

Northern Ireland Kidney Research Fund Limited
Company limited by guarantee

Trustee' report
Year ended 5 April 2024

Trustees' report for the year ended 5th April 2024

The Trustees, who are also the Directors of the Company under the provisions of the Companies Act 2006, present their annual report and the audited financial statements for the year ended 5 April 2024. The Trustees have adopted the provisions of the Companies Act 2006 and the Statement of Recommended Practice (SORP) "Accounting and Reporting by Charities" FRS 102 in preparing the annual report and audited financial statements of the Charity. Needs changed

Reference and administrative details of the charity

Details of this information are included in page 1.

Structure, Governance and Management

The Board of Trustees (who are also the Directors of the charitable company for the purposes of charity law) under the provisions of the Companies Act 2006 have pleasure in presenting their annual report and the unaudited financial statements of the year ended 5th April 2024. The Trustees have adopted the accounting policies and comply with the Charity's Constitution applicable law and Reporting by Charities: Statement of Recommended Practice which applies to charities preparing their accounts in accordance with Financial Reporting Standard applicable in the UK.

The Northern Ireland Kidney Research Fund Ltd (NIKRF) is a charitable company limited by guarantee. The company was established under a Memorandum of Association which established the objects and powers of the charitable company and is governed under its Articles of Association. In the event of the company being wound up each member may be required to contribute an amount not exceeding £1.

The Trustee Board, consisting of six members, oversees the running of the charity. This board convened four times in the past year. They are responsible for all strategic and operational decisions concerning the charity's daily operations while maintaining close relationships with our medical advisors and researchers. New board members are elected through a process involving nomination, a proposer, and a seconder from the current board, with a majority vote required for the election to proceed.

NIKRF met with its 'family and friends' five times last year with prominent speakers at each meeting.

The NIKRF operates under a clear and effective management and decision-making structure designed to ensure transparency, accountability, and efficient operations. The structure promotes collaborative decision-making and empowers the trustees to fulfill the charity's mission and objectives.

Trustees' Responsibilities

The Trustees are responsible for preparing the Trustees' Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practices.)

Company law and the law applicable to charities in Northern Ireland require the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources for that period.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and which enable them to ensure that the financial statements

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comply with Companies Act 2006. The Trustees are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustee Board received remuneration of Nil

The Charity undertook a review of the Articles of Association which will be published in next years report. Training will also take place for all trustees and policies will be drawn up to ensure that the Charity is kept up to date with legal and recommended guidelines.

Objectives and Activities

The Charity's Objectives are:

- to raise funds to support and promote research into the cause, prevention and possible cure for kidney disease;
- to provide specialised equipment for research and advances in the treatment of kidney disease available from the National Health Service;
- to increase public awareness of kidney disease, its causes, prevention and modern treatment including transplantation
- to actively promote and support organ donation; and such other charitable purposes as the Trustees in their absolute discretion may decide from time to time.
- to increase profile of the charity

NIKRF provides public benefit in the advancement of health and saving of lives as our core mission of raising money for research into kidney disease. This is done by supporting clinicians and scientists researching causes, prevention and treatment of kidney disease.

Achievements and Performance

Research

The NIKRF supports a wide variety of research projects that explore why persons develop kidney failure and assess the best forms of treatment for these kidney conditions. Research has played a vital role in developing the best evidence for current care of patients with kidney disease.

Our medical advisors and scientist recommend and oversee these projects. Whilst completing these research projects trainee doctors and scientists gain an immense amount of practical experience. Other avenues are always explored first before our funding to ensure best possible use is made of our funds. Research can contribute to innovation in clinical practice and higher standards of patient care.

In the year 2023-2024 NIKRF supported the following research areas:

- International Mapping Exercise on Arts Based Therapies for persons with Kidney Disease
- Renal Cachexia
- Why do Kidney Transplants Fail so early in Young People?
- Can Cost Effective Strategies Identify and Stabilize Higher Risk Patients with Immunoglobulin A Nephropathy and prevent End-stage Disease?
- Using the ADAPT Guidance to Refine a Video Education Series for Kidney Transplantation and Living Donation: A Four-Step Approach.
- Exploring new Approaches for Telomere Associations with Kidney Disease
- Save the Veins
- How do Education and Renal Clinicians maximise their impact on the doctors of tomorrow, empower them to be powerful ambassadors for organ donation and build a future renal workforce to care for the increasing number of patients living with CKD?

