OklahomaRare

RARE VOICES. SHARED STRENGTH.

THE OKLAHOMANS BEHIND THE DIAGNOSIS

2025

In Loving Memory of Kayden.

“Kayden loved trips and seeing the world, even though he had SMA, it didn't stop him from doing what he wanted."

Amanda Chaffin, Kayden’s mom

OklahomaRare

Oklahoma is home to over 300,000 living with rare diseases—each with a unique journey marked by resilience, hope, and significant challenges. Too often, these voices go unheard, and their struggles remain unseen. This compilation of stories seeks to change that.

Within these pages, you will find the stories of 16 Oklahomans navigating life with or supporting a loved one with a rare disease. Their experiences shed light on the barriers they face in accessing timely diagnosis, appropriate treatments, and necessary support systems. More importantly, their stories highlight opportunities for meaningful policy change—initiatives that can improve healthcare access, enhance research opportunities, and provide critical resources for those impacted by rare diseases across our state.

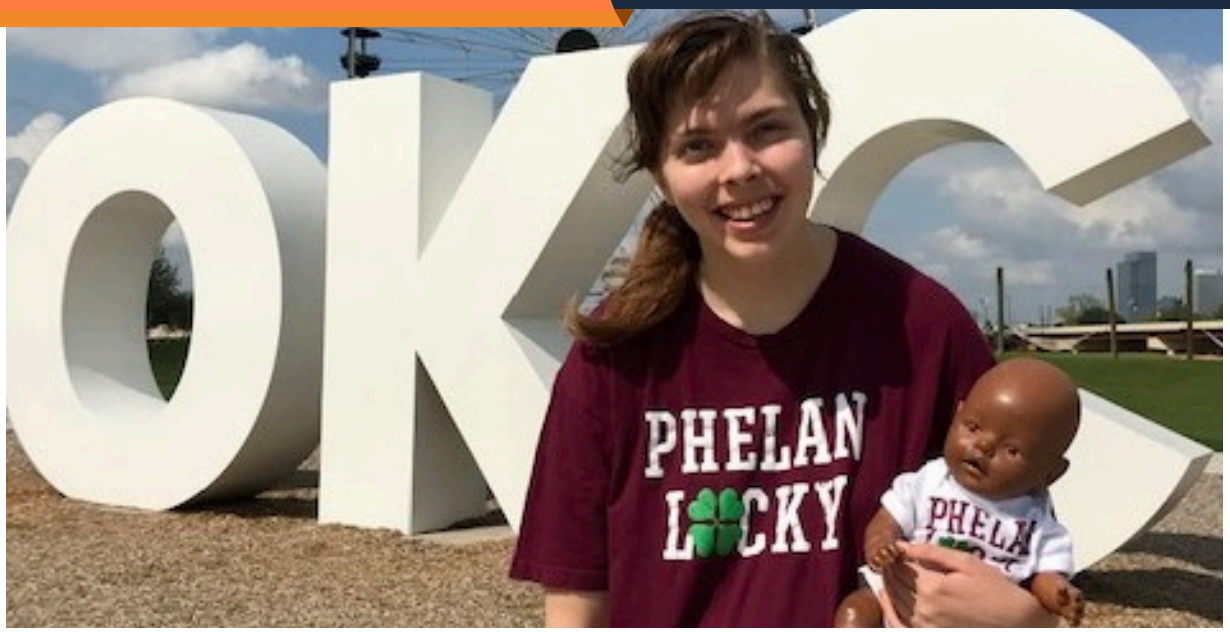
One vital step forward is the creation of an **Oklahoma Rare Disease Advisory Council (RDAC)**—a dedicated body that would bring together patients, caregivers, healthcare professionals, and policy experts to provide informed recommendations on how to better serve the rare disease community. More than 25 states have already established RDACs, ensuring that rare disease voices are represented in policymaking. Oklahoma should be next.

As policymakers, you have the power to shape policies that ensure Oklahomans with rare diseases are not left behind. By championing solutions like an RDAC and increased patient support, you can help create an Oklahoma where every rare voice is heard, and every rare life is valued.

