

## Section 1: John

### Chapter 1: In a shimmer

Everything changed with a shimmer.

John Orrock Christiansen, my father, came into the world on September 21, 1924—a ten-pound, husky baby boy. John was the fifth child and second son born to Hans and Maud Christiansen, my grandparents.

He was born at 310 North 300 East in Beaver, Utah in the Munford I Home, as my relatives called it. Small communities back then didn't have hospitals to go to, and it was too far to travel while in labor.

John was a strong healthy baby, and a welcome addition to the family.

Around the time John was able to sit up on his own, Hans and Maud noticed the glimmer in one of John's eyes when the light hit it. Maud and Hans looked in their other children's eyes, but they didn't have the same glint. Concerned about what it could mean, Maud began to experiment with him while nursing. She'd cover one of his eyes at a time and moved something in his line of sight. She could see that his normal eye followed the movement while the eye with the gleam just stared blankly.

It didn't take her long to realize that her son couldn't see out of that eye. Hans and Maud took John to the local doctor, Dr. Shepherd. He told them of another child that had a tumor in their eye, called Glioma, that had died from the condition. He assured them this was probably not the case with my John, but they were still concerned enough to see a specialist.

As Maud feared, the multiple specialists they took their son to all confirmed he had Glioma on his eyeball.

Glioma, which would later be called retinoblastoma, is a rare child cancer affecting the eyes.

Only about 200-300 children are diagnosed with retinoblastoma every year in the US.

Retinoblastoma affects infants and children under the age of two. Diagnoses are rare in children over the age of six. 1 in 4 cases impact both eyes. In the 1920s, the prognosis wasn't great.

"What are we supposed to do?" Maud asked. "I've heard children die from this."

Was their young son going to be taken from them so soon after coming into this world?

"We can remove the eye that has the Glioma," the specialist explained. "He will be partially blind, but as long as the Glioma isn't in his optic nerve, he has a chance to lead a relatively normal life."

"He's only twenty months old! Why did this happen to him?" Maud asked her husband.

"This is the only way to save his life," Hans assured.

"I have to warn you that even if this procedure is successful, there is a chance the tumor could grow back or infect his other eye. We won't know he is out of the woods for sure until he is about six years old," Dr. Neher, the physician performing the procedure, informed them.

It was devastating news. They could save him today, but would it matter in a few years?

Hans and Maud went through with the procedure. They knew this was John's best chance at survival. Even as a tiny baby, he was still fitted with a prosthetic eye that matched his real eye,

which was blue. As long as he remained healthy, no one would ever look at him and know he was partially blind.

Hans and Maud prayed that John was through this impossible challenge, and they turned their attention back to their family and Hans's dreams.

## Chapter 2: A dream and a nightmare

Hans, dreamed of buying a farm for his family and homesteading the land.

It was the same dream that his parents came to America seeking.

Hans Anthon Christiansen was born to Hans Anton Christiansen and Ane Kirstine Olsen in 1883.

From the time his family settled in Utah, they seemed doomed to experience hardship from generation to generation.

Hans and Ane, originally from Denamrk, both grew up working on farms. They even met working together at a large dairy and fell in love. Hans even converted Ane to Mormonism (The Church of Jesus Christ of Latter-Day Saints), which inspired their relocation to Utah in order to be with the other saints.

Married in 1880, Hans and Ane were living in Nephi where the language barrier was brutal.

They were taken advantage of while trying to buy a home and farm. When they couldn't make their payment, the owner swindled them out of everything they had—even Hans' pants!

They persisted and were able to settle down and start a family. Their first child, a girl named Clara, was born in 1881, my great-grandfather, Hans Anthon Christiansen was born in 1883, and Ole was born in 1885.

And then, tragedy struck again.

Clara, not even 5 years old, died a tragic, early death from typhoid fever in June of 1886. Her father—Ane's husband—passed away just ten days later. Ane was left a widow of two small boys, one of which, Ole, frequently fell ill.

Little Hans was forced to grow up quick and become the head of household. He put his own schooling on hold so he could support his mother and help raise his brother.

By the time he reached his mid-twenties and Ole was an independent young adult, Hans had return to school to get a proper education and had a teaching job. He met Maud Ellen Orrock, another teacher, and fell in love with all 5 foot 1 inch of the feisty sparkplug she was. They were married in 1911 and were both eager to settle down and start a family.

Hans hoped the hard times were behind him while getting back to his farming roots.

He came with his family to Beaver, Utah for a great job as the county agricultural agent.

Beaver is a Southwestern Utah town situated in a high, broad valley, surrounded by mountains, some of which peaked at over 12,000 feet. The cooler climate and 6,000-foot elevation made for better livestock conditions than agriculture. Although it was small, Beaver was the birth place of western outlaw Butch Cassidy and Philo T. Farnsworth, who invented the television.

As their family continued to grow, Hans purchased 640 acres, roughly one square mile, located five miles northeast of Beaver at North Creek. Across the creek, up a winding, broad, worn dirt road sat a little house with just two rooms.

