Supporter Newsletter



www.kidneyresearchyorkshire.org.uk

Registered Charity Number: 1106412

SPRING 2023



INTHIS ISSUE:

Ball Raises £20K

KRY Fund equipment to research Heart Disease in Kidney Patients

Patient Stories: Focus on Living Kidney Donation

Creating a Force for Good with Kidney Research UK

Welcome!

Dear Friends and Supporters,

Welcome to our Spring 2023 Newsletter which provides an update on the work we have been doing and some of the wonderful fundraising that our supporters have been doing over the past year. We also share some inspirational stories highlighting the incredible impact that organ donation has made to the lives of patients living with kidney disease.

It has been an exciting year for Kidney Research Yorkshire as we have finally purchased our CPEX Bike and computer which will be used to research the affects of kidney disease on the heart. The purchase was delayed due to various shipping issues due to COVID and Brexit, but it has now arrived, and we are delighted to share how this will enable vital research to take place over the coming years to improve understanding of heart disease in kidney patients.

We are also very excited to have partnered with Kidney Research UK to fund two new projects based at the University of Leeds over the next three years, which you can read about in this

Brothers Jermaine and Guy Jones organised an incredible fundraising dinner and awareness evening in the Autumn of 2022 for over 300 guests raising an amazing £20,000. We were also delighted to have been chosen as the Charity of the Year for Consilia Legal, a family and employment law firm based in Leeds who raised nearly £2000 from various fundraising events during the year.

We'd love for you to get involved by doing your own fundraising, either by organising your own activity or taking part in one of the organised events we are proud to be part of which you can check out on our new website.

Thank you to all our fantastic supporters, without you we would not be able to fund our vital research, making Yorkshire a hub for research into kidney disease.

Please enjoy the read and get involved this year!!

Julian Wiley, Chair of Trustees

Keep in touch for up to date news

Connect with us online:



kidneyresearch



kidneyyorkshire



kidneyyorkshire

Or visit www.kidneyresearchyorkshire.org.uk

Get in touch with the team:

Tel. 07944 953960, email: david@kidneyresearchyorkshire.org.uk

Tel. 01484 400430, email: louise@kidneyresearchyorkshire.org.uk

Our Patrons

Grateful thanks are extended, as always, to all our patrons:

Stuart Andrew MP

Professor Alex M Davison RD, MD, FRCP

Trevor Gurney FCA

Danni Hewson

Tim Hogarth

Professor Graham A Leslie Hon. DBA, CBE

Matthew Lewis

The Lord St Oswald

Kevin Sinfield

Christine Talbot

Judith Blake, Baroness Blake of Leeds

Key Staff and Trustees

Julian Wiley

Chair

Rachel Dunhill

Secretary

Hilary Marryat

Trustee

Andrew Mooney

Scientific Advisor

David Fisher

Fundraising Manage

Louise Stee

Administrator

Welcome to our new Committe Member



We are delighted to welcome our newest member to our committee, Niketa Macwan.

Niketa is an Indian born, Journey Enhancement Analyst at Barclays. In 2018 she was diagnosed with chronic kidney disease. In the beginning, she was on dialysis three times a week and the doctors mentioned that kidney transplant would be the only way forward. Somehow, however, her kidneys are stable now, and she had come off dialysis and the transplant is on hold for now while her condition is stable. Niketa was introduced to Kidney Research Yorkshire charity by Dr Sunil Daga who is her consultant, and following our Holi Day event at Leeds Hindu temple last year, she came along to one of our committee meetings and has become an active member.

Niketa says 'Having experienced the difficulties in the past and considering the future challenges, I have personal interest in this research. I am aware that in the UK, the minor ethnic background patients have longer waiting times for transplants. I have keen interest in raising awareness about living organ donation.

I am looking forward to working with fund raising and awareness campaigns. It has been interesting learning while getting involved in various discussions, especially as we develop more collaborative working with other kidney research charities, such as our work with Kidney Research UK.

I am very proud to be part of this organisation and greatly appreciate the support and warm welcome from all the committee members.'

WHAT A BALL!

On Saturday 17th September, thanks to the amazing efforts of supporters, Guy and Jermaine Jones, over 300 people enjoyed a fantastic evening of fine food and great entertainment which has raised over £21,000 towards our work. Guy and Jermaine are two brothers who have first-hand experience of the importance of organ donation and are doing all they can to raise awareness of this to their friends, family and the wider community.