We invite you to read these stories not just as narratives, but as calls to action. Together, we can build a better Oklahoma for those living with rare diseases.

THE WILSON FAMILY

OKSD 23
OKHD 47



Alyssa is a beautiful child in the declining body of an adult. She loves Barney, her Baby, and balloons. She's never met a stranger and will brighten your day if you just spend some time with her. Looking back, and knowing what we know now, **it would have made a huge impact had we had a diagnosis early on instead of waiting till she was 21.** There are many things we could have mitigated had we had only known earlier. Phelan McDermid Syndrome is serious enough to be on Social Security's Compassionate Allowance list, so we are cognizant of the fact that her future is hazy. PMS recently was granted its own ICD code (Q93.52), our next prayer is that it's included on Newborn screenings, so another family doesn't need to be in the dark for so long.

Until it was determined our family was poor enough for her to qualify for Medicaid at age 5, we had accumulated $6000.00 in medical debt. That wasn't erased. While Medicaid helped with healthcare costs, we were still spending so much on incontinence supplies and other items we struggled.

DIAGNOSTIC JOURNEY

18 yrs

SPECIALISTS **8**

TRAVELED OUT OF OKLAHOMA FOR CARE? ✓

“A Disease may be rare, but HOPE should not be. This rare disease journey may be a long winding treacherous road with no end in sight....but I sure do love my tour guide.”

Janet Wilson, Alyssa’s mom.

LEAH CAMPBELL

OKHD 47 OKSD 45

When my husband and I moved back to Oklahoma, we were forced to move in with my mother. She consequently had to quit her teaching job in Texas and go back to teaching in the same town where we lived in Oklahoma in order to be closer. Shortly after that my ex-husband left and filed for divorce. There have been major out of pocket expenses for personal care assistants not covered by insurance, wheelchair accessible vehicles, home modifications like wheelchair ramps and roll in showers, and a whole house generator. I myself have experienced financial difficulties with not being able to find employment since becoming paralyzed. **Insurance doesn't cover alternative therapies needed to maintain a spinal cord injury/disorder like massage, chiropractor, and exercise therapy.**

My diagnostic odyssey began on May 25, 1989, when I was 10 years old. I was totally blind one month after my 12th birthday. I was misdiagnosed with Multiple Sclerosis in October 1993 at the age of 15. I was eventually treated with MS therapies for 7 years. One was a chemotherapy that paralyzed me as a quadriplegic on July 15, 2001, 2 months and 3 days after I graduated from Rhodes College in Memphis Tennessee with a bachelor's in mathematics. Several years later the Mayo Clinic isolated the protein responsible for Neuromyelitis Optica and consequently developed a laboratory test for it in 2006. I was tested, and on May 31, 2006, I tested positive for Neuromyelitis Optica Spectrum Disorder. Two months later I was placed on Rituxan and have been relapse free since then. I recently began a new preventative called Enspryng in December 2023.

