



STRATEGIC PLAN

2021 - 2025

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Introduction

We developed this Strategy over a period of time. We surveyed our members to understand their needs. In specially convened meetings, we asked our membership and stakeholders what their priorities were.

We held meetings with staff. We discussed these findings with Branch Officers. We adjusted the Strategy for the impact of COVID-19, insofar as this is possible.

As a Board we discussed and reviewed what our priorities should be. This Strategy gives us the best possible chance to rise to the challenges and take advantage of our opportunities.

ABOUT US

The Irish Kidney Association (IKA) is a registered national charitable voluntary organisation founded in 1978. We are dedicated to meeting the needs of people living with or affected by end-stage kidney disease (ESKD). These needs are spread across all aspects of life – medical, social, economic, and psychological. The profile of the kidney patient ranges from early life to the elderly who are undergoing various methods of treatment, haemodialysis, peritoneal dialysis or CAPD and patients who have received a kidney transplant.

The IKA is an organisation for patients and their families which is led by patients and their families.

The IKA also promotes organ donation. We have a positive impact on the lives of patients with kidney disease as follows:

SUPPORTING PATIENTS AND THEIR FAMILIES

From practical supports such as financial aid, providing free holidays and support centre accommodation to emotional supports such as the provision of professional counselling services, we enable patients to take control of their lives.

“

IKA provides emotional support; there is always a happy friendly person on the line to you with any query, some financial support and free holidays.

“

The staff in the Support Centre are all renal patients and couldn't be nicer to you. There is always a friendly chat, we exchange stories, and they know what you're going through.



Who we are

DEVELOPING COMMUNITY

Our network of 25 Branches provides local community supports, runs events and ensures every member has local informal peer support. We enable patients and their families to develop long lasting friendships and relationships in a supportive community.



Being part of the IKA has meant a lot to me. It feels like a family watching over you; many a joke over the years have been shared back and forth between us.

EDUCATING AND INFORMING

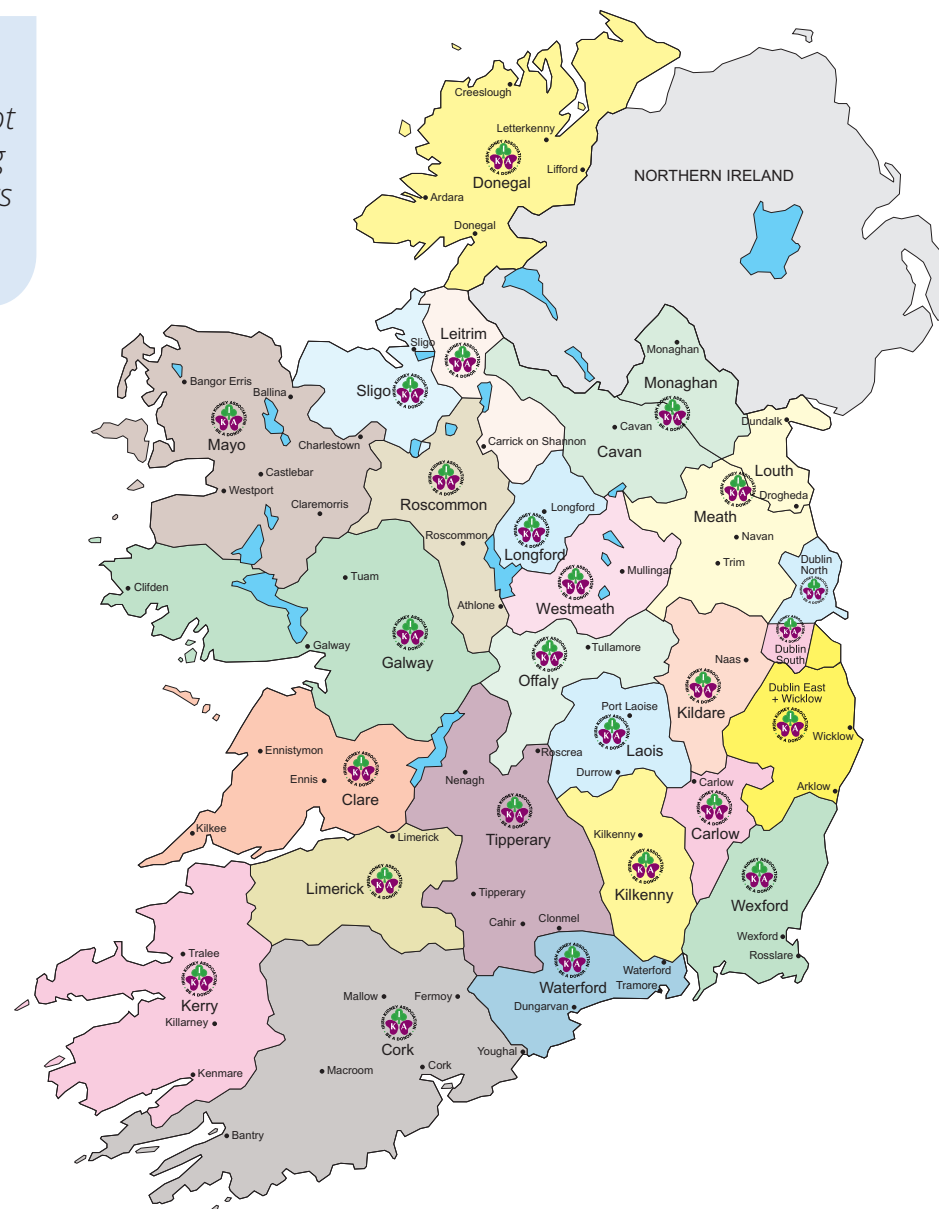
Our information events, leaflets, booklets and online resources ensure people are well informed about their condition and how to live well with end stage kidney disease. Knowledge is power and key to empowering patients to manage their own self-care.

