I have a secret from the world, that most of you don't know. Won't hear it in the way I talk and eyes no clue will show. If you listen to my story, something new to learn you'll find. For though I'm looking straight at you, I'm legally blind. It's not a simple yes or no, I'm more a shade of grey. I rarely venture out alone, as things get in the way.

For what I see affects my days, in much more ways than one and this for some continues, until little left has gone. But still this pains invisible, to those that pass us by. There’s some afraid to hold a cane, because of questions why. Accused of making up our claim and made to feel a fraud. Feel drained of all my confidence, feel trapped behind this door. Now hardest thing to come to terms, that makes my days feel long.

It holds us back, knowledge they lack, for all who’ve got it wrong. To hear they're judge and jury, even though their facts aren't straight. Feel misdirected fury, wish opinions now could wait. To take the time to get to know, the visions that we share. Come join me in this tunnel, hold my hand and show you care.
My name is Dave Steele and today I’d like to share with you my journey living with sight loss and how it’s brought me here to be with you today.

Almost 6 years ago I walked out of my local opticians after it was confirmed that I had Retinitis Pigmentosa and at that moment my world came crashing in on me.
What is RP?

- For those of you that don’t know Retinitis Pigmentosa or RP is a hereditary eye condition that in most cases results in blindness which has no treatment or cure.

- Around 1 in 4000 people worldwide are affected by RP. The way most people experience sight loss with RP is by a slow gradual loss as the retinas die as they become clouded with pigment.
In most cases it starts with night blindness, struggling to adjust from light to dark places and being extremely sensitive to light. Followed by a loss of peripheral vision like a tunnel closing inwards. Once the peripheral vision has gone the central vision goes next resulting in lots of cases of not being able to recognize face or see shapes in detail. The world we know becomes a pin-holed tunnel of haze.
I first heard that RP was in my family when I was just 7 years old. I wasn’t a part of the muffled conversations I sometimes heard behind closed doors. As I got older I was never told of my chances of being affected like my mum and one of my sisters were.

Although I found myself struggling to adjust to dark places in my early 20’s I never considered what might be the cause. I was too busy enjoying my life travelling the world working as a singer.

It wasn’t until that day walking out of the opticians that I realized I couldn’t deny my vision loss any longer.
I was 38 and had just begun a new cycle in my life.

I’d not long moved back to my hometown Salford Manchester after the break up of the relationship with my daughters Ellie’s mum.

I had been left homeless, not for the first time in my life and I was in a really dark place when I arrived in Manchester November 2011.

But the clouds lifted in February the following year when I met Amy.
We met through an online dating app which I’d never done before and instantly we knew there was a real connection. We loved each other from that very first night.

Amy had 2 sons from a previous marriage who were of similar age to Ellie and after a few weeks they met for the first time and we felt like a family instantly.

The next year was like a whirlwind. Amy fell pregnant in October 2012 and in June 2013 our son Austin came in to the world. But due to complications which almost resulted in Amy losing a lot of blood during labor, she was left with PTSD and postnatal depression.
Austin & Engagement

Though the first few months of Austin’s life were hard we grew stronger together as a family and on Christmas Day morning 2013 I asked Amy to marry me as our children unwrapped their presents. We started 2014 full of excitement as we’d set a date of getting married New Year’s Eve that year.

But in April our worlds came crashing in when I walked hand in hand with Amy out of that opticians.
The months that followed were some of the darkest either of us had ever experienced. I was declared severely sight impaired in May. I was unable to work due to being unable to drive any longer and as we desperately tried to get financial support we fell into debt which resulted in us using food banks and faced losing our house as we could no longer afford the rent.
An Anxious Existence

