**Updates from the PKD Foundation**

Welcome everyone to our new panel updates from the PKD Foundation: Research, Advocacy, and Education. My name is Craig Ramseyer, I'm a member of the board of directors for the PKD Foundation.

I’m finishing up my sixth year on the Foundation board. I am a PKD patient.

I have finished up 12 years as a recipient of a donor transplant. I’d like to welcome you to today's program.

As we work to end PKD, creating resources in a community for those impacted is a top priority.

That's why we've created PKD Connect. So patients and caregivers can find educational webinars, nutritional tips, pain management advice and whatever else they need to better understand and manage PKD. With events like the walk for PKD and PKDCON we’re able to combine that education with ways to connect as a community because no one should be alone on their PKD journey.

And when it comes to the PKD community advocating for their needs on Capitol Hill, is another important function of our Foundation that includes securing protections for living donors and other patient-centered legislation.

Through our advocacy efforts we've helped make major changes at the state level for living donors. As you all know funding PKD research is one of the biggest ways the Foundation works to end PKD.

With over 1300 funded research projects, and more than $50 million provided for PKD research, we’re not slowing down in our fight to find a cure. Through tools like the ADPKD registry, our understanding of PKD, the needs of PKD patients, continues to grow.

Throughout the PKD Connect conference, we have raised over $26,000.

Thank you to everyone who's donated. If you've enjoyed the PKDCON and want to see more PKD education from the Foundation, please consider making a gift using the QR code, or the link appearing on the side of your event page, or the Foundation’s page right now.

We love being able to provide education and opportunities for the PKD Foundation to connect. All of you play a big role in making that possible.

Now that we've taken a brief look back at everything the PKD foundation has achieved over the past few decades, it's time to focus on everything going on today in the Foundation's plans for the future. With me today is chief executive officer Andy Betts, Chief Research Officer Dr. Chris Riscone, and Chief Advancement Officer, Chad Iseman, to share the latest updates, on all things, research, advocacy and education.

So Gentlemen, let's tell the folks what's new with the PKD Foundation and Andy, why don't you lead us off?

Absolutely. Thanks Craig.

Appreciate your service to the board and to the community as well. And thank you for joining us for this session today.

This conference is all been about hope.

Everything we do at the PKD Foundation is to bring hope. We do this, obviously through this conference, but also through our peer mentoring program, Our Hope line. So please use those facilities, go to our website, go to PKD Connect and make sure that you’re plugged in, so you’re not alone on this journey.

What we want to talk about today, however, is a little bit more of that what we call the real hope, the ending PKD.

Next year, we’ll have been at this for four decades, 40 years, and we’ve learned a lot in that time. But there’s still a lot to learn, and I know at times it might feel frustrating about the progress, but this is a marathon, let’s not think of it as a sprint. As you all know too well.

I want to show this slide to you before I pass it over to our Chief Research Officer, Chris Riscone. And this slide really demonstrates, what we've done, where we've been and also where we're going to go in the future. So, five years ago, this four-pillar foundation, if you like, only had one color and it was very much that far left pillar there, our program for research. We've been doing research along time, funding those basic and translational grounds as much as we can. And so part of that pillar, we've funded more than 50 million dollars in grants to 1,300 different research projects and researchers. And what thats meant, is that in the last five years we've increased the amount of grants we've given by 230 percent.

So we have made sure that we want to accelerate as much as we can and we will making sure that we're building towards the future as much as we can.

Out of those grants that currently being given a grant from the foundation, over half of them are able to go out and leverage even more funding from the NIH, and federal funding, which is fantastic news, we want to make sure that that continues. Over 1.5 billion dollars has been leveraged and we continue to do that through our advocacy efforts that Chris will talk about in this presentation.

So that's what we've done on the left-hand side, but we've really tried to create you heard Bev talk about this yesterday, was the Future Focus campaign. So we’ve raised 68.9 million dollars towards the 70 million dollar goal, and this has really allowed us to build these other pillows out, so that we can end PKD.

So what that has meant, is that now we have 18 million dollars in our endowment, which allows us to sustain the grant model into perpetuity, so we don’t have to worry about funding it every two years, we’re committed to funding it every year, and we’re committed to sustaining the level to make sure we get to a cure.