ADVOCATING FOR CHANGE

We listen to our members and work with a wide variety of stakeholders to advocate for better policies, access and delivery of services. We work with international organisations to understand developments worldwide. From the new Human Tissue Bill to obtaining mileage payments for patients travelling for dialysis, we ensure the voice of the patient is heard.



I hope to continue being a member of the IKA indefinitely and being more proactive, as you always get more than you put in.



Mission, Vision and Values



MISSION

To be the national patient-led organisation which supports, educates, and advocates for people living with or likely to be affected by end-stage kidney disease.



VISION

To bring about the best quality of life for those affected by end-stage kidney disease, with quality and equality in their care and treatment.



VALUES

The Irish Kidney Association is guided by these core principles, which underpin everything we do.

PATIENT-CENTREDNESS

The IKA places the rights, needs, and wants of patients and their families at the centre of all we do. We respect and listen to patients and their families, respond to them with support and compassion, and empower them in their journey with end-stage kidney disease. We believe patients must be involved in kidney policy.

VOLUNTEERISM

The IKA is built on the principles of volunteerism, where, as a collective group, there is generosity and commitment of time and effort in the service of others. Without our volunteers the Association could not support patients and their families in the way we do. The ethos of volunteerism is fundamental to the continued work of the IKA.

EQUALITY

The IKA is committed to the principle of equality: that all patients have the right to equal care and treatment, and to IKA support. The IKA works with and advocates for patients to achieve this, particularly with those that are vulnerable.

PARTNERSHIP

The IKA believes that we are stronger and more effective when working together: working with our patients, our families, our Board, our Branch Officers and members, our staff, the medical professionals, our donors, and the voluntary and the statutory sector, to achieve the best outcomes for those living with or affected by end-stage kidney disease. We are committed to a collaborative, partnership approach.

INNOVATION

The IKA wants to work on behalf of end-stage kidney patients in the most effective way, embracing creativity and innovation and leading change where this allows us to better serve the needs of patients and their families, and funding research to develop new care and treatment options for patients.

QUALITY

The IKA is committed to the highest standards of quality, both in our own work and in the services provided by others to end-stage renal patients and their families. We strive for quality in all we do, and we advocate for quality improvements from the health system in the care, treatment, and support for patients.





Our **Environment** 2021–2025

We live in an incredibly challenging time. COVID-19 has impacted both our physical and mental health. People with kidney disease are particularly affected.

This has meant curtailing many of the IKA's activities such as the Renal Support Centre at Beaumont Hospital and entailing a move to online activities. It has temporarily broken the strong bonds of face-to-face connection within our community.

The number of transplant operations has declined in the face of COVID-19. As these operations are not just the best treatment for patients on dialysis but are also the most cost-effective treatment, we need to prioritise advocacy for our community on this issue.