Six and a half years ago, Guy and Jermaine's mum, Judith needed a kidney transplant, and at the time, both were tested to see if they would be a match to donate a kidney through a live donor transplant. Guy was the best match so donated one of his kidney's which has dramatically improved her standard of living.



Just a few years later, Jermaine was then diagnosed with FSGS, a type of kidney disease that causes scarring on the kidney filters, which gradually reduced the function of his kidney to the point that he had to start dialysis treatment three times a week. At the time of his diagnosis, Jermaine was a police officer, but is now a contracts manager for a retail fit out company.

Jermaine was one of around 5,000 people waiting for a kidney transplant in the UK (480 in Yorkshire) — with the average wait for someone on the list being 2 ½ years. This is increased to around 3 ½ years for people from Black and Ethnic Minority groups, like Jermaine.

Jermaine, however, had a live donor transplant in November from his friend, Ben, using the paired donor scheme meaning he no longer needs to have dialysis and after a period of rehabilitation will enable him to get back to doing all the things he loves like football, rugby and kickboxing, which have all taken a back seat as the condition worsened.

Due to their family experience, they wanted to do something to help raise awareness of organ donation, and from January to September 2022 worked very hard to organise an awareness and fundraising ball on behalf of Kidney Research Yorkshire.

The event took place on Saturday 17th September at the Queen's Hotel in Leeds. The 300 guests enjoyed a fantastic night with great food and music and through various fundraising activities including

a raffle and auction has raised an amazing £21,000, including over £6,000 in donations from people who couldn't make the event.

On top of this the guests also heard both Jermaine and Guy's stories, and Nick West also shared his kidney transplant story, having received his new kidney in October 2021. Dr Andrew Mooney, Consultant Renal Physician at Leeds Hospital, and the Scientific Advisor at Kidney Research Yorkshire spoke about the importance of the work we do at the charity and the importance of organ donation. Huge thanks to Jermaine and Guy for their amazing work in fundraising and raising

awareness of just how important organ donation is. Thank you also to all of those who supported the event in person, or via donation, and everyone who donated amazing prizes for the auction and raffle.

Make sure that your family knows your personal decision on organ donation by sharing your wishes with them and registering your organ donation decision on the NHS Organ Donor Register, and if you have a family member or friend who needs a transplant, please do find out more about the living donor scheme.



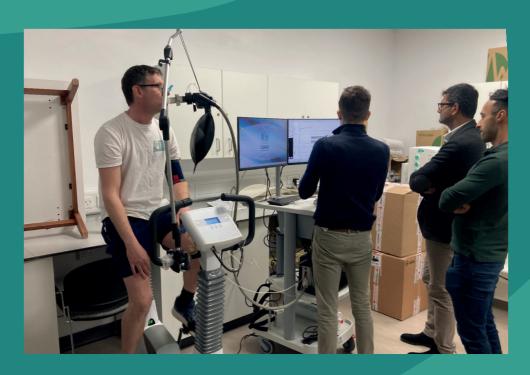
UNDERSTANDING THE HEART DISEASE...

Thanks to you our amazing supporters we have been able to purchase a Cardiopulmonary Exercise Bike which will be used to research the affect that kidney disease has on the heart. The machine is being used at Leeds General Infirmary, where Dr Shammi Chinnappa will use the equipment to help understand heart disease in kidney patients. Dr Chinnappa explains here what they will be doing:

Many patients with kidney disease develop heart disease during the course of their illness. There is a clear distinction between the type of heart disease seen in the general population and the ones seen in

kidney disease. Coronary heart disease that occurs because of build-up of fatty material inside the blood vessels is the common type of heart disease in general population, whereas in kidney disease, heart failure that results from weakening of heart muscle is the commonest type. About 1% to 2% of people in the adult general population have heart failure, whereas, in advanced kidney disease, especially in patients undergoing dialysis, this number can be as high as 40%.

Understanding the emergence of heart failure in kidney disease and its early diagnosis before



...IN PATIENTS WITH KIDNEY DISEASE

the patient develops overt symptoms of heart failure is a research priority. Studies in the past had consistently shown that patients with kidney disease have bulkier hearts, but it was not known whether this thickening of heart muscle meant poorer function. As the measurements were made at rest, they lacked the ability to differentiate between normal and impaired heart function.

