

Rob Roth: Good afternoon and good evening, everyone, depending on which time zone you're in. For all of you attending the PKD connect conference for the first time. Thank you for joining us. Those of you who have attended before, we're glad to have you back. My name is Rob Roth, and I'm the chair of the PKD Foundation's board of directors. I'm honored to be a part of PKD con 2022.

This educational conference brings together every part of the PKD community with one goal in mind, education and connection. This weekend, the foundation and PKD experts will provide you with information research resources and networking opportunities. I'm sure there's a topic for everyone on this year's agenda.

My former life I served as the Chief Financial Officer at Home Box Office better known as HBO network behind the Sopranos, and many other hit shows. Now that I'm retired from the fictional world of film and television, I've been dedicating some of my time to improving the real world. Like all of you here, I hope to one day see a cure for PKD. And like many of you, I come from a PKD family.

My grandmother, mother, brother, and myself have all been affected by this terrible disease. I was fortunate enough to receive a kidney transplant seven years ago, from my long-time college friend of over forty years, but I know what a challenge this disease can be and how important it is to find the right support and resources to navigate daily life. It's why I dedicate my time to advocating for PKD research and spreading organ donation awareness.

Over the course of this weekend, you'll see sessions about the kidney donation process, and I'd encourage anyone who's interested to attend them. And serving on the PKDF board of directors I see first-hand how committed the PKD Foundation is to this community, our community. Advocacy, research, education support services, they're always thinking about how they can be better stewards to those impacted by PKD.

As we host our second free PKD connect conference, I want to thank everyone who supports the PKD foundation and makes all this work possible. And a special thank you to our event sponsors, Otsuka American Pharmaceutical Inc. Palladio, biosciences, Reata, pharmaceuticals, and

Telaris therapeutics. Since announcing PKD 2000 PKD con 2022. We've already raised almost \$10,000. And we're incredibly grateful to everyone who's donated so far. As you listen to these sessions, we'll have a donation page linked on the PKD con platform homepage.

If you feel inspired to donate, you can also give using the QR code or use the link appearing on the side of your event page or on the foundation slides right now. Your donations will further the foundation's creation of informative education for every member of the PKD community. Speaking of the PKD community building connections with one another is one of the main reasons we come together for PKD con. That's why I'm so excited to announce that the 2023 PK D con next year will be a hybrid conference with an in-person option for those looking for a different conference experience. As an exciting offer for each session evaluation that has completed this year following an educational session. Each of you can add your name and email address to the evaluation for an opportunity to win one of three free registrations to the in-person portion of PKD con 2023. Lastly, education is what this conference is all about. To end this first day, I'm thrilled to announce our keynote speaker for tonight, Jeremy Poincenot.

Jeremy is a professional inspirational speaker and performance coach who shares his story with audiences around the world. He's been featured frequently on TV including MTV, true life, and ABCs 2020. CNN.com has called him one of the best golfers in the world just not in the sense you might be thinking, espn.com wrote about Jeremy's experience meeting and inspiring Green Bay Packers quarterback Aaron Rodgers, who now follows Jeremy on Instagram and Twitter.

There was a little bit of storytelling today Jeremy hopes to provide perspective and share how we can all use the inspiration around us to become stronger. Get ready to be inspired. As we welcome Jeremy Poincenot.

Jeremy: Awesome. Rob, thank you so much. What a lovely introduction. Thank you so much for sharing your story and I have HBO at home, and I had no idea that stood for Home Box Office. So, you stumped me. And I'm assuming many others who are on right now. Thank you so much for that introduction.

And thank you PKD con for having me. I look forward to sharing some stories with all of you, like Rob said, sharing stories, hopefully inspiring you, and getting us to think a little bit differently about things.

And then afterward, we're going to open the floor up for Q&A. So, if you have any questions that come to mind during my presentation, please type them in. We're in Robin, I will do a Q&A at the end. And I hope we have a lot of fun together. So, thank you so much for having me. A young boy and his father are walking along a path in the forest. And they come across a large branch on the ground. The boy looks his father is dead. Do you think I can move that branch? The father says, yes.

If you use all of your strength, I think you can. Young boy tries to move the branch he's unable to do it looks to his father and says, dad, you're wrong. I can't do it. Father says try again. If you use all of your strength, I think you do it, young boy tries to get as hard as he can and when the branch is unable to do it looks to his father disappointed this time, and says, dad, you were wrong. I can't do it.

The father says, son, I advised you to use all of your strength. You didn't. You didn't ask for my help. Like the young boy in the story, I grew up thinking that I needed to be independent, to be successful. I thought the key to success is by being independent, getting things done on my own, and never ever asking for help. As a teenager, I gradually gained my independence. I got my driver's license to wherever I wanted whenever I wanted. graduate high school went off to college where I lived in the dorms, joined a fraternity, and studied sometimes I didn't really study that much. The next year moved to an apartment off campus with a group of friends got a part-time job paid bills, went grocery shopping, and cooked.

If you include top Ramen, I mean, that's really all I was cooking. At that time. I really wasn't cooking more than that. But everything in my life was trending in the right direction. Everything was going great. One day when I was a 19-year-old sophomore at San Diego State University. I remember walking around on campus with a group of friends. They noticed that I had to squint to read a sign. For me that was abnormal. Because I perfect 2020

vision my whole life. So, I did what any other 19-year-old in college would do in that situation.