The new Human Tissue Bill will have a major impact on organ donation in Ireland, putting organ donation on a proper statutory basis; this will impact our donor awareness campaigns and how we work with other stakeholders in this area.

This Strategy has a strong focus on delivering a range of high quality services to both

members and Branches at a reasonable cost. The world of information technology and digital health presents many opportunities for us to help our members more effectively.

We also aim to improve patients' ability to live well with end-stage kidney disease, participate fully in their communities and reduce the structural barriers which hamper their ability to participate in society.

We are also faced with increasingly onerous regulations, which also have a cost. However, it is right that we be both transparent and accountable to our members and to the people who so generously donate their time and money. Not only must we continue to be of assistance to our community, but the positive impacts and results of our activities must also be seen.

We acknowledge our heartfelt gratitude, appreciation and thanks to our donors, donor families, funders and all our supporters. Without them the Irish Kidney Association would not be in such a strong position to deliver this Strategy.






Our Strategic Objectives

We see our main strategic objectives set within five overarching themes which are all connected to each other.



Supporting Patients is key and underpins everything we do.

The objectives within these themes are summarised below and detailed in the pages that follow:

THEME	OBJECTIVES	
SUPPORTING PATIENTS AND THEIR FAMILIES	<ol style="list-style-type: none"> 1. Provide relevant and meaningful services 2. Develop peer support programmes 3. Improve education programmes and information resources 4. Expand our physical support centre network 	
LIVING LIFE WELL	<ol style="list-style-type: none"> 5. Expand holiday opportunities 6. Develop activities programmes 7. Develop membership benefits 8. Develop sports and fitness activities 	
DYNAMIC AND ACTIVE BRANCHES	<ol style="list-style-type: none"> 9. Strengthen and develop Branch network 10. Increase volunteer base 11. Enhance supports for Branches 	
ORGANISATION FITNESS	<ol style="list-style-type: none"> 12. Promote good governance 13. Ensure financial sustainability 14. Ensure the best team 15. Collaborate with other organisations 	
RESEARCHING, CAMPAIGNING AND ADVOCACY	<ol style="list-style-type: none"> 16. Work towards improved patient care and experience 17. Lobby for changes to policy and practice 18. Deliver patient centred research 	

These strategic objectives and themes make up an overall picture of the IKA's strategic vision. They are not rigid; they are intended to be flexible. Objectives may contribute to several themes at once. This Strategy encompasses all of the complexity of the IKA and its work.

On the following pages, we outline how we intend to pursue and achieve these key strategic objectives.

1

Provide relevant and meaningful services



Why is this important?

Meaningful and relevant services enable those impacted by kidney disease to live fuller lives. We do not provide clinical health care services but we do play a very important role, as research shows supporting patients to self-manage their illness delivers better clinical outcomes.

Key Actions

We will seek to consolidate the positive things about our services and build sustainability and a clear focus into all of the services we provide. We will seek to understand what are the strengths and weaknesses in what we offer, consolidating what we do well and improving what we do less well.

We aim to achieve this objective by:

- Conducting external evaluations of IKA services.
- Regularly surveying service users and obtaining feedback as to their experiences.
- Developing our services further to meet the patient at the different stages of their journey through end-stage kidney disease (ESKD) e.g. from diagnosis (managing a chronic disease, psycho education) to return to work, volunteering or self-employment.
- We will aim to make our services even more inclusive to those from a minority background.
- We will investigate the feasibility of providing seed funding for new innovative developments.
- Creating a service improvement plan.

What are the intended outcomes?

- Service level commitments for all IKA services – outlining what patients and their families can expect at a minimum and what we hope them to experience at a maximum.
- A plan for the quality improvement of existing services.
- A range of new and innovative services developed with patients and their families.

2

Develop Peer Support programmes



Why is this important?

Patients' support networks are crucial to improving the experience of being a kidney patient. We will enhance and facilitate peer support networks within the Association, because we know that sometimes the best support is simply speaking with someone who has 'been there' and experienced it.

We aim to achieve this objective by:

- Establishing a local and national peer support network infrastructure which can be accessed online, and face-to-face. These peer support groups will be tailored to the stage the patient is at.

What are the intended outcomes?

