# AT Banter Podcast Episode 282 - Dave Steele The Blind Poet

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**SPEAKERS**

Rob Mineault, Lis Malone, Dave Steele, Ryan Fleury

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R **Rob Mineault** 00:21

Hey and welcome to another episode of AT Banter. I love it when Steve's not here because you guys always leave a dead spot and it's great. Very cute. This is of course the podcast where we talk with advocates and members of the disability community to educate and inspire better conversation about disability. Hey, my name is Rob Mineault, and joining me today, Mr. Ryan Fleury.

R **Ryan Fleury** 00:53

Hello,

R **Rob Mineault** 00:55

Miss Lis Malone.

L **Lis Malone** 00:58

Hi there.

R **Rob Mineault** 01:00

And no Steve Barkley today. Hence, the big, big empty space where there normally is a banter, banter.

L

Lis Malone 01:12

Womp womp.

R

Rob Mineault 01:13

Yeah. Hey, you know what, maybe we should make that sound clip "Womp womp". when no Steve. Ryan. Yes, Rob. I am excited about today's show. Why don't we get things started right away? And why don't you tell the fine folks at home what the heck we're doing today and who we are talking to?

R

Ryan Fleury 01:38

Today we are speaking with Dave Steele. Others may know him as the blind poet. Dave, thanks so much for joining us this evening.

D

Dave Steele 01:46

Absolute pleasure. Thank you for inviting me on.

R

Rob Mineault 01:50

Why don't we get things started by just giving the audience a little taste of of who you are, and how you sort of fell into this this title of the Blind Poet?

D

Dave Steele 02:04

Yeah. Okay. I'll give you kind of the abridged brief version, sir. It's quite a long story. But yeah, so I have a condition called retinitis pigmentosa RP for short, which is a hereditary sight loss condition with no treatment or cure. And it's genetic. Runs in the family. In my particular case, it comes from my mom's side. And every time there's, you know, a person born there's a one in two chance that that child is going to develop RP when they're older, with a particular type of RP. And I have because there's lots of different genetic mutations. But I was officially diagnosed with the condition pretty much eight years ago, I think the anniversary is like next week, from where it was officially diagnosed. I always kind of knew we had RP in the family, but I was always told it wouldn't affect me till much, much older. And yeah, I went for a routine eye exam, walked into my local kind of opticians. And when they looked in the back of my eyes, they've noticed that there's been a massive change since the last time they saw me, they told me to kind of stop driving straight away, I had to be referred to a retinal specialist. And then literally like two weeks later, I was diagnosed with RP officially and declared legally blind, which here in the UK is called severely sight impaired. You've got two levels of sight loss, which is partially sighted and then severely sight impaired, which is legally blind. So yeah, you know, diagnosed nearly eight years ago, and the first kind of eight and nine months of that diagnosis, were really quite tough, actually really quite a dark time for me in the family, I lost my job, I was working in car sales at the time, I was also working as a singer, and kind of everything I did involve me driving, you know, getting around independently. And when I was unable to do so my employer let me go. We had a really tough year where we were struggling to get the help and support we needed. And then when I was kind of at my lowest, I got invited to a support group for people with RP, and another condition called Usher's Syndrome, which is the same sight loss as RP, but with hearing loss as well - so deafblind. And when they heard that I previously worked as a singer, they said to me, would you be the entertainment and come and sing some songs for the support group? And I said yes, immediately because singing and being on stage and talking like this has always been kind of my comfort zone. And going into that support group at that time, was something I was really really anxious about. I was struggling with anxiety and depression, not just for the sight that I was losing but also the financial pressure, that the whole situation and kind of put on my family. And so you know, being asked to be the singer for the support group kind of took that anxiety away, go into a support group, seeing people you know who were have already lost the sight or losing the sight or people using canes and people using guide dogs was kind of like a bit of a scary glimpse into the future for me. So when I was invited to be the same guy immediately said yes, because, you know, that gave me a purpose to be there. And then this is where it all kind of changed for me the night before the event on the support group, I was in bed, going over ideas of songs to sing. And I just had this really cool idea where I thought it'd be great if we could take a song that everyone knows, and change the words and talk about my kind of experience so far with, you know, with low vision and blindness. So I rewrote the song, 'Stand by Me' by Ben E King. And then when I performed it, the following day, the kind of reaction that got within the room was quite emotional. People were saying that I was able to kind of describe how they'd always felt. And the words that I'd written was making them feel less alone. And it was just like flicking on a switch. For me, it was like, here's something I can do now, that is going to make a difference and help people as well as help myself kind of come to terms with it. And that was a start for me, where I just started to write poetry about everything that we were going through as a family and me individually every single day, and post them online. And kind of fast forward now, you know, eight years later, I've written 900 poems, four books, three of them, were number one releases on Amazon in America in Australia. And people use my poetry as a way for them to kind of feel less alone. But also the main thing is they use it as a way for them to describe to their loved ones, their friends and family, how they feel when they can't find the words themselves. So it's, it's more than poetry. But it's a support thing for people. And, you know, that's kind of where I'm at now, I speak at events all over the world. And I try my best to help people every single day through the poetry.

R Ryan Fleury 06:48

I have to say, Dave, that you've come such a long way in such a short time. Really, you know, we've spoken to a lot of people, I myself, I'm totally blind. And what you've accomplished in seven, eight years, is, is truly remarkable. How important do you think it was to your recovery to get involved in community in those support groups?