Earlier work, funded by Kidney Research Yorkshire, has shown that kidney patients have covert impairment in their heart function even when they are otherwise well. We demonstrated this by measuring the peak performance of the heart as opposed to resting measures, akin to taking a car for a spin to judge its performance. We showed for the first time that the peak power and the reserve power of the heart was impaired in kidney disease even when there was no known underlying heart disease or diabetes. The importance of this work was acknowledged by the highest-ranking renal journal in Europe, Nephrology Dialysis Transplantation, by placing the results on the cover of the March 2018 issue. Our further work explored the relationship between heart size and heart function in kidney disease and showed that as the heart gets bulkier its performance gets weaker demonstrating clearly that there is heart muscle disease (cardiomyopathy) in kidney disease.

The phenomenon of hidden impairment in heart function demonstrated above has broad application in understanding the nature of cardiomyopathy in

the wider kidney disease population ranging from early kidney disease to dialysis or kidney transplant patients. More importantly, the study tool can be applied in evaluating different treatment strategies in preventing or reversing this early impairment in heart function thereby preventing the emergence of overt heart failure in kidney disease.

Kidney Research Yorkshire has funded a state-of-the-art cardiopulmonary exercise (CPX) lab costing over £50,000 to assess peak performance of the heart using a quick and precise tool. Compared to the previous technique, this newer equipment will cut down the study time from 2 hours to less than 30 minutes for each test. This refined device is automated requiring just one operator to perform the test. This will enable the conduct of large-scale studies in this important research area.

The lab is based in the Advanced Imaging Centre, a University of Leeds cardiac research facility enabling close collaboration with the cardiology clinic and lab scientists. Dr Shammi Chinnappa will commence studies in summer 2023 applying the above techniques in gaining deeper understanding of cardiomyopathy in kidney disease, and the effect of various treatment strategies in preventing progression of this condition.

Dad donates kidney to give daughter her life back

Life has not been straightforward for Jodie Burnley, but following a double lung transplant ten years ago, and a kidney transplant last year, she is once again living life to the full.

Jodie was born with Cystic Fibrosis, which, with the aid of medication and the care of the NHS, she was able to live with and enjoy a relatively normal childhood through her early school years until the age of 14, when complications started to cause inflammation in her lungs. Jodie's health gradually went downhill, and she was added to the waiting list for a double lung transplant. Having struggled through her GCSE and A Levels, she was delighted to receive the call to say the day had arrived for the transplant at the age of 18!

The transplant was a complete success and Jodie's health improved so that she was able to go on to live a full life as she entered adulthood, starting a career as a photographer, and enjoying time away from this with her family and her love of horses.

Having an organ transplant, however, is not without risks, and as a side effect of taking anti-rejection treatment for the lungs, her kidneys began to be affected. By the time she was 27, her kidney function was at a point where she had to start dialysis – which is a treatment whereby a machine does the job of the kidneys. This meant spending around four hours at the dialvsis unit in Pontefract, three times a week which as you can imagine had a big impact on her day-to-day life, as well as that of her family. Roger noticed how Jodie's energy levels picked up after a dialysis session, then visibly dropped around 48 hours later before her next session.

Over the years, Jodie has become an expert in her own condition, giving her an understanding of how her organs are and what she needs to do to keep them as healthy as possible, and she has always been involved in the discussions around her treatment options. At the time she started dialysis, Jodie also joined the transplant waiting list, which has an average waiting time for a new kidney of between two and three years.

It was at this time, Jodie's parents, Roger and Lucy started looking into the possibility of them donating one of their healthy kidneys through the living donor scheme. Both went through the necessary testing to see if either were a suitable match and they were delighted to discover they both were, meaning that either of them could potentially donate their kidney to their daughter.

The decision was made that Roger would be the donor, a decision made as a family.

Roger wanted to be able to do something for his daughter after years of working long hours as a business leader, which meant that Jodie's mother had been the main care giver. Roger was now working part time, though, and felt it important that he was able to do this one special thing for her.

Following all of the necessary tests, and preparation, the transplant was done in September 2022 at St James' Hospital in Leeds. The operations were successful, and following a short stay in hospital to start their recovery, both were back home within a couple of days to continue their rehabilitation.