We have different collaborations that are happening, with a group called CPATH and over monthly meetings over a hundred different attendees are joining that from Regulators from the FDA and NIH, from industry, and from Academia as well.

We want to make sure that we facilitate those conversations so that we can find the next biomarker, the next drug development tools that's going to get us to treatment faster. This is a central part of what we've done with the total kidney volume.

And we want to make sure that we can accelerate the level in which we can build our collaborations. So we can get industry more involved in the space.

What else has happened in the last 18 months and you may have heard this from a workshop earlier today. We have launched the ADPKD registry. That registry has over 2,000 registrants and this is a big part of what we want to do as an organization, to make sure that we understand more about the disease and the researchers are able to understand more about the disease.

This is essential, it's something that we've worked hard at, and I think as we move forward, we're going to make sure that that grows even more.

So the next pillars, are a different color. And this is pretty much because these are the things that we want to do next. So when you look where we are right now, and look where we've come from in five years time we're going to achieve so much.

We're going to have these four pillars in place.

We want to make sure that the National Standard of care that were working with clinics across the country.

We're working with institutions, we want to create Flagship Center of Excellence for PKD to make sure you get the right care.

You have a care team available to you.

That's accredited.

That's working on the best clinical research that's possible. At the same time for those that can't be a flagship we want to make sure that we have mentor and mentee programs so that we can get as much health care education, as possible, local. And above all, we want to see the registry expand.

We want 10,000 different datasets in this registry. The more data we can get longer to do longitudinal data sets.

The more researchers can work towards getting clinical trials filled and making sure that we get to treatments faster.

So we've come a long way.

We've still got a lot to go, but we are committed to this. We want to see an end to PKD. And we know it’s not a small task and it’s going to take a lot of commitment, a lot of effort and we're here to see that through with you our generous and wonderful community.

So I'll pass it over to Chris Rusconi, our chief research officer, to make sure he can deliver on those goals.

My jobs to pass it over to Chris, and he delivers right?

That's the way it's supposed to work.

Thanks, Andy, and hi, everybody. Appreciate you joining us for this session. I'm Chris Rusconi, I'm the chief research officer of the foundation. And for the next about 20-ish minutes, what I'll do is share updates on Research, education and advocacy programming.

And they'll hit it off to Chad Iseman, the foundation's Chief Advancement Officer to share why it's an exciting time to be part of the PKD Foundation.

So now this is a really important table setting. So basically the Foundation serves you the patient.

And so when you look at that ring, a patient need basically what we're focused on doing at the Foundation is integrating our program efforts that would be our education, our advocacy, our support, and our research to bring the maximum benefit to you and your families.

And so, what I'll do is I'll start with discussing research and education programming, and then we'll share an update on advocacy.

So the Foundation, both funds and conducts research, and we do this through four pillars designed to improve your outcomes.

First is our grants program to improve our understanding of the disease.

Next is the Polycystic Kidney Disease Outcomes Consortium, or of often refer to as PKDOC to help accelerate treatments. Then it’s the ADPKD registry which is designed to improve outcomes, and then coming in the future, as Andy alluded to, are the Centers of Excellence program to improve care, each of these programs rests on the foundation of our advocacy and education programming that are designed to amplify and support these efforts. So now in this presentation, I'll often speak of PKD generally in discussing our research efforts so before I take a deeper dive into the programming I want to specifically highlight our ARPKD efforts on the next slide.

So included in our current cohort of grantees the Foundation has committed 1.4 million dollars in AR- focused grant funding to nine investigators since 2016.

This year we introduced ARPKD as a topic within PKDOC as a means to accelerate drug treatment development for patients and families with ARPKD. And we’ve recently formed an ARPKD task force within the Foundation, composed of board members, staff, and community members to develop a multi-year research communication and advancement strategy to guide our efforts in developing research and programming for families impacted by ARPKD.

So now I want to take a deeper dive into our research programming. And so our portfolio of research programming has been built really to leverage research efforts along the Continuum in which research can bring benefit to patients.

So that starts with our grant program where we're funding a pipeline of projects to increase our understanding of the disease.

Next comes PKDOC where we fund and co-lead these efforts to accelerate drug development and work to pull industry into the development of treatments for PKD.

