Our impact
Our impact in 2016-17

Foreword

Research is essential if we are to better understand kidney disease and develop new and improved treatments. Kidney Research UK both funds the research we need to unlock answers to kidney disease and develops the careers of those working in the field. This in turn builds the research capacity we need to accelerate knowledge for the future.

In this report you can see some examples of that capacity building, and examples of the innovative research that the very brightest and committed researchers are undertaking.

We have illustrated just some of the impact we have made through that work. Not only are we delivering vital steps along research journeys in laboratory science but are also funding work that is helping improve the quality of life for patients today. You will see that we have increased our investment in research every year over the last five years, and were able to invest £6.7 million last year, a record amount. But as you will read from Sandra Currie, this is not nearly enough to fund all the research we need to.

We face a challenging environment, including uncertainties for the international research community, and an ever-increasing pressure on our research colleagues’ time, on whom we depend for our collaborative approach. I should like to thank them and all those who support us through volunteering their time, making gifts or undertaking their own fundraising. We will not deliver a brighter future for kidney patients without that generous support.

There is much to celebrate in this annual report. We have funded more research than ever and taken forward some ambitious collaborative projects with external partners.

We have amplified our messages about kidney disease and our work. We continue to strive to ensure that patients are with us as we develop our approach and to improve the experience of those who generously support us. We have made some changes to the way we are organised, to improve how we work so that we can reduce waste and make faster progress. But I know that there is so much more to do.

I am always disappointed when I have to write to grant applicants to tell them their excellent research ideas will have to be turned down because we don’t have the money to fund them. Who knows what future breakthroughs might be in their ideas, and the benefit for patients they might have realised more quickly? I look forward to the day when I don’t have to write any of those letters; to get there we have to make the burden of kidney disease ever more relevant and attract the significant investment we need to unlock the answers to this silent killer.

A few months ago, I was enthusiastically describing our progress and plans to a young man with kidney disease, and his brother, at a reception. He listened with interest to my reassuring outline of how much work we are doing, grateful that so many people are making progress that he will benefit from. His brother was not so reassured and said: “That’s all very well, Sandra, but it’s not enough, is it?” Of course he was right. Too many people’s lives are still being cut short. Too many patients endure a poorer quality of life. Together we can realise our vision of lives free from kidney disease. We are grateful to the people who help us in so many different ways, and we remain dependent on the supporters who give time, energy and money throughout the year. They help us make swifter progress as we tackle the problems faced by patients every day.
Our vision, mission and strategy

THE KIDNEY HEALTH PROBLEM

- Kidney disease currently has no cure
- Increasing kidney failure
- Black, Asian and ethnic minority groups at even higher risk
- Acute kidney injury
- Low awareness of kidney disease
- Impact of social, economic and political changes on CKD

ACHIEVING OUR MISSION – STRATEGIC PRIORITIES

- Treatment is expensive
- Poor quality of life on dialysis
- Transplants don’t last long enough
- Not enough donated kidneys
- Late diagnosis

ENABLED THROUGH INCOME GENERATION

- Gaps in research evidence
- Not enough funding for kidney research
- Not enough research capacity
- Limited patient involvement

OUR VISION IS: LIVES FREE FROM KIDNEY DISEASE

OUR MISSION IS TO:

- Fund and deliver life-saving research into kidney diseases
- Improve treatments for people with kidney diseases and enhance their quality of life
- Increase awareness of kidney health, and support the early diagnosis and prevention of kidney disease and damage

INVESTING IN RESEARCH

- Broaden support for research careers
- Build research capacity through collaboration
- Work with industry and other funding partners
- Increase innovation

ANSWERING KEY QUESTIONS

- Address evidence gaps in renal research
- Understand why black, Asian and minority ethnic groups are at higher risk
- Develop research methods to learn how to improve the healthcare system

WORKING WITH PATIENTS

- Where appropriate, fully involve patients in all aspects of research and development
- More clinical trials

RAISING AWARENESS

- Address health inequalities
- Develop health education
- Influence change

LEADING TO STRATEGIC OUTCOMES

- More people know about kidney disease and the risks
- More people diagnosed earlier
- People on dialysis live better for longer
- More patients in clinical studies
- More people receive timely and effective kidney transplants
- Transplanted kidneys work better and last longer
- The creation of a more robust research nurse capacity
- We are developing cures for some forms of kidney disease
- We are delivering breakthroughs that are changing people’s lives
- Equal access to research and treatments
- Research culture embedded in clinical service
Our goals for 2016-17 and how we did

