

## Usher Syndrome Coalition | Timothy Chambers shares how one sees with Usher syndrome (retinitis pigmentosa)

---

Hey, everybody. I am Tim Chambers. I am a professional artist, and I have Usher 2A, and I thank you for the opportunity to introduce myself.

I have had Usher syndrome for all my whole life, obviously, but I was diagnosed about 27 years ago when I was 30. I went in for a routine eye checkup, and one thing led to another, and next thing you know, they say, hey, you've got this eye disease. You're going to go deaf and blind. Didn't really see that coming. But I've learned to grow a lot from it. So I'd like to share what I've learned and a little bit what I'm doing.

So I have about 17 degrees of vision right now, which is about 10%, or less than 10% of what normal vision is. I have a hard time seeing in low light, and some colors get mixed up. Like, I have a hard time seeing yellows and purples sometimes. And of course, as an artist, there are plenty of funny stories to go along with that.

So let me show you about my hearing. On my hearing, I have what they call a base curve. So without my hearing aids, I can hear drums, I can hear my dog barking, and maybe someone pounding on the floor or a door.

With my hearing aids, I still depend a lot on lipreading. But I will hear vowels, and I can hear-- let's see, what else can I hear? I can hear music, which is great, and TV, regular conversation, but again, I depend on lipreading. I can't hear the birds or the rustling leaves there at the top of the screen in that graph, but I can whistle [WHISTLE] and I can hear that. So there's always little adjustments that come along the way.

What I've been doing for the past 30 years is painting portraits. And I grew up watching my father paint in the studio. He's a professional artist as well. And I thought, that's what I want to do. And so with his blessing, I had good training and everything. And so I've earned a living as a portrait artist.

So my favorite painting is outdoors, and outdoors at the beach is great. I love the colors of nature. And I studied with an impressionist for a few years. That's a great story. And I learned to see color. And so it's just-- it's funny.

God has a sense of humor when he gives an artist this gift of painting and, like, oh, my goodness. Thank you so much. And then he's told, by the way, you've also got an eye disease. It definitely makes things interesting.

I also paint a lot of corporate portraits. And I meet a lot of really amazing people, not just adults but amazing kids as well. And what I really love about portraiture is that there's always a story. And this portrait of Chuck Colson, there's a neat story behind it. There's a story in how things are arranged. There is the newspaper, *The Washington Post*, of course. If you know anything about Watergate, Chuck Colson was a central character in that with Nixon and everything.

There's the Bible, which represents his faith. You have the pen and the papers in his hand, which is his current manuscript at the time. At that point, he had written 23 books. On the table to his right, he had-- I said, wait. What are your three favorite books that you've written? And he told me, and so I have those there.

And there's a funny story with the painting. I had to deliver it for this massive unveiling before it was done. And there was the path that was in the grass behind him that was crossing. Well, I forgot to paint it coming out the other side, because I had to change the background at the last minute.

Someone came up to me and said, oh, is there a symbolic meaning behind a path just going to one side of Chuck and not the other, like all truths end at his head? I said, no. I just forgot to paint the other part of the path. So there's always sometimes a funny aspect to a story.

I paint a lot of kids. The great thing about kids is you see who they really are. And we adults know how to sit up right and sit proper, and the kids, you get what you get. One of the great things about kids' portraits that I learned is I'm not painting who I think I see necessarily, but I'm painting who the mom thinks she sees.

So I'm shown photos. I'm like, hey, this one's a great photo for the portrait. And the mom will say, that's not my kid. I'm like, of course it's your kid. But no, I have to find out who is that child that's in that mom's mind. That's what I'm after.

I studied with an impressionist for a few years. And an 80-something year-old impressionist who was-- he's one of America's greatest painters ever. And he taught me a lot about color. And ever since, I've been smitten with painting landscapes.

Painting portraits is incredibly challenging, which I love, but painting landscapes is like having dessert. Obviously, there's no mother saying, no, that's not the way it looks or that tree doesn't go there. It's just pure fun. I'm out there responding to the beauty in front of me.