DIAGNOSTIC JOURNEY

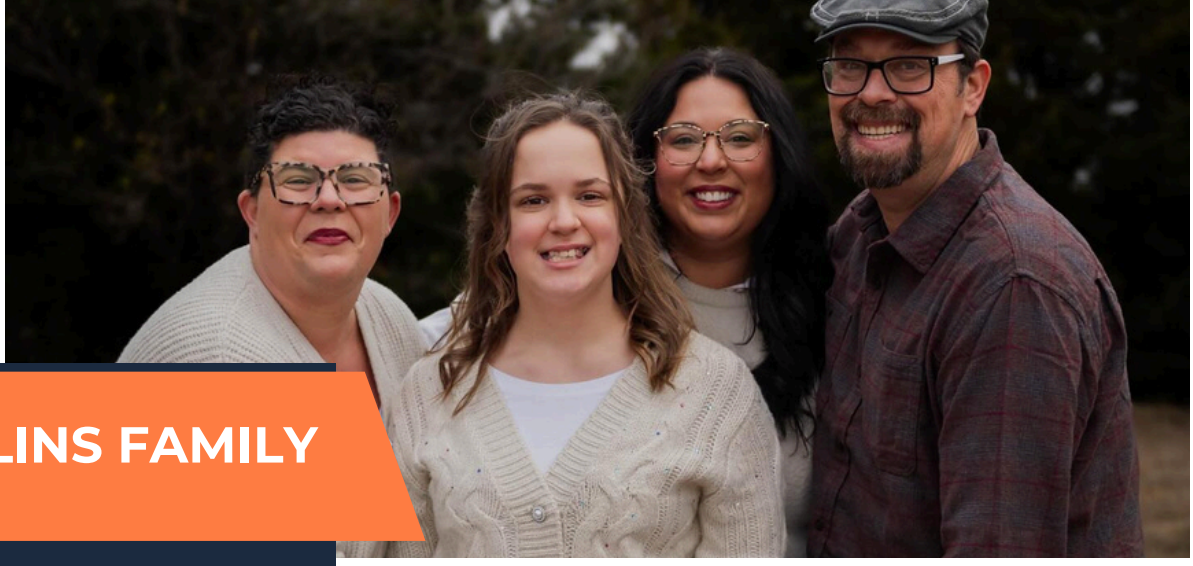
17 yrs

SPECIALISTS

17

TRAVELED FOR OUT OF STATE CARE?

Yes ✓



THE COLLINS FAMILY

OKHD 83
OKSD 22

"As a parent of a child with a rare disease, I've come to realize that rare isn't the toughest hurdle. The real challenges lie in navigating complex systems—healthcare, caregiving, and support. Our daughter desires what so many do: a life filled with choice and purpose, where she can pursue her passions. Similarly, our family seeks what countless others want—accessible healthcare and the opportunity to thrive financially."

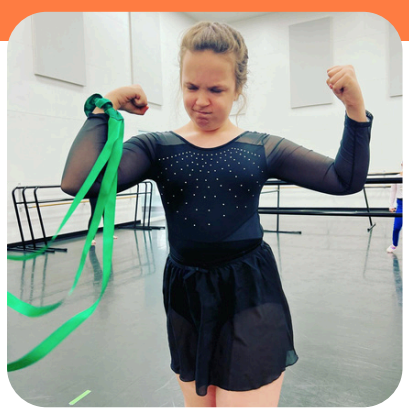
Sky Collins, Presley's mom

Presley is, in many ways, just like any typical 12-year-old. She adores Taylor Swift, loves cheerleading, and enjoys spending time with her friends at school. However, she is also "ultra-rare." In 2021, after 8.5 years of searching for answers, she was diagnosed with Malan Syndrome, an ultra-rare condition that impacts every system in her body.

Presley is diagnosed with an intellectual disability along with numerous other diagnoses related to Malan Syndrome, and she sees 14 different medical specialists.