- Patients to have access to a peer support network that provides them with information and support from those who understand best.
- Patient-led volunteerism ethos of the Association to remain central to the support we provide.
- We want all patients to know they are not alone.
- Peer support networks have been independently evaluated.



3

Improve education programmes and information resources



Why is this important?

Research shows that patients participating in education and with access to information resources are better able to self-manage their illness.

We acknowledge the fact that for those recently diagnosed and for the public in general, kidney function, kidney disease and the implications of living with kidney failure can be poorly understood. We will develop our suite of information and education programmes to ensure that patients and their families can engage with and understand the Association and the illnesses whose effects we are committed to fighting.

We aim to achieve this objective by:

- Reviewing our existing suite of education and information programmes and resources, particularly around organ donation and mental health.
- Investigating the feasibility of providing online structured education programmes.
- Investigating the feasibility of providing educational resources for people not currently requiring dialysis but who may require dialysis in the future.
- Developing an education programme for newly diagnosed patients living with kidney disease. This will focus on both physical and mental health.
- Working with health care educators to bring the patient voice into renal disease education and training programmes for doctors, nurses and other allied health professionals through the provision of trained patient educators and information events.

What are the intended outcomes?

- Patients and their families to have the best possible understanding of their treatment choices, conditions, and the impact this could have on their lives.
- Healthcare professionals to hear and take cognisance of the patient's voice in providing clinical care.
- A more personalised understanding by future healthcare professionals of the real-life needs and concerns of renal patients.

4

Expand our physical support centre network



Why is this important?

Our Beaumont Support Centre is not just a roof over people's heads, away from a sterile hospital environment, but a place of comfort, safety and warmth. It is a place where patients and their families can relax together, have a cuppa, cook their own meals, talk to staff who are also patients, and also chat to other families experiencing the same struggles. Strong and lasting relationships are formed there.

We will build on the success of the existing Renal Support Centre at Beaumont Hospital and holiday accommodation. Currently this Centre is sequestered by Beaumont Hospital. We aim to reopen the renewed and refurbished Centre as soon as the Covid emergency allows. We will explore the potential to extend our capacity to support patients and families in respect of additional Centres in other parts of the country.

We aim to achieve this objective by:

- Developing a strategic plan to maximise use of our physical accommodation while managing costs and infection risks effectively.
- Developing a state-of-the-art Renal Support Centre in Cork.
- Staffing and resourcing the Centre to provide support to patients and their families attending Cork University Hospital in respect of end-stage kidney disease treatments.
- Ensuring that the financial model underpinning the operation of the Centre is sustainable.
- Undertaking a feasibility study into the development of additional Centres subject to financial sustainability.

What are the intended outcomes?

- A successfully operating Renal Support Centre in Cork, along with the continued operation of the Centre in Dublin.
- A sustainable financial model for the operation of the Renal Support Centres.
- A completed feasibility study presented to the Board for consideration in relation to further potential Renal Support Centres.



IKA Renal Support Centre,
Beaumont Hospital



Cork IKA Support Centre

5 Expand holiday opportunities for patients and their families



Why is this important?

One of the key activities of the IKA is the provision of free holidays for renal patients. This is particularly applicable to dialysis patients who continue to require dialysis treatment during their holidays. It is our belief that the availability of holiday opportunities contributes hugely to the welfare and well-being of our patients.

We aim to achieve this objective by:

- Maintaining present holiday accommodation to a high standard.
- Exploring the feasibility of purchasing/renting further accommodation in other holiday locations, both in Ireland and abroad.

What are the intended outcomes?

- Increased participation of patients in the holiday programme.
- Additional availability of holiday opportunities.
- Wider choice of holiday venues.



6

Develop new activity programmes



Why is this important?

There is a huge variety of events, initiatives and activities run across the IKA Branch network for the benefit of patients, their families, and support networks. We plan to invigorate the programme of activities and initiatives run by the IKA to ensure that there is something for everyone, whether it be locally in each Branch, or nationally.

We aim to achieve this objective by:

- Evaluating the calendar of IKA national events.
- Listening to member needs.
- Developing a plan to address these needs while recognising that different members have different needs, e.g. physical activities, social outlets, hobbies, etc.
- Focusing on the development of inclusive and welcoming events.

What are the intended outcomes?

- A range of events to be provided and supported by the Association across the country and across the spectrum of patient ability.
- Patients and their families, no matter who they are, to have the opportunity to take part in events appropriate to their mobility/health, their interests and their stage of life.