This is a scene not too far from my house, the one that's up on your screen right now. And it's on the

Appalachian Trail, which runs from Georgia all the way up to Maine. And we're about not quite halfway. But the beauty on it is amazing. And I love all the hikers that I meet along the way.

Here's me in my studio, and I'm working on a portrait that I call a statement portrait. And the title of it is, *Please Don't Look...Away*. And the title of that tells the story on it. The two people in it, Yazmin and Dr. Kizilhan.

Yazmin is from Syria, and she was-- ISIS came in and just totally displaced 400,000 of the Yazidi people. And they were homeless, and the ISIS soldiers oftentimes would take women and just capture them and rape them repeatedly. Yazmin went through that. When she escaped, she escaped to a refugee camp.

And at one point, she thought she overheard the voice of one of the men who had raped her. And she snapped and goes, I can't take this anymore, and she doused herself with gasoline and set herself on fire. And you can't really see it in the painting from this distance probably, but she suffered burns over her whole body.

Dr. Kizilhan enters the picture with a team from Germany, where they came to rescue over 1,400 Yazidi women and children and bring them back to Germany for medical healing, counseling, and so forth. And Yazmin is one of them. And they allowed me to tell their story in the painting. And it's just amazing. She is doing really well now after a number of surgeries.

What I begin to have done is take my portraits and my landscapes to the next level. I was talking with my retinal specialist at Johns Hopkins, and I said, hey, I'm trying to see colors like I used to. Are there special glasses for that? And what he had said was, hey, Tim. Why don't you show us how you see. Paint the world as you see it, not what you think it should be or what it used to be for you. And so that's what I've begun to be doing.

The photo on the left side of your screen is how the scene looks to someone with normal vision. I asked my wife. I said, hey, let's take a picture, and I want you to match this so it looks like what you're seeing. And she did, and that's what she saw. Cameras don't do adjusted for color, but the photo on the right is my painting. And what that is is a quick study to show, here's how I see that scene.

And you can see there's a difference, especially where the light is coming over the tops of the trees, where you might see the distinction of all of the leaves at this top. For me, I don't. The sunlight just kind of obliterates that.

But let me show you some more pictures about that. So here is-- before we get into that, let me just talk to you about some other artists. Edgar Degas was one of the original French impressionists, and he had fine vision. So the picture on the left is of a figure study he did, *Woman Combing Her Hair*. And his vision was clear.

But then he began to lose the acuity in his central vision. And years later, everything was blue to him. And you can see the difference in his painting. The one on the right, *Woman Drying Her Hair*, is more coarse and lacks the detail that he had in his earlier paintings.

Another French impressionist, Water-- Walter. Claude Monet. I was thinking *Water Lily Pond*. Not Walter Monet but Claude Monet, he also had eye trouble, and he had cataracts. He didn't want to submit to having surgery, because another artist friend of his, Mary Cassatt, had cataracts, and it didn't go well. And this is over 120 years ago. So times have changed. But with the cataracts, his visual is getting worse, losing acuity and his color sense. And let me show you what I learned about this.

If you take a color scale, like those shown on your screen, on the left side, that's what a color scale would look like to someone with clear vision. And that painting corresponds with it. The colors are clear, the acuity, the details are sharp.

Well, 20 years later, with Monet's cataracts getting really bad and very brown, that's what the same color scale would look like to somebody with very advanced cataract. Dingy, brownish, and fuzzy. And that shows up in Monet's painting.

So this is the color scale, what it looks like to me. I thought I was going to run the same test. And so what I did is I took that color scale, and I compared it to what it looks like indoors when my eyes are adjusted to the light. And what you see on the right side of your screen, that's me holding that color scale. It's a medium-gray background with crisp colors all the way across. I can see them all distinctly and crisply.

I have a little bit of a hard time with the four green bars that are on the left side. They go from being yellowish-green to bluish-green. In certain lights, I can't tell the difference on those. In other lights, I can. So like an incandescent light, I can't see a yellow highlighter pen's markings on a book, a page that you're reading. But bring it by a window, in daylight, and I can see the yellow just like that.