D Dave Steele 07:16

Yeah that was the biggest kind of advice that I got at the beginning was actually from my sister, who was the first one to be diagnosed with RP. And she said to me, you know, when I was probably at my lowest that the best way of understanding what you're going through, is to actually speak to other people who are going through the same thing. Because quite often, when you get a diagnosis, any kind of diagnosis, it's not just low vision and blindness, but it's always tends to be done in a very kind of clinical matter of fact, kind of way, you know, you've got this thing, you're going to lose your sight, there's no treatment or cure very, you know, wanting to kill, you know, chancy children might have it all this kind of information. So actually, you know, when you when you get to speak to people who are going through the same thing, you realize, first of all, that you're not on your own, which is, you know, one of the big things that my poetry does, because with anything like this, it tends to be it can be very isolating. And, and quite often you can feel like, you're the only one in the world who's dealing with this, because you're quite, you're not quite ready to speak to other people. And maybe you, you know, you, you haven't met anyone else that's losing the sight. So, you know, you can feel quite isolated. So getting involved with online communities and support groups and, and just talking to people who really get it is a massive, massive help. And that was that was a big part of me, understanding what I was going through, and then being able to relate it to other people through my writing.

Rob Mineault 08:42

Yeah, I mean, quite often, the other thing that we do we really hear from people who go through vision loss, is, you know, that first year is always incredibly tough. There's a lot that that people have to juggle and you know, in terms of like, they're, you're really you're dealing with with, it's almost a grieving process. What kind of resources did you have, during that time to sort of help you through that? Or were you pretty much kind of just left on your own, to just kind of deal with it?

Dave Steele 09:16

Yeah, a bit of both, really. I mean, we were kind of like a lot of people we kind of fell through the net and the system really let us down. I'm, as my wife would say, I'm an optimist. And my wife is a realist. So just to kind of put you in the picture when when I was first diagnosed was a really kind of tender time in my life. I just started a new circle. I split up with my, my, my daughter's mum, who was living with in Scotland, I've moved back to Manchester, to be near family and then met Amy, who's now my wife, and we kind of met and fell in love very, very quickly. She fell pregnant, and our son was born in Jun 2013 And then on Christmas Day 2013, I proposed asked her to marry me. And we set a date to get married on a New Year's Eve 2014. And we'd started that year kind of really excited saving for our wedding. You know, my daughter, Ellie was the same age as her children. I've got two stepsons one, one was 16, the ones 14. And, and, you know, everything was good. And then it was, you know, it was actually, you know, April, in, in 2014, when I walked into that Opticians. So, you know, I came out, we, you know, us had lost the job, we lost our house, we had to feed our kids on food parcels for a little while, while we applied for support through the benefit system. And at the time, there was a nine month kind of process of, you know, getting through all the paperwork and, you know, being basically assessed, so you're actually qualified, which is just crazy, really, actually, when I think about it, because, you know, when surely, when you are declared legally blind or severely sight impaired, that should be enough to get a certain level of support. But unfortunately, that's not the way the system works. And it's flawed. So, you know, that's why I said right at the beginning, I was really struggling, not just with the anxiety and depression of me losing my sight quite rapidly, but also the financial pressure now having to move into social housing, and everything else it was, it was a really tough time. And actually, my first book, was actually writing about a lot of that, and I found that speaking about the hard times, I think there's great strength in being able to talk about your weaknesses, and being able to kind of, say, to somebody through a piece of poetry, you know, I've struggled with that, too, is a really powerful thing that can really help a lot of people. That's what I found anyway.

R Rob Mineault 11:56

So in terms of the services that are available, and you know, we can, of course, only kind of speak to North America. But, you know, what, what kind of organizations are there over there that help people with vision loss?

D Dave Steele 12:12

So you have kind of, you've got, like, the main kind of big charities, the biggest one here in the UK, is the RNIB, the Royal National Institute for the Blind, but I kind of dealt with everything on a local level. So I went to my local blind society, and they helped me with the kind of the paperwork to go through, you know, the government and get kind of support that kind of way. But as I said, you know, it was literally eight or nine months, before we kind of received a first kind of payment and to help support. So we were left on our own falling into debt, and really struggling for about eight or nine months, while we went through this process, it was, it was torture at a time and, and you know, all of the systems a bit better than it was back then it's still not perfect. And then there's a lot of people who really struggle with, with the things you have to go through. But, you know, eventually everything kind of did fall into place. And, you know, we got to a level where we could kind of survive, but it's it's definitely still a very flawed system in this country.

R Rob Mineault 13:20

Yeah, and that's exactly how we would describe our system as well. I mean, it's, you know, it's there. But again, you know, the, the waiting periods, and just the type of resources that people are offered, really, really tend to fall short.

D Dave Steele 13:35

Well, let me let me just give you an example on that. So, my, my wife, her sister, Kath, she actually lost her son, Josh, in September, last year. He was terminally ill to a condition called Duchenne Muscular Dystrophy, which is a terminal muscle wasting disease, and he passed away 18. And he, when he was about 16, they had this kind of switch where his benefits is support over and he, someone came out and had to assess it. And they walked in to see him in his fully electric wheelchair, realizing that this kid was terminal with a condition and just felt so embarrassed that they've been even sent to assess somebody who was obviously clear without anyone going round that he needed, you know, a certain level of support. But the system, you know, was designed to be, you know, flawed like this and put, you know, undue pressure actually on families. So it's, yeah, there's a lot that needs fixing. We need to speak to people within the communities and people like ourselves to actually get it right, rather than, you know, take advice from elsewhere.

