting any younger either and it's quite scary to think I have spent half my adult life running one team or another.

So with a likely move to another part of the country in the offing in the years to come, now is the time to reduce my involvement.

Vince Taylor the deputy TM also stood down after the 2023 games. I had worked with Vince for all of those 14 years. During that time the team topped the medal table in 2017 and 2018, something never achieved before. We also won the swimming trophy in 2010 - another first. Thank you to Vince for his continued support over the years, I know he feels I have made the right decision and I believe he has too.

So the end of a great partnership, all good things come to an end!

I have appointed Charlie Lewis as a joint team manager, since I no longer go to the games myself. Charlie will be running the team on the ground and dealing with some other team matters. He is already working on a new team kit for the participants this year which I'm sure will go down well.

Charlie is relatively new to the games, he is a golfer and is in his third year of competition. He is a very keen and very capable young businessman, I'm sure he will do a fine job in the years to come.

The games are in Nottingham this year from 1st to 4th August. Charlie will be attending the managers meeting in February and touring the venues.

New participants are welcome to contact me in the first instance as it will be a transition year, at [catharinehall@hotmail.com](mailto:catharinehall@hotmail.com)

Thank you again to Vince Taylor and I wish Charlie every success in his new role.

# FINANCES

## 1st October – 31st December 2023

Lesley McAllister, Treasurer has supplied the following figures and acknowledges on behalf of BAKPA our grateful thanks for all the monies received.

### Donations

Donations and Membership £512.17

Paypal £106.74  
(C.Garcia, J. Pomeroy, D.Rumsey, K.Durman, M. and L.Hayes, D.Mansfield, D.McDermott)

Just Giving\* £1511.79

*\*Due to a technical problem we have been unable to list all donors but acknowledge their kind generosity and the hard work which has gone into fund raising events to make them such a success.*

*We also wish to thank all members who send donations by standing order and those contributing by Charities Aid, PayPal and Just Giving.*

If you would like to donate through 'Just Giving' please see our page at

<https://www.justgiving.com/bakpa/>

You can also donate directly to BAKPA on the Donations page of our website [www.bakpa.org.uk/donate-to-bakpa](http://www.bakpa.org.uk/donate-to-bakpa)

### Collecting Pots

If you would like a Collecting Pot to place in your work place/ local pub/ shop etc., please contact Colin Marrs on 0117 9590930 or at:

**webmanager@bakpa.org.uk**

Concorde News £95.18  
Gales Meats £34.76  
10 o'Clock Shop £31.22

### Other Income

Bank interest £333.77

### Expenditure

Hales House £1236.55  
McAllister House £6411.40  
Headphones Ambleside Unit £100.00  
Sundry Items £426.30

Please send all donations (Except membership and McAllister House) to:

Lesley McAllister, Treasurer  
Bristol Area Kidney Patients Association  
11 Fenton Road, Bristol, BS7 8ND

All cheques payable to BAKPA.

## PIP (Personal Independence Payment)

**Kidney Care UK** have developed a new, free online PIP Helper tool and they need some help beta testing this before launch.

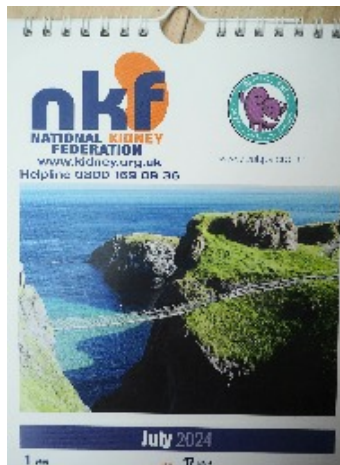
The PIP Helper includes an overview of the application process and form, as well as a breakdown of each question with example answers, and will provide instant advice and support for you if you're going through the process.

To find out more, and to register to help with the testing, please contact [comms@kidneycareuk.org](mailto:comms@kidneycareuk.org)

## NKF calendar

Bakpa has sponsored a page for the month of July in the 2024 calendar, one of the 12 entries. It is still available to order from the NKF for £2.50 + postage.

<https://www.kidney.org.uk/shop/nkf-2024-calendar>



## **BAKPA committee**

President Dr James Bushnell

Chairman Vicky Gardner


 0117 3291696  chairman@bakpa.org.uk

Vice Chairman Vacant

Treasurer Lesley McAllister  treasurer@bakpa.org.uk

Membership secretary

Stephen Nicholls

 9 Medina Close, Thornbury, BS35 2DJ

 01454 417864  secretary@bakpa.org.uk

Secretary Sharon Nicholls - contact details as for membership secretary

Fundraising Anne & Andy Strange  events@bakpa.org.uk

### **Committee Members**

John Gardner, Catharine Hall, Colin Marrs, Paul Filer, Melanie Belfield and Leora Sharp