Next is the ADPKD registry, this is us, the Foundation, directly engaging with you patients, to conduct research and develop data sets to teach us how to best treat patients. And to accelerate clinical trials and coming in the future, as the centers of excellence program, this will initiate this will initiate as an ADPKD centers of excellence program and what this will is the Foundation engaging directly with health care providers and with you to improve clinical care.

So now, I want to do for the next bit is basically walk through each of these programs, share what we've done and where we're going.

So our grants program is designed to launch new avenues of PKD research.

This program is in really great shape having moved to a sustainable annual funding model under Andy's leadership.

And so these days we’re focused really on two things which is sustainability and looking for ways we can improve this program. And so before going on and sharing some statistics around this program, I just want to talk about the most recent, the most recent feature we've added to this program to improve it, and that is adding the patient voice to the review process. So, we now have a group of stakeholders. Reviewers who collaborate with the scientific advisory committee, and Grant review.

And this is really important for us, for two reasons. First from the Foundation perspective, it gives us the direct patient voice and understanding the impact of research as we make our funding decisions.

And also importantly, this model of having stakeholder consumer reviewers is becoming more common throughout the throughout grant funding programs.

And so it gives us an opportunity to have you as patients involved, and help our researchers understand how to communicate with you in the grant writing process and improve their competitiveness in these other grant programs. So now I want to do is share some statistics on the grant program on this slide.

So now I want to do is share some statistics on the grant program on this slide.

So as we provided in our most recent annual report the foundation is currently funding 19 grants with the total commitment of almost 2.9 million Dollars, which I think is a funding level that we should all be proud of.

Now you think about our grants program as I've described it. It's really a seed program to start efforts. And then one of the features of our advocacy work is that we work hard to make sure that there is federal dollars available for funding of PKD research.

So these programs work together. And what I want to do in the next in the next few bullets is basically share the amazing job PKD researchers have done in obtaining additional funding. So first, our grantees have been incredibly competitive in accessing NIH funds with more than fifty percent of our 2014 – 2019 achieving success in obtaining additional funding. And this is really an amazing achievement.

It's much higher than the average than the average NIH applicants. So, the researchers are doing great. Then we look at funding, currently there's more than 30 million dollars of active, NIH funding for PKD research, which is a very high level of funding.

And then when we look at the Department of Defense, funding the access to which is enabled directly through the advocacy work of the Foundation, there's more than 28 million dollars in active Department of Defense funding for PKD search.

So all in all we think this is truly fantastic.

Both with respect to our grants program and importantly the matriculation of these grantees into Federal funding for the continuation of their research.

So let's talk a little bit about the Polycystic Kidney Disease Outcomes Consortium, or PKDOC for short. So, along with Ron Perrone of Tufts Medical Center, Frank Czerwiec of Goldfinch Bio and John-Michael Sauerof the Critical Path Institute, I co-chair this Consortium. And what I want to share of the next few slides is what PKDOC is, what it's done to advance treatments for ADPKD, and what we’re doing to evolve our efforts to expand the drug treatment pipeline for both AD and ARPKD through PKDOC. So PKDOC is a collaboration between the Foundation, the Critical Path Institute and the FDA. And in its background the Critical Path Institute, which is often call CPATH, is a public-private partnership with the FDA formed to advance Medical Innovation. And so back in 2010 the Foundation co-founded PKDOC with Ron Perrone leading those efforts for the Foundation with CPATH and the FDA. And we do this for a couple reasons. First is to bring together health authorities, industry and academic scientists to defined how to develop drugs for ADPKD, or for PKD. And secondarily, to collaborate in building these tools needed to accelerate the development of drug treatments for PKD.

So now what I’d like to do is share what PKDOC has accomplished and where we’re going.

So I don’t think it’s an exaggeration to say that the PKDOC efforts are responsible for the current pipeline, the current ADPKD treatment pipeline. And, it’s worth noting that when you look at other rare genetic kidney diseases, such as Alport’s Syndrome, or FSGS, ADPKD is the only one with an approved treatment. I think that is really related to the collaborations such as PKDOC, the collaborations of the patient community, the real dedication of clinical scientists and the dedication of the industry sponsors and in space.

Now if we go back a decade, PKDOC identified a need for a biomarker to support clinical trials in ADPKD, and then collaborated with that large community of research and Regulators in the development of total kidney volume.