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- To evaluate the Effectiveness of the Compassionate Mindful Resilience (CMR) programme for people living with advanced kidney disease and kidney transplant through a randomized wait-list controlled trial.

We raised awareness of kidney disease and promoted organ donation.

Partnership between NIKRF and Queen's University Belfast

The Northern Ireland Kidney Research Fund (NIKRF) and Queen's University Belfast (QUB) formed a partnership to promote kidney research and provide enhanced support for new researchers. We believe that this partnership has enormous potential.

We have made a substantial commitment to provide grant funding to QUB for three years initially. This new funding will be overseen by the Queen's Foundation, which is the charitable body in the university that promotes research and training to all of the alumni. The Foundation will ensure that the researchers and NIKRF receive maximum publicity for kidney research and that all monies are spent wisely. Thus we will have opportunities for the good work of the NIKRF to be highlighted on an international stage.

Using our funding Queen's will recruit, train and support early career researchers who are passionate about kidney research.

Two posts will be advertised for scholars who have already completed a PhD :-

- i. one for a scientific researcher and
- ii. one for a clinical researcher

The successful applicants will be provided with ongoing mentorship and career development opportunities to help them become independent kidney researchers.

The long-term vision for the NIKRF-QUB partnership is to recruit, train and retain the next generation of skilled kidney researchers. The first post of a scientific researcher should be in place by August.

In parallel with these two research posts, a new administrative post has been created for an Operations Manager. The postholder will be based within the Centre for Public Health QUB, to work directly between the charity and the university. The person will support the existing kidney research team and widen opportunities for the NIKRF to recruit postgraduate research students to work on kidney related topics. The Operations Manager will be an employee of QUB, whilst at the same time, working to further the aims of the NIKRF locally, nationally and internationally.

The Dr Jennifer McCaughan Bursary

This bursary enables an individual to present a high-quality renal research project at a conference.

The inaugural Bursary was awarded to Professor Joanne Reid who presented her abstract titled, 'Developing a Multimodal Integrative Intervention for the management of renal cachexia for individuals with End-stage Kidney Disease and their Carers,' at the EDTNA/ERCA 2023 conference in Vilnius.

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The Janet Greeves Legacy

This legacy funds the following projects:

1. Legacy Lecture
2. Legacy Training Grant
3. Legacy Fellowship

We launched this Legacy by funding a key note speaker "Prof." Dicken Ko, Professor of Urology and Transplantation at the Warren Alport Medical School, Rhode Island at the Transplant Symposium in May 2023

Further Training Grants were awarded:

1. Summer 2023 a studentship training grant was awarded to Tiernan Coulter to explore new approaches in association of Telomeres with kidney disease.
2. January 2024 a training grant to support Mr James McDaid, transplant surgeon to gain experience in pediatric transplantation in Great Ormond St and Evelina hospitals, London.

Activities

The fund has had a very busy year. There were many fundraising activities together with outreach in order to increase funds and raise awareness of kidney disease and organ donation.

Some of the main activities were:

- Organ Donation Manager was a speaker at one of our meetings to inform us of the upcoming change in the organ donation law in NI in June, 'Dáithí's Law'
- Attendance at Conference for Charity Trustees
- NIKRF relay teams fund raising at the Belfast Marathon
- Outreach at Balmoral Show
- The Organ and Tissue Donation (Deemed Consent) legislation, known as 'Dáithí's Law' came into effect on 1st June. NIKRF played an active part in this as a stakeholder and raising awareness
- Volunteers raised funds at Billy Old rectory by serving afternoon teas for donations.
- The annual Waringstown Cavalcade's theme was Porsche v's BMW and this is NIKRF's main fundraising event.
- We became a charity partner to Robert Stewarts Spirit Grocer and raised awareness of kidney disease and organ donation.
- Our ambassador Paula McIntyre donated the proceeds of a cookery demonstration.
- We had cycling enthusiasts who cycled in 'Lap the Lough' demonstrating the importance of keeping fit while raising money.
- We had various praise services when the offering was in aid of NIKRF.
- We took part in the NI Science Festival.
- One of our members opened her garden for the Snow Drop festival and proceeds of teas were given to NIKRF.
- We took a stand in the foyer of the BCH for world kidney day and met up with a renal nurse who had just won the title of Miss Lisburn and who had nominated us as her chosen charity.
- We also took a stand in the Students' Union at QUB on World Kidney Day

Financial Review

The trustees are satisfied that the Fund is in a sound financial position to meet the commitments of the charity to Research Fellows over the next 3 years and ensure Investment for future research projects.