In the short time since the operation, Roger has fully recovered, being back in the gym



and running again, and Jodie is now back on her horse and has the freedom of her life back without the regular dialysis treatment which had a huge impact on her life before.

Before the transplant, Roger had taken on the role of Chair of the British Transplant Games, Leeds committee — with Leeds hosting the games in July 2022 (two years late due to the impact of Covid) — and has since gone on to continue his involvement with the games committee – with the games taking place in Coventry this year.

As the chair of the games, Roger has come across amazing people including transplant recipients, donors and family members of transplant patients. As well as the patients, Roger has the most respect for altruistic donors, people who have offered to donate an organ through the living donor scheme to someone who is not a family member, or even someone they do not know. Knowing that by donating a kidney or part of their liver, they will give someone else the chance to their best life.

Roger says that "donating my kidney to Jodie is the best thing I have ever done. Seeing the impact it has had on her life, even the day after the transplant I could see that her cheeks were rosy again — it has made such a remarkable difference. I would recommend anyone who is able to do the same — being able to change a life is incredible."

"I would also like to offer my heartfelt thanks to everyone involved in Jodie's care, and the amazing transplant team — I am in awe of what they do and the wonderful difference that they make."

A Year of Fundraising from Consilia Legal

We were delighted to have been nominated by Consilia Legal as their Charity of the Year for 2022 after being nominated by staff member Kieran Conlon who having lived with kidney disease for many years, underwent a third kidney transplant in 2021.

The team at Consilia organised various events throughout the year including raffles and quiz, and took part in the Nidderdale Walk. Thank you so much to everyone at Consilia, and all who supported their fantastic fundraising efforts through buying raffle tickets, attending the quiz and sponsoring their team of walkers.

We are delighted to have been nominated and thank you so much for raising an amazing £1,880 to support our vital kidney research work in Yorkshire.

FINK

We are thrilled that Fink in Boroughbridge have been supporting us throughout 2022 and are continuing their support in 2023 by holding one of our collection tins in their shop in Boroughbridge. They have also raised additional funds through a hamper raffle. Thank you to Fink and their customers for their amazing support.

www.thinkfink.co.uk

If your company has a charity or the year or can have one of our collecting tins, please do consider nominating Kidney Research Yorkshire - we would love to have you on our Team

Find out more on our website: www.kidneyresearchyorkshire.org.uk/ corporate-partnerships



FUNDRAISING CALENDAR 2023

There are many ways you can **get involved**, either by organising your own events, joining an event taking place local to you or coming along to one of our events or those organised by our event partners.

Sign up to your chosen event and then let us know by:
...emailing david@kidneyresearchyorkshire.org.uk
...or calling David on 07944 953960 so we can send you a Fundraising Pack

These are just a few of the ways you can get fundraising for Team Kidney this year:

Sunday 14th May 2023: Nidderdale Walk www.nidderdalewalk.co.uk

Sunday 18th June – Leeds 10K – www.runforall.com

Sunday 6th August – York 10K – www.runforall.com

Sunday 21 August — Yorkshire Dales Festival — www.runforall.com

Saturday 15th October: Yorkshire Marathon and Yorkshire 10 Mile
Leeds Marriott

We also work with Global Adventure Charities who provide a wide range of challenge events in the UK and overseas that you can take part in to raise vital funds for our work.

Find your next adventure at www.globaladventurechallenges.com

CREATING A FORCE FOR GOOD

Two joint awards totalling £475,000 from Kidney Research UK and Kidney Research Yorkshire have been given to researchers at the University of Leeds and are due to commence later this year. We're combining our efforts to accelerate the fight against kidney disease.

The two teams, led by Professor Andrew Macdonald and Professor Colin A Johnson, will conduct their work at the University of Leeds with the hope of discoveries emerging in the next three years.

Andrew's work will look at how viral infections in transplant patients can be managed. Kidney transplant recipients have to take immunosuppressant medications to ensure that their new organ is not rejected by their immune system, but this makes them more susceptible to viral infections. The BK virus is common and not harmful in most people, but for transplant patients, it can be particularly dangerous. It can potentially damage the transplanted organ, sometimes leading to it being rejected by the body. The team will look specifically at a gene known as CFTR and the role it plays in BK virus infection. If Andrew and his team can find new approaches to manage this

virus, it would prevent kidney transplant patients from often having to reduce their immunosuppressant medications following infection.