I fell into depression as my vision started to rapidly decline, I lost all my peripheral in 8 months. I felt anxious out in public and would step outside my door without Amy, often gripping tightly to Austin’s buggy as my chest tightened.
But though all of this despite her own battles, Amy held me up. She focused herself on planning our wedding. She was determined we’d stick to our plans of marrying on New Year’s Eve to ensure I’d have enough vision to see her walk down the aisle. She even made our table decorations to cut down on the costs and with the help of some family I knew our dream wedding would happen. On the days when she felt weak, I was there for her as she was for me. We took turns on being strong when the other one was a mess.
In the November before the wedding I was slowly trying to get myself together. Through the advice of my sister I had joined a few of the support groups on Facebook for people with RP. I found great comfort in being able to speak to others who truly understood what I was going through. I had been put on the waiting list for a guide dog and was taking cane training as I battled with my independence.
RP had took my pride, my confidence but the biggest thing it took was my purpose. Everything I’d done in my life had involved me being able to drive or get myself around independently, a thing most people take for granted but something that now filled me with fear.
An Unexpected Invitation

But through a group of people I’d connected with on one of the Facebook groups I found myself invited to sing for the first time since my diagnosis at an event for people with RP and Usher Syndrome, a condition related to RP but with the added symptoms of profound hearing loss. The night before that event sparked an idea that changed everything in me and brought me to where I am today.
Search For Song

The evening before the event I was in bed with Amy going over ideas of songs to perform when I had the idea to take a song that everyone would know but to change the words so it would have more of an impact with my new RP and Usher friends.

Rewriting A Classic

I chose the song Stand by me by Ben E. King because the opening line “When the night has come and the land is dark and the moon is the only light we’ll see” reminded me of what it’s like having night blindness or the early stages of RP.

20 minutes later I’d written a song which was to become the catalyst to a journey I could never have imagined possible and me regaining my purpose
I performed Stand By Me RP the following day and the response was overwhelming.
A few days later I recorded a version on a mobile phone at a friends house and uploaded it to YouTube and various Facebook support groups and the messages from people all over the world flooded in.

They told me I was able to describe how they felt living with blindness in a way they never could and how my word made them feel a little less alone.
Over 6K Views on YouTube
From that moment the words begin to spill out of me.

I began writing poetry about everything me and my family were going through dealing with my journey into blindness. Good days, bad days where I couldn’t face the world lay in my bed with the curtains drawn to avoid the pain of the glare from sunlight. No matter what I vowed to bare it all and write it in poetry in the hope it would connect with someone else struggling like me.

And it not only did, the comments and messages I was getting daily from people in places I’d never dreamed my words would travel was filling me with a new found pride.
On New Year’s Eve 2014 Amy and I married in front of close friends and family. We begun 2015 with a hope that our future would be filled with happiness despite what RP had in store.

My new found ability to write poetry about my vision loss had gone in to overdrive. I was writing everyday, sometimes 2 or 3 poems a day. The words were pouring out of my heart and using the notes app on my iPhone I began to build up a following around the world that would see the creation of my Stand By Me RP Facebook page which is now one of the largest online RP support groups in the world.
When I reached 99 poems I decided I’d make my 100th poem the story of everything that had come to that point. I entitled it “My Story.”
My Story

It was only just last year you see, when the news of blindness came.
And one thing that I knew for sure, my life would never be the same.
The thing that hurt the most that day, told I'd never drive again.
I knew one day get used to it, just didn't know quite when.
My purpose in the future seemed, to me now so unclear.

If anything was positive, then I refused to hear.
Retreated from the outside world, for feeling vulnerable.
Affected by the brightest light, as well as slightest dull.
Frustration grew inside me, as the bruises they increased.
As some friends slipped away from me, my social life deceased.

I tried to get the help I'd need, but no one seemed to listen.
To keep a roof above our heads, became my only mission.
To get most basic of support, the system made me wait.
I knew that one day help would come, and prayed it's not too late.
My wife picked up the pieces, whilst my children looked afraid.
This blindness taking things we'd built and future plans we'd made.
I reached out through my iPhone, to the online community.
I didn't know these strangers, Would soon feel like family.
I listened to their stories, all so similar to mine.
In seeing all their struggles, made me realize I'd be fine.
Then one night as I lay in bed, my goal was clear to see.
Use music to open hearts and minds, the birth of Stand By Me.
The lyrics flowed from pen to page, poured out my fragile heart.
And instantly I knew that this, would only be the start.
Spent each day writing poems, for the ones who feel alone.
We'd hold hands now together, take first steps outside our homes.
I pushed my words around the world, in to their warm embrace.
The messages received each day, from all my new found friends.