R **Rob Mineault** 14:51

What kind of barriers did you find that you were surprised with once you started going through vision loss that you had to sort of deal with?

D **Dave Steele** 15:00

Yeah, I mean, probably the same as most people. I mean, I know, obviously, from the work that I do now about the ridiculously high unemployment rate within the blind community, you know, it's nearly 75%, which is just crazy. And a lot of that is down to lack of awareness and education and the misconceptions that are out there, you know, it's not until you, you know, you're affected by something, that you actually realize that there are many misconceptions that are out there, and I was guilty of it just like everyone else. So it's not particularly anyone's fault. It's just a lack of education. You know, and when I first lost my job, I remember applying for jobs that I could do standing on my head. And the minute I mentioned that I was losing my sight, you know, excuses were made, the phone went down, and it was crazy. So I had to kind of find my own path, which is, obviously what I've done through the, through the poetry, and I'm very fortunate that I've been able to do that, that I'm able to, you know, kind of make a living and travel the world and do all the things that I get to do now, but it's crazy that actually, you know, people who live with disabilities or different challenges actually show, you know, determination. And a lot of the key skills that employers should be falling over themselves to actually kind of get in that stuff, the strength that we have, and the resilience and all these kinds of things, the determination, so actually, you know, it, it should be a lot higher, you know, the, the employment rate, you know, we shouldn't be, you know, she shouldn't be 75% unemployed. It's crazy. And it's something that there needs to be a lot more education about.

L **Lis Malone** 16:46

Dave, I also have Retinitis Pigmentosa. And I will say though, when you say retinitis pigmentosa, it almost makes it sound more charming than when I say -

D **Dave Steele** 16:56

The power of the English accent.

L **Lis Malone** 16:58

Oh my gosh, yeah, absolutely. It's like wearing a cape. Yeah. I love it. I said, Oh, my God written, I just pigmentosa I was like, Oh, my God, that's lovely. That's lovely. Anyway, not so lovely. But I wanted to ask you, when you were diagnosed eight years ago, because and I don't know, if a lot of people are aware of this, there is a ridiculous number of mutations of RP, which makes it so difficult for researchers to find treatments and cures for that reason. So because of all the different types of mutations, genetically, the rate of progression really will vary from person to person. So for you, at eight years, were you very symptomatic at that stage. I'm just I think it's good for people to kind of know what the warning signs of RBR so that they should maybe take more action and go see their, their specialists?

D **Dave Steele** 17:53

That's a really good question, actually. And only and only something that someone with RP would ask, which is really great. So yeah, I was in denial. For a long time, I probably had, you know, the early onset of RP, which, for those people who don't know anything about retinitis pigmentosa so that again, in a posh voice, it starts off generally with night blindness. So struggling from light to dark places, the way I often describe it is, it's like your average sighted person walking from a brightly lit area into a cinema, it may take them a couple of seconds for the eyes to adjust someone with night blindness, you know, wouldn't be able to adjust in what is relatively just slight them light, it'd be like complete blackness. Sunlight, you know, is can be really kind of glaring. So it's really light sensitivity. And, and then from there on, you then start to lose your peripheral vision, like a tunnel closing inwards, and then you central vision then tends to go as well. So, early 20s, I probably had the night blindness aspect, but very, very gradual. And it wasn't really affecting me. But I was probably in denial it was RP even though I deep deep inside, I knew I just kind of got on with things because I didn't have to really make any adjustments. And it wasn't until as I said my late 30s When I was officially diagnosed, it really started to you know, dip quite fast where I lost all my peripheral vision in the first kind of eight or nine months. Obviously stress adds to that. And now where I'm at is my left eye, I've got no useful vision in the left eye. I've lost all my peripheral vision in my right. And I've got a tiny bit of central vision which I use pretty well but now that's starting to go as well where it's getting fair fairly blurry pretty quick. So I'm kind of at the last stage of my useful vision at the moment. But actually and I want to add this you know, we talk about like all the tough times and everything else. It does get you into some funny situations and I want to tell you a quick story forgot time. When I before I was officially diagnosed when I was working as a singer I was doing some gigs on the south coast of England and a couple of days off in between shows I decided to check myself into a nice hotel just to kind of relax. And this was where they just had kind of the the night blindness aspect. And I was in the hotel in the daytime just relaxing, went to the gym, for I'd go for a swim went for a sauna, went to go to use the sauna, and they open the sauna door. And it was quite dark inside. There was a lot of steam and I stood in the doorway waiting for my eyes to adjust the light. And that took about a minute. And then when my eyes have adjusted to my horror, I realized that there was one woman on her own in the sauna. And basically what I've done is open the door and stand in the doorway motionless, staring straight at her. Like some kind of shadowy, scary figure. Literally as soon as I walked in the sauna she left. So yeah, it does kind of get you into some tricky situations.

R **Rob Mineault** 21:01

Oh, man.

R **Ryan Fleury** 21:05

We gotta get her on the show.

L Lis Malone 21:07

If she's out there, give us a call. We want to hear her side of the story.