And if you're not familiar with what total kidney volume is, it's basically a measure of how can these kidneys grow with ADPKD progression.

So to find Total kidney volume as a biomarker to select patients for clinical studies and responses to treatment. That's led to the current ADPKD pipeline, it was very instrumental in the approval of Tolvaptan.

And so, where are we going? We're going to focus on two things now within PKDOC and it's a similar evaluation of what's needed to develop drugs and it’s really in two areas. One is for the earlier treatment of ADPKD. So if you look at the current drugs approved for ADPKD they are for patients at rapid risk of progress.

We'd like to see drugs approved that are able to treat patients, improve for treatment of patients earlier disease. So provide patients with a greater Health span. And further reduce the risk that any patient with ADPKD will reach kidney failure. And the second is to focus on tools to treat and tools and Regulatory science to treat ARPKD. We think one of the reasons there’s not a pipeline yet for ARPKD is that there is not a clear path for drug development. And so we think that by bringing ARPKD into the consortium we can help facilitate the development of a pipeline for ARPKD. And so if we are successful going forward as the consortium has been successful in the past, what we think is this will evolve into an ADPKD pipeline and an ARPKD pipeline.

We kicked off the efforts on these priorities with a regulatory Summit last month. All the Summit Materials are available.

I'd encourage you to listen to the talks from patients and scientists and panel discussions to get a deeper understanding of what these efforts look like to meet these goals for expanding, the AD Pipeline, and creating an AR pipeline.

Now, in an earlier session today, Elise Hoover the Foundation's director of research provided a detailed update on our ADPKD registry.

So what I'm going to do here is just provide a snapshot of the current status and then talk more about where we're going with the registry in the context of creating the Centers of Excellence program.

So we just take a look at the registry to glance.

It's approaching two years old and we're really grateful for the tremendous engagement from you all in supporting this effort. We released our first annual report back in March of this year to share what we've learned so far.

And if you haven't read this report, I encourage you to visit the registry home page and download it. In terms of Engagement more than two thousand patients have signed up and are participating in this registry, making it the largest patient reported outcomes registry in the United States.

We're currently collecting several hundred data elements through nine patient reported outcome surveys. These survey topics, and in many cases of surveys themselves, are constructed in consult with the registry steering committee and the registry patient advisory committee.

These surveys currently cover a number of topics they include Basics on disease status and family history, surveys to understand pain and the impact of living with PKD, surveys on extra-renal manifestations of PKD, and most recently we’ve added surveys on healthcare utilization and access to help inform our advocacy efforts. And over the past nine months we’ve employed the registry to connect patients with clinical trials and the registry has made more than 3100 patient contacts to support recruitment for five different clinical studies.

So I just want to wrap up this slide by saying we believe we are building a really powerful tool to understand how ADPKD progresses, and what approaches improve outcomes and want to say thank you to those of you who are already participating.

Keep completing those surveys because the most powerful data is repeated observations over time.

And if you're not currently participating in the registry, please consider signing up and joining us in this effort.

And so now, just to wrap up the research efforts, I want to share a new effort that the Foundation is working to launch, which is the PKD Centers of Excellence program. So the centers of excellence program is designed to improve Patient Care by direct engagement with clinicians, expansion of the registry to help develop data sets to drive care, quality improvement and expansion of our education efforts to create a learning ecosystem, focused around this Care Improvement. And so I'll touch on these aspects at a high level over the next several slides. And we'll start with a table setting, slide to share a vision, strategy, and objectives for this program.

For the vision for this program is to improve care for all ADPKD patients by integrating a care team concept, research and education by establishment of the centers of excellence Network.

Our strategy is multi-pronged. First, it involves building off current best practices to build a care team. Model for PKD.

Second, it involves collecting the needed data to inform the creation of standard of cares, or clinical care guidelines. Now I’m going to pause on this a little bit to explain what I mean when we say, “standards of care or clinical care guidelines” because it’s really important.

So by definition, a standard of care is basically a diagnostic and treatment process that a clinician should follow for a certain type of patient illness or clinical circumstances.

These are derived from data from observational studies like our registry, from interventional clinical studies, and from clinical practice and they're available for many diseases, but they're not yet available for PKD.