I called my mom. I said, Hey, mom, I think I need glasses or contacts. I'm not sure which. Can you set up an optometrist appointment? Let me know if it is call me back. Love you. Bye.

That's how I talked to my mom. I went saw the optometrist the day before Thanksgiving, and he ran the normal tests on me. I'm sure you've done it. What do you see better with one or two, two or three? And everything was routine until he had me cover my left eye. When I covered my left eye, I couldn't see anything on the HR. I couldn't even see the big E. And I thought, okay, maybe I'm going to need some thick glasses. But I thought I could get some thick glasses, go back to school still be accepted by my friends. Not a problem.

But the optometrist wasn't as optimistic as I was. He said, Jeremy, I'd like to run some more tests on you. I need to call your parents in. And we need to discuss what's going on. I go take some more tests. Go back in his office, both my parents are sitting in the room. He says Jeremy, I think you might have a brain tumor. On Thanksgiving Day, I went got an MRI done to check and see if I had a brain tumor.

And thankfully, found out I did not have a brain tumor. But over the next few months, my family and I went on what we call a medical mystery tour, where I went saw multiple different doctors and was misdiagnosed with several different disorders. And in this two-month span, my vision drastically deteriorated. And it spread from my right eye and matter of months, and went to my left eye as well, and went from perfect 20/20 to where it is now.

I am now legally blind. With no central vision. Due to a rare genetic disorder, I had no idea I had called the labor's hereditary optic neuropathy or L H. O N. L.H.O.N happens to one in 50,000 people. Only about 100 people in the US are diagnosed with *[Unclear]* each year and unfortunately, has no treatment and no cure. To put my vision in perspective for you what does it mean to have no central vision? If you could, for me, please put one hand on top of the other, and put them directly in front of your face. And look around

the room you're in right now with your hands directly in front of your face like that. Next slide, please. That's what my sites like all the time. To somewhat be able to see my computer screen ahead of me, I got to look above, below, or to the sides.

But everything I look directly at is completely blurred out. On the screen is a good depiction of what my sights like on the left is perfect 2020 What I had the first 19 years of my life. And on the right is what my site's been like the last 13 years now. Because of this, I'm no longer able to read without extreme magnification or assistive technology. Imagine going on a date with someone you're trying to impress.

And you have to ask them to read you the menu like you're five years old. I'm no longer able to drive, and to hand my car keys over to my parents at 19 years old and forfeit the independence of driving. And I'm no longer able to distinguish faces. Do you know how hard it is to know someone for years? And every time you see them, you have to swallow your pride and ask who it is because you're unable to recognize them.

I mean, especially during this time with COVID and social distancing. For someone who's legally blind and unable to see that far, six feet apart, I'm unable to recognize anybody. Talking to someone from far, a definite challenge. All of a sudden, this happened to me at 19 years old, out of nowhere, and I was devastated. I was depressed. I thought why me every single day for months? I didn't know that you could go legally blind in a matter of months and 19.

And there wasn't some type of a shock a pill, a surgery something that could fix it. I just couldn't comprehend it. At this time, I took incomplete from my five-class schedule at San Diego State. And I went back to my parent's house where I pretty much resided on the couch in their living room. And I complained and talked about my situation every single day. And I was sleeping on that couch every day until noon.

One in the afternoon, which for a teenager is not that abnormal. We like to sleep in. But I was doing it every single day. And my dad came up to me one

day he said Jeremy, you should wake up earlier. Try and get your day started sooner and be more productive.

Maybe that will help you be happier. And my response was, dad when I'm sleeping. In my dreams. I see 2020 I see perfectly fine, I can drive. I can see my friends from across campus. Everything's the way it should be. When I wake up, I'm legally blind. Where would you rather be done? Or would you rather be, and that's the tough world I lived in where I would rather be sleeping in a dream state where I could see and wake up and be hit with this harsh reality of being legally blind again? During this time in San Diego, where I'm from, there was a big news story going on an F-18 plane crash lands and destroyed a couple of houses. The pilot, the only one in the plane ejected safely. And he survived. But from the wreckage, four people died from this accident. It was a man's wife, his mother-in-law. And his only two children were the only four people to perish from this accident. And for some reason, while I was on that couch in my parent's living room, I had the news on TV.

And they held a press conference for this guy. And he came up to the podium bawling his eyes out crying. And he said if anyone knows how to deal with this type of tragedy, please help me. And when I heard him say that, "Whoa," this is a reality check for me. What this man just went through his unimaginable. He just lost four family members. And he's not up there at the podium complaining about a situation. He's asking for help.

And so, I decided from that moment on, I would no longer complain about being legally blind. Did I like what happened to me? Absolutely not. But I was going to do the best I could to go day in and day out focus more on what I had rather than what I'd love and move forward with that. He provided me with a lot of perspectives. I think that something that we all need to maintain during these challenging times, is to maintain perspective on our situation.

And that's what he did for me. At this time, school, for me was an afterthought. I didn't want to go back to San Diego State, I had a good year and a half, and I had a lot of fun. I didn't want to go back to school, I thought the easiest thing for me to do, and the best thing for me to do was to drop out,

I wanted to drop out because I didn't want to deal with all the awkward moments that were definitely going to arise.

