

BEAUTY OF SIGHT

A LIONS EYE BANK

Fighting Darkness and Finding an Eye-Opening Life

Fatemeh Sugrue was born with Peters anomaly, a rare congenital eye disease. Throughout her life, she has faced numerous challenges and undergone several procedures in the hopes of restoring and maintaining her sight. Now 35 years old, she is married and a mother to two young boys. Her life's mission is to advocate for others who suffer from this rare condition and to connect with those who share similar struggles.

The name Fatemeh, a common name in the Middle East, is often associated with women who are strong, formal, refined, serious, mature, natural, and wholesome. Fatemeh Sugrue, a 35-year-old wife and mother of two, embodies all of these qualities and many more, as she continues her lifelong journey of living with and managing the challenges of Peters anomaly.

Fatemeh came into the world without sight, without light. Her parents quickly realized that their newborn daughter could not see. However, they were also faced with the harsh reality that there were no ophthalmologists in the city where they lived. Still determined to find answers, they learned of a British ophthalmologist who visited a nearby town once a month to hold an eye clinic. When Fatemeh was six months old, her parents stood in a long line, holding their daughter in their arms, hoping for help.



After a brief eye exam, the visiting ophthalmologist gave them the diagnosis: Peters anomaly.

Peters anomaly is a rare congenital condition characterized by cloudy corneas and abnormal development in the front part of the eye. The disorder affects fewer than 100 children each year in the U.S. Treatment is often complicated, requiring surgical intervention, and even then, the outcomes vary from person to person.

The ophthalmologist's instructions were clear. If they wanted their daughter to have any chance of seeing, they would need to take her somewhere she could receive the advanced medical care she so desperately needed.

Fatemeh was not born into wealth. But what she did have was a strong, close-knit, and supportive family. As a young girl, she experienced the power of that support in profound ways. One of her aunts had moved from the Middle East to the United States and was living in the Dallas, Texas area. When Fatemeh's parents reached out to her for help, she responded without hesitation, expressing unwavering commitment and saying she would do anything for her niece.

At about nine months old, Fatemeh underwent her first corneal transplant on both eyes. Shortly after, she also had glaucoma surgery. Both procedures were successful. Within a matter of days, baby Fatemeh could see the world around her for the very first time.

Her family was overwhelmed with joy and gratitude. Her mother, however, also felt the ache of absence. While her daughter was experiencing her first sights, she was thousands of miles away.

"My mother knew that sending me to the U.S. to live with my aunt was best for me during that time, even if it meant missing out on a lot of milestones–when I first ate solid food, when I first sat up, when I first walked," Fatemeh shared. "Thirty-five years ago, you couldn't just pick up a phone and FaceTime,so once or twice a month, my aunt would dress me up and take me to a studio for professional photos, which she would then send to my mother so she wouldn't miss any stage of my growth."



As a growing toddler, Fatemeh made a full recovery from her transplants. At two years old, it was decided that her aunt would return her home for a visit. However, for years, her family had been working toward the goal of immigrating to the United States permanently. They had sold their possessions and were determined to reunite with their daughter and give her the future she deserved.

Just before Fatemeh's third birthday, her family finally made the move to Palm Beach County, Florida. The warm climate reminded them of their home country, but the decision was also strategic as Palm Beach was just one hour away from the Bascom Palmer Eye Institute, one of the top eye care centers in the world. Fatemeh's first ophthalmologist there was Dr. William Culbertson, a renowned professor specializing in corneal and external diseases.

Information on Peters Anomaly

- Peters anomaly is a very rare condition that affects the eyes. It develops before birth due to a genetic mutation. People born with this condition experience vision problems due to cloudy patches on the cornea, iris and lens of the eye.
- There are treatments to mitigate symptoms, but there is no cure for this condition.
- The effects of Peters anomaly causes thinning of the cornea and a clouding of the cornea's surface. It also affects the connection between the cornea and the iris, the colored part of the eye.
- The condition is named after Dr. Alfred Peters. A German ophthalmologist who was first to describe the condition in modern medical literature.



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An Eye-Opening Life

Fatemeh grew up in Florida, where she excelled in school. She was an outstanding student, though sports weren't her strength. "It was hard for me to see the ball," she said with a smile. "But I do love dancing."