So now, let me show you what happens. So this is the color scale inside by daylight. That's what I see. Now, if I was to step outside, and let's say it's midday and the light is just like you see here on me. And

I step outside into bright, noon-day sunlight, that's what that same color scale looks like to me.

It's almost like I'm looking through this white haze. Everything gets lighter. Even the black, it's no longer black for me. It's kind of like a light-medium gray. The only color that is-- or rectangle that's distinctive is that white one. Everything else is kind of hazy, like you're looking through a dirty windshield with the sunlight beating on it.

Now, what happens when I step from that bright light back inside? Let's take a look. So at the bottom of your screen there, you can see the same color scale now, and that's what it looks like to me when I come inside. Everything looks really dingy. It looks dark. I have a hard time making out the distinction, the edges of all the rectangles or the squares. Even the white is far from being white. It's kind of like a dingy gray.

So that's what happens when-- and I don't quite understand the scientific part of it yet, but I'm working on that. And I will be sharing that in my exhibit at the USH Conference, Virtual USH Conference.

But basically, when you have someone like me who goes from one lighting condition to another, it really helps if you're patient. You know, instead of just start walking, I can't see when I first go outside. It's just too bright. And same if I go inside. Like, if we're outside and we say, hey, let's go in here and grab a bite to eat at this pub. It's really dark. It's like all black for me for the first minute or so.

And so what my wife would do, or friends, they'll just kind of do small talk with me for a minute and then we'll kind of say, hey, can you see now? Can you see the tables? And we're not going to walk into somebody or walk into someone's table. Yes, and so then we move forward. So it's just something to keep in mind when you're with somebody like me.

Now, here's the fun part. Putting the scale aside for a moment, what I did is I decided to test how things look. So I found the church steeple not too far from my house I can walk to. And I set up my easel, and there's me painting. And you can see the church steeple in the background.

And what I did was I painted that same church steeple in different lighting conditions, kind of like Monet painting the haystacks or the cathedrals in different lighting situations. I did that with the church steeple. So the one here, that's a finished painting, and that's what that scene looks like to me.

So you can see the distinction of the whole church and everything, where for me, on the left side of that screen, you can see that. In bright sunlight, I can't see that. I can see the picture now, but in

bright sunlight, when that sunlight is coming out from behind the steeple, the sunlight just kind of obliterates everything. I can't see the roofline. It's almost like there's yellow pixie dust just spread, sprinkled through the whole scene. And that's what it looks like to me.

So let me show you some other examples. So on here, there's four scenes. Same church steeple but different daylight situation. The one on the left is *Twilight*. So the sun hasn't come up yet. Night is still kind of lingering, and I can see that steeple, and I can see the church building.

I can see the edge of the roofline and the building contour and everything, no problem. Things still have kind of a-- of course, the colors aren't bright, like in a middle of a sunny day or anything. But I can see everything.

Now, *Sun Hiding*, the second from the left there, that's where the day is starting to begin. The sunlight starting to come up, and it's behind the steeple dome. So there's no bright light just blasting away. But the sky is getting lighter, and it's starting to affect things.

The third from the left, *Sun Peeking*, now that's like in the previous slide that you saw, where the sun is coming from behind the steeple, and now it's starting to dominate. Now sunlight is sending that yellow pixie dust over everything and edges get obscured.

And then, the one on the far right, *Sun High*, that's where the sun is up in the sky and everything's bright. That's where you have your sunglasses on and you can see, for me, the top of that steeple is lost in the sunlight. And everything else has this really light cast from the bright sky on it. So that's one example. Let me show you two more.

Here are two. One is the same steeple on a cloudy overcast day. That's on the left side. And I can see the steeple, everything clear. Has that cloudy day, grayness about it, like it's about to be misty out almost. And then on the right side is that *Sun Peeking*. Now you can compare it. Same steeple, but that's how different it looks to me.