But now suddenly being leaked blind. I didn't want to have to share the story with every single person. And quite frankly, I didn't want to get vulnerable with people. I didn't feel comfortable getting vulnerable. But so, the easiest thing for me to do was to drop out. That's what I wanted to do. Next slide, please. But one of my best friends, Josh, he called me. He said, Jeremy, come back to school, and take two easy classes.

And in my five-class schedule, I'll take those same two classes with you. And that's exactly what he did. I came back to school the following semester; I didn't miss a semester. And I took two easy classes. I took Intro to music, and intro to film. That was my class schedule. His, intro to film for a blind guy was actually a lot tougher than I thought it was going to be. Josh and I showed up the first day of class, we sat in the front row, and I was like, Alright, we're going to find a way to get through this.

The professor walks in, he says welcome to intro to film. Thank you for signing up for my course. For those who want to appreciate the best type of film. So, you understand the best side of cinema are silent films. Here's an hour and a half of Charlie Chaplin. That was my nightmare. Thankfully, the class was not intro to silent films. And it got a lot better after that. But Josh took those same two classes with me in his five-class schedule. He helped me walk to and from class. He helped me tell the professors that I was legally blind. And I needed accommodations. And he helped me study for the exams in the classes, which helped me pass those classes. What Josh did for me, was monumental. It was life changing. I graduated from San Diego State with a degree in business. And I know this would not have been possible, had it not been for what Josh did for me.

In life, we tend to be so inwardly focused. We think so much about ourselves, what can we do to make our own lives better? But do we take enough time to look around at our friends, our colleagues, and the people around us and think I wonder how he's doing? I wonder what she's going through. Is there

anything I can do to help them? Because each and every single one of us has the power to impact someone's life.

The way Josh impacted mine. Next slide, please. Each one of us has the power to change someone's life. So, be a Josh be the Josh in someone else's story. I remember one day walking around on campus with Josh that semester and saying to him, Josh, I really appreciate your help man. It means a lot. But I know I'm a burden.

And I'll never forget his response. He said, Jeremy, you're not a burden. You're a blessing. And I thought, what the heck is he talking about? What could he be getting from this? At that point, I thought I was the only one benefiting from our friendship and our relationship. But the first time I realized I might not know everything when it comes to this. And maybe there's something here that I'm not fully seeing.

Being diagnosed with a rare genetic disorder was especially tough. When I first learned that L.H.O.N had no treatment and no cure. I thought I've got no, nothing worth living for. I should give up. But the more I start to think about my situation with a positive mindset, I started to think, no treatment, no cure. Let's give me a purpose in life now. And choose to fill to do everything in my power to help raise as much money and awareness now, and find a cure for LHON, that's possible.

So, my roommate at the time I lost my sight, Mark. He and I were talking one night, and we said why don't we create some type of a fundraiser to raise money and awareness to help find a cure for LHON. Mark said, you know, I've always wanted to do some type of a fundraising walk. Why don't we do that? I said I don't need to see to walk, I could do that. He said, you know, I've never been to Seattle.

Why don't we do a walk from San Diego to the Space Needle in Seattle? To a little bit of research, find out that's 1200 miles. Can I do it? No way. I enjoy walking it's not nice don't want to go that far. Let's do something shorter, please. So, we kept bouncing different ideas off of each other. And at this time, I learned about tandem cycling. You know, these cool double bikes where there are two people on a bike for someone who is blind or visually

impaired can be on the back of a tandem and participate in bike rides that way. So, I came back to Mark and said Mark, why don't we do some type of a fundraising bike ride. He said, great idea. Let's go from San Diego to Seattle. No, again, I don't love cycling. We haven't even done this tandem thing yet.

Let's, let's try to start small, please. We ended up creating our own fundraising bike ride. And we call it the cure ride. It's an acronym, that stands for cycling under reduced eyesight. It's a four-day ride from Santa Barbara, California to San Diego 240 miles, much more manageable than San Diego to Seattle would have been that's for sure.

And in our first year, we had four riders raise just over \$3,000. *[Unclear]* *[00:31:34]*. Let's do it every year, we did it 11 years in a row and held over \$350,000 to rally to and research. And that's not just a drop of water in a large bucket that's helping making an impact for finding treatments for this rare genetic disorder.

We haven't done it since COVID. But we look forward to doing it again when it's safe. And we're comfortable and getting together again. But we did it for 11 years. And we found this opportunity to do something. Next slide, please. That's Mark and myself on the tandem cycling down the California coast having a great time. As you can see, I consider myself extremely lucky.

Because I've talked to a lot of other people out there who have lost their sight due to LHON when like I have, a lot of them say that their friends abandon them. They become depressed, resort to drinking or doing drugs because of it. I'm lucky because my friends rallied around me and supported me during this tough time, which helped make me a happier person, which in turn, I think makes it easier for them to want to be around me. And when I think about the inception of the cure ride.

I realized what Mark did was he created an opportunity for us to do something together about what I remember when my dad told me to wake up earlier get my day started sooner be more productive. That was a good idea. It was a good thought. But what Mark did was he created an opportunity for us to do

something together. When we first created the idea of the cure ride, and we started talking about the dates and where are we going to go.

