



Charity Commission

The Northern Ireland Kidney Patients' Association Annual Report

April 2023 - March 2024

NIKPA is fully self-funding and run by volunteers who are patients, their relatives, friends and members of the Multi-Disciplinary Team. Our range of activities are supported and progressed for and by them.

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 manage day to day banking.

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

Our Office Bearers are renal patients and our Committee is made up of patients accessing dialysis, transplant recipients, an altruistic kidney donor or family members of patients.

Honorary President: Dr Ciaran Doherty, Retired Nephrologist

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

The Northern Ireland Kidney Patients' Association (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.
- Participation in fundraising events which not only finance NIKPA's activities but additionally 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

Events/Activities:

NIKPA's committee communications with patients and stakeholders continues primarily through its updated website and a social media presence (Facebook and Instagram) Public engagement activities are face to face events.

- Following on the success of the event in September 2022 NIKPA again invited renal patients and their families together with renal staff and families to for a Family Fun Day at Jungle NI in September 2023. Despite the less than pleasant weather conditions we welcomed over 200 guests.
- NIKPA AGM 2023 focussed on the benefits of Organ Donation. A family of five siblings who were either transplant recipients or kidney donors directly to each other or through the UK paired donation scheme clearly demonstrated the true meaning of the 'gift of life' that is organ donation.
- New for 2023, NIKPA organised a Wellness Day at a mid-Ulster Hotel with activities such as flower arranging, laughter yoga, singing, mindfulness, table games and manicures. Men and women enjoyed all activities, even those they were unsure of!
- In collaboration with the Renal Arts group, NIKPA contributed to an arts taster session at the Ulster Hospital demonstrating the therapeutic benefit of singing.
- In November 2023 NIKPA supplied materials and attended a two day event at the Belfast City Hospital promoting the concept of Shared Care for Dialysis patients
- As part of the Renal Nurses Specialist Course offered by the Queens University NIKPA was invited to share a 'patient's perspective' of renal disease.
- Our annual Christmas Pantomime for Paediatric Dialysis Patients was attended by 144 patients, their siblings, parents and in some instances by grandparents. Special appreciation for the organisation of the event to Marty Taggart and Paediatric Ward Sister Hazel Gibson.
- NIKPA Christmas Cards were sold widely throughout NI. Those receiving a Christmas greeting card from a friend would have noted the NIKPA logo: another awareness raising opportunity.
- NIKPA joined the global campaign for World Kidney Day 2024. Equity in access to healthcare is a key goal to improve the overall health of the population and contribute to the construction of fairer and more equitable societies.
- NIKPA continued its 'Walk and Talk' gatherings through to the spring of 2024. An opportunity to talk and listen to those sharing a similar medical condition while out in the open air is always beneficial for mental and physical health.
- NIKPA Care Bags, gifted to recently transplanted patients contain useful items to aid the transition to what is hoped a more healthy life. Approximately 113 were gifted to kidney recipients in 2023
- Through Organ Donation specialist nurses based at the Belfast City hospital NIKPA presents a Golden NIKPA badge to each altruistic kidney donor. This is a simple though symbolic token of thanks.

The noted events and activities contribute to the public benefit of heightening awareness of organ donation and the opportunity to connect those with similar renal health challenges. It is a privilege to provide a listening ear for those who need support whether it's for short or long term.

Advocacy

Acutely aware of the mental health challenges of living with a chronic medical condition NIKPA in partnership with Kidney Care (a UK wide renal charity) wrote to the Chief Executive of Belfast Trust to raise concern that renal patients did not have full access to psychological therapies in Belfast Trust. Indeed, there is no consistent and comprehensive service throughout Northern Ireland Health & Social Care Trusts. Meetings were held with Belfast Psychological Care managers and staff in October 2023 and again in January 2024 initiating plans to ascertain the opinions and wishes of patients connected to the Belfast renal unit.

Collaboration

- NIKPA is represented on the Charity and Stakeholder Advisory Sub group established by the Public Health Agency and Chaired by Northern Ireland's Organ Donation Promotion Manager.
- NIKPA is further represented on Kidney Care's Patient Advisory Group. This is also a reference group for this influential national patient group.

- The Science NI festival (February 2024) NIKPA partnered with the Renal Arts group to publicise advances in renal medicine.
- NIKPA member sits on the Advisory Board for a project gathering patient insights and experience related to clinical trials in IgA Nephropathy (IgAN)

Supporting Research

NIKPA does not fund research though, through patient engagement, the charity continues to support research proposals from Hospital and University based staff. As patients and carers are 'Experts by Experience,' NIKPA is keen to understand the range of research projects coming on stream.

- Renal disease in impoverished Belfast areas. Dr Butler
- Sexual health assessment in kidney disease: an unmet need. Megan Raynor
- 'MoodMaps' project to explore variation in psychosocial care across the UK for patients with CKD. Christina Pearce
- British Transplantation Society UK: Guidelines on Transplantation from Deceased Donors after Circulatory Death. Dr Stephen O'Neill
- Improving the quality of life for people with cachexia and their families. Dr Joanne Reid

Helping Hand

NIKPA continues to offer grants to patients following a referral from any member of the medical team. Such grants have included a contribution towards fuel bills, the purchase of a Fridge-Freezer contribution to general house expenses following damage to the property of a dialysis patient who was unable to work due to his medical condition and, for another patient, the purchase of a garden shed in which to store dialysis fluids and associated goods where the patient's home did not have the necessary storage capacity.

All grant applications come to NIKPA via members of the hospital Multi-Disciplinary Team who know their patients' needs.

The NIKPA Committee has sought to ensure the Public Benefit to renal patients has been satisfied by its activities over the past reporting year. We would further endeavour to pursue these aims in the following year.

None of the activities carried out by NIKPA would be possible without the continued fund raising and financial support of so many throughout Northern Ireland contributing small and large amounts. A special thanks to all who have done so over the past year.

It is important also to acknowledge the tireless efforts on the part of all the renal medical teams who make difficult decisions each day in an effort to sustain and improve the health of patients. We owe then a debt which cannot be repaid. 'Thank you'