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Charitable Activities

The Trustees approved Grant applications requested by our medical advisors to fund two PhD Studentships and a Research Fellowship with an estimated cost of £274k over a 2-3 year period (plan £200k) the purpose of the funding is to carry out renal research projects at Queens University Belfast subject to a number of conditions.

The charity donated £600k which is a Gift to the Queens University of Belfast Foundation, £200k per year over the next 3 years (2024/25-2026/27) to fund a Scientific Post- Doctoral Research Fellowship and a Clinical Post-Doctoral Research Fellowship undertaking high- quality kidney research in the Centre for Public Health. Also £187k to fund a Research Operations Manager based in Queens University Belfast over the same period.

A donation of £6,000 from the PuncHESTOWN Kidney Research Fund to the Dr Jennifer Bursary Award was received.

NIKRF have considered the current financial climate and with the continued commitment from the charity's fundraising groups, supported by the local community, it raised circa £141k (prior year £103k) and received legacies of £32k. Investment income continues to perform well with an increase of £27k.

The Groups are community based and retain strong links with renal services through the Nephrology Dept. in the Belfast City Hospital updated and guided by our medical advisors and research programme, advances in treatment and future planning.

The Waringstown Cavalcade, one of our main fundraising events which is held on the last Friday in June, involves a lot of planning and dedication by the local group and the loyal support of the local community who collect for us and promote the charity. It proved to be a successful evening with fewer collectors raising £10.1k

The Cost of generating voluntary income has remained in line with the prior year.

The advertising/publicity budget was increased in line with prior expenditure of £18k which took account of the many additional fundraising events held during the year where promotional material was required.

Future Plans

The Trustees will endeavour to recruit new volunteers and seek to ensure that the Board of Trustees will have representation from all our groups.

The Articles of Association are still with the Charity Commission and the next priority will be the formulation of policies.

We will look at ways of optimising the charity and taking some pressure off the Trustees who have found their work load increasing dramatically.

We will endeavour to fund more quality research to meet our objectives of being the best we can be.

The charity medical advisors are very keen to support clinical trainees, postgraduate students and scientific staff to undertake kidney research projects. In the years 2024/25, 2025/26 the NIKRF will be supporting a clinical nephrology trainee and stipend for a PhD studentship at an estimated £200k over a 3 year period. The outcome will be a strengthening of the scientific base and resilience beneficial to team and patients and satisfying the aims of the charity.

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Grant making policy

Applications for grants are made to the fund's medical advisers. These applications are reviewed against the objectives of the fund and grants are awarded if applicable.

Principal funding sources

The company's principal source of funding is voluntary income generated from support groups, donations and legacies.

Investment policy

The Company has engaged Evelyn Partners as an investment manager to pursue a policy of maximising income whilst maintaining some capital growth.

Risk management

The trustees have assessed the major risks to which the charity is exposed, in particular those relating to the operation and finances of the Fund and are satisfied that systems are in place to mitigate any exposure to those risks. Risks are considered on an annual basis.

Reserves policy

The company's policy is to maintain a level of unrestricted funds excluding fixed assets (the free reserves) at approximately a level sufficient to meet the average charitable expenditure and running costs for a period equivalent to six months expenditure, which equates to approximately £234,290 (ignoring any revaluation gains). These "free reserves" amount to a deficit of £884,349 arising from a change in the market value of investments included within fixed assets. The policy is reviewed on an annual basis.

Funds held as custodian trustee on behalf of others

There are no funds held as custodian trustee on behalf of others.

Statement of trustees' responsibilities

The trustees (who are also directors for the purposes of the company law) are responsible for preparing the Trustees' Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year. Under that law the trustees have prepared the financial statements in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law), including FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland".

Under company law the trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of the affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period.

In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and accounting estimates that are reasonable and prudent;

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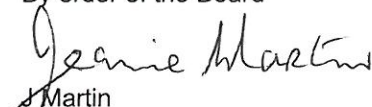
- state whether applicable UK Accounting Standards are FRS 102 have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Small companies' exemption

This report has been prepared in accordance with the special provisions relating to small companies within Part 15 of the Companies Act 2006.

By order of the Board


J Martin

Company secretary

Date: 4 September 2024