How are we going to go about fundraising? Mark gave me something to look forward to during a time I had absolutely nothing to look forward to at all. And so, I ask you, are you creating enough opportunities for yourself and for others, to not only be able to survive, but to thrive? Like how Mark did for me. When I first started seeing doctors, they said that I was going to be legally blind. The rest of my life. When I started seeing an LHON specialist, he said you're going to be legally blind for the rest of your life and you need to avoid drinking alcohol or smoking or being around smoke of any time. I told you I was a member of a fraternity, right? It was really hard to learn that from the doctor. But he said that if I were to do those things, it could make the central boiler worse forever. And that was tough. That was tough to take tough to hear.

And I had to cope with that. But I thought about I said okay, it is what it is. What can I do? Let's focus on what I can do rather than dwell on what I can't do. And so, I thought you know what, I'm going to be the guy at events, parties' gatherings that people can come to have good conversations you want to do you want to have a heart to heart you want to chat. I'm your guy. And that's what I did.

I had late-night conversations with guys, girls talked about life, school family, you name it, that I really enjoyed those conversations. And I enjoyed that. I wasn't dwelling on what I couldn't do. But focusing on Hey, I can do this. And this is a lot of fun for me. One day, my fraternity went up to the Rose Bowl stadium, because San Diego State was taking on UCLA and a football game. got there early, to tailgate, of course.

And while my fraternity brothers were partaking in, let's just say extracurricular activities, I was off to the side sitting down and having a conversation with another fraternity brother. And I noticed in my periphery that there was a girl standing there, I stood up, I offered her my seat, she sat down. Next slide, please. And that's the first time I met Ellen. Ellen and I started chatting and really hit it off. And it was the first time I was talking

with somebody, where I immediately told him that I was legally blind, I felt extremely comfortable with Ellen.

And within a minute told her, Hey, you know, I'm legally blind, right. And I didn't do that with anybody up until that point, I was still really self-conscious about it, and anxious and nervous to even share it. So, I felt really comfortable with her. We really hit it off. And we started dating. Not too long after that. Early in our relationship. We went on a lunch date, and we both got salads. And we're really enjoying each other's company.

And I'm trying to get something on my plate, and I'm not able to get it. And I asked her, I say Hey, Ellen, what is this? And she's not talking her mouth full and I respect that. That's fine. And I finally puncture this curtain. I put my mouth and I bite down. Because I bite down Ellen yells. No, no, no, that's a pad of butter wrapped in foil. Right as I bite down, I feel a sharp shooting pain go for my teeth to my brain and I'm just in pain.

I'm going into extreme pain and not only am I in pain, but I'm also extremely embarrassed. I'm extremely embarrassed because if I was fully sighted, I wouldn't do that. And then I start to go down this rabbit hole of thinking why Ellen is even putting up with this? Why is she dating me? There's got to be better people out there for her than me. Why is she dealing with us? But she never cared. She didn't mind when her roommates would ask her what's it like being a legally blind guy. Do you really have to do all the driving and you have to read in the menus? Like really? She never cares. Walt Whitman said and maybe more famously, Ted lasso said, "Be curious, not judgmental." Be curious, not judgmental. We tend to judge people off of this much of what we know when there's all of this, we know nothing about when we ask why do we ask why would judgments behind it are with genuine curiosity.

Next slide, please. Ellen and I got married four years ago. And I'm extremely lucky and grateful to have her as my wife, my best friend, my partner. And I've learned so, many things from her from our relationship and our time together. But one of the things that she's taught me and I hope that I can relay to all of you has to learn to be a little more curious. And to be a lot less judgmental. Growing up, I was an athlete. I love sports.

My favorite sport was golf. We can argue about whether or not that's a sport. That's a fair debate. I played three years varsity in high school, and I played every Sunday from when I was 12 to 17. With my dad. It was our bonding time, our ritual, how we became so close. If I beat my dad on a Sunday, I give him a hard time the whole next week. Better believe it. If he beat me, I would stop hearing about it from him.

That's how my dad and I became such good friends. I was especially devastated after losing my sight to think I could never play the game I love ever again. My mom who's incredible. She came up to me one day she said Jeremy, Jeremy, there's such thing as the US BGA, the United States blind Golf Association, and these golfers playing tournaments all over the world. And I thought mom, that's really cute.

But how do blind people play golf? I thought she was kidding. I thought she was cracking a joke to boost my spirits. But there is such thing as blind golf and there and they do have tournaments all over the world. Now you can't go drop me off at the local golf course and say go have fun, Jeremy. I be lost. But every blind golfer has a guide, someone who helps him out each and every single shot. And for me, that was an easy choice.

The next slide, please. My dad, my dad is my guide in every competitive round of blind golf that we play in. What we do, as you can see in the photos, my dad points in the direction we want to hit the shot. I try to envision where he's pointing, I have no idea where he's pointing, I step over the shot, and from behind, he looks at my feet and says, go a little right. Little more left.