This might have been Han's dream but it was Maud's worst nightmare! Maud loved living in town where she had friends and community.

It was the perfect place to grow a family, but, as it turned out, not a very good place to farm. And shifting to a life of farming and homesteading presented challenges for the family.

Originally, the goal had been to build an addition on the house and make it big enough for the family. But Hans's family was headed for another great struggle.

### Chapter 3: With a glimmer

When the glimmer appeared on John's eye, it took priority over building a larger house. John's condition was like a massive gut punch that paved the way to an emotional rollercoaster of heartache and economic stress.

The medical care and surgery were a massive financial setback, the first of many while the family attempted to realize Hans's dream for homesteading.

Without indoor plumbing, the family had to find a way to get water to the house. That meant they used an outside pit toilet—a hole in the ground to collect excrement covered with a toilet seat or squatting pan—which Hans had to periodically clean out, a task that was unpleasant, smelly, and disgusting. Hans surveyed the area but because it was so close to a hill, he didn't think they'd be able to dig a well. Instead of having a well, he built an 8-by-8 cistern with a pump attached. That once problematic hill became an invaluable asset, water running down it to fill the cistern.

Maud was never a fan of the cistern. It was always her least favorite aspect of farm life, especially since she had to clean it. Down the manhole she'd go, scrubbing and cleaning the basin a few times a year when it emptied out. A very unglamorous job for a lady. She never felt like she could get it clean enough.

Space was another serious issue in the small house for a family of seven. When the weather was nice, my aunts, John's older sisters, Maureen, Ion, and Louise, would often sleep outside in a cramped little tent when the weather was warm because there wasn't enough room inside. Hans managed to scrounge up a temporary, half-solution in the form of an unfinished one-room house.

He loaded that single room onto a wagon and had it hauled across the farm, much to the joy and amusement of the children.

It was positioned at the back of the house as a new bedroom. Everyone was excited to be getting more space. There was one major drawback, though. No heat, no insulation, and no interior walls! That new bedroom was freezing. The entire family would pile in when it was cold, snuggling together and clinging to wool blankets in the wintertime. The only thing colder than the bedroom was the brave adventure to the outhouse.

It would be several years before a kitchen was added and the “new” bedroom was split into two separate rooms.

Between John’s Glioma and the struggles of building up the farm, Hans couldn’t manage his teaching job on top of it all. Hans felt like his attention and energies were split and they’d never get ahead if he had to put half his time into teaching and half into the farm. In 1929, he decided to leave his teaching job and focus on the farm. The family carried a big debt from buying the farm and they couldn’t pay the debt and have money for the necessary building costs.

The farm itself had become productive. There was a great garden with watercress, rhubarb, and other vegetables. The farm supported mutton and there was plenty of milk to go around. It gave the family food, even if a limited selection.

But that fall, The Great Depression struck.

Where there’d been a little money before, suddenly there was none! They should have been able to sell the farm’s produce—but no one had any money to buy anything. Hans regretted leaving his teaching position.

He regretted a lot of things...

The Christiansen family was fortunate to have food on the table, but there was no money to expand their home or their farming operations.

Then, in the midst of financial hardship, just three years after the first spot was discovered, little John started having problems with his left, healthy eye.

#### Chapter 4: Aren't those doctors so mean?

After a glimmer was found on John's left eye, Maud and Hans were faced with an impossible decision: Remove John's second eye or let the disease take his life.

"I'm not going to stand by and watch my son die," Hans argued.

"But to leave him completely blind? Death is better than total blindness," Maud reasoned.

"He's our son! We have to give him a chance," Hans insisted.

"He'll live in total darkness. I'll never see that spark in his eyes ever again. That's not truly living," Maud stood firm in her opinion.

Eventually, Hans's argument won out and Maud acquiesced, and John was scheduled for his second operation. At four years and ten months old, John had to say goodbye to a world of light, colors, shapes, and beautiful imagery to live in total darkness.

Maud sat by John's side as he came out of the anesthetic haze post-surgery.

"Mama, Mama, where am I?" he asked, looking around without being able to see. "What happened to me?"

John's face was wrapped in bandages, his hands tied to the bed so he wouldn't scratch at or tear the bandages.

Maud couldn't open her mouth, or all her sadness would spill out. She sat beside him, unable to speak or move as John repeated his question two more times.

“You’re in the hospital, John,” she explained, finally. “There was a harmful sore in your eye and the doctors had to take your eye out to get rid of the sore.”

“Really?” John asked, excitedly perking up. “When will they put eyes in me that will let me see everything?”

Maud, holding back her sadness, spoke softly. “You can’t get new eyes. We can only see with the eyes we are born with and both of yours had to be taken.”

John’s mood changed quickly. “Aren’t those doctors so mean? They took my eyes away!” his voice sobering to the reality, even at four years old.