Colin's work will look to see whether a technique known as 'exon skipping' can be used in conditions such a polycystic kidney disease (PKD). In PKD cysts form on the kidneys, which can impair their function and lead to kidney failure. The team will study specific structures that form on the surface of kidney cells known as cilia and their role in PKD.

Colin and his team will look at whether telling certain cells to skip the part of the genetic code that has been mutated could help treat PKD and develop healthy cells. Exon skipping has already been used in genetic disorders such as Duchenne muscular dystrophy and spinal muscular atrophy. If the team are successful, it could open up new avenues for future treatments.

Elaine Davies, director of research operations at Kidney Research UK, said: "Working in partnership with Kidney Research Yorkshire has helped us to expand the scope of our funding capabilities and support these two

exciting projects in Leeds. If successful, the two research projects could be the foundation of future treatments that will greatly impact the kidney community in Yorkshire and beyond. Despite the ongoing challenge of the cost-of-living crisis, we remain fully committed to funding lifechanging research that can be translated into real-world benefits for kidney patients."

Julian Wiley, chair of trustees at Kidney Research Yorkshire said: "We are delighted to have the opportunity to work with Kidney Research UK. As a local charity, it is important for us to maximise the impact that the funds our supporters raise for us has. By co-funding projects with Kidney Research UK, we are able to do just that by ensuring that these important research projects receive the funding necessary to go ahead. We are very excited about this partnership and look forward to working together on more opportunities in the future to help us achieve our aim of developing Leeds as a vital hub for renal research."



Siobhan gives Uncle Jim life back through living kidney donation

Siobhan Curtis got a first-hand insight into the process of being a living kidney donor when her Mum, Helen, received a kidney from her best friend in 2016 after spending six months on dialysis. Her friend had one of her healthy kidneys removed in Nottingham, which was then transported to Liverpool where xxx received the kidney. She got to see how they were both looked after by the fantastic transplant teams, and renal staff at both hospitals.

It was after Helen's diagnosis that conversations started across the family as it was possible that the kidney disease, she had was hereditary. There were 5 siblings in the family, and all were tested to see if they too may have complications with their kidneys. Jimmy, Siobhan's Uncle was diagnosed with having kidney disease too.

Uncle Jim was always the life and soul of the party at family gatherings, having fun with his nieces and nephews always joking and causing mischief. But at a family get together in December 2019, Siobhan noticed a difference in him; he was tired not engaging as much as usual and seemed drained — he was not the Uncle Jim she knew. His health gradually deteriorated until the point that in December 2020 he was told he would need a transplant, and that he would soon need to start dialysis if a kidney could not be found in time. After this, Siobhan spoke to her Mum saying that she wanted to see if she was a potential match to offer Uncle Jim one of her healthy kidney's and start the process of testing. She did not want to tell her uncle at this time though, until she knew if she was a match or not.

Siobhan got in touch with the Renal team in Nottingham where her uncle's renal team was and started the process. It was not a quick process, taking a while for tests to come back, but in March she found out that she was a blood match. At the same time, one of Siobhan's Aunties was also being tested, so Siobhan held off completing any more tests until she knew if her Auntie was a match — as this would be the preferred option sue to her being older.

It was not until the September that Siobhan found out that her Auntie was not a match, so Siobhan contacted the Renal team in Nottingham again to continue with the process. She underwent lots of tests in Leeds, and she was shocked by how easy and quick everything was from that point. The team were superb throughout. They explained everything so well and there was never any pressure — Siobhan knew that she could stop the process at any time if she didn't want to continue.

It was then 22nd December 2021 when Siobhan got the call to say that she was a definite match, and at this time, she needed to tell her uncle that she had been tested and wanted to donate her kidney to him. Siobhan's mum was planning to go and see Uncle Jim the following day, so Siobhan went with her wondering how to tell him such a big piece of news.

She told Jim her decision, which blew him away, he was not a man of many words, and all he could say was 'wow'. Siobhan left him to ponder her offer and left it to him to decide whether he wanted to accept — knowing that it would also have an impact on her too. Then on Boxing Day, Jim made up his mind and

chose to accept her offer, so the process continued in January with pre-screening tests.