D Dave Steele 21:13

Yeah, we don't. And worse was actually did the same thing later on that afternoon. But the second time I went back, I opened the doorway, heard that it was busy in there saw a gap on the bench next to these two women so I thought I'm just gonna go straight for the gap rather than standing in the doorway. When straight sat down in the gap next to these two women then realize there was a whole empty bench on the other side. So they still know. I've never been back to that hotel since and apparently of me by reception.

R Rob Mineault 21:48

Beware the sauna stalker.

D Dave Steele 21:51

Yeah, exactly. Do not admit this guy.

L Lis Malone 21:55

There's Dave furthering our cause. Thank you, Dave.

D Dave Steele 21:57

Absolutely.

R Rob Mineault 22:01

Okay, well, let's, you know what, let's switch and talk a little bit about the poetry. So I'm curious, before all of this happened. Had you had you tried writing poetry before? Was it something that you dabbled in? Or was it just completely new?

D Dave Steele 22:17

Well, kind of. So I'd written obviously, I worked as a singer for the best part. 20 years. So I, you know, attempts to write a couple of songs. And I've written a couple of poems about, you know, women, girlfriends, and all that kind of thing. But you know, nothing, nothing serious. And it really wasn't until that moment, you know, when I wrote or rewrote, stand by me that it just kind of started to literally pour out of me. I mean, you know, 900 poems later, and I've never written anyone that's taken longer than 20 minutes. It's literally like, someone sat on my shoulder every time I sit and write, it's very, it's very weird. You know, I actually talked about how, before I started to lose my sight. I had many years where I actually wasn't happy with my life, I felt cursed. You know, nothing would ever go right for me. And then the minute I started to write the poetry and you know, once I started losing my sight, and kind of got on this path, it's quite spooky, how Right Place Right Time and things kind of happen, where I get these amazing opportunities, and I'm able to help people. So yeah, you know, just, it's quite spooky, how it happens. I still write pretty much every single day.

**Ryan Fleury** 23:28

You also get together with a group on Wednesdays, don't you called Tea and Poetry I think it is ?

**Dave Steele** 23:32

Yeah, that was. That's the thing. So you know, when I released Stand by Me RP, my first book. As I said, it became a number one release on Amazon in America and Australia. So my kind of biggest part of my following and audiences always been typically America. And I think that's down to kind of you guys are a little bit more open about talking about feelings compared to people in the UK, who tend to be a little bit more reserved, and especially men. You know, there's quite a high suicide rate, you know, people don't tend to kind of talk about emotions and become very isolated because of it. So America is always been where I've always had my biggest kind of response. So with Tea and Poetry that actually emerged through the pandemic, and 2020 when we went all went into lockdown. Literally, just before we went into lockdown, my bags were packed - I was due to fly over to DC to be the host of these big awards, called the Helen Keller awards, Helen Keller Achievement Awards for the AFP and and then everything shut down. I was like, gutted, you know, I was really excited about going there and everything stopped. So we kind of went, you know, how do we stay in touch with people and how do we support people? So, like everyone else, we kind of went to zoom and went virtual. And I think the first one before it was entitled to poetry was just We got a load of people together on a zoom call, we spoke about how everyone was feeling during the pandemic, and almost how it felt like the whole world had stepped into the shoes of someone with a disability because people were having to deal with things like anxiety and isolation and, and that's stepping outside your door, and having to think twice. Everyone was having to kind of experience these things for the first time. And that's how people like us have, you know, been experiencing things in life for years. So from kind of people's experiences and how they were talking on the call about what you were feeling, I then wrote a piece of poetry about it and debuted at the following week, and it's just grown and grown to the point now where it's called Tea and Poetry. And we have people that tune in from kind of all over the world every Wednesday at 9pm, UK time, which is like 4pm Eastern. And, and yeah, it's just, it's a really great, you know, support for a lot of people in a nice way of me writing new poetry every week.

**Rob Mineault** 26:02

We've talked to people on the show before, who have some, like really amazing stories. People who didn't even dream of, of being athletes, but then they went through something like vision loss, and two years later, they're they're competing in the Paralympics, you know, I think that these things that are that are big life changes, yes, they, they, they, you know, you're dealing with grief, that can be a really terrible experience. But at the same time, it's, it can be a transformative one as well. My question is, I guess, having gone through that, do you have any advice for people who say are going through the beginning of their journey in terms of like finding their thing, whatever that is?

Dave Steele 26:48

100%. So, you know, one of the things I've been talking about a lot recently is, disability isn't, it isn't an excuse to do less, it's a reason to do more. You know, when you are losing the ability to do something, whether it be to see, to hear to walk, whatever, you know, it gives you a new focus on a new perspective on life, I always say that, I use that small tunnel vision that I have to appreciate the beauty in this world. So it makes me it gives me that urgency to do things now. And not to wait and not to put things off. And I think that's a great way to live life. I you know, that's one of the things that I'm so grateful for, because of my sight loss is that, you know, it's given me that ability to cherish moments that much more. But my biggest advice, actually, to kind of anyone going through anything similar is not to focus too much on what, what may be tomorrow, we all have a habit, when you know, when you lose insight, you have a habit of getting hung up on what it's going to be like in the future, what it's going to be like, when I lose all my sight, what is going to be like, you know, five years time, a year's time, whatever. And I think actually, the best advice I can give is to actually not worry too much about tomorrow, but focus on what you have and what you can do now. And I think that's the best way. And actually, you know, I know, you're just saying there US people on the call with with no remaining vision. And actually those people with no sight whatsoever, remaining no light perception or whatever, are actually a lot better adjusted than then people like myself who were trying to use something that you've got no choice to use, because you've still got a little bit of sight there. But actually, it's broken. That's the hard part. You know, it's you know, when you've got no other choice to adjust to have enough, then you move past that a lot quicker.