And so what we want to create through these efforts are national care guidelines, such that any health care provider treating a patient with PKD would know how the patient should be cared for, based on the specifics of their case. Now given the complexity of PKD, this is going to require not a single care guideline, but a number of care guidelines. It will be a multi-year effort, we will build off of the current understanding of the disease. Current efforts to create consensus documents like what is going on with KDIGO, but this is really going to be central to our strategy.

In addition to collecting data for that purpose. We're also going to collect data to inform Health disparities in PKD, we know they exist.

We want to understand what those gaps are, so that we can develop an action plan to close these gaps. And then, based on what we're learning, we're going to create education programming to teach both patients and Healthcare Providers how best to care for patients with PKD.

So in the long term, that boils down to basically three objectives. The first is to accredit and fund a network of centers of excellence that meet pre-defined criteria. And I’ll talk about some of those in a moment. And as Andy alluded to, an expansion of the registry in a couple of ways. One, to include up to 10,000 at least patient records, and collect this data from centers of excellence and directly from patients and include the now the expansion to include verified clinical record data as well as the patient reported outcome survey data we’re already collecting, again to drive the development of these of these standards of care and Care guidelines.

And then the last objective is to basically improve Care Quality by providing education to healthcare providers and patients to drive the adoption of these standards of care, that will be derived from these efforts.

So now we're getting to talk a little bit about care teams.

I'll talk about the registry and I'll talk about education.

So this slide talks about what we mean by care teams.

It depicts what an idealized care team should look like for an ADPKD patient.

Now, you will see that this care team is comprehensive. It includes not only nephrologists specializing in PKD, but also a range of specialties such as Radiologists, Cardiologists, Hepatologists, Pain Management teams, and mental health professionals, to name a few needed to help address potential complications of living with PKD from both a physical and mental wellbeing perspective. And it also includes specialists for example, such as renal dieticians who can advise you on actions you can take in the present to improve your quality of life.

Importantly, if you look at the upper left-hand corner, this also, this model also includes the patient navigator to help coordinate your care so that you're not alone in this journey but there's someone helping you manage the access to this comprehensive care team. And so it's this model depicted on the slide that we are intending to help develop both through the site selection process of becoming a Centers of Excellence, and then as well through incentives that would be provided to sites selected to be a Centers of Excellence program to help them develop this full care team structure.

So how does the Registry fit into this program? So this image depicts the current Registry data collection, and I’ve talked about the importance of collecting additional data needed to find out how best to treat patients.

So to expand the registry to include this type of data will connect the Registries directly to sites participating the centers of excellence program, to collect that verified medical record data and we truly believe that with an expanded registry data set of patient reported outcomes combined with verified clinical record data that will teach his best how to treat patients and will facilitate the development of these national standards we’ve been talking about.

So, for the last bit of this section, I want to show you how education fits into this picture.

So the Foundation sits at a really unique position within our ecosystem of having access to both patients as well as Healthcare Providers, and so we're going to leverage that full ecosystem to provide education programming to improve our outcomes and this is how we're going to do it.

So historically our major education program has been to provide patient education via what we're doing now at PKDCON and via PKD Connect and our weibnars and this is something that we're going to continue to do as we build out this Vision.

Now recently, what we've done is begun the process of piloting certified medical education to healthcare providers. To better inform them around, PKD care. And our vision, for the center's program is basically to expand it integrate these efforts by providing local patient education, through centers, and then providing additional Health Care education from peer-to-peer education, and best practices from those sites that are centers out to the broad healthcare provider community.

And ultimately, our vision for these efforts is to create this learning ecosystem, where practice informs research and research informs clinical practice, and where we're using our education program to teach Physicians how best to care for patients, teaching patients what care they should expect.

So you're empowered to educate, to advocate for the care you deserve.

So now, I'd like to finish up with a few slides highlighting our work in advocacy.

So we develop and provide our advocacy programming via collaboration with CURA Strategies.

I encourage you to check out our advocacy booth and if you're interested, attend the advocacy breakout session right after this session. This year has been a great year.

We saw the creation of a dedicated Grassroots advocacy Network and working together with you all we had a really successful year in achieving our legislative or legislative goals and we've set an ambitious set of goals for the upcoming year and I'll share a bit of each of these with you on the next few slides.