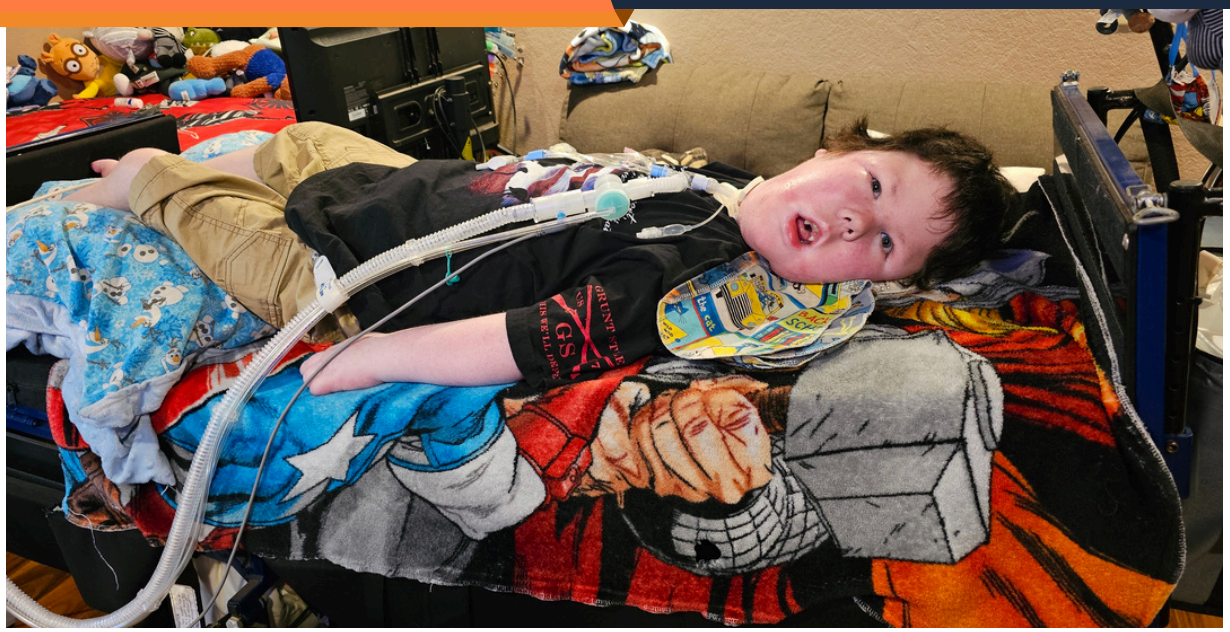
As a family, caregiving has transformed our lives into a one-income household, with my husband, a former gas and oil field technician, providing her full-time care. This shift has brought financial challenges—struggling to make ends meet, covering medical expenses, and constantly juggling numerous appointments.

DIAGNOSTIC JOURNEY	SPECIALISTS	TRAVELED FOR OUT OF STATE CARE?
8.5 yrs	**14**	**Yes ✓**



THE CHAFFIN FAMILY

OKSD 16
OKHD 46



My youngest son has spinal muscular atrophy, we are extremely blessed that he will be turning 12 soon. When he was diagnosed at 6 weeks old, the diagnosis wasn't great and he was labeled as terminal. 1 in 40 people are carriers for SMA, something me and his dad didn't know. It also takes two carrier to have a child affected by SMA. We've sure watched the times change over the years, we now have three FDA approved treatments (not a cure). As well as newborn screening in all 50 states. I know moving forward, less children will be at the level of complexity as Kayden is with these advancements. Kayden is what we call an OG type 1, as he's teach and ventilation dependent. He lays flat and uses a large wheelchair, he also just started 6th grade last week. The mind is not effected, he enjoys school and thrives in Math and science.

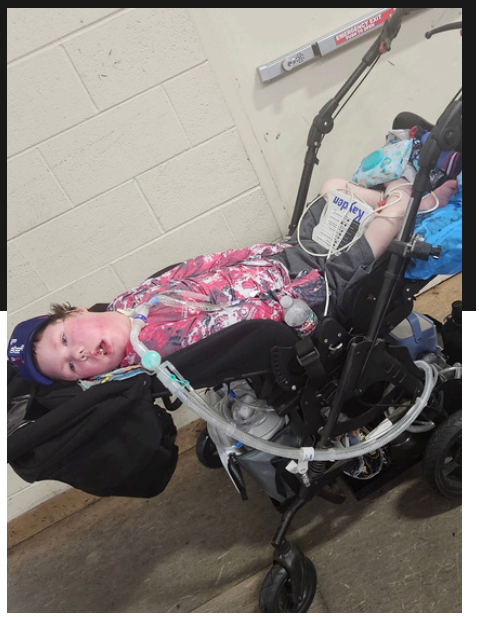
He is full of spunk and attitude, loves keeping us on our toes! We wouldn't have it any other way, as he's such a joy to our family.