INVESTING IN RESEARCH AND ANSWERING KEY QUESTIONS

<table>
<thead>
<tr>
<th>What we planned to do</th>
<th>What we achieved</th>
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<tr>
<td>Invest just over £6 million in research and award at least 52 career and research grants, with further contracts to support ongoing projects. We planned to introduce new awards for nurses and allied healthcare professionals, and award the David Kerr Fellowship.</td>
<td>We invested £6.7 million in research and awarded 53 career and research grants (and 40 other contracts). We were not able to award the David Kerr Fellowship, but we allocated other funds to enable us to increase the allied healthcare professional fellowships to two awards instead.</td>
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<td>Recruit the target number of patients for our intravenous iron clinical trial (PIVOTAL) and bring on new sites for our project to identify people at greatest risk of kidney failure (ASSIST-CKD). We also planned to complete a study into the health benefits of intravenous iron in patients with advanced chronic kidney disease.</td>
<td>We recruited over 1,800 patients to our PIVOTAL trial and began the follow-up work. New sites were added to our ASSIST-CKD project but we experienced delays to the Iron and Heart study, which is now recruiting well and will finish in 2017-18.</td>
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<td>Start two major projects collaborating with pharmaceutical industry partners – implementing a data and tissue biobank and a new joint fellowship.</td>
<td>Working with our partners we finalised the plan to invest in a unique kidney biobank covering England, Scotland and Wales; we will start collecting samples from kidney patients in 2017/18. Working with Medimmune, we awarded a Post-Doctoral Fellowship to study acute kidney injury.</td>
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<td>Review our strategy, ensuring our plans reflected the key research themes emerging from the UK Renal Research Strategy. We wanted to take account of the outcomes of the patient survey and the priority setting partnership work with the James Lind Alliance on Transplantation. We planned to support the implementation of the UK Renal Research Strategy.</td>
<td>Our trustees completed the review and we published our new strategy which you can see in this report. We launched the UK Renal Research Strategy in April 2016 and working with the UK Kidney Research Consortium, are monitoring progress against its aims across the renal sector.</td>
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<td>Complete a review of our work in health inequalities and commission a project to identify important research questions that should be addressed to understand better why certain groups are at greater risk of kidney disease.</td>
<td>Whilst we made good progress, we were unable to complete this work within the year, and are scheduled to complete the review and report by the end of 2017.</td>
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RAISING AWARENESS

Further increase awareness of the charity’s work and of kidney disease amongst the general public and healthcare professionals, and continue to increase our influence amongst decision-makers and policy leads.

We continued our awareness work and saw a small rise in the number of people who had heard of the charity, but a small fall in those who had good or some knowledge of kidney disease. We engaged with healthcare professionals at conferences and in our public affairs work, and ran three successful parliamentary events, along with other policy engagement.

GENERATING INCOME AND MANAGING OUR ACTIVITIES EFFECTIVELY

Improve the experience that all supporters, volunteers, patients, donors, funders and researchers have when they engage with us. We planned to develop a programme of enhanced experience that will lead to more people helping us in more ways.

We made good progress across many of our stakeholder groups and this is an area we will continue to focus on. In particular, we changed our approach to give people taking part in our events a personalised experience and helped them to raise more funds for our research.

Plan for major changes in our income over the next three years to reflect the completion of some major projects. We wanted to raise a total income of £9.8 million in 2016-17 and undertake a review of our reserves policy to achieve the right balance between investing in research and providing for a sustainable future.

We raised £9.6 million, an increase of nearly £600k on the previous year, but a little short of our plan. We re-planned our budgets for the following years and implemented a new reserves policy to achieve the balance we needed.

Invest in development opportunities for our staff and volunteers so that the charity can meet the challenges of future years.

We increased our investment in training. We introduced a core training programme and delivered over 90 individual training opportunities.

Whilst ensuring the quality of what we do, invest 77 pence in every pound into our charitable activities, with 23 pence going to raise the next pound; to continue to measure our progress and work as effectively and efficiently as we can, as we plan for a cost ratio for future years that ensures the health and future stability of the charity.