The operation was then booked in for April 2022 and everything was set until Siobhan got Covid in the week of the pre-op! This was a big setback, and hard for her to tell her uncle that the operation would need to be postponed. Siobhan knew that if the delay was too long, he would have to go on dialysis. The delay ended up being seven weeks, with the operation being rescheduled for Tuesday 31 May 2022.

On the day of the operation, Siobhan had her operation at 9am, having walked herself into surgery, she started the procedure, and the next thing she was waking up in recovery at 1pm. Her kidney then arrived in Nottingham at 4pm, with Jimmy starting his operation at 7:30pm. Siobhan was discharged the following day at 5pm feeling a little tender and with some pain relief and blood thinning medication. She says "I had 2 days of pain which gradually subsided, and I felt some bloating on one side at first, but I built up my walking each day and took 6 weeks off work. Now I feel no different to before the operation, with no adverse effects from having a kidney removed." Siobhan is delighted that she was able to donate her kidney as she now has her Uncle Jim back, and her cousins have their day back. Having seen him so withdrawn when his kidney was at its worst, she is very grateful that she was a match and able to give her uncle his life back.

Just two months after the operation, Siobhan volunteered at the British Transplant Games which took place in Leeds. It was perfect timing for Siobhan, and she was honoured to be able to volunteer, and felt honoured to be part of the transplant community.

Siobhan will always advocate for organ donation

now, knowing the difference that it makes to someone living with kidney disease. Both her Mum and her uncle are now able to live their lives to the full because of their donors. Siobhan is also very thankful for the amazing staff in the renal units in Nottingham and Leeds for making the process so easy.

Jim said: 'How do you say thank-you to someone who has given you the Gift of life — the Gift of a normal life! The fact that Siobhan was willing to donate one of her kidneys to me is truly amazing, a living donor. I could plan, not worry and not have to undergo dialysis which I was dreading. My new kidney started working immediately and being a live donor increased my chances of a successful transplant. My experience from start to finish has been exceptional and I simply must mention the transplant teams at Nottingham City Hospital and Derby Royal Hospital for their continued aftercare. Thank-you Siobhan and all those who donate their organs — it really is a 'Gift of Life' the difference it has made to me and my family is incredible'



How you can get involved

There are many ways to get involved in the work of Kidney Research Yorkshire; from fundraising or volunteering, to acting as an advocate in your community - however you can help, we very much welcome and appreciate your support!

How you get involved is up to you, the choices are endless. From jumping out of a plane to selling cakes - however you fundraise we are here to support you.

We would also love to hear from you if your company is involved in charity fundraising or a local community group or



school that you are connected to - anyway that you can help to fundraise or raise awareness of our work, we would love to get involved - just get in touch and tell how, and we will do all we can to help you make the most of your efforts!

Check out our website for details of all of the events and activities you can get involved with to support our work or call David Fisher who will be more than happy to help develop and support your fundraising ideas and plans.



DONATION FORM

Kidney Research Yorkshire received no government funding. We Are entirely funded by voluntary donations and every contribution received allows us to do more. Every year an increasing number of patients are diagnosed with serious kidney disease and kidney failure and there is still not enough money available to fund the vital research that is required.

in that tax year then it is my responsibility to pay the difference.

There are still huge gaps in knowledge and awareness which need to be filled. Research helps us to find the answers to deliver the best treatments and therapies and make a huge difference to many people.

As an example of what your support can achieve — just £25 pays for one hour of additional research

Mr/Mrs/Miss/Ms/Title	Address
Full name	
I would like to donate (£)	
Signature	Postcode
Date	Mobile
Keep in touch: Please let us know if you would like to be kept up-to-date with our work and fundraising opportunities by: □ Post □ Email □ Telephone giftaid it	Please make cheques payable to : "Kidney Research Yorkshire" Then please return the completed form to:
GIFTAID YOUR DONATION AND MAKE IT GO EVEN FURTHER Increase your donations by 25p for every £1 you donate I want to gift aid my above donation and any donations I make in	Kidney Research Yorkshire St Peg's Mill Thornhill Beck Lane Brighouse HD6 4AH
the future or have made in the past 4 years to Kidney Research Yorkshire. I am a UK tax payer and understand that if I pay less income tax and/or	Please include this form with your donation
capital gains tax than the amount of Gift Aid claimed on all my donations	Thank you