Okay, you're good. I hit the shot. And we do that the whole way around the course. Our first tournament together was in California, and it was an interesting experience. There's a lot of bickering back and forth between my dad and I. Because I see it as I've got some perks to this, believe it or not. I see it as for every good shot, I hit follow me, I'm the man. And for every bad shot I hit, it's my dad's fault. I've got someone to blame it on. I think it's great. He and I don't really see eye to eye on that. But he'll come around. Eventually, he'll learn one of these days. He's smart. He'll learn. The next tournament we played in was the national championship of blind golf in San Antonio, Texas

in 2009. Now, let me explain to you something about blind golf. And blind golf, there are three different sight categories. So, we all know that 2020 is perfect sight.

There's the B three site category, which is worse than 2200 vision, which is legal blindness to 2600 vision. There's the B two sight category, that's my sight category, which is worse than 2600, but not totally blind. And then you have the B ones who are totally blind. They can't see a thing. So, in the first round of the national championship, my dad and I are paired with a B one. Somebody's totally blind. Can't see a thing. His name is John Casolo. John's half my size. He's 80 years old. He's from Connecticut. And he's always got his guide dog, Halley, with them.

I think I do a pretty decent job describing him, but I think a photo does him more justice. Next slide, please. As John Casolo he's the man. So, in the first round of the national championship, my dad and I paired with John. Now let me explain you something about golf for those you might not know. In golf, you want to shoot the lowest score possible. The lowest number is the best. So, anything under 100 That's good. 101 to 125 It's not really good.

But it's not horrible. We can get better. 126 To 150 You should probably practice more. Takes more lessons. You should do anything over 150, 151 above. You should sell your clubs on eBay and pick up a totally different sport. PKD con I'm just trying to be honest with you if you're shooting over 150 golf is probably not for you.

So, in the first round of the national championship, my dad I go out and we shoot a 97 I was livid. Because daddy line yep, wrong on so many different shots. On the third hole, the tee shot, that went out of balance. That was all your fault. The fifth all the bad chips shot again. All you and the eight hold the three-point I'll never forgive you. Walk away. Leave me alone. Well don't go too far. And we kept bickering back and forth.

John Casolo came in and John shot a 324. He shot a 324 that's astronomically horrible. I don't care if you've never played golf in your entire life. You could go out tomorrow and be a 324 that's how bad that is. I go and shake John's head off the runway, John I want to play with you. He said Jeremy it's just a

game. Enjoy yourself. And I thought it's just the game. Enjoy yourself, what an idiot.

Now him for me all of a sudden, I think here's another reality check. Here I am. Yeah, I'm legally blind but I can still see some I shoot a 97 and I'm mad at the world arguing with my dad, whose John Casolo who's totally blind can't see a thing. He should say 324. Do you know how long around golf that was? That was a long day. And he said he just has a time of his life that day. I learned something from John that day. That not only in golf would in life we need to enjoy our experiences more in the present moment. We need to enjoy the people we're surrounded with. I need to enjoy just being out on the golf course with my dad and not get so caught up on what I think we need to shoot for me to then be happy. We need to get rid of these if-then statements we created.

If this happens then I'll be happy once I'm through with this and everything will be okay. Next slide, please. John taught me to focus on the good rather than dwell on the negative. So, often in life, if we were to write a pros and cons list of the things going on, and we wrote 10 pot, sorry, 10 pros and two cons, we tend to think so much about the cons that outweigh the 10, good things going on.

It's human nature to want to fix things. If something's broken, we want to fix it. If something isn't going, right, we want to make it better, that's fine. But we also need to focus on the good more. Now, I don't expect you to see this slide here, what I just said, and all of a sudden, you're focusing on the good now way to go. It's not just a flip of the switch. It's not that easy. I wish it was. But it's a muscle. It's something it's a practice, it's something we can build and get better at.

And what I do and what I'd recommend you do, is when you wake up in the morning, start tomorrow, write down or think about at least three things you're grateful for. And write down or think about at least one thing you look forward to doing that day. And before going to bed, write down or think about at least three other things you're grateful for. And write down or think about at least one thing you enjoy doing that day.

If you can put that into practice and do that day, after day, you'll notice that you start to focus on the good more rather than complaining and dwelling on things that aren't going well. I think that's something that we need to work on by ourselves, but hopefully collectively as a whole. We can learn to focus on the good more. Be grateful for what we have rather than dwell on what we don't have. Tony Robbins says our focus goes, energy flows.

So, why not focus on the good more? Next slide, please. There's a great story. I love the Chinese farmer parable and it goes like this. The Chinese farmer's one and only horse run away. The farmer goes into town that night, townspeople heard about what happened. They said we heard your horse ran away. That's horrible news. We're so sorry. Next slide, please. And the farmer says, maybe the next day, his horse comes back with three wild horses.

farmer goes into town that night, townspeople heard about what happened. They say you have four horses now. That's amazing. That's incredible news. We're so happy for you. And the farmer says maybe the next day his son is trying to tame one of the wild horses gets bucked off and breaks his leg. farmer goes into town that night, townspeople heard about what happened, say, we've heard about what happened, your son breaking his leg. That's horrible news. We're so sorry. And the farmer says, maybe the next day the military comes to draft his son and take him off to the war.

But he has a broken leg and can't go. farmer goes into town that night, townspeople heard about what happened. They say your son doesn't have to go to the war. That's incredible news, we're so happy for you. And the farmer says, say it with me. Maybe. So, often in life, we want to place judgment on things immediately. Something's presented to us. And we want to say that that's amazing.