We always knew Kayden wouldn't qualify for regular childcare. But at this point, we can not even get home nursing coverage. 6 years ago I made the choice to go full time from home, due to the fact finding and hiring a nurse for my child, is next to impossible. **Due to multiple reasons. I could rattle off daily the amount of medical needs that are not fully covered or come with high copay.**

DIAGNOSTIC JOURNEY

6 wks

SPECIALISTS **14**



"Children now picked up on Newborn Screening are able to get treatment before they are symptomatic. This is so important, but we are still having issues in the Oklahoma health system where this is not happening. Because they are lacking education on the urgency of the children receiving treatment. **I believe having more resources available will help reach those seeing these children.**"

- Amanda Chiffon

WATTS FAMILY- MIRACLE WALKING

OKHD 75 OKSD 25

"FAMILIES WHO LIVE WITH RARE DISEASES ARE SPECIAL NOT BECAUSE OF THE DISEASE, **BUT BECAUSE THEY CONTINUE WE FIND HOPE AND STRENGTH IN ONE ANOTHER."**

Jeremiah is a young person who was born with two genetic conditions, sickle cell disease and multicystic dysplastic kidney. Throughout his 19 years, the Watts Family has faces many challenges, with the recent challenge of dialysis. Sickle Cell impacted Jeremiah's one kidney and caused him at the young age of 16 to have to start dialysis. This has been life changing for Jeremiah's family. It has been through faith, family, and hope that the Watts Family strives everyday.

THE WATTS FAMILY BELIEVES THERE IS ALWAYS "HOPE"

DIAGNOSTIC JOURNEY

DIAGNOSED AT BIRTH

SPECIALISTS

5

TRAVELED FOR OUT OF STATE CARE?

Yes ✓

THE ORMAN FAMILY

We knew our sweet Kylan was going to be special during my pregnancy as the cosmetic differences and organ anomaly's were already apparent in ultrasounds. Shortly after he was born we got a diagnosis after advocating for some genetic testing of Chromosome 2q deletion effecting the long arm gene from 31.1-33.1, this being a deletion of approximately 25,000 letters. **When born in 2017 he was 1 of 30 in the world.** This is so rare we follow him to tell us what is next day by day. Our weeks never look the same, and he often throws curve balls. Throughout Kylan's life we have added two more major diagnoses and that is Cerebral Palsy and Dandy Walker Syndrome. Kylan has visual and hearing impairments. Kylan has cosmetic differences such as club feet that needed surgical intervention and clenched hands. Kylan is g-tube dependent as his throat muscles do not work properly to prevent aspiration into his lungs. All of Kylan's organs have anomaly's that affect them each differently and none of them function as what typically would be referred to as, "normal".

We currently are seeing 17 different specialist this excluding our pediatrician. If I could change things in our path not a single one of them would be Kylan. He is the most joyous soul to be around and lights up any environment he is in. Imperative changes needed in Oklahoma are public education and medical care. Kylan has never gotten good continuity of care in either of these areas. Our special education programs in this state are so poorly supported it's really disheartening. Our worry for his safety and well being while at school should not be so high on our worry list; let alone battling for fairness in IEP meetings, getting access to resources, and the list just goes on. In the last 6 months we have moved 4 specialists around because they leave. **Why can Oklahoma not maintain pediatric specialists?** I am unsure, but it's a revolving door that we're stuck in when you parent a child with extraordinary needs or is medically complex in our state. As his mother I have vowed to be a voice and use my advocacy skills to drive systematic change. My focus is not solely on my son, it is on the entire population because if I can create change for everyone he is included in that.

DIAGNOSTIC JOURNEY

6 yrs

SPECIALISTS

17

"It takes a toll on our family due to medical and travel costs. We are blessed to be TEFRA recipients, but have still ran into some things that we still need to pay and cover."

CLAYTON & GARCIA FAMILY

OKHD 78 OKSD 35

I am a single mother of 3 girls who have a rare diagnosis. As a family we discovered this rare diagnosis 6 months after my divorce. We also found out about this rare diagnosis being genetic through myself and my ex-husband, both my parents and at least one grandparent on my fathers side. I am an educator for early childhood and I am working towards being the best advocate for my children as I can be.

As a single mother of 3 I am consistently needing to take off work to take the children to see the specialists, and regular appointments. This does not include the time off due to the autoimmune side of this rare diagnosis.

