Leading transformation in kidney health.

Our charity strategy 2020-2030.
Leading transformation in kidney health.

As the leading kidney research charity in the UK, nothing is going to stop us in our urgent mission to end kidney disease. We’re here to be heard, to make a difference, to change the future. This is a disease that ruins and destroys lives. It must be stopped.

Our vision is the day when everyone lives free from kidney disease.

Research is what we do. It is the only way to discover future preventions, treatments and cures. It is vital to keep our loved ones safe.

Kidney disease affects three million people in the UK, treatments can be gruelling and currently there is no cure. Our research has changed the future for so many kidney patients over the last 60 years but, even so, kidney failure is rising. And factors contributing to it are also growing, such as diabetes, cardiovascular disease and obesity. This means that today, we are more essential than ever.

Only research will end this, by offering kidney patients and their families hope for the future.

We’re taking it on.

But we can’t do it without you.
The Covid-19 pandemic has made life for people with kidney disease even tougher. Being at higher risk of becoming seriously ill or dying from the virus meant shielding was vital. But some kidney patients had no choice but to put themselves at risk by attending their life-saving hospital dialysis. Or to take their immunosuppressant medicines to keep their transplanted organ alive, yet know it means their immune systems can’t fight infection as easily. Lockdown exacerbated the mental health problems that come with living with kidney disease.

Due to Covid-19 more people are also living with kidney disease. Currently, we don’t know the full effects Covid-19 will have in the long term.

People from minority ethnic groups are five times more likely to develop kidney failure.

Worldwide, around one in nine people have chronic kidney disease, for which there is no cure.
The time has come for change. Alongside everyone living with, affected by, or at risk of kidney disease, we will lead that change.

Over the next ten years we will drive a revolution in kidney health. We’ll do this by working with others to put it on the UK’s health agenda. We’ll drive research and see it through so that discoveries quickly translate into life-changing advances. We’ll be responsive; adapting to changes in the landscape that affect kidney health. Despite the devastating impact the pandemic has had on the world and the charity, we will make life better for people with kidney disease.

Our ambitions in this strategy are bigger than ever before and grounded in the hopes and needs of the kidney community.

With your help we can protect kidney health and give people the power to live life better with kidney disease.

Enough is enough.

Kidney disease ends here.
20 **People** develop kidney failure every day in the UK. **Nearly 30,000** people need dialysis to survive.

**Around 40%** of people with diabetes will develop kidney disease during their lifetime.

**Dialysis** is one of the most taxing treatments modern medicine has to offer.

5 **People every week** die while on the waiting list for a kidney transplant.
Our charity strategy 2020-2030.

Our vision:
The day when everyone lives free from kidney disease.

Our values:
Ambition
Bravery
Passion
Urgency

Our purpose:

Prevent kidney disease by finding ways to see it coming and stop it happening.

Protect people from reaching kidney failure by learning how to spot disease early, halting disease progression, and repairing kidney damage.

Treat: Transform treatments by making dialysis more tolerable and making transplants last longer until better alternatives are available.
Our impact:

Our actions will change the future for people living with and at risk of kidney disease, so that by 2030 there will be:

- **Better awareness.** More people, particularly those in at risk groups, know how to look after their kidney health.
- **Earlier diagnosis.** We’ll have new ways to detect kidney disease earlier so that people get treatment before irreversible damage is done.
- **New treatments.** There will be new ways to slow disease progression so that kidney patients avoid dialysis or a transplant for longer.
- **Better treatments.** Technological advances in dialysis, to make it more tolerable and effective.
- **Better kidney transplants.** We’ll make advances that make transplants last longer, reduce the burden of treatment and monitoring, and improve quality of life.
- **Kinder monitoring.** We’ll have a new and less invasive alternative to having multiple biopsies to monitor kidney disease.
- **Better care.** New models of healthcare delivery that improve efficiency and equity of kidney care, so everyone in the UK gets the best quality treatments and support they need.

How you can help

We need people like you to give your time, money or voice to help us make this happen. **Get in touch and get involved at [www.kidneyresearchuk.org](http://www.kidneyresearchuk.org)**

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Our 10 year plan to make it happen:

**Accelerate discoveries.** We’ll fund, prompt and pave the way for a step change in the research effort, to deliver major advances in our fundamental understanding of kidney health and disease.

