

---

# Prelude

After presenting to the Twin Cities Chapter for the Blind in March 2023 regarding my experience applying, training, and living with a guide dog, I found out that my niece was writing a research paper on Usher Syndrome. It was for her biology class (Genetic Disorders) at the University of Iowa. I was so moved in learning this that upon spontaneous impulse, I offered to travel to Iowa City to speak to her class of 120 students. She immediately reached out to her professor, and the next thing I knew, was that I had another presentation opportunity for an entire hour. Call me Professor H, if you will. And of course, my handsome assistant, Comet, would come along for the gig. I recruited my mom as our driver and caretaker for the 4-5 hour trek. After a few days of creating a powerpoint slide show for my presentation, I was ready. Then there was this dilemma on whether I should wear my (rival) Minnesota Gopher sweatshirt just to see what kind of a reception I would receive. So instead, I took care of that in one of the powerpoint slides of my presentation. When that slide appeared on the big screen, there was some laughter and some scattered comments. I turned to the professor and said, “I think we better move on to the next slide before I lose my audience”. The professor replied, “I think you already did!”. A fun moment for sure.

The professor was very accommodating in changing the slides for me throughout the presentation, and even took us out to lunch. We learned that he is a dog lover himself, having 2 dock dogs that compete. Dock dogs run and jump (far) in their attempt to snare a target hanging over a pool of water. Like dock dogs, sometimes you need to take a leap of courage, even if it's far away, to achieve that special moment, or even something greater. What a fantastic experience this was!



# Genetic Disorder: Usher Syndrome

By Shawn Hewson

University of Iowa

April 25, 2023





---

# Goldy Gopher says HELLO!



---

# Perspective

If you are to persevere in your struggles and overcome obstacles, it is essential to step out of your comfort zone. This allows you to grow in strength, confidence, and courage over time.

Be honest with who you are and what you need. Because at some point in time, “getting by” isn’t good enough anymore.

(Shawn Hewson 2018)

# Introduction



Family



College



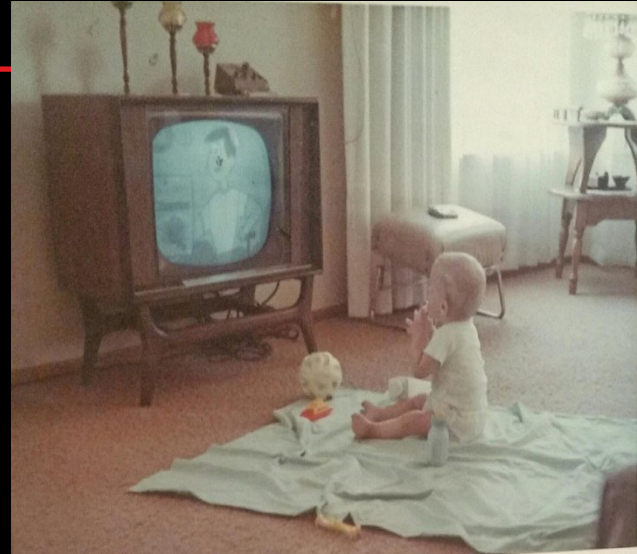
Career

# My Diagnosis

1972 (age 4)  
Hearing loss  
(Hearing  
Aids)

1975 (age 7)  
Vision loss  
(Retinitis  
Pigmentosa)

Usher  
Syndrome





# My Ears



**Cochlear  
Implant (L)  
70% clarity**

**Hearing  
Aid (R)  
15% clarity**

**Roger  
Pen**

**Background  
noise**

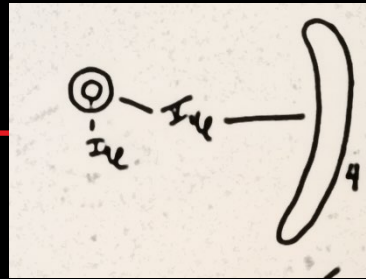
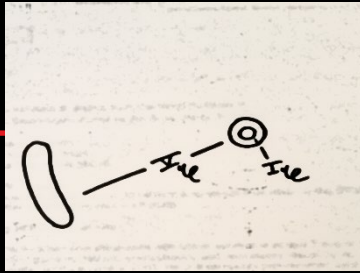
**High/Low  
pitch**

**Lip  
reading**

**Consonants  
& Vowels**

**Music  
TV  
Phone**





# My Eyes



20/100  
central

12-15 degree  
peripheral

Night  
blindness

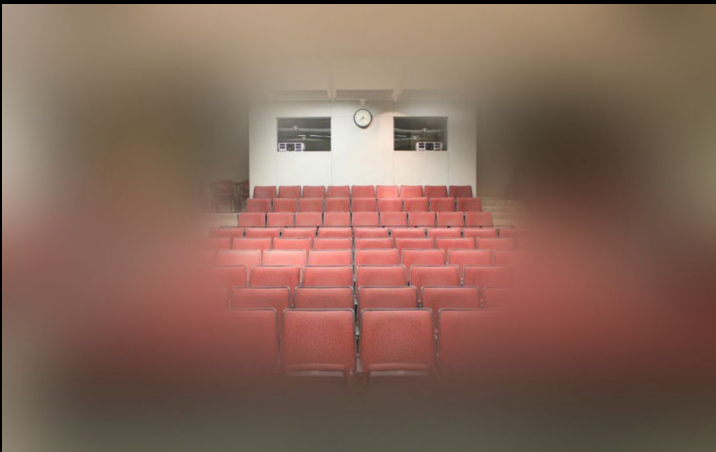
Color  
blindness

Bright light  
sensitivity

Slow  
adaptation

Contrast

White cane  
Guide dog



# Navigating life with Usher Syndrome

Anxiety  
Identity  
Involvements  
School  
Workforce  
Sports  
Doctors  
Marriage  
And.....



---

# Navigating life with Usher Syndrome

...parenthood



And, so everybody's there



---

# Story Time

---

---

Astronomy Class

---

---

The Stroller

---

---

The 16<sup>th</sup> Hole

---

---

Job Interview

---

---

Train!

---

---

Cookie Jar

---

---

Spider Man

---

---

Blind Hockey

---





---

# Perspective

If you are to persevere in your struggles and overcome obstacles, it is essential to step out of your comfort zone. This allows you to grow in strength, confidence, and courage over time.

Be honest with who you are and what you need. Because at some point in time, “getting by” isn’t good enough anymore.

(Shawn Hewson 2018)



---

# Questions?