7

Develop membership benefits



Why is this important?

Currently we provide services to patients who are not members. This will continue, but we will develop a wider range of member only benefits to encourage more patients to join us. This will enable us to improve communications with more patients and help to strengthen and inform our advocacy on behalf of our members.

We will work to raise the profile of the IKA – among patients, medical professionals, the general public and policymakers to encourage more people to join as members.

We aim to achieve this objective by:

- Identifying member needs and developing a tailored menu of benefits to different types of members.
- Developing members and carers resources.
- Encouraging those who contact the organisation for advice to become members.
- Establishing a communications strategy for the organisation.
- Securing access agreements with renal units for access to patients for the provision of information to patients, in particular newly diagnosed patients.
- Evaluating/creating a social media strategy for the Association.
- Evaluation of the IKA's branding and communications strategy.
- Developing stronger relationships with those in the health service who interact with patients with serious kidney disease, i.e. consultants, nurses, etc., so that they understand the value of the IKA for their patients and routinely refer patients to the Association while respecting the patient's right to privacy.

What are the intended outcomes?

- The Irish Kidney Association to be recognised by patients, their families, and the public as the 'go to' organisation for support and information around issues relating to kidney disease.
- Newly diagnosed patients will know about the Association and its services as soon as possible.
- We increase membership of the organisation so that the majority of renal patients are members.
- Medical professionals to recognise the organisation and refer patients routinely to the Association.
- An increased range of benefits for members with clarity about the benefits of membership and being a core resource for the IKA and each other.
- The Association to have a larger, thriving membership supporting its Branch network and national functions.

8

Develop sports and fitness activities



Why is this important?

The sports programme has run very successfully for many years under the brand Transplant Team Ireland. The service is open to all organ and bone marrow transplant recipients and people on dialysis, while family members are also actively encouraged to engage. The programme has proven to be a strong peer support network throughout the year for those involved.

We plan to expand the remit of the programme to encompass the promotion of healthy lifestyles in general and not just sports specific activities. We will also continue to use the programme as a platform for showcasing the impact of organ donation with our involvement in the World Transplant Games and the European Transplant & Dialysis Sports Championships, amongst other events, as cornerstones for our summer organ donor awareness activities.

We aim to achieve this objective by:

- Evaluating the current calendar.
- Listening to member needs.
- Engaging with existing service providers in the community.
- Developing a plan to address these needs at local and national level while recognising that different members have different needs, e.g. physical activities, social outlets, hobbies, etc.
- Focusing on the development of inclusive and welcoming events.
- Working with other organisations such as, for example, Healthy Ireland, Exwell Medical, as well as local partnerships, to deliver tailored programmes.
- Consider hosting the European Sports Championships from 2024 onwards.



What are the intended outcomes?

- A range of events to be provided and supported by the Association across the country and across the spectrum of patient ability aimed at promoting an all-round healthy lifestyle.
- Patients and their families, no matter who they are, to have the opportunity to take part in events appropriate to their mobility/health, their interests and their stage of life.

9

Strengthen and develop Branch network



Why is this important?

Our Branch network ensures that there is a local 'home' for every kidney patient in their local region. While Branches can operate with some independence, they remain always under the direction of the Board of Directors and must comply with the Charities Regulator's Governance Code. The Association aims to ensure equality of service, support, and communication across the Branch network.

We will further develop the Branch community network ensuring a learning culture.

We aim to achieve this objective by:

- Listening to the needs of Branches.
- Capturing best practice (in terms of governance, events, services and facilities) and communicating this across the Branch network using 'show and share' events.
- Developing an on-boarding programme for newly elected Branch Officers to ensure that the correct skills and knowledge are in place.
- Providing a wide range of training and support for Branch leaders/facilitators in the running of the Branch.
- Investigating whether technology can help reduce the governance and administration burden for Branches.
- Ensuring standardisation of approaches to communication, advocacy and administration.
- Identifying Branches in need of additional support and invigorating them through collaboration and support.
- Updating the Branch handbook.

What are the intended outcomes?

- A vibrant and active Branch network across the country with good ideas shared and replicated.
- Adequate support and guidance for Branches, recognising and supporting the enormous efforts of the Association's local Branch Officers.

10 Increase volunteer base



Why is this important?