**Make it count.** We’ll make sure discoveries are put into practice, so that advances in research rapidly make a difference to people with or at risk of kidney disease.

**Rally together for change.** We will not stop until kidney disease is treated with the urgency it demands. We’ll bring people together and lead a revolution to improve the UK’s kidney health.

To deliver these actions, we need to be at the top of our game. We have a strategy to transform the organisation and **strive for excellence** in everything we do.
Action 1: **Accelerate discovery**

Only through research will we discover how to see kidney disease coming, and how to cure it. But not enough research is happening, making progress too slow.

We’re going to give UK kidney research a shot in the arm. We’ll fund, prompt and pave the way for a step-change in the research effort, giving the best scientists the tools they need to accelerate discovery.

This will lead to major advances in our fundamental understanding of kidney function and disease, opening the doors to better detection, diagnosis and treatments within a decade.

### What we’re going to do:

**Work with you, so we get it right**
- Involve those living with and at risk of kidney disease in everything we do, so our research priorities are grounded in their realities.
- Ensure kidney researchers and health professionals understand what it’s really like to live with kidney disease.
- Make sure every kidney patient has the chance to be involved in research.

**Get kidney research adequately funded**
- Raise and spend significantly more on research ourselves, and in partnership.
- Identify pressing gaps in knowledge, and commission research to fill them.
- Push major funders to recognise and address the under-investment in, and urgent need for, kidney research.
- Think outside the box to leverage new sources of investment into kidney research.

**Use the power of partnerships**
- Connect and work with others, across borders and beyond our traditional collaborators, to speed up progress and find answers to shared problems.
- Encourage researchers to work together by creating and supporting networks in which they can share ideas and insights.

**Support researchers to achieve greater success**
- Work to remove barriers that make kidney research harder and slow down progress, for example by improving access to biobanks and data.
- Make careers in kidney medicine and research appealing and sustainable by promoting the field and providing a ladder of funding opportunities.

**Share our impact**
- Track how our research is making a difference to individuals and families and use these stories to inspire people to support us.

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This strategy gives me hope that Jamie’s transplant could last longer, that drugs could be better, and that treatments could be better and less life-limiting.

Deirdre Jennings – whose husband Jamie experienced kidney failure and dialysis, before having a transplant.
Discoveries are just the start. To make an impact, they must move on to the next stage of research, or be adopted into routine healthcare to prevent, diagnose or treat kidney disease.

This relay of knowledge is moving too slowly. Kidney patients are being denied the chance of having the latest evidence-based care, so successive generations have to face the same prospects.

We will fire up our research pipeline so that discoveries rapidly translate into advances in policy and practice, and the reality of kidney care is improved.

What we’re going to do:

Be a catalyst for progress
- Swiftly identify research evidence that needs progressing, and take action to make sure it moves forward.
- Publicise research discoveries with the whole kidney community, and beyond.
- Urge and support health professionals to adopt the latest evidence into care for people with and at risk of kidney disease.

Exert greater influence
- Work with others to present one powerful and unified voice for the kidney community.
- Demand change to health policies and kidney care guidelines in light of compelling evidence.
- Support people affected by kidney disease to become campaigners for change.

Share knowledge
- Support and encourage the spread of health information to people affected by and at risk of kidney disease.
- Give people more knowledge and confidence to ask questions and make informed choices about their care, by making it easy to discover what the latest research evidence means for them.

I feel like Kidney Research UK understands both the urgency and the underlying frustrations that people with kidney disease go through.

Gareth Hughes – living with a rare type of kidney disease – fibrillary glomerulonephritis, or FGN.
Kidney disease affects three million people in the UK and 850 million across the world. It has a devastating effect on lives. And yet it does not occupy the public consciousness in the way that other diseases do. We’re going to change this.

We’re growing a community of people who’ll join us to wake up the world to the impact of kidney disease. Together we’ll protect the nation’s kidney health and ensure that research to end kidney disease is properly and urgently funded.

What we’re going to do:

Be loud and clear
- Publicly challenge misconceptions about kidney health and disease.
- Make it normal for at-risk groups and health professionals to ‘think kidney’.
- Push kidney disease up the agenda with policymakers and opinion-formers.
- Raise awareness of the link between kidney health and other diseases, and the urgent need to improve diagnosis, detection, and treatment.