Began to help my pride return, the hole in my heart mends.
A dream I never dreamed before, to print my words in book.
To give back all the things to us, that this RP has took.
So here I am now asking you, to help me change my life.
And lift the pain of blindness that sometimes can cut like knife.
But all the while my journey in to darkness must progress.
The symptom of this RP is, we all see less and less.
Although my future fades now, like the world in front of me.
I'll change how they all view us, make them see how we all see.
I'll try to help those near and far, who wait for distant cure.
Live for today, not worry, bout a future still unsure.
So share my words around the globe, then one day they'll all know.
For this is the beginning and we have a way to go.
February 12th 2016

My first poetry book Stand By Me RP was released and as Amy and I were heading out to lunch to celebrate I received a phone call from the charity guide dogs to say they’d found me a match. The following week my book became the No1 release in both America and Australia in European poetry and I met my guide dog Christopher.
Dave & Christopher
New Best Friend

I'm waiting for my new best friend
Though we have never met
I never thought I needed one
but now my mind is set
And if I put my trust in you
You'll give me back my life
My confidence to start anew
Go out without my wife

Cause recently I have been afraid
to go out on my own
I'm tired of bumping in to things
They think I'm accident prone
But truth is I am losing sight
Fear soon be totally blind
and that is why I need you now
safe path for me to find

So when you finally meet me
all the months that you have trained
I know you will have questions
But in me they'll be explained
Our bond will be unbreakable
I'll have no fears to hide
We'll learn to trust each other
My new found friend to guide.
Christopher’s Impact

Though the poetry was retuming my pride and my new found partnership with Christopher was retuming my independence. There was still plenty of good and bad eye days for Amy and I to cope with in our first year of marriage.
We received the results from genetic testing that the type of RP I had meant there was a 1 in 2 chance that my daughter Ellie and our son Austin who at that time wasn’t even 2 could lose their sight when they were older. This filled me with guilt and still to this day is the hardest part of living with RP for me. But I kept my vow and wrote about every emotion, no matter how hard. For my son Austin I wrote “Shift This Cloud.”
How do I break the news to what I may have done to you
Won't know for sure but doctors say the odds are 1 in 2
I look in to your eyes and watch for signs I hope aren't there
Pray this RP will end in me no faulty gene is shared
This tunneled world I live in hope one day won't be your view
Don't follow in my steps or place a foot inside my shoe
The battle for acceptance will be just a story told
With perfect sight not hurt by light clear vision break the mold
I carry heavy guilt through sleepless nights and secret tears
I wait to know the answer ticking clock of RP's fears
But if in future blindness does come knocking at your door
I'll lead you by example show that life is so much more
My son be proud we'll shift this cloud and dance in heavy rain
I'll show you all that's possible strong heart and long white cane
With poems raise awareness this will be my legacy
Four words that travel round the world my Stand By Me RP
So years from now when you're fully grown
if blindness burden shared just look at what your Dads achieved
So you'll be more prepared.
February 2017 I released Stand By Me RP volume 2 and once again it became the No1 European poetry release in both America and Australia but this time in its first day. My sight was now down to around 5 degrees remaining but my writing was going from strength to strength. I'd adopted the name The Blind Poet and my Stand By Me RP mission has now become not just about the poetry. I was still writing poetry everyday but I was also writing blogs and speaking to people all over the world who were struggling coming to terms with blindness by offering a kind word my friendship and support in any way I could. My new found purpose was healing me and my determination to help people was stronger than ever.
I believed that it was ok not to be ok and there is great strength in being able to talk about the days we’re not as well as share our strength on the days we are.