We are very fortunate to have an active and very engaged volunteer base. However, our volunteers are ageing and we need to attract more volunteers, some of whom will in time become Branch Officers and run local events for patients as well as fundraise.

We aim to achieve this objective by:

- Reviewing what we offer volunteers to understand what might attract more people to volunteer with the Association.
- Developing a volunteer plan setting out the future demand for volunteers, the skill sets and experience required, and the approaches to putting these in place to support our volunteers.
- Using the Branch network to provide local support and events to attract new members.
- Increasing and capitalising on our social media presence.
- Developing a volunteer handbook with clear roles and supports available, e.g. once-off, short-term, long-term, project campaigning, event management, Branches and head office etc.
- Providing volunteer training and development opportunities.
- Investigating the feasibility of family volunteering.

What are the intended outcomes?

- A succession pipeline for Branches.
- More opportunities for patients and families to participate in the IKA.
- The IKA to have a volunteer network of committed, trained, and well-supported volunteers across its Branch network, working to raise funds, run Branches, and support patients and their families at local level.



Emma and John Hurley.

11

Enhance supports for Branches



Why is this important?

As outlined in Objective 9, our Branch network ensures that there is a local 'home' for every kidney patient in their local region as well as organising much needed fundraising. With increasing governance requirements, we now need to ensure that there is a clear separation between the activity of running a Branch and running events for members. Branches running varied, interesting and engaging events, will benefit patients more and will attract increased numbers of volunteers and funding.

We aim to achieve this objective by:

- Listening to the needs of Branches.
- Capturing best practice (in terms of governance, events, services and facilities) and communicating this across the Branch network using 'show and share' events.
- Developing an on-boarding programme for newly-elected Branch Officers to ensure that the correct skills and knowledge are in place.
- Providing a wide range of training and support for Branch leaders/facilitators in the running of the Branch.
- Investigating whether technology can help reduce the governance and administration burden for Branches.
- Ensuring standardisation of approaches to communication, advocacy and administration.
- Identifying Branches in need of additional support and invigorating them through collaboration and support.
- Updating the Branch handbook.

What are the intended outcomes?

- A vibrant and active network of activities across the country with good ideas shared and replicated.
- Increased sense of community both within and across Branches.
- A wider range of activities for members.





Principles of the Charities Regulator Governance Code

- 1** Advancing its charitable purpose
- 2** Behaving with integrity
- 3** Leading people
- 4** Exercising control
- 5** Working effectively
- 6** Being accountable and transparent

12

Promote good governance



Why is this important?

Good governance has many benefits, from more effective cost control, better decision-making, and the ability to respond to challenges, in a positive culture. We need to be transparent and accountable for all we do.

The Irish Kidney Association is committed to best practice in governance and will ensure that the right governance structures and procedures are in place to support the work of the Association, to reassure our funders and beneficiaries that we are accountable and transparent, and to comply with all regulatory requirements in respect of governance.

We aim to achieve this objective by:

- Achieving full compliance with the Charities Regulator's Governance Code and conducting a comprehensive review of the Constitution of the Association to identify the extent to which it needs to be amended to reflect modern-day needs and requirements.
- Reviewing and developing our organisation structures to support service delivery at all levels, including the Board, management, and staff. This will entail improving our processes and support arrangements.
- Conducting a review of the current arrangements for the nomination of board members, seeking recommendations as to how these can best serve the interests of patients and the Association.
- Conducting a review of the current procedure for the election of the Officers of the Board.
- Entering Good Governance award competitions and acting on feedback received.
- Developing improved systems for measuring our impact.

What are the intended outcomes?

- The Association to have excellent governance structures, practices, and procedures in place.
- The IKA to be fully compliant with all regulatory requirements, including the Charities Regulator's Governance Code.
- The structures and processes in the organisation to operate to support its work efficiently and effectively.

13

Ensure financial sustainability



Why is this important?

Ensuring we have the financial resources to continue and expand our work means we can make more of a positive impact in our patients' lives.

The Association will ensure that it operates on a sound financial footing, with a financial model underpinning our work that is sustainable and sufficient to deliver on this Strategy.