We invested 78 pence into research and awareness, with 22 pence going to raise the next pound. We also planned some changes in our resources to ensure our continued development and quality.
Our year in numbers

2,100 Patients who responded to our survey on research priorities, telling us their most important research areas

62,000 People engaging with Kidney Research UK on Facebook, Twitter and other social media

1,800 Patients taking part in our clinical trial on the optimum use of iron when treating anaemia

£6.7 million The amount we invested in research in the year, 53 career and innovation grants awarded and other research contracts

2,600 Supporters who ran, cycled, walked and parachuted to raise nearly £570,000 for research

60 Patients who received a kidney transplant using the innovative warm perfusion technique, funded by Kidney Research UK

170 Academic papers published by our researchers advancing our knowledge about kidney disease

11 More young people we have encouraged to consider a career in renal research by funding a year’s study each through our intercalated degree programme

5,200 Supporters who gave us a monthly gift, helping us to fund research now and into the future

1,900 Patients in just one site referred to their GP as being at higher risk of progressive kidney disease through our ASSIST-CKD project

550 People who helped us in our work by volunteering their time and skills, including those who kindly volunteer to peer review grant applications

18,000 Supporters and patients helped with information by our Supporter Care team
Examples of our impact – our research

Growing our investment in research

We have managed to sustain our growth in research investment over recent years. We invested a record £6.7 million in the year, which produced 53 new career and innovation grants to address key research questions, and further investment in other major projects, such as our anaemia clinical trial (PIVOTAL).

We fund as many high quality studies as we can, but last year we had to turn down £2.4 million worth of proposals that we really wanted to accept. Sadly, we have to turn away many exciting and potentially lifesaving ideas, because we don’t have the money to say yes.
Identifying people at greatest risk of kidney disease today

Our ASSIST-CKD project looks for early signs of progressive kidney damage in patients by combining data from routine blood tests carried out by GPs and hospitals through graphs of kidney function over time. In one site alone, Doncaster, in the course of the year, more than 1,900 patients were identified as being at higher risk. This means that they can be monitored more closely and referred to a specialist promptly, if needed.

Supporting careers and building research capacity

We want to attract and inspire the brightest medical undergraduates to consider a career in renal research. Our intercalated degree grants of £5,000 enable students to take time out of their degree studies to join some of the UK’s leading renal research groups and focus on special year-long research projects. One of these is Alex Hollis (24), who joined the renal research group at the Institute of Biomedical Research, Birmingham, to focus on kidney metabolism prior to transplantation. Alex hopes his work, which completed in 2016, will eventually help us to find new ways to alter the metabolism of donated kidneys in storage so that more become viable for transplantation.

As a measure of Kidney Research UK’s impact, we were delighted to learn that Dr Rachel Lennon (University of Manchester), a clinician scientist, was awarded a prestigious Wellcome Senior Research Fellowship in Clinical Science, worth more than £1.7 million, to help identify therapeutic targets to treat chronic kidney disease. The charity previously funded Rachel’s work through a studentship and a project grant and her success illustrates the importance of Kidney Research UK in developing the careers of renal researchers.

We are very proud of the 50 years of our support for research into childhood kidney diseases. We decided that it was time to build on that legacy and join together with Kidney Research UK, to ensure an even brighter future for this area of renal research.”

Dr Richard Trompeter, Chair of Kids Kidney Research

Simple technique offers future hope for childhood kidney diseases

For the first time in the UK, scientists have used kidney cells extracted from patients’ urine and successfully treated these cells; this non-invasive technique allows us to study their behaviour. At our 2016 Fellows Day conference, Dr Shalabh Srivastava (Institute of Genetic Medicine, Newcastle University) reported on his work to gain a better understanding of Nephronophthisis, a type of inherited cystic kidney disease which generally affects children. Shalabh and his team also deployed an innovative technique called Exon Skipping whereby they can make a signal ‘skip’ over parts (exons) of defective genetic code, to make cells act normally, rather than abnormally.

A charity merger means a positive future for research into childhood kidney diseases

During the year we agreed with the charity, Kids Kidney Research, that combining forces would create an even stronger platform to drive innovation in understanding and treating childhood kidney diseases. The founders of Kids Kidney Research first began fundraising in 1967 and the charity now awards around £400k in grants every year. Following the year end, in September 2017, we completed our merger and Kidney Research UK has increased its investment in paediatric kidney research.

Regenerative medicine – inspiration and hope

We convened a meeting of 35 clinicians, scientists and patients to begin a new collaborative journey in the field of kidney regenerative medicine in the UK. The charity plays a vital facilitating role in bringing experts together to accelerate research. The outcome of this meeting was to launch a regenerative medicine network to foster new collaborations and innovation in this cutting edge field. Kidney Research UK will continue to support this initiative.