Ryan Fleury 28:50

It's interesting, you say that, because you know, being totally blind, I've often wondered what it would be like to have partial vision. You know, it would be okay if that partial vision was stable. But how torturous would it be to know that your vision is going to go at some point, but you just don't know when?

Dave Steele 29:11

That's another one of the biggest misconceptions is actually that a lot of people think that if you partially sighted or you have a little bit of sight, is that you see one way all the time. And that's just not the case, the way I describe it is I have a retinal disease. So the retina is the thing that sends the signal to the brain translate what the eyes are seeing. So if I, with my little limited vision that I have, if I'm in a space where there's not a lot of movement in front of me, not a lot of objects or an open space. So for say, for example, a good example would be when I go and pick my son up from school, my eight year old son asked him if I'm in the playground, and it's just a few parents waiting for the doors to open and the kids to come out. I feel like I can see fairly well. But then all of a sudden When the bell goes and the doors open, and all of a sudden all these little moving objects come out the door spill out the doors. And because my retinas can't deal with that amount of information, all that movement, in a split second I go completely missed it fogged over blind, I can't see anything, because my retinas can't deal with the inflammation. And that can, that's probably the most, you know, brings on the most anxiety.

**Lis Malone** 30:29

And if I can add on to what you just said, Dave, and I can completely 100% relate to that. People who have RP we will often have good days, and then really shitty days. And when you have one of those really, really bad vision days, you are left with that? Oh, my God, I can I was able to do this yesterday, I can't do this today is this my new normal?? And just like you said, the anxiety can sometimes just be paralyzing. And then it might just be because of the the, the the blood vessels are under so much strain. And you know, trying to get those little retinas to fire up as much as they can, that it might just be like, you know, you were a little anxious that day. And sometimes, you know, it'll it'll affect portions of your your field. But it is that it's that constant readjusting that anxiety and just the unknowing. So, I mean, I'm just echoing exactly what you said, and in so many ways, but it is one of those things that people don't understand that it is it's like, it's like living in a world where you are constantly on eggshells.

**Dave Steele** 31:41

Yeah, there's so many things that affect it, you know, stress, illness, you know, if you're tired, the weather, alcohol. All these you know, all these things, you know, like, obviously. I was in San Francisco last weekend, and then you come back and you've got the jetlag, and then, you know, eventually that'll hit your eyes. And you're exactly right, you have a dip in vision, you thinking, okay, is this it? Or is this down to just me being tired or stressed or whatever? Is this something I've got to kind of get used to? So yeah, it can be tough, and a lot of people, you know, just don't realize that, and it's something that I try and talk about, through the poetry.

**Ryan Fleury** 32:26

So I guess since I've been blind for 27 years, no sight at all, I should start to learn to celebrate my blindness.

**Dave Steele** 32:33

100%? Absolutely. Absolutely. You know, I think it's really important to kind of let people know that because, you know, people are worrying about a future that actually is nowhere near as stressful as the present.

**Rob Mineault** 32:52

Yeah, that's, that's really fascinating. I mean, RP is such a, you know, I don't want to call it a common condition, but, but it kind of is, you know, within that, that realm of a vision loss. And common condition, but, but it kind of is, you know, within that, that realm of a vision loss. And it's such an insidious one, too, because a lot of people find themselves in the situation where they are, are diagnosed with something that's going to happen. And they're, and they're left to dealing with that. And that's gotta be really, really tough.

Dave Steele 33:22

Yeah, but as I said, that's where it comes in, you know, the trick that I found is just to basically, you know, train yourself to focus on the here and now and not and not panic and worry too much about tomorrow. Because, you know, tomorrow's, you know, that saying, tomorrow is never promised to anyone. That's so you know, that's, there's a lot of a lot of good times in today. And if we, if we spend too much time worrying about the distant future, then we'll miss out on all the, all the memories we can make. Now, the reason I do what I do now is I just want to try and be there for people in the same way I wanted someone to, for someone to be there for me right at the beginning. So I genuinely do care, you know, when I don't just write these poems for, you know, followers, or shares or likes or whatever, it's genuinely my way of trying to actually help people. And I do jet. You know, I always say, I don't just write the words and mean them. And I hope that kind of comes across. When I'm talking and certainly through, you know, my words that I always say, you know, if you relate to a piece of poetry, and you're struggling, message me, anytime, reach out to me, I'll always message you back. And that's a promise that I stick to and I try and support you know, families all over the world and, and it's something that I never take for granted.