The impact my poetry continued to have was humbling and at the same time surreal to me.

Hearing the stories from people about how they’d use the books to communicate to loved ones how they feel when unable to find the words themselves or how certain poems just resonated with them in a way they thought wasn’t possible. People would often say it was like I’d written their deepest thoughts into the poems.
One person's story which would stick with me was that of a lady called Suzanne Clark. She'd worked as a nurse for years giving palliative care until her diagnosis with RP. She fell into an all too familiar cycle of anxiety and depression until she went online and stumbled upon this poem.
It’s ok to be scared
it’s ok to be afraid
For all the sight we’re yet to lose
as our loved ones faces fade
But don’t let that fear consume you
Push the ones you love away
Despite all that’s gone
to them hold on
Through the fog they’ll lead the way
But if friends and family leave you
Because they don’t understand
Just remember you are not alone

This life never goes as planned
Though we may be total strangers
and reside on different shores
Through these poems know your story
For my tunnel’s Same as yours
It’s ok to be scared
It’s ok to be afraid
Though you may not see
You’ve a friend in me
that will never be betrayed.
That poem just sparked something in her that inspired her to turn her life around. We still regularly speak and she’s now using her previous skills and experience as a nurse to volunteer for the UK charity RNIB supporting others with sight loss.

Like a pebble rippling through the water I’ve learned how powerful these poems can be for those reading them at just the right time.

The stories of their impact reach me every day and I’ll never take them for granted.
Other Testimonials

- Jackie Wilson, a young girl from Amarillo in Texas, who at the age of 6 used lines from my poems to come back at bullies.

- A teenage girl with Usher Syndrome who took an overdose but after I wrote her a poem reminding her of why this world of haze and blur is still a wonderful place where she can achieve her dreams. Now that same girl is inspiring others with her story.

- We’ve all had a particular song that has gotten us through a broken heart or dark time in our lives and that’s the same with poetry.
Music, song lyrics and poetry are all the same to me. They have the unique ability to heal the heart, to mend the soul like few things in this world.

This is my aim with everything I do in life.

To help others through my poetry. To reach more people and replicate the impact these books have already had and with the support of people like you I know I will.
The last 6 years have given me opportunities I never dreamed of. I released Stand By Me RP volume 3 which was the last in that poetry series in February 2018.

I have spread my Stand By Me RP mission via tv and radio shows. I’ve spoken at events as my various ambassador roles for Henshaw’s in the UK and other organizations.

I’m more determined than ever to be a voice for others within the blind community.

My next exciting project is a series of children’s books about a visually impaired boy and his guide dog based on my son Austin who’s now 6 and my guide dog Christopher.
I’d like to leave you with this poem that pretty much sums up all that I’ve spoken about today and the message I try to communicate.
All the tears that I have shed and scars upon my wrist have made me who I am today prepared me now for this
I wouldn’t be so strong
if I had never failed before
I’d still be isolated scared to step outside my door
I’m not saying that I’m over this those bad eye days still come
For even now whilst reading this I’m blinded by the sun
I’m anxious and my chest is tight I feel like giving in
But deep inside my heart I know I’ll never let this win
I promised just four years ago when blindness certified
Through poetry I’d share my tale to others far and wide
So no one ever need to feel alone with losing sight
Explain their thoughts to loved ones through these verses that I write

But never did I imagine that my words could do so much
They’ve healed the hearts of strangers
Opened doors with slightest touch
I’ll be a friend My pride will mend
My purpose clear to see
3 books will be my legacy My Stand By Me RP
I know that soon these faces that I look upon today
Will disappear but I won’t fear
These memories will stay
My wife my sons my daughter
In here will never age
My love for them is printed in each poem verse and page
When last has gone I’ll carry on to make my family proud
To be a voice for others help them lift this hazy shroud
Inspire them to grab a cane and step outside their home
4 words each poem’s message saying
YOU ARE NOT ALONE