Further investment in transplantation research

For many people a transplant is not even an option. For patients who have more than one transplant their immune systems become highly sensitised and therefore their chances of finding a suitable donor kidney decrease considerably. Under our Making EVERY Kidney Count Appeal, with a substantial gift from the Garfield Weston Trust, we awarded funding to Dr Sian Griffin (University Hospital of Wales) to test a new combined treatment. This aims to reduce antibodies in highly sensitised patients’ systems to a manageable level, thereby increasing their chances of undergoing a successful transplant.
Empowering patients to make the right choices

Our project team of Peer Educators worked with clinical colleagues at the Heart of England NHS Foundation Trust to help patients make the right choice of dialysis treatment. There is a disproportionate take-up of home-based treatment, particularly amongst people from black, Asian and minority ethnic (BAME) communities. Our volunteer Peer Educators are patients and carers, and can help empower fellow patients to reach the right choices for them. They helped over 40 patients reach a treatment decision and held five well-attended patient information days.

Celebrating Women in Science

To celebrate the UN’s International Day for Women and Girls in Science, we ran a successful nationwide awareness campaign to feature the female researchers we fund and their achievements in tackling kidney disease. Our campaign also highlighted some of the particular challenges women face in their academic careers.

Spreading the word about kidney disease and our work

Overall, our communications work in the year produced over 700 mentions in the media and a wide social media reach through our 62,000 followers. We learned much about the stories and features that particularly interest our followers.

The infographic below about transplantation reached over 150,000 people on Facebook as it was so widely shared. Here is just one of the comments we received:

My other half is still waiting for his kidney, currently been waiting nearly 7 years for the call. Has high levels of antibodies so can’t find a match. His brother was tested but not a match, mum had cancer so can’t donate. Been on dialysis almost 10 years.

Please don’t give up hope, we are funding research into transplantation of highly sensitised patients and hope one day to find answers. Best wishes.

Kidney Research UK

Getting our voices heard in parliaments

We continued our profiling of research, and the policy recommendations arising from the UK Renal Research Strategy, at a series of meetings with parliamentarians across the UK. Assembly members, kidney patients, researchers and health care professionals gathered in Cardiff where they were addressed by Vaughan Gething AM, Cabinet Secretary for Health and Wellbeing. Similarly in Edinburgh, Deputy Convenor of the Health and Sport Committee, Claire Haughey MSP, spoke to a capacity audience to hear about Kidney Research UK’s work. Along with a round table meeting we held in Westminster, these events brought together all key stakeholders to raise the profile of kidney disease and research.

Renal research priorities of respondents

1. Cures for kidney diseases
2. Prevention of kidney diseases
3. Finding new sources of organ transplants
4. Early detection of kidney diseases
5. Improving treatments to make damaged kidneys last longer
6. Improving methods of transplantation
7. Stem cell research

I’m incredibly impressed with Kidney Research UK. They really are, as a team, utterly, totally, committed to raising money and spending that money in the best way to try and drive forward research and help patients.”

Professor Jeremy Hughes, University of Edinburgh, speaking at our Holyrood parliamentary reception in December.

Asking patients’ views on research

We undertook our third survey of patients to find out their views on which areas of research they think should be a priority. Previous surveys were run in 2007 and 2013 and, in 2016, we had our best response ever, with 2,100 patients giving us their views. The survey results suggest that future research should focus on discovering a cure for kidney diseases, prevention and early detection, and finding new sources of organ transplants. These findings will inform our future activities in research development and strategy.

Dr Claire Sharpe
Generating income and managing our activities effectively

Raising our income

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<tr>
<th>Source</th>
<th>Amount</th>
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<tbody>
<tr>
<td>Trading e.g. our lottery and shops</td>
<td>£875k</td>
</tr>
<tr>
<td>Investments</td>
<td>£381k</td>
</tr>
<tr>
<td>Legacies</td>
<td>£3.16 million</td>
</tr>
<tr>
<td>Trusts and Partnerships</td>
<td>£2.40 million</td>
</tr>
<tr>
<td>Donations and events sponsorship</td>
<td>£2.55 million</td>
</tr>
<tr>
<td><strong>Total Income</strong></td>
<td><strong>£9.4 million</strong></td>
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Our income was nearly £9.4 million. This is where our income came from in 2016-17

Profiling research in Liverpool

We wrote to supporters to tell them about Liverpool-based researcher, Dr Rachel Floyd, enclosing a letter from Rachel. In this she told the story of how her research career developed and how Kidney Research UK had supported her with a three-year Fellowship, leading to her now becoming a lecturer at Liverpool University. Her work concerns how E. coli can cause infection in the urinary tract, and why these often become resistant to antibiotics. Our supporters responded to Rachel's letter by kindly donating £40,738 to Kidney Research UK.