And I don't know how it is for other people with Usher. I've found that everybody with Usher has different experiences. Some people feel better when they have a baseball cap on. Some people say no, that doesn't help me. So it can be very independent from one person to another.

The main thing is, if you know somebody with Usher, take the time to just ask them. Put yourself in a different situation and say, OK, when you're looking at this, describe what you see. You know, even looking out a window with window panes, ask them, can you see the window pane? Sometimes the

light just kind of wraps around a window pane, and we can't see that crisp window pane like you can.

What else? You could ask them what it's like in different situations, in a restaurant, at nighttime, in the moonlight, with the car shining the headlights, on a bright day, a sunny day, a hazy day. The more you ask, the more you understand, and it really makes life easier for people like me. And it can be kind of fun to learn those things as well.

So here's two other paintings. These are not part of the steeple thing, but you can see, the painting on the left, I'm just in love with the color on these roofs in town here. My goal in that painting was to capture the bright sunlight coming down on the roofs. I just think it's-- I love sunlight. I love warmth. So that was my goal, so that someone would look at that and say, oh, that feels like a hot summer day.

The painting on the right is called *A New Day*. That's also in the summer. And that is at sunrise. And I was getting the sense of sunlight coming up from behind the buildings. And you can see it's like in that steeple painting, the sunlight just kind of makes the trees and the roof lines and the chimney start to get shrouded in that yellow pixie dust, the sunlight pixie dust again. Fairy dust maybe.

But what's funny is, if you look at the foliage in the front of the painting on the right, I can see it clearly. It's crisp. It's defined, and that's because it doesn't have the sunlight right behind it.

Now, how can that help you? Well, somebody like me, when you're standing in front of a bright window or something bright is behind you, you become very hard to see. But if you're standing in front of something dark, that makes it easier for me to see. If something bright is shining on your face, but you're in front of something dark, that's the easiest way for me to see your face and, in my case, lipread.

Why I'm honored to share my work with you at the 12th Annual USH Connection Conference, in addition to sharing how a person with Usher sees, you're going to find a host of original paintings and prints that will be for sale to assist the coalition's efforts to reach and help people.

So this is just a small selection of the paintings that I have available. There will be an online gallery, and these paintings can be purchased and shipped to you.

Now, I've been a full-time portrait artist for 30 years, maybe longer if you count all my training, and despite Usher syndrome, I am painting better than I ever have. And part of it is because I can see what's in front of me. So I can see you, and I also have a lifetime of knowledge up there and experience.

So if you are interested in having a portrait painted, I'd be happy to talk to you about that, and I am very happy to travel anywhere in the world, especially even exotic vacation spots. That's a joke. But I am willing. I love traveling.

You also have prints there. And these are a fraction of the cost of the original paintings, obviously. But just so you know, a generous portion of all sales of any artwork that you purchase from me will be donated to the coalition to help find and connect the global Usher syndrome community, moving us all closer to treatment and a cure. For more information, see the Usher Syndrome Coalition website, you'll find details there.

I really look forward to seeing you at the virtual conference. I know we all thought we would be in Texas this next month, but I think, what it sounds like, they've got a great week planned for us virtually. And the good thing is, we don't all have to wear a mask, and so I'll be able to lipread anybody who's talking. So that's really good.

For more information, go to [usher-syndrome.org](http://usher-syndrome.org). That's usher hyphen syndrome dot org. You'll find information about the conference, about the exhibition, and obviously a plethora of helps and resources for anybody with Usher or somebody who knows somebody with Usher.

If you'd like to find out more information about me or read my story, go to [timothy Chambers.com](http://timothy Chambers.com), and you'll find everything you want there. Thank you for spending the time with me, and I hope you have a terrific conference. And please check in, and I'll be happy to share more of what I'm learning in my study about how somebody with Usher sees.

Take care, and thank you so much for spending the time. And again, I hope you have a great conference, as I try to figure out how to turn this exhibit off. And somebody like me, you know, you have to keep scouting around a computer. And there we go. So everybody, take care, and have a good conference.