Rob Mineault 34:40

Yeah, well, I think that that's, you know, that's one of the things about you know, the the digital era, you know, as far as much as we complain about things like social media and and the online realm, really, in terms of building community and building support systems, never, never before in history have we had such a, such an easy and powerful way to build those connections, across great vast distances,

Dave Steele 35:10

it's crazy, you know, how you can, you know, just click a button and send, you know, a message and, and social media gets a bad rap, you know, but, you know, I, it's been nice to see so many people from not just the low vision and blind community, but the disability community using it in such a positive way, especially over the recent years. And I've had some amazing, you know, stories and things that have come from that. For example, when I was doing my first USA book tour in 2019, I was in Rhode Island, and I was doing an event at Rhode Island College there. And when I was doing my talk my kind of our keynote, there was this guy in the room that was, for some reason was just drawing my attention. He looked like it comes straight from work. He was late 20s, early 30s, and a high vis jacket, like a builder, a workman or something like that. And eventually, you know, it comes up when I'm doing a book signing and introduces himself. And I said to him, you know, what's your name? He said, I am Derek, so pleased to meet you. What brings you here today? And he said, Oh, I was diagnosed with RP on Monday, and this was like Wednesday. So immediately, I turned around and said, Just come over here a second. And, you know, I asked him what was happening. And he said, he thought he had cataracts went for an eye test. He said, they told him you've got this thing called RP, you know, there's no treatment or cure your kids might have it and loaded all this information on him, he left the appointment with his head spinning and went home, jumped on a computer, started researching RP, and then found one of my poems. And it kind of when he read it, it started to make sense to him a lot of things that he was maybe in denial about things that happened. And he said he was in work that day, and his wife called him and she said, you never will believe this, but Dave Steele's in America. And not only in America but Rhode Island, and this guy walks straight out his work and came straight to see me. And you know, and that's the power of social media, it was just what are the chances this guy is just diagnosed, finds one of my poems, and I just happened to be there. It was crazy. And I've had lots of little kind of, you know, stories and connections with people all over. And that's the power of it.

R **Rob Mineault** 37:18

Yeah, and I think at the end of the day, you know, for, you know, in terms of organizations can provide, you know, a certain amount of resources, they do it, they can, but at the end of the day, really, it's these communities, and it's this this support between the people in those communities that I think really do the best work.

D **Dave Steele** 37:38

Yeah, definitely is the first line. You know, with as far as like the clinical side of things, the still trying to, you know, discover a lot of things as you're just saying there about RP, for example, having lots of genetic mutations is still, you know, find a lot of information out and actually the best way is just to speak to other people who are going through the same thing. And that's why I think it's key that a lot of the big kind of three letter organizations out there, your AFP, NFB FFB, all these places in America that I'm connected with now, why it's so important that we have people with working within those organizations, who are living with the conditions that you know, the people that they're trying to support.

R **Rob Mineault** 38:20

I think the other really interesting thing about this, though, is that the arts, creativity, and you know, certainly poems, specifically, I think, really do something kind of special, because it allows it allows people to really absorb these feelings and the this information in a really short condensed way that just nothing else does. Reading a blog or listening to a podcast doesn't hit people as hard as something like a poem. And I think that you're really tapped into something really special there.

D **Dave Steele** 38:57

I couldn't believe there was more people doing it actually, when when I first you know, kind of had the idea with this 'Stand by Me' RP song. And you know, is poetry music is the same thing. You know, we've all got a song that's been there for us, you know, in a dark time, or breakup or whatever we turn to these kinds of music and storytellers. You know, the best singers, songwriters, the storytellers and what they tend to do is the best ones, the ones that we really relate to and, and have a bond with are the ones that really open their own lives and talk about the, you know, bear the soul and talk about the things that they go through. They're the ones that really hit home and that's something that I promised right from the start that I was going to do that. I was going to you know, talk about everything the good days, the bad days, and hopefully that people will connect with my words would be helped by it.

R **Rob Mineault** 39:49

So now that now that hopefully we're kind of in the tail end of COVID, what's kind of next for you what what are you working on now? Any more tours in the works?

D **Dave Steele** 40:02

Yeah, 100% lots lots. I mean, the biggest thing of the moment, something I'm so so proud of, is the latest book that just got released in December, which is the first in a new series of children's books, called Austin's Amazing Adventures. So these are short poetic stories based on my son, Austin, who, as I said, has got one in two chance of losing his sight when he's older. But he's not there's no signs at the moment. But in the story, he's a young, visually impaired boy, going to a mainstream school with his best friend who's his guide, dog, Joe. And the books are about kind of the interactions that he has, and the challenges that he faces. And the idea behind them is that it's going to normalize disability and challenge different challenges for children, living with them within schools, break down those misconceptions and those social barriers that you face. So the children that are reading them with disabilities and different challenges will relate to the characters within the stories. And those who are affected by disability or different challenges will realize that these kids are just like them. And you know, the first book is about Austin. But where we're going with the future books, because I wrote the first six stories in one night, is that we're going to have characters secondary characters within the stories where we can talk about things like autism and ADHD, and wheelchair use, and all these things that if you walk into any mainstream school that you're going to see and normalize them for these kids. So that's kind of the next big, big project as well as obviously all the speaking engagements and, and doing all the other things. But yeah, I'm really proud of that. And obviously, Austin, being the main character in the book is really cool. We're actually coming to the Foundation Fighting Blindness have an event in June, called Visions 2022. And it's how he's going to be held at, at Disney World in Orlando, and myself, my wife, Amy and Austin are coming to actually speak at the event. And it's going to be Austin's first time in America. And what a great way of being able to kind of come to America for the first time go to Disney World and speak about your book.

R **Rob Mineault** 42:22

For anybody out there who is interested in your work, where can they find you online, if they want to find out about you, if they want to attend the Tea and Poetry or if they want to look into some of your books? How can people find you?