Some feedback from a supporter who received Rachel's letter:

“With all the bad things going on in the world today it is the likes of you, Rachel, and your colleagues, who bring a ray of hope and goodness. Thank you.”

Building research capacity through collaboration

We were delighted to partner with pharmaceutical company, MedImmune, who contributed over £100k to fund a post-doctoral Fellowship. This was awarded to Dr Chia-Te Liao, of Cardiff University, to study the role of molecules, called MicroRNAs, in acute kidney injury and the progression of chronic kidney disease. Collaboration between industry, academia and the charity is a vital part of growing capacity for kidney research and guest speakers from MedImmune spoke on this subject at our Fellows Day conference.

Improving our supporters’ experience

We set out to improve the experience that our supporters receive from us and made good progress, receiving some great feedback from people who supported us in many different ways. We worked hard to offer more personalised support to our events participants to help them realise their fundraising goals, and to ensure they feel part of our #TEAMKIDNEY. Improving the experience for our stakeholders, be they supporters, volunteers, patients, researchers or partners, is really important to us and will continue to be a key focus.

“I wish to say how grateful I am and to thank all those who support us, our kind customers, the wider community, my staff and volunteers. Every donation you make, no matter how small or large, makes a difference.”

Darryl Hagley, Shop Manager, Exeter
There has been progress, but there is more need than ever

In 2006, 44,000 people were being treated for end stage kidney failure. We estimate that figure has risen to 64,000 at the end of 2016 and continues to rise.

The number of patients living with kidney failure increases at 4% a year.

In 2007-8, the waiting list for a kidney transplant was 6,980. By 2016-17 this had fallen to 5,233.

1 in 5 emergency admissions into hospital are associated with AKI.

We estimate there are 60,000 premature deaths each year in people with CKD.

Over 3,700 people a year die while on dialysis and around 250 people a year die while waiting for a kidney transplant, which is more than five people a week.

Kidney failure is 5X more common in people from black, Asian and minority ethnic (BAME) communities.

The lives of more than 3 million people are at risk as a result of moderate to severe chronic kidney disease (CKD).

Two million are on the CKD register, meaning that there is a missing million of undiagnosed patients.

1. UK Renal Registry, 10th Annual Report
2. Estimated figure for December 2016 based on UK Renal Registry, 18th Annual Report
3. UK Renal Registry, 18th Annual Report
4. NHSBT Activity Report 2016-17
5. NHSBT Activity Report 2016-17
8. Kidney Research UK
What we plan to achieve in 2017/18 and beyond

**INVESTING IN RESEARCH AND ANSWERING KEY QUESTIONS**

- Increase how much we invest in paediatric kidney research by completing the merger with Kids Kidney Research and introducing a new £500k grants round.
- Answer more research questions by investing £8.5 million in research, increasing the number of high quality research grants we fund from 53 in 2016-17 to 58 in 2017-18.
- Begin collecting samples to support future research advances by implementing the first unique kidney biobank for England, Scotland and Wales.
- Identify the research questions that will address priority evidence gaps through facilitating new research networks.
- Identify people at greater risk from chronic kidney disease by working with GPs, pathology labs and hospitals.
- Improve quality of life for people on dialysis by preparing to complete our study into the optimum way to manage anaemia.
- Provide hope for communities that are at greater risk of kidney disease by identifying the questions we need to answer to understand the root causes.
- Drive future benefit for kidney patients by developing partnerships with organisations who work in areas related to kidney disease, such as diabetes.

**RAISING AWARENESS AND WORKING WITH PATIENTS**

- Help people from communities facing health inequalities in treatment choice and organ donation by continuing our peer educator work.
- Raise the profile of kidney disease through our awareness work and by engaging with policy-makers, in line with the aims of the UK Renal Research Strategy.
- Increase our engagement with patients and provide support to patient groups to enable them to discover more about innovation and research progress.

**GENERATING INCOME AND MANAGING OUR ACTIVITIES EFFECTIVELY**

- Fund growth in our work by raising a total income of £10.7 million.
- Ensure the quality of what we do, whilst aiming to invest at least 75 pence in each pound we raise into our research and awareness work, with 25 pence or less helping us to raise the next pound.
- Equip ourselves to achieve our ambitious aims by investing more in the training and development of our people.
Ambassadors
Stefan Booth
Lawrence Keogh
Lauren Laverne
Richard Pitman
Nina Wadia
Jacqueline Wilson

National President
Lord Chandos, Baron Lyttleton of Aldershot

Company secretary
Anne-Marie McCarthy

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October 2017