That's horrible. But when we do that, when we say that something's amazing right away, we set such a high bar and expectation for it that we have a tough time truly letting it live up to that height. Or if we immediately say that something's horrible, we put a dark cloud over it and have a tough time coming back from it.

What I'd like for us to do is to suspend his judgment, to say maybe go through the experience. And then we can always look back on it with hindsight and determine whether it's actually positive or negative. There are some things that are negative. And I'm not saying we sugar-coat those and say maybe, death of a loved one death of a family member, that's a negative. There are things that are amazing. And we can say that in the moment right away, like PKD con. Like this presentation. I'll allow it. You want to say it's amazing right away totally fine by me. We don't need to say maybe okay, we're okay to say amazing. But what I'd like for us to do is to work on suspending judgment. When Ellen and I are in situations and one of us says, oh, no, this is interesting, or this won't be great for whatever reason. The other will say, hey, look the Chinese farmer does. And that kind of reminds us to hey, let's suspend judgment. We'll go through the experience. And then we can always look back on it with hindsight and determine whether it was actually positive or negative. So, let's go back to that golf tournament, the national championship. My dad and I for the second round, the final day got paired with someone other than John Casolo If I said to my dad, Dad, let's play more like John, and let's not argue as much.

And let's see how that works out. We ended up shooting 88 shots, nine shots better than the first day tied for second lost in a playoff and finish third. In the next tournament, my dad and I were invited to play in the World Blind Golf Championship in England in 2010. Yes, there is such thing as a World Blind Golf Championship. There were 60 competitors from 14 different countries. And my dad and I went out there with one goal, one purpose, we want to enjoy our experience as if we were John Casolo. After the two-day tournament, we did exactly that. When we made the final putt on the final green, we were walking off the course and a large British guy who's bigger than me taller than me, grassy by the shoulder spins me around as Jeremy, you tied for the when you're going to play off. That's amazing.

And I looked at him, I said, maybe. I'm going to show you a video, but I'm going to set the scene first. I'm in this playoff against the guy from England. And we both end up having short ship shots of the hole what I do for the short ship shots, I'll walk the on paces or yards that is from the ball to the hole. I

vividly remember walking the 19 paces to the flag. There was an audience behind the green watching to see who would win the world championship. And I thought, how many times in my life am I going to have this experience where I'm in the world championship in a playoff with an opportunity to win? And there's an audience watching. I got to soak this up. So, when I got to the flag a mile and I waved to the crowd, I go back to my shot. What my dad I do for the short chip shots. Since I'm unable to see the flag, my dad will stand in between me and the flag on the line we want to chip it on. I line up to his backside. He moves out of the way I liked his backside. I told him he's good. He moves out of the way, and I hit the shot. And this is what happened you can roll the video.

you're all muted, so, I just imagine you screaming and applauding at your computer screen. So, thank you. Thank you. Thank you very much. I feel the love. I appreciate it. As you could tell from that video that was all me. My dad had nothing to do with that. I'm totally getting up by far one of the coolest experiences of my entire life. And what's really funny is that videos on YouTube say Jeremy points in a wins World Blind Golf Championship. My dad came up to me one day and said Jeremy, you messed up. Like what are you talking about that? You said absolutely chipped it in, you threw your hat up and you caught it.

No one's going to believe you're blind. So, that's a fair point. So, after I watched the video, I said, Dad, you're totally right. I messed up. But you saved me. He's like, what are you talking about? I said, after I threw my hat up, and I caught it, you went in high five. Now if you don't learn anything else from my talk today, I hope you learned that you never go in for a high five with a blind guy without at least giving me a fair warning, say high five bump something like that.

It's by far, one of the coolest experiences of my entire life. And what's especially cool is if Jordan Spieth wins a golf tournament, congratulations, Jordan, how does it feel? Whereas I didn't win the world championship? My dad and I did it together as a team. And we get to share that bond and that experience together forever. And I noticed at that moment when we were

collecting those trophies that my dad was getting just as much, if not more enjoyment from the experience.

And I was it made me think back to my friend Josh. Maybe this is the blessing he was referring to. Maybe the gift is something far more meaningful. For more powerful than independence. Next slide, please. Maybe the gift is seeing the power of interdependence. My dad and I can live separate lives from each other independently and be perfectly fine. With his eyes and my golf swing on the golf course, you make a formidable team. With interdependence, I want us all to be more comfortable in asking others for help. and offering to help those around us. Think about how it makes you feel when someone asks for your help. I feel special wanted needed. Why do we rob others from feeling those feelings? Why are we afraid to ask others for help? Because we're afraid of being vulnerable. Coming off as being too dependent, or not seeming self-sufficient. independent thinkers think I don't need anyone's help, I've got this.

Whereas interdependent thinkers know that it's not a matter of need, but an opportunity to work alongside others to work smarter and more efficiently toward the common goal. To help you implement interdependence in your life more, I created what's called the see method. Next slide, please see, is an acronym. And with it, it starts to seek help. I think it's the hardest of the three. But we need to be more comfortable in seeking help.