D **Dave Steele** 42:35

Yeah, so really, really simple. Go to my website, which is the blindpoet.net. And one of the really cool things about the internet at the moment is it's really cool. You can just go into really cool things about the internet at the moment is it's really cool. You can just go into Google and type in the blind poet, and all this stuff kind of pops up. Now. There's been many blind poets through history, I think the first one I'm aware of who have actually got tattooed on my arm was a guy called Homer. Not Homer Simpson, Homer who wrote The Iliad and The Odyssey through and he was the original blind poet. So which is why I've gotten tattooed on my shoulder. But it's quite cool that you can just go on and type in the blind poet and, and find a lot of my stuff.

Rob Mineault 43:12

Awesome. And we'll be sure to include that in our show notes as well. Dave, I thank you so much for for dedicating the evening to come and talk to us. It's it's been incredible. Best of luck with the new book series. And actually, when once you get a few more books under your belt in that book series, you got to promise to come back and talk to us again.

Dave Steele 43:35

Oh, my pleasure. Absolutely. I'd love to.

Ryan Fleury 43:37

Let us know if you ever come into Canada, the West Coast, preferably.

Dave Steele 43:40

Oh, yeah, of course. Yeah, I am actually. I just I just did a TV interview in Canada a few weeks ago. For and I can't remember the name of the TV channel.

Lis Malone 43:52

AMI.

Dave Steele 43:53

Yes, AMI. Yes. Yeah. Yeah, ami interview, which I believe it goes out in like June or July. I think

Rob Mineault 44:02

We'll get you published before that. So it looks like they're ripping us off. All right, Dave. Well, listen, take care. And best of luck, and let's stay in touch.

Dave Steele 44:16

**Dave Steele**

Yeah, thank you so much for having me on.

**Ryan Fleury** 44:18

Thanks a lot. Dave.

**Lis Malone** 44:20

What a charming man.

**Rob Mineault** 44:22

Yeah, it's all about the accent for you. It's like just, yeah, I know. I tell you, I wish I wish I was better at accents.

**Lis Malone** 44:30

You should go to a language coach and say I want to sound charming.

**Rob Mineault** 44:36

I need to learn how to say 'Lis' and 'Google'. And I want an English accent

**Ryan Fleury** 44:41

To everyone in our audience. If you want to hear Rob's Irish accent send an email to cowbell@atbanter.com

**Rob Mineault** 44:49

Way to get them to never email.

**Ryan Fleury** 44:54

They might finally email us they hear that

**Rob Mineault** 44:57

All right. I'll hold it the bank. Anyways, that is so cool. I mean, what a turnaround, right? Gotta be, that's got to be really something to just have the, you know, the worst nine months of your life. And then just slowly it just turned around and you know, eight years later you're in a completely different world.

L Lis Malone 45:21

And I hate to say this and sound like Debbie downer, and no offense to anyone named Debbie. Butwhat Dave has done is certainly the exception and not the norm. Because when you you know, some people, you get that news. I mean, I got that news, too. And there are so many people who just who don't turn it around.

R Rob Mineault 45:47

I mean, it's, it's hard, right? Like, it's, it's hard to find your thing. You know, certainly that is even harder to do when you're going through a big traumatic life event like that. And I think that I think that everybody has that in them somewhere. It's just a matter of if you're lucky enough to tap into it, or get that opportunity to bring it out.

L Lis Malone 46:11

Taking advantage of all the support systems, the support groups having a core group around you, family, good friends. I mean, that that's really where so much of that, that good juice comes out of. And so I think that, that, that Dave seems to have that that secret sauce, and I think it's it's, it's wonderful.

R Rob Mineault 46:36

Yeah, well, and especially that he can take that and then help others is, you know, even better.

R Ryan Fleury 46:44

So go to blindpoet.net, buy his books, buy his T shirts, whatever.

R Rob Mineault 46:51

I really enjoyed that.

R Ryan Fleury 46:53

So Wednesday, probably around he said four so probably 1pm. Pacific, you can check out Tea and Poerty

**Rob Mineault** 47:01

Yeah, what else you're going to be doing on Wednesday at 1? You should go check it out. You can duck away from your your tech support duties for an hour and go go listen some tea, or go listen to some poetry, you know, you know, listen,

**Lis Malone** 47:19

I'll be there. With my little pinky extended.

**Ryan Fleury** 47:22

It's right. It's right.

**Lis Malone** 47:24

A little shocker

**Rob Mineault** 47:30

God, whenever we're just never going to live.

**Lis Malone** 47:34

He's got Tea and Poetry, I would have tea and shocking.

**Ryan Fleury** 47:41

There's a podcast in there somewhere.

**Rob Mineault** 47:43

There isis you wanted to rename the podcast, boom,

**Lis Malone** 47:48

boom, there you go!

**Rob Mineault** 47:51

Go marketing team

L Lis Malone 47:55

We are dismissed

R Rob Mineault 48:05

I love this story. And but I mean, how? So? Actually, Lis went, so when you got diagnosed, where were you in that whole process?

L Lis Malone 48:18

So I was diagnosed fairly early. So I was one of those early birds, who was told that there was this horrific thing coming down the pike. So when when when Dave was talking about trying to focus on today, and not what will happen, I had all the doom and gloom of oh my god, my life is gonna suck when I reach a certain age. So I was diagnosed at 21. And I was not legally blind until I was 30. Right. And originally, they had said, we think you're going to be legally blind at 40. So it actually came 10 years earlier. So yeah, but I but the way I described it today was that I felt like I was walking on eggshells. I'm like, Oh, God, now I can't drive I won't be able to do this. All these things are going to be taken away from you. i It was very hard not to, at that time get really entrenched and focused on all the things I'm going to lose. Yeah. And so I was there at an early age, but thankfully, I didn't. I was similar to Dave like, I had my period of just really feeling like oh my God, everything life is gonna suck to then figuring out what my place is going to be moving forward. So working on that. It's a work in progress.