We aim to achieve this objective by:

- Developing a financial model projecting the required financial resources for the objectives set out in this Strategy.
- Compiling yearly budgets and reviewing these quarterly to ensure financial outlay and time frames are being adhered to.
- Increasing our fundraising efforts and considering new ways to attract funding, including increased use of social media.
- Maintaining our statutory funding sources.
- Undertaking a feasibility study into new and diversified sources of income, whilst preserving our patient-led ethos.
- Optimising the cost-effectiveness of our work, in line with good corporate governance and the expectations of our contributors and funders.
- Using information technology to streamline and enhance the effectiveness of our business processes and supports for members and Branches.

What are the intended outcomes?

- The Association will have a detailed financial plan setting out how the strategic objectives will be funded.
- There will be increased income from fundraising and other sources to fund the critical work of the IKA.
- Increased ease and efficiency of business operation and improved management information.



14 Ensure the best staff team



Why is this important?

The IKA's key resources are its Board, its management and staff team, and its volunteers who we could not do without. The staff team support the wider community of volunteers, and ensures that key tasks are completed.

We will work to support and develop our staff to ensure that they can continue to deliver at the highest standards for the Association and for patients and their families.

We aim to achieve this objective by:

- The CEO and Officers reviewing the staffing structure of the organisation.
- Development of a HR policy and a suitable HR administration process to ensure that it is the optimum for the needs of the IKA.
- Developing employee handbooks.
- Enhancing the training and development of all employed staff.
- Arranging an annual forum of the Board with all of the staff for discussion and exchange of ideas.

What are the intended outcomes?

- A strong, well-trained staff team who continue to be committed to delivering the best services and support to patients and their families.
- A comprehensive HR strategy that is aligned to the Strategic Plan.
- A better understanding by the Board of the everyday running of the Association and the problems which can arise, and an appreciation by the staff of the role and function of the Board as well as their own role in driving the organisation forward, thereby leading to an enhanced sense of team work.



15

Collaborate with other organisations



Why is this important?

Despite its considerable impact, the IKA is a small organisation. By collaborating with other organisations and participating in networks we can meet the needs of its patients more effectively and quickly and build a better world for people with ESKD.

The IKA shares some goals and interests with a range of other representative, charitable and state organisations. For instance, organ donation is a topic of particular interest to several charities. It is important that we explore opportunities to work with and learn from other charities, state agencies and representative groups where our interests align and where it serves the interests of patients and their families.

We aim to achieve this objective by:

- Identifying organisations, state institutions or forums for collaboration.
- Developing memorandums of understanding with other organisations to deliver services to our members.
- Establishing and refreshing memorandums of understanding with like-minded charities in respect of:
 - Transplantation,
 - Access to health services,
 - International partners.

What are the intended outcomes?

- Learning from international partners' different innovative ways of supporting renal patients.
- Improved awareness of issues and concerns surrounding transplantation waiting times and other policy/service issues.
- Using our joint platform to help bring about systemic improvements to the Irish health services and assisting others to do the same.



16

Work towards improved patient care and experience



Why is this important?

The patient's in-centre dialysis experience can be very different, depending on location. For example, Tallaght hospital has recently opened a new dialysis unit with increased capacity, whilst the dialysis unit in Sligo remains overcrowded with patients waiting in a narrow corridor.

The IKA will work behind the scenes and in public to keep the issues affecting kidney patients and their families high on the agenda of public discourse around healthcare and the planning and provision of renal treatment services.

We aim to achieve this objective by:

- Supporting and working with the relevant agencies for increased transplantation of both deceased and living donor organs.
- Establishing multi-lateral dialogue relationships with renal units/consultants and the HSE.
- Supporting academic standard surveys of patient experiences to understand the treatment journey and to highlight the particular problem points to be addressed.

What are the intended outcomes?

- The development of a care experience which enables renal patients to have as normal a life as possible.
- Patients and their families to have access to the right care, delivered by the right clinicians, in the best place, at the most convenient time.



17

Lobby for changes to policy and practice



Why is this important?

Patients with ESKD do not exist in a vacuum. Improvements in healthcare services, for example a higher rate of organ transplants, can be life-changing. An increase in disability benefit or mileage payment for travel can make life easier and less stressful.

The Association will lobby policymakers in the health system and wider government to reform and improve services for kidney patients and to implement changes that will increase access to treatment options and improve the quality of life for patients with ESKD.