She also enjoyed drawing and photography. Her mother has saved boxes full of sketchbooks, filled with her pencil drawings. As a teenager, Fatemeh was drawn to health and science. At 18, she began working as a pharmacy technician.

Since she didn't drive at night, she often caught rides home with a coworker. One evening, that coworker asked if she'd like to stop by Denny's for something to eat. She said yes. Seven years after that spontaneous dinner, she and Andrew were married.

A few years later, they became a family of four, welcoming their sons, Daniel and Ryan, now six and four.

In 2013, Fatemeh completed nursing school, earned her RN degree, and was excited to begin her career. But just a few months after receiving her license, she woke up one morning with sudden and severe vision loss.

Doctors found that she was experiencing corneal edema, a condition that clouded her vision and required treatment. Fortunately, the condition improved, and she was eventually able to return to work, this time at a pharmacy. A couple of years later, Fatemeh took on a new role as a tele-nurse for AstraZeneca.



"When I wake up in the morning, I don't look at the clock, I look out the window. Because I could lose my sight at any time."

FINDING THE SWEETSPOT

Fatemeh is Helped From Beauty of Sight's Serum Tears

Fatemeh experiences dry eye, especially when she's in cooler environments like the hospital. To help manage this, she uses Beauty of Sight's autologous serum tears – an ophthalmic biological therapy custom-made for each patient. These drops are created by combining the patient's own blood serum with sterile, preservative-free saline or a balanced salt solution. For Fatemeh, using the drops requires special care: if too much liquid collects behind her corneas, it can increase pressure in her eyes. That's why she has to find the perfect "sweet spot" when applying the serum tears.

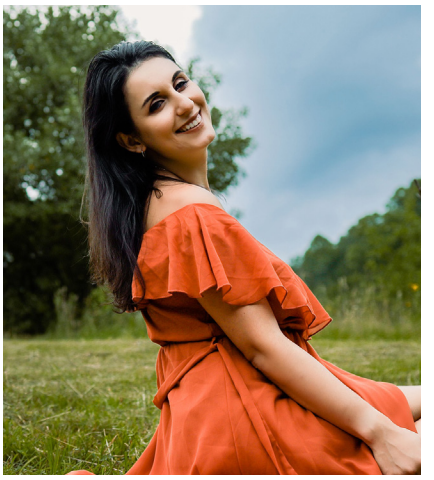
But working full-time in front of a computer screen began to take a toll on her already-fragile eyesight.

"After a while, I saw the negative impact on my eyes from looking at a screen all day," she said. "I went part-time to protect my vision, but my husband encouraged me to stop working altogether and focus on my health."

With fewer than 100 new cases of Peters anomaly diagnosed in the U.S. each year, there's very little public awareness or research funding for the condition. Fatemeh realized there was a need for connection, for community, and for hope. So, she started a blog.

"Very few people have this disease. I created the blog mostly for information–for people with Peters Anomaly or their families," she said. "People from more than a dozen countries have reached out. Some are from the Philippines, Africa, Australia. It's a way to give hope."

One story stands out in her mind, a mother with a baby recently diagnosed with Peters Anomaly contacted Fatemeh through the blog. "She read about my life and saw hope for her child's future," Fatemeh said. "That's why I keep doing it."



In recent years, Fatemeh has undergone additional surgeries including more corneal transplants, with donor tissue generously provided by Beauty of Sight. These surgeries have helped her maintain her vision and stay present in her children's lives. In addition to surgery, Fatemeh uses Serum Tears, specialized eye drops made from her own blood, which provide essential nutrients to her corneas and help reduce inflammation and dryness.

But the risk of vision loss is always looming.

"Peters anomaly is like a domino crash," she said. "We have to keep working in and out with the corneas. When I wake up in the morning, I don't look at the clock, I look out the window. Because I could lose my sight at any time."

Fatemeh no longer drives. When she takes her boys outside to play, she always brings another adult along just in case. Though her condition presents daily challenges, she remains grounded and hopeful.

"There's not a lot of research because this condition is so rare. That means fewer new ideas and innovations," she said. "It would be amazing if something came from my story if it could lead to a key, or spark research. But for now, I take care of my sight as much as I can."

One of her doctors once told her that she might not be able to see her sons graduate high school.

"I like when I'm told the truth," she said. "And I'm going to keep my sight for them, the best I can."