When we refuse to seek help, we limit our ability to be successful, we limit our ability to connect with others. And quite frankly, we limit our ability to be relatable. The second is, embrace help. When someone offers to help us, I think the most common reaction is to say no, I've got it thanks. But I'd like for us to take a pause before saying that next time when someone offers to help us, I'd like us to pause and think you know what, could I take them up on their help? If the answer is yes, take them up on it.

If the answer is no think, well, could I learn something from this? Or could they learn something from helping me with this? And if the answer is yes, I recommend taking them off on it. Because it's a shared experience, you might learn something you might not have expected, they might learn something

that's going to help them for in perpetuity. So, embrace help when you can. Not easy, also not easy. But then finally, extend help offer to help those around you. I can't thank my dad enough for all that he's done for me on and off the golf course. But that's not why he doesn't he doesn't do it for praise or thanks or gratitude.

He gets just as much from the experience as I do. I'd like for us to leave my presentation, go on tomorrow, go on beyond this. And embrace interdependence in your life. Seek help, embrace, help, and extend help as often as you can. Because if you do it with the right people, at the right time in the right way, it makes a world of difference. When I think about interdependence, I think about my dad and me on the golf course, I think about my mom and finding blind golf and allowing me to pursue my passion again.

I think about my loving wife, my incredible wife, Ellen, and the interdependent relationship we have I think about Mark in creating the opportunity of the cure, right for us to do something purposeful and meaningful in our lives together. And I think about Josh, who helped me get back into school to be able to continue on, in graduate. There's a great African proverb that says if you want to go fast, go alone, if you want to go far, go together.

And that, my friends, is the epitome of interdependence. Since winning the world championship, I've had some phenomenal experiences and opportunities. My Dad, I've gone on to win a total of three world and eight national blind Golf Championships. And the best part is that we're able to share those experiences together. As Rob mentioned in the introduction, I was filmed in a feature on an episode of ABC's 2020.

That's kind of ironic. I've got way worse than the 2020 vision. I don't know why they wanted me on the show. But it was a great experience. And I'm glad I have the part. And I keep saying these things that were one of the best experiences in my life but by far the best experience of my life. Next slide, please. 18 months ago, a year and a half ago, Ellen gave birth to our first child, our son Palmer. I'm a golfer you can guess where that name came from.

But I think the greatest title in the world I've ever had is dad and being Palmer's dad has made me empathize with my dad and why my dad will travel around the world with me, guiding me on the golf course without even hitting a golf shot himself. I love being Palmer's dad and I love seeing how dependent he is on Ellen and me. And I love seeing him slowly gain his independence. It's really fun to see.

And then I look forward to him seeing beyond independence and embracing interdependence. Because you better believe when he turns 16 years old is legally blind, dad's going to force him to drive them wherever you want. But in all seriousness, I look forward to seeing him embrace interdependence in his life as well. If you were to come up to me after my presentation, if you were to say to me, Jeremy, I've got something that will give me your sight back.

Do you want it? I would say no. I'm okay. I'm happier today at 32 years old and legally blind. And I wasn't 19 years old and fully sighted.

Because I don't take as many things for granted anymore. I focus more on the good like this peripheral vision I do have, rather than dwell on the negative, like the central vision, I don't have. And I love being a professional, inspirational speaker and performance coach, traveling the world sharing my story to inspire audiences by providing perspective, and helping them see the power of interdependence in their life.

Because let me tell you when we learned that alone, we are limited. But together, we are limitless. It opens our eyes to see things we may have never seen before. And like the young boy, in the forest with his father, I'd like for you all to learn to use all of your strength to be strong, strong enough to ask for help. And like the wise man, John Casola once said, it's just the game enjoy yourself.

You can go to the final round. Thank you very much. Thank you so much for having me PKD con in, Rob and I are going to do some Q&A. And I really enjoyed this and look forward to doing some Q&A, please. I'm an open book.

If you can't tell and fire away with any questions. I really enjoyed this time with you. Thank you.

Rob Roth: **That** was great Jeremy. I'm tempted to say that was amazing. But I guess I'll have to say for now, maybe.

Jeremy: No, no, no, no, I said you could say amazing with the presentation, please. Amazing is perfect.

Rob Roth: All right. We'll stick with that. As you said, you are certainly willing to take any and all questions. So, we have a few that have already come through. Let me start. The first one we have. Do you feel your experience would have been different if you had become legally blind at a different age?

Jeremy: That's a really good question. It's interesting, I met a gentleman who lost his sight to the same condition as me. And I met him because he lost his sight at 50. He immediately liked after losing his sight, took his golf clubs, and threw them in the trash. Little aggressive, but I get it. And he said that he heard me on a podcast, and then took his clubs out of the trash. And he now competes in blind golf tournaments with me.

And at one of the tournaments. He said to me, man, I feel so bad for you that you lost your sight at such a young age. He said I got to live 50 years of my life fully sighted, and then this happened to me, I feel bad for you. And I said to him, I feel bad for you. I was 19. I was in college; I didn't know what I was going to do with my life necessarily. I didn't have a wife, a kid, a mortgage, things of that nature.

So, I could kind of live in this purgatory of, we'll find it out. So, I think the answer is yes, is thankfully I was kind of in this gray area of you're in college figured out. It's okay. I can take two classes in one semester. And it's not that big a deal. If it happened to me right now, I think it would be a different situation.