“I’m so sorry, John. We did everything we could to save your eyes but there wasn’t anything more we could do,” Maud explained to her son. “You’ll have to learn to use your ears, feet, and hands as your eyes. You’ll still be able to do everything you could before, just differently.”

It was a heartbreaking day for young John, his mother, and father. But Maud and Hans didn’t want John to feel bad for himself. They’d already agreed that John would never hear them cry over him or feel pity or shame for his blindness.

“Now, John, you won’t feel bad anymore, will you?” Maud asked as they finished their conversation in the hospital.

“No, Mama, I won’t,” John agreed.

For years after that conversation in the hospital, Maud worried that John would grow up to resent her and Hans. She was haunted by the thought that he would one day ask, “Why didn’t you let

me die when you had the power?” She never wanted him to be unhappy with his life and his disability and it pained her to think that she would be the one he blamed.

While Maud struggled with her feelings over John’s future, Hans struggled with his faith. The Mormon church had been very supportive through John’s sickness and surgeries. They’d been a solid, stable community for Hans and Maud to lean on. All the prayers in the world couldn’t save John’s eyesight.

With the financial complications and John’s blindness, Hans wondered why unfortunate things kept happening to his family. The questions and frustrations and doubt made him question his faith. They had prayed so hard ...

Why had God let this happen? Had God abandoned his family? Were they being punished for something?

Faith and his devotion to the church won out in the end—he felt lost enough, and he would feel even more lost by leaving the church or giving up on his faith. But John’s blindness tested his father’s faith like nothing else ever would.

## Chapter 5: Navigating a darkened world

As it turned out, John only had a handful of memories of being able to see. The first was a memory of color—blue and green on cars. He also remembered seeing his mother’s face. He was maybe three or four at the time, and he recalled seeing her in the kitchen and noticing a dimple on her cheek, and that she had been cooking. He remembered her looking down at him.

He also recalled a cold day, late in the afternoon, seeing his dad walk in all big shouldered wearing a burly black coat. It was how John always remembered his father.

When Maud came home with his younger brother Robert in a blanket, John recalled looking at his mother and saying, “Put him down and let him run around. Let’s see him!” Everyone laughed and laughed at the suggestion that a 12-day-old infant was going to be able to run. In those days, women were sometimes held at a home where they gave birth, and they would typically stay there 12 days.

Finally, John vividly remembered a heavy, thick, muddy rainstorm, and seeing a wagon wheel with its outer rim and spokes sunk deep into the mud below the axle.

There were a lot of challenges in raising a disabled boy in the 1930s. Not just within the family but from outside the family. Hans and Maud never wanted John to feel bad for himself or feel like the family pitied him. His parents and his siblings never cried around him or showed any sympathy toward him for his disability.

Maud and Hans wanted John to feel comfortable in his identity. They always made sure to dress him in clean, nice clothes and keep his face and hands washed and his hair combed nicely. Even when they couldn’t afford new, nice clothes for everyone in the family, John was given the best.

Kids with disabilities were targets for bullies and criticism. His parents feared John would get called a “dirty little blind boy” if he wasn’t dressed nicely.

It was important to the whole family, despite their financial struggles, that John never felt like he didn’t belong or that he couldn’t have a normal life like the rest of them. All of John’s siblings were kind and good to him, especially his younger brother Robert.

As John learned to navigate a darkened world, someone new came into his life that would be a huge help in his development. Robert Ogden Christiansen, my uncle, the last child Hans and Maud would bring into their family, was born on June 5, 1928. He was even larger than John at 11 ½ pounds!

After John was born, Hans and Maud hadn’t been planning on having more children. Robert came as a surprise but was a great blessing. He became John’s eyes and continual playmate.

Whenever John could hear Robert at his side, he could do everything Robert could do. They would roll tires down the street side-by-side and John had no trouble keeping up. In Robert’s mind, what John didn’t know wasn’t worth knowing. He didn’t feel the need to describe the world to John through colors, shapes, and images, rationalizing that if he couldn’t see and experiencing them, he didn’t need to know about it.

John’s other siblings helped him out with playing and discovering the world as well. His older brother Dan was protective and kind to him. Dan made him a Chinese checkers board that had big holes he could feel with his fingers so he could play without sight. On the other side of the board Dan made a regular checker board that had raised slats so John could feel where the spaces

were and play checkers with his siblings. As a young child I took great delight in playing on this board with my father and now play on that same board with my grandchildren.

As John started growing up, another pressing issue began to weigh on Hans and Maud. Beaver, Utah, didn't have the right educational facilities to assist blind students. To get a good education, John would need to have access to resources like Braille, system of raised dots and dashes that represent letters., and other peers with whom he could connect.

Murray B. Allen, executive secretary of the Utah Commission for the Blind, helped Hans and Maud navigate a path for John's education. Allen, who was blinded during his childhood, was the first sightless graduate of the University of Utah and later served as an advocate for blind people like John.

Despite losing his sight, John had a sharp mind and a desire to learn—and he was a perfect candidate to enter the Utah State School for the Blind.