



## Charity Commission

### The Northern Ireland Kidney Patients' Association Annual Report

#### April 2022 - March 2023

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:** Nathan Fairbairn stepped back from his role of treasure for the day to day management of NIKPA finances. He remains a committee member with oversight of engaging NIKPA Audit and Charity Commission submission. Day to day banking is managed by three members: Joyce Guy, Emma Proctor & Rebecca Geddis.

Our Committee Office Bearers are renal patients or family members. Represented on Committee is the daughter of one of NIKPA's founding members. We are additionally delighted to have an Altruistic Donor who provided the 'gift of life' to an individual she does not know. The remainder of our committee are transplant recipients.

**Honorary President:** Dr Ciaran Doherty, Retired Nephrologist

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

**Vice President:** Dr Ying Kuan, Consultant Nephrologist Altnagelvin Hospital.

NIKPA is generously supported our three Renal Consultants.

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

**Events/Activities:**

NIKPA's committee interactions with patients and stakeholders continues primarily through its updated website and a social media presence (Facebook and Instagram)

◇ NIKPA together with the Public Health Agency approached the BBC Nolan Show suggesting an organ donation feature. Altruistic Kidney donor, Stephen O'Boyle was interviewed and his story went 'aired' in October 22.

◇ Our annual Christmas Pantomime for Paediatric Dialysis Patients was almost lost to us in 2022. Only days in advance of our planned visit, our usual event venue contacted the charity to state the performance would not be taking place. With significant effort on the part of Committee member Marty Taggart and Paediatric Ward Sister Hazel Gibson another venue and pantomime were secured.

Christmas Cards were sold widely throughout NI. Two images were kindly gifted by NIKPA supporters. While this was a fund-raising project the NIKPA logo reached a wider audience.

◇ A new venture marked Organ Donation Week September 2022. NIKPA invited renal patients, their families, renal staff and families to be our guests at an outdoor activity centre, Jungle NI. Over 200 attended. Very positive feedback would indicate this should be repeated next year.

◇ The Science NI festival (Spring 23) included a public renal event in a Belfast City Centre location. Titled, 'The Future of Kidney Research is STEAM Powered.' Clinical and Genomic Research featured along side a NIKPA presentation on the transformative benefits of renal transplantation.

◇ NIKPA organised bi-monthly 'Walk and Talk' gatherings thus providing an opportunity for patients to meet and a chat while getting some fresh air and exercise. Walks have centred on the Belfast area.

◇ The noted events contribute to the public benefit of heightening public awareness of organ donation and the opportunity to connect those with similar renal health challenges.

◇ NIKPA Care Bags, gifted to recently transplanted patients contain useful (a Water Bottle / Factor 50 sun cream) and playful items (Mindful Colouring Book and pencils and stress ball) to aid the transition to what is hoped a more healthy life.

◇ Through Organ Donation specialist nurses based at the Belfast City hospital NIKPA presents a Golden NIKPA badge to each altruistic kidney donor. There is little that can be said or done for an altruistic donor, this token is a simple 'thank you'

### **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. With the passing of the Organ and

◇ NIKPA is further represented on Kidney Care's Patient Advisory Group. This is also a reference group for this influential national patient group.

◇ The Renal and Transplant Alliance, (R&TA) made up of NIKPA, NI Kidney Research Fund, Children's Kidney Fund (NI), Altnagelvin Renal Support Group and Kidney Care UK continue to meet at regular intervals presenting the united voice of renal patients.

◇ Royal Assent for Northern Ireland' Organ Donation law was given March 2022. There followed a 12-month period of preparation, implementation and a comprehensive programme of public awareness to which NIKPA contributed by attending public/community events distributing Public Health Agency materials and speaking with those passing our 'stands'

- ◇ NIKPA attended a consultation meeting to revise the Human Tissue Authority Codes of Practice, bringing it into line with existing NI rules with the incoming Donation Legislation.
- ◇ NIKPA continues to engage with and support research proposals from Hospital and University based staff. A range of topics were referred to NIKPA which represents the 'Experts by Experience' consultee prior to the lodging of research proposals.
  - 'Development of a Supportive Intervention for Informal Caregivers of Patients with End Stage Kidney Disease (Haemodialysis)' Michael Mathews
  - 'Why do those living in socially deprived areas delay presenting to Renal Services' Dr Daniel Butler
  - 'Acorn Study Caregiver Experience of Conservatively Managed End-stage Kidney Disease: Informing the Development of a Psychosocial Intervention'
  - 'Impact of Renal Biopsy' Dr Michael Toal.

### **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 for a specialist wheelchair when Covid measures resulted in delayed access to NHS support. Other grants have supported families where the main income came to an abrupt end due to a patient's admission to long term medical care. Another application was for a lady with significant visual impairment. NIKPA purchased a radio and wireless headphones for her to more easily 'pass the time' as she spent 4hours three times a week attending hospital dialysis.

Our 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.

To do so, we fully acknowledge those who financially contribute to the work of the charity.

In tune with many facing chronic illness we applaud our renal staff together with all the support teams, cleaners, porters, clerical. We exist because of their professionalism and humanity.

'Thank you' to each.