So in 2020, we launched the advocacy Champions Network or ACN as we refer to it in shorthand and this is a group of PKD community members across the U.S. engaged in formal advocacy efforts with federal policy makers.

We currently have 36 members from 22 states. They’re hand-picked based on an application process and as I go through our successes on the next slide, this group is, as all in the community who provided really powerful ways to support of our advocacy and legislative efforts. And to say if this is something you're interested in, please consider applying for the 2021 ACN class, you can find more information about this at the advocacy Booth as part of PKDCON.

So what do we do this past year?

Well, as part of the Honor the gift Coalition, we advocated for the successful passage of the comprehensive immunosuppressive drug coverage for kidney transplant patient act, or the immuno bill for short and this bill ensures Lifetime Medical Care coverage for immunosuppressive drugs for kidney transplant recipients. So that was an important piece of legislation that I think as a community we're very proud to have been a part of getting past.

We also successfully advocated as we've talked about already for the inclusion of PKD as a topic within the Department of Defense congressionally directed medical research program, which just in this year, alone through the efforts of our researchers, enable them to secure a greater than 12 million dollars in research grant funding. And finally we have started to dip our toe in the water of state-level advocacy, and we've expanded our efforts and participated in a National Coalition to secure the passage of the living donor protection act in six states listed here and these efforts continue.

So what's on our agenda for 2021?

Well first, as we always do will Advocate to maintain and maximize Federal research investment in PKD, under the congressionally directed medical research program. Second, we're going to advocate for legislation that directly impacts and encourages kidney donations among the PKD community, including living donor protection act legislation.

So keep an eye on Foundation advocacy alerts and ways you can engage with us in working on the passage of this legislation.

And finally, there are significant Health Care disparities in kidney care, including for PKD. So one of the other key advocacy efforts we’ll be engaging in is really elevating and addressing the consequences of racial disparities in kidney disease diagnosis, treatment and access to transplantation through PKD lens, so it’s not totally clear yet what these, what the legislative efforts will look like here, but we are committed to participating and helping lead in the lead in the advancement of those legislators efforts. And so with that, I just want to conclude by saying that I hope you see that we're working to expand and integrate our research, advocacy, and education efforts, really, to address the needs of you and your families.

And so with that, I want to pass this session over to Chat Iseman, the Foundation's chief advancement officer to share why it's an exciting time to be part of the PKD Foundation.

Thank you, Chris.

I love it.

I've seen that presentation a time or two and every time I learn something new and even as an employee, I'm impressed by the work that this organization does. So hi, my name is Chad Iseman and I’m the chief advancement officer here at the PKD Foundation. Before joining the PKD Foundation in June of last year, I was a vice president with the National Kidney Foundation where I spent 15 years, delivering programs and fundraising on behalf of kidney patients. It’s my professional passion to support you.

And I'm really honored to be part of the PKD Foundation and the PKD community.

Great. Let's give one more big thanks to this year’s sponsors for helping underwrite the cost of putting on PKDCON, and helping make it free to attend. At the Diamond level Otsuka. And at the Platinum level Reata Pharmaceuticals and Sanofi Genzyme. At the Gold level, Natera, and at the Silver level Palladio Biosciences, Talaris Therapeutics and the Roger L. Kohn and Kay M. Gilbert fund.

It was with their support that we are able to provide this great education for free.

Thank you again.

So 2021 marks the year of many milestones for the PKD Foundation. In addition, to hosting the first virtual PKDCON, we will also be completing our largest fundraising effort ever, as you've heard the $70,000,000 Future Focus campaign. Since 2018, this ambitious fundraising effort paved the way for a two hundred and thirty percent increase in research investments, and our way to 300%.

As Chris just mentioned Future Focus also provided the resources to launch the country's largest Nationwide ADPKD Registry. To help us complete the 1.1 million dollars remaining in the Future Focus campaign, consider supporting the PKD Foundation with a gift that's meaningful to you.

If you scan this QR code with your camera on your smartphone and you have a digital wallet, like Apple pay or Google pay, Microsoft pay set up. You can make a donation without even entering your credit card information, making it easy to give to our mission.

