



NI Kidney Patients' Association
Charity Commission Trustees Report
Year: APRIL 24 - MARCH 25

The Trustees present their report along with financial statements for the year ending March 2025.

NIKPA's elected office bearers for the period of this report were;

Chair: Patty Gilbert

Vice Chair: Jean Michelo

Secretary: Emma Proctor

Treasurer: Joyce Guy.

Emma Proctor and Siobhan Marron support the Treasurer in the making of payments.

Nathan Fairbairn has oversight of engaging NIKPA Audit and Charity Commission submission.

Honorary President: Dr Ciaran Doherty, Retired Nephrologist

President: Dr Aisling Courtney, Consultant Nephrologist, Belfast City Hospital.

The election of Office bearers takes place at NIKPA's AGM in September of each year. Any member can be nominated or put themselves forward for nomination for officer posts of Chair, Vice Chair, Treasurer and Secretary.

The NI Kidney Patient's Association (NIKPA) represents patients experiencing a range of kidney conditions or renal failure together with their carers and families living within Northern Ireland. NIKPA is run entirely by volunteers and supported in its activities by staff at the 6 adult and one paediatric renal unit within our geographical area.

NIKPA provides support and a voice for anyone impacted by Kidney issues. It also promotes organ donation. The direct benefits which flow from our Mission Statement are;

- Representation of Renal Patients at governmental, HSC and public levels
- The provision of financial assistance to renal patients through our Helping Hand fund.
- Organisation of social outings for renal patients, family members or carers.
- Support those fundraising for NIKPA
- Raise public awareness of renal disease and organ donation
- The promotion of the benefits of organ donation. This additionally contributes to an increase in public awareness of renal disease.

The beneficiaries of these purposes are people living in Northern Ireland who have been diagnosed with renal disease, are in receipt of dialysis therapies or who have undergone renal transplant. Other beneficiaries are family members, friends and carers of renal patients. There is no private benefit flowing from these purposes. NIKPA is additionally made aware of the benefits by means of feedback from patients, their relatives and members of the Multi-Disciplinary Medical Team who care for renal patients

Expenditure:

We are very much aware that NIKPA's ability to be involved in such a range of activities would not be possible without the consistent commitment of all on the NIKPA Committee and those who continue to support our endeavours by their fundraising efforts.

Examples of payments made from NIKPA Helping Hand Fund include;

- Children's summer schemes to allow time for a kidney donor and recipient to recover from surgery
- Two month's rent on a family home while a patient recovers and is able to return to work.
- Two coastal holidays for patients and their family
- Sofa bed so that a dialysis patient can host her sister to stay for short visits.
- Bedding for patient commencing home dialysis

- Fill of oil for patient suddenly commencing dialysis and unable to work
- Contribution towards the purchase of a wheelchair.

Additional expenditure:

- NIKPA Care Bags, gifted to recently transplanted patients contain useful items to aid the transition to what is hoped a more healthy life.
- Commencing in September 2022 NIKPA's Annual Family Fun Day continues to attract over 250 patients, staff and their families to Jungle NI.
- Christmas Pantomime for Paediatric Dialysis Patients was attended by 120 patients, their siblings, parents and in some instances by grandparents.
- Promotional material to be given or sold at events eg. pens, lanyards, winter hats, 'Thankyou' cards

NIKPA Engagement Activities

- Organ Donation Charity Sub Group which promotes public awareness of Organ Donation
- Patient Advisory Group of the national charity, Kidney Care.
- Renal & Transplant Alliance – a collective of NI donation charities collaborating to speak on behalf on the wider group of donation patients (eg Liver, Heart Pancreas donation)
- 'Expert by Experience' speaker on the Queens University Specialist Renal Nurse Course
- 'Expert by Experience' speaker on Ulster University 1st Year Nursing Degree course
- Patient Representative engagement with the NI Ambulance Service review of Haemodialysis transport
- 'Transplant Tales' As part of Belfast Science Festival 25
- Supporting Dialysis Patient Education Projects at Belfast Renal Unit
 - 'PINT SIZE' focusing on fluid management in haemodialysis patients
 - 'Time to change' - focusing on attendance to treatment, taking prescribed medications
 - 'Just a Pint' – focussing on fluid intake adherence

Research Patient & Public Engagement:

- ‘PAINT ‘project: maPping exercise of **Arts Interventions in reNal uniTs**:
- Social Prescribing Research for Renal Patients
- ACORN Study workshop: developing the key components of a psychosocial support intervention for informal carers of people with end stage kidney disease
- Glomerulonephritis: it’s evolution/ prevalence / how many people reach end-stage and require dialysis AND/OR transplantation.

Finally, at a time of ongoing pressure with the NHS, NIKPA is fully aware of the highest standards of professionalism and care provided by staff at Renal Units throughout Northern Ireland. Additionally, the Belfast City Hospital Renal Transplant team continue to demonstrate an enviable level of success of which many in NIKPA are beneficiaries. As patients, we owe each our gratitude.

Patricia Gilbert
NIKPA Chair