Be authentic
- Share real life stories about living with kidney disease to demonstrate why research is so important.
- Ensure the voices of people who are affected by kidney disease are heard in our communications so we are always realistic and relevant.

Be inspiring and engaging
- Offer a range of ways for people to take action, get involved and influence change.
- Exceed supporters’ expectations by making interacting with us easy, personal and positive.
- Engage with people in ways that are inclusive, relevant and accessible.
- Make people feel genuinely part of a movement – Team Kidney – working to collectively transform kidney health.

Stop the anxiety and worry of becoming ill and stop the increasing fear of needing dialysis and transplant. It would reduce the guilt and worry of being ill whilst my baby needs me.

Earlier diagnosis would have saved my left kidney and saved damage to my right kidney.

We need to know much earlier, that way we can make informed choices.
Action 4: **Strive for excellence**

To deliver all that we’ve set out to do, we need to be at the top of our game. From our governance and leadership, to our day-to-day processes, we will create a culture of continuous improvement to achieve excellence.

We will strive to be an organisation that learns quickly, works fast, and leads change.

And we’ll do everything we can to help our people be at their best.

What we’re going to do:

**Make best use of resources**
- Encourage, support and harness the passion, energy and creativity that our staff and volunteers bring to the charity.
- Fund only studies that are aligned with our research strategy and geared towards making a difference.
- Behind the scenes, ensure our systems, structure, technology and facilities enable our teams to be at their best.
- Be a financially sustainable organisation now and in the future.
- Achieve diversity across our governance, advisory and leadership structures, making sure decisions are made in an inclusive way.
- Embed green practices into our work so we reduce any negative environmental impact and make a positive difference to society.
- Encourage and support the need for research to mitigate the potential impact of the climate emergency on kidney health and the environmental impact of the treatment of kidney disease.

**Be a learning organisation**
- Build an inclusive and diverse culture for all our people to succeed and feel like they belong.
- Challenge why and how we do things, then embrace change that makes us better.
- Be evidence-based by using data and insights to inform everything we do.
- Be transparent about our successes and failures, learn from others, invite scrutiny, and work collaboratively.
- Keep our eyes on the horizon, so we can spot and respond to emerging developments and opportunities and new challenges.

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A long-term, bold strategy is needed if real progress is to be made in kidney disease research related to prevention, treatment and positive long-term outcomes. This makes me feel really hopeful.

*Emma Headings* – mum to four-year-old Isabella, born with small non-functioning kidneys, who’s experienced peritoneal and haemodialysis and has had a transplant.
Our priorities.

Our ambitious strategy has set out many areas to tackle kidney disease. We are treating some of them as priorities, as we feel they are areas of greatest need or we have the best chance of making a difference for people living with it.

Building a community

We can’t transform kidney health and improve the lives of those affected by kidney disease on our own. We want to grow a vibrant and diverse community of people – including supporters, patients, researchers and influencers – and work together to make it happen.

The team kidney community will be crucial to driving change, investing more in research, raising awareness, and spreading the word about our vital work.

I live a good life with kidney disease because kidney research strategies are designed to ensure people with rare kidney conditions like me survive.

Kola Ponnle – who thanks to a drug called eculizumab, which we helped discover could treat aHUS, was able to have a kidney transplant.
Transforming kidney treatments

When kidneys stop working correctly, treatments people receive – dialysis and kidney transplants – are tough. We want to improve these life-saving but harsh treatments, to make them better, and remove the fear and anxiety that comes with them. We also want to develop new ways to treat different kidney diseases.

Our plans aim to make kidney transplants last longer, reduce the burden of treatment and monitoring, and improve quality of life for people. It’s not just about improving treatments, we also want to develop new ways to monitor kidney health and wellbeing.

These days, people are generally using various devices, apps and technology to do this, but this is not the case for people with kidney disease.

We want to harness and develop technology for people with kidney disease and those who may develop it in the future. This will encourage them to take control of their own health, help them manage it better around their lives, and relieve the pressure on the healthcare system.

Helping people living with several health conditions

Kidney disease usually doesn’t appear on its own – often people are also living with other health conditions, such as heart disease, cancer, diabetes or mental health problems. This combination can have a huge impact on people’s lives and even make them more likely to die early. You might hear this described as multi-morbidity.