And where do your donations go once you give the PKD Foundation? 80 percent of every dollar goes directly to support our mission, including our grants program, the registry, support our outcomes Consortium, and all of our education efforts and we're proud to be a four- star rated Charity Navigator nonprofit with the highest rating possible.

It’s worth repeating, in total the PKD Foundation in 40 years has funded more than $50 million in basic research, for more than 1300 researchers, and we've leveraged another 1.5 billion dollars in funding for PKD researchers from other sources.

The PKD community’s generosity has led to many significant milestones over the past 40 years. Including funding the very first researcher in the PKD space, finding the first gene related to PKD, and many more since. And establishing total kidney volume as the critical biomarker needed to approve the first treatment for PKD, not to mention the half dozen other drugs in clinical trial as we speak.

But to continue this process, we need you to be involved. The easiest way to get involved is by walking with us. So the Walk for PKD is the country's largest PKD community, bringing together over 55 cities, ten thousand walkers, nearly a thousand teams every year and just like last year, we're celebrating virtually in 2021.

We have some fun and exciting additions in store this year. Our goal is to raise 1 million dollars.

One hundred percent of which goes directly to research.

So if you skipped last year, come back. If you're new to the PKD foundation, there's no better way to get involved than to walk with us at the Walk for PKD. You can sign up any time at walkforpkd.org

Another fun way to support the PKD Foundation is the Team Kidney and Fundraise Your Way platform.

The Team Kidney fundraising platform provides all the tools you need to be successful. You can start a fundraising page to donate proceeds from a bake sale, a restaurant percent of sale, or your own event like a trivia night or karaoke.

You can also create a personal challenge, so if you're like to run, you can donate gifts in honor of a marathon you're running or a 5k. A distance bike ride, maybe even set up your own unique challenge to top the ice bucket challenge.

And lastly, you can celebrate milestones and significant events with us.

You can raise support for your birthday, transplant anniversary, wedding, or any other meaningful, occasion, and raise awareness for the PKD Foundation the same time.

Our online platform makes it easy, and our community fundraising team is here to help you out.

So now that PKDCON is nearly over and you're leaving this weekend a little more enlightened, how can you continue the momentum and stay involved, and inspired in your own health, and the happenings of the PKD Foundation.

No further than our website and the top right corner of pkdcure.org and you'll find access to nearly everything you need to stay connected including social media links, signups, ways to get involved and ways to give back.

And to stay informed with everything going on at the PKD Foundation, PKD News is your go-to source. This once monthly e-newsletter provides updates on Research, education, events and ways to stay involved in the PKD community.

Click on the envelope in the top right corner of our website to subscribe.

And last but not least, subscribe to the free PKD Life magazine.

You're the center of everything we do as an organization. And PKD Life magazine is no exception.

When we create a PKD Life, we started by listening to what you want it to read as a patient.

So this lifestyle magazine was created for you by. You subscribe at pkdcure.org/pkdlife.

On behalf of the entire PKD Foundation staff and board. Thank you.

You've just been part of what we think, we still have some numbers to crunch, but we think this is the largest single PKD event in the nearly 40-year history of this organization, nearly 2,000 registrants from 40 countries attended twenty-five different sessions and round tables. As staff and volunteers, we take our mission to give hope very seriously and we sincerely hope your time with us this weekend is inspiring and enlightening.

Thank you for being part of PKDCON 2021.

Chad, thank you so much for your presentation. Andy and Chris, thank you as well for your presentations. Folks, I think you can see why the progress is being made so rapidly in terms of the funding of various programs for PKD.

When you have gentleman like this and others so many others at PKD Foundation. doing such great work. We hope everyone has enjoyed this update on the PKD Foundation and its efforts to better the PKD community.

As we near the end of our first ever virtual PKDCON, we want to thank you for joining us.

We hope you learned a lot, made some new connections and feel hopeful about the future of PKD research.

Keep an eye on your email for a survey immediately following the conference and announcing the recorded PKDCON sessions later this summer.

Next up on the agenda, these are the patient roundtables please head on over and join us there. All the round table topics are listed on the agenda, please join a Roundtable discussion.

You do that by just clicking on the topic of your choice.

These round tables are an opportunity to connect with other members, and feel free to visit more than one table during the next hour. Thank you all for joining us.