But I do think that if you have the right people surrounding you, it expedites the process, it gets you to acceptance faster than if you don't and I you know, without Ellen, my, my parents, my siblings, my friends. Whether I had to happen to be a 19 or 50, I don't think would have made much of a difference

but by surrounding yourself with quality people. I think that's more important than anything else.

Rob Roth: Okay, next question. relates to your suggestion about the list at night. When you write your list at night of the three things, you're grateful for what seems do you see show up most often on your list?

Jeremy: Yeah, it kind of ties into the first one it's people. It's family, its friends. It's my wife and I think it's okay to repeat these in that I won't. When I do the six right three in the morning and three at night. I don't do the same thing in the morning, that I do at night. I keep them different, but I noticed that it's people far more often than anything else. So, you know, it's going to be Ellen, Palmer, and someone else and I'll go beyond three or five if that's where I'm feeling how I'm feeling that morning or night. But, you know, I'll list them out, then I'll list something else out at night. And then a couple of days later, I'll repeat Ellen again, because, man, she stepped up and helped me out with something or she stepped up and did things with Palmer that were amazing. So, for me, it's, it kind of all comes back to people.

Rob Roth: So, in that area, reruns are okay.

Jeremy: Absolutely, absolutely. I will try not to do reruns on the same day. But absolutely rerun throughout the week, without a doubt. And honestly, I'd rather you do a rerun and do three than only write two.

Rob Roth: Okay. A couple of people have asked questions about whether you have a book or other presentations that they could watch.

Jeremy: Oh, that's really nice. So, I think on the final slide, I had a thing where if you want, I do a, I have a newsletter that I send out every other week, it's called points, the first six letters of my last name points of perspective. It's if you'd like to sign up for that you can, what you can do is you can text the word see, SEE, 255444 sounds like an infomercial. But if you text that, then you can just send your email address and you're in my email list.

And I send out kind of short story short essay every other week, that's either inspirational thought provoking something that provides perspective. And I do that every other week, I have a book outline I have. I have all the things

for a book, but I was working with a book agent. And he said to me, that COVID kind of up into the book industry. And he said, until I have over 20,000 Instagram followers or 10,000 people in an email list, he cannot get my book published traditionally.

So, the answer is no, I do not currently have a book. I do send out that newsletter. And it's a good way to keep in touch. So, if you, I just had one come out this Tuesday. The next one will come next week, but the one after, and if you sign up for and you receive them, you can reply to it and tell me what you think. Did you enjoy it? Did you not? What do you learn from it? And it's an easy way to kind of keep in touch too.

So, my social media, LinkedIn, Instagram, and those newsletters, like the main ways to kind of keep in touch with what I'm doing. And when the book comes out, it will happen. Eventually. I will definitely let you know through those forums.

Rob Roth: I expect a signed copy in the mail.

Jeremy: Oh, sure, sure. I will send you a signed copy, for sure make that happen.

Rob Roth: Okay, next question. And a number of people have used the word amazing. So, I don't want you to think about getting rave reviews. -

Jeremy: I can't see the review. So, please tell me that I appreciate it. Thank you.

Rob Roth: Question. Do you ever share your story with children or teens with special needs? That would seem like that would be a great audience for your message.

Jeremy: I have, I've definitely I've been speaking professionally for over eight years now. And I've spoken to middle schools, and high schools early in my career. I don't really focus on it much now in this stage of my career doesn't mean I don't do it, or I don't have the willingness to do it. But I do a lot actually with the LHON community, the disorder I have. Every other month I host a zoom call with LHON teens. So, really anyone 13 to 18.

And then LHON adults, sorry, young adults, and that's anyone 19 to 29. And we do that every other month. And it's just the ability to kind of have like

you're doing with PKD connect, the ability to connect, and really, there's a difference between sympathy and empathy in my opinion. And when I would share my story to Josh or Mark and my friends who are fully sighted, they could sympathize.

But folks who have lost their sight too early too and like me, they can empathize because we know what it's like to be socially distant during COVID and struggle with seeing things and telling people sorry, I'm unable to see that far. Can you explain it to me more and it's so, that's what I do currently is kind of host those types of things for sure.

Rob Roth: Well, I think your message really resonates I know it does with me. You mentioned about having your Josh as mentioned before, I had my Stuart, who was my college friend and really came through for me and being a living donor. And otherwise, I'd be on dialysis, and probably would have a lot of other health-related issues to deal with. So, I know it's something that probably a lot of us in the audience can relate to.

Jeremy: Seven years ago?

Rob Roth: Seven and a half yeah. And my donor and I are both doing well, health-wise. So, that's the best outcome possible.

Jeremy: Yeah, without a doubt, like you said, Josh Stuart, there are so many people like that. And I don't think they get highlighted enough. But there are so many of them out there and we got to surround ourselves with as many of them as possible.

Rob Roth: Exactly. So, I think we can wrap things up for tonight. Again, thank you everyone for the great questions. And thank you, Jeremy, for the wonderful presentation. Amazing presentation. Please join us again tomorrow for more breakout sessions, patient roundtables, and a research update from the PKD foundation. Have a wonderful evening and thank you again for joining us tonight.

[Audio End] [1:11:11]