We aim to achieve this objective by:

- Ensuring the IKA consults with its member group and patient members and carers.
- Working closely with Organ Donation and Transplant Ireland (ODTI) and other stakeholders to improve organ donation awareness and successful transplantation rates.
- Providing a voice for patients and carers on issues that affect them, seeking representation on relevant groups and committees that address the needs of kidney patients.
- Developing a plan for our lobbying.
- Monitoring progress on Government commitments and holding Government and agencies to account for delivery of these commitments.
- Preparing position papers with evidence-based recommendations and input from IKA members for policy and practice change, and in the delivery of services to kidney patients.
- Collaborating and partnering with other stakeholders in the healthcare, not-for-profit, education, disability, community and social justice sectors.
- Mobilising our membership to make publicly visible the support for a better kidney health system.

What are the intended outcomes?

- Key policy changes to be made to improve outcomes for kidney patients.
- The Association to be at the forefront of the drive for changes at Government, medical, service and societal levels.
- Improved organ donation services in Ireland and increased awareness and prevalence of organ donation.
- Policymakers to be aware of the work of the Association and its impact on patients and their families.

18

Deliver patient-centred research



Why is this important?

Research can lead to improved treatments and can also lead to better understanding of the patient experience and needs.

We understand the need to continuously push the boundaries of our scientific understanding of kidney disease and other morbidities which affect renal health. We will support and contribute to the understanding of this with a particular focus on a variety of research disciplines. These will help to illustrate and contribute to the improved general health and wellbeing of kidney patients.

We aim to achieve this objective by:

- Identifying research academic partner(s) to carry out patient-centred research using a participatory action focus approach. This approach involves working with the people in the system as co-participants in the inquiry with a view to transforming that system from within as a principal focus of the research process itself.
- The IKA will be included in, and be an active participant in, the research design process.
- Research tenders, contracts, and memorandums of understanding will be approved in advance of the research funding/process commencing and will comply with charity corporate governance standards.
- The Research Report and recommendations will, prior to publication, be finalised in partnership with the IKA, launched, and then published.
- Research topics funded by the IKA will be based on academic/social field's best practice, be peer reviewed where appropriate, and only be on 'a not-for-profit' basis.

What are the intended outcomes?

- A number of research projects, in respect of improved outcomes for kidney patients, to be led and supported by the Association.
- The Association to have a genuine impact on the national and global understanding of kidney disease treatment and to make a measurable difference both to the health service in Ireland and patients' experiences.

Implementing the Strategic Plan

This Strategy charts an ambitious course for the IKA, setting goals and objectives which will be challenging and exciting. Implementation is a shared responsibility between the Board, the staff and the volunteers of the organisation.

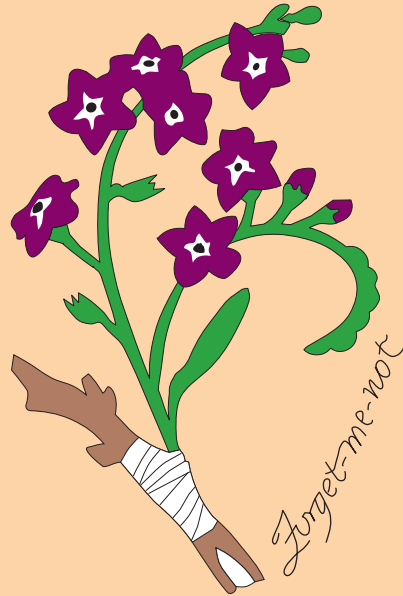
The Board's role is to set the Strategy and monitor its implementation through reports from the CEO and staff.

The CEO will establish detailed annual work and operational plans setting out the approach to bringing the Strategy to life, implementing our plans and achieving our goals. All staff reporting to the CEO will be responsible for working towards those plans and implementing the Strategy, providing regular and detailed reports to the Board about implementation to meet the Board's expectations.

The Strategy, combined with our operational plans, will form the roadmap for the organisation for the next five year period 2021 to 2025, documenting the detail of how the IKA will work towards all of the strategic objectives.

We will report on progress in relation to each action in our Strategic Plan within our annual report, with a formal mid-term review of the Plan taking place in late 2023.





*The “Forget-Me-Not” flower is a symbol of life
– the dead wood of the Irish Kidney Association’s emblem
represents the failed organ and the bandaged graft,
with the new flower, symbolises the transplant life-giving organ.*



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CHARITY REGISTRATION NUMBER: 20011260