We want to understand if and how each disease is linked, and if one condition leads to another. We want doctors to be better equipped to treat their patients as a whole person, rather than to treat one condition at a time. Ultimately, this could revolutionise the way people with kidney disease are treated, so they get more personalised treatments based on health needs they have.
Making kidney health equal for everyone

Social deprivation, ethnic background, gender, mental health, age and geography all affect kidney disease risk. They affect how the disease progresses, how it is treated and how patients fare. These factors often interact with each other.

Reducing health inequalities underpins everything we do. We want to build on the work we have already done in this area to better understand why some people fare worse than others. We want to support those at increased risk of kidney disease, improve diagnosis and detection, and improve the outlook for them. We will use our knowledge to change healthcare services so everyone’s chances are better. We also want people from these under-represented groups to take part in research.

Ultimately, we want everyone in the UK from all communities to have equal access to care and treatment they need regardless of their circumstances.
Influencing and driving progress in kidney health

Influencing and driving progress in kidney health is vital to make our research discoveries count for kidney patients. We want to rapidly translate them into the clinic so we better prevent and treat kidney disease. We’ll work with the right people to make this happen.

We want to ensure kidney health is on the NHS agenda by campaigning for it to be included in NHS strategic plans in the four nations. We will continue to advocate for kidney patients and kidney services. We will reduce kidney disease by advocating for early detection and intervention in people at higher risk and supporting doctors to make clinical decisions. We will help kidney patients to add their voice to help us raise awareness of kidney disease and kidney health.

We will advance kidney care by encouraging new tests and treatments to be adopted and delivering healthcare differently. We will work hard to ensure everyone in the UK gets equal access to treatment and support, and transform mental healthcare support for people with kidney disease.

We know that things will happen that we are not expecting and we have to respond to it. Covid-19 is a good example. We’ll always an eye on the external world and ensure we are responding to the needs of kidney patients, and if necessary adapt our priorities so they are doing what’s needed, right now.

I LOVE the sentiment of the mission statement and the fighting spirit. We must show the challenges of kidney disease in everyday life – and make people as aware of kidney disease as cancer.

Dale Robinson – after crash-landing into kidney failure and dialysis, Dale had a kidney transplant.
Message from our chief executive, Sandra Currie

Since 1961 our research has played a vital role in the health care for kidney patients and has saved and improved the lives of many.

But with the increasing number of people developing kidney disease and with the available treatments developing at only a steady pace, we are pledging in this new strategy to accelerate change and do more.

More for every single patient facing dialysis, for every family affected by inherited kidney disease, who live, often for decades “waiting for kidneys to fail” and who describe kidney disease for them as a “ticking timebomb.” More for every person worrying about when their transplanted kidney “might not fancy it today,” placing them right back where they started. More for everyone who is in a group described as “at risk”… we will play a leading role in changing outcomes sooner.

Our strategy to 2030 is the plan to do that.

To improve kidney health for everyone at risk we must tackle three key areas. We must prevent kidney disease by finding new ways to identify the risk and diagnose early, gaining valuable time to stop the decline in kidney function. We need to protect from further harm and eventual kidney failure by finding ways to slow down progression and repair. And in the meantime, we must transform treatments creating better, and less risky alternatives for all. These areas are reflected throughout our strategy.

None of us can expect to realise these ambitions in isolation. Scientists and researchers will not achieve this on their own. We will work with and influence others to transform kidney health and tackle kidney disease. We will combine our efforts with those who share our passion to drive forward progress and to make substantial change a reality, many of those will be directly affected by kidney disease.

Most importantly we need people like you to lend your support with your time, voice and money to help us fund the research and create greater change, sooner.

Thank you to everyone who has helped us develop this strategy, a broad and varied group of people combined with one purpose. The way forward for the charity is clearer and our resolve to make it happen has been strengthened by your commitment and your advice. I hope that we can continue to count on you to stay with us, help us keep the momentum of change, and share the positive outcomes from this plan in the future.

If you can, please send me your thoughts about how we could work together with you, or with others to implement the strategy and achieve its goals. You can email me at chiefexecutiveoffice@kidneyresearchuk.org