R Ryan Fleury 49:41

Well, like I mentioned, I think the worst part of that scenario would be not knowing when that vision is going to go. I I guess you can't really understand or comprehend what that's like. I lost my sight instantaneously. Boom, it was gone. I Having that kind of gentle reminder teasing you day after day after day after day of not knowing when it's gonna go. Because you know it's going I, that would be so hard to deal with.

L Lis Malone 50:14

Well as goofy as it sounds, I'll even have moments where my it'll be my own hair will sort of fall in front of my face. And I won't feel it touching my cheek, it'll just kind of block my vision. And I say, oh my god, oh my god. Oh my god, I can't see my Oh, my God my central is gone. And I'm like, Oh, my God it's my hair. Okay. So it's that first feeling of like, oh, shit!

R Ryan Fleury 50:37

Yeah.

**Lis Malone** 50:38

So it Yeah, you kind of are, you have these moments when you're on edge a lot. Because when something drastically changes, you're thinking, Oh, my God, you can't help but think the worst.

**Rob Mineault** 50:49

So in that makes me wonder like, are there any resources for people who are newly diagnosed that are living through that? Because, you know, I would think that that's a really big hit to your mental health to specially have to deal with that for years.

**Lis Malone** 51:05

It's very hard to get it as a state sponsored resource, because here in the US everything is state run, in terms of what kind of resources you get for, for conditions. And he, unless you have private insurance, you're not going to you're not going to get you're not going to get seen for months.

**Rob Mineault** 51:31

Don't I don't think that there's anything here either. I suspect that there's there's really not certainly not anything that's funded. So I mean, I think that, you know, that's even a problem. You know, people who are who are living under sort of the, the cloud of this coming, I mean, they they need help, they need resources to deal with that, because it's, it's, it has to be a really big burden to to face. So I mean, hopefully, there are lots of support groups and stuff out there, that it can help in that regard.

**Ryan Fleury** 52:10

Well, I think it's like Dave said, you know, that's kind of the one of the benefits social media can have is it broadens our community to be a global community share. It can be, you know, a dumpster fire. But, you know, you can choose not to attend those groups and find the groups that are supportive and encouraging. Yeah. Because, you know, everything is based around the medical model, right? Yeah, you're diagnosed and then you go for your follow ups, and you go for your follow ups, and you go for your follow ups. But at the end of the day, you're still left on your own with your friends, your family. That's right. And hopefully you can get plugged into a community.

**Rob Mineault** 52:44

Yeah, yeah, whatever support system that you can sort of manage to put together for sure. Well, we can't change the world today, I'm afraid because we still have to have lunch.

Lis Malone 53:01

You must be fed before you change the world.

Rob Mineault 53:03

That's right. Exactly.

Lis Malone 53:05

No one changed the world on an empty stomach.

Rob Mineault 53:08

Nope. Hey, Lis.

Lis Malone 53:11

hey, what's up, Rob?

Rob Mineault 53:13

Where can people find us?

Lis Malone 53:18

If they choose they can find us on the web at atbanter.com

Rob Mineault 53:23

Hey, they can also drop us an email if they so desire at cowbell@atbanter.com.

Ryan Fleury 53:30

What's this? If they choose to find us and if they desire to send us an email? They will go to atbanter.com and they will send an email to cowbell@atbanter.com.

Rob Mineault 53:42

Wow okay.

L

Lis Malone 53:46

These are not the droids we're looking for.

R

Rob Mineault 53:51

The Jedi Mind Trick, I approve. Hey, they can no feeds. Facebook and Instagram are Wait no Facebook, Twitter or Instagram. Go to Facebook and Twitter and you can find us there too.

R

Ryan Fleury 54:28

Absolutely. Or any of your favorite podcast apps.

R

Rob Mineault 54:33

You want to send some money your way to while we're commanding them to.

R

Ryan Fleury 54:38

That's coming. Yeah.

R

Rob Mineault 54:41

Wait till the we will need some funds for the for the AT Banter anniversary party.

R

Ryan Fleury 54:46

Yes. A lot of tequila. Speaking of which we need a meeting.

R

Rob Mineault 54:53

Yeah, I know we need a meeting. I know. We will meet we will meet and stare blankly at each other probably.

L

Lis Malone 55:02

Yeah. And drink.

R

Rob Mineault 55:05

Well, that's a thing. I think drinking has to be at home.

L

Lis Malone 55:09

Always.

R

Ryan Fleury 55:10

Yeah.

L

Lis Malone 55:11

I was turned back to alcohol. I don't know. I mean, there's a ya know, I just noticed that myself. Maybe I need to check myself.

R

Rob Mineault 55:19

No, you're fine.

L

Lis Malone 55:20

I'm good. I'm good.

R

Rob Mineault 55:21

You're good. You're fine. I'm fine. Yeah. See Poetry and Tequila for you. Yeah, we're done. That is going to about do it for us this week. Big thanks, of course to Dave Steele for joining us, and we will see everybody next week.