(From Dr. Eric K Fanaee, MD) The spoon theory is an introduction to understanding how chronic illness, chronic pain, and disability impact a person's capacity to perform everyday tasks, engage in work and social life, and meet longer-term goals. Becky Bikat Tilahun, a clinical psychologist with the Cleveland Clinic, considers it a strategic planning tool.1 The theory suggests that people living with chronic illness, chronic pain, or disability have a limited amount of energy (represented by spoons) to spend on completing tasks on any given day. This means people living with chronic health conditions have to make many difficult, energy-consuming choices about how to spend their limited energy. How many spoons it takes a person to complete a given task can vary considerably from day to day, too. This can make planning for future events more challenging when you're unsure of how many spoons you may have at a future date.

DIAGNOSTIC JOURNEY

I HAVE ONE DAUGHTER DIAGNOSED AND 2 DAUGHTERS UNDIAGNOSED BUT CONFIRMED TO HAVE THE MARKERS.

SPECIALISTS

7-9

JENNY JONES

OKSD 23 OKHD 47

DIAGNOSTIC JOURNEY	SPECIALISTS	TRAVELED OUT OF STATE FOR CARE?
1 year	7	Yes ✓

Familial Adenomatous Polyposis (FAP) is a rare hereditary colon cancer syndrome that guarantees colon cancer at a younger age than the general population with higher risks for several cancers and other issues and has run in my family for several generations At 7 I began having chronic abdominal pain but with a HMO insurance plan, my PCP refused to refer me to a GI specialist for evaluation even knowing my family history of FAP, stating I was "just a whiny child". My parents had to change insurance plans for me to be evaluated and I was diagnosed at 8 with FAP and required my colon removal at 9, in 1995, due to my colon polyps already starting to turn cancerous. I had life threatening complications from my colon removal and when I was taken to the ER, the first complication resulted in me being restrained to have my infected incision reopened without any sedation or effective pain medication. When I was taken to the ER for my second complication, inadequate testing was completed, and I was sent home by the doctor stating I was "just a whiny child". When we returned the next day, a different doctor did thorough testing to find my small intestine had wrapped around itself and surrounding organs, cutting off my blood supply. We were told it was a miracle I had lived through the night and due to the lack of blood supply, part of my small intestine died resulting in my second rare disease Short Bowel Syndrome, a rare malabsorption disorder that can become life threatening. I had 3 more surgeries within the year following my colon removal, developed medical PTSD and lived with an ostomy for 6 years before it was able to be reversed in 2001. I again had life threatening complications requiring in and out of state extensive medical testing, another surgery, and constant treatments to keep me alive. I required my 8th surgery in 2021, unknowingly also related to FAP, and experienced unexplained debilitating pain afterwards. It took me 6.5 months and 7 specialists to diagnose what was causing my pain and another year to fully recover from the aftereffects of this surgery to regain my quality of life. **Due to my medical experiences, I established Life's a Polyp in 2012 with the focus of awareness, empowerment, and funding FAP research. I also started the National Organization for Rare Disorders FAP Research Fund in 2015, to which I donate profits from Life's a Polyp Shop and my FAP Children's Book - Life's a Polyp with Zeke and Katie.**

My ultimate goal in life is to help others avoid the same medical and mental health experiences I did as a child with rare diseases and to empower others in the navigation of their own chronic illnesses.

THE BANTA FAMILY

OKSD 47
OKHD 96

My daughter Jemma is 2 years old and has a diagnosis of Alternating hemiplegia of childhood, and despite the name this disease is life long. This disease cause her body to randomly paralyze. And that can range from extreme weakness, complete paralysis, or stiff and painful paralysis. These episodes can affect one body part, one whole side of the body, jump from one side to the other, or the entire body. They can last minutes to months at a time. The only thing that "breaks" the episode is sleeping and when they wake up it's a 50/50 shot that the episode will start again or not. During the episode it can cause her to stop breathing, her digestive tract to stop, and even her heart to stop. She currently eats through an iv that goes to her heart because her gi tract isn't working. Her longest episode was almost 11 months. and the longest she has stopped breathing is 2 minutes. This disease is 1 in a million, most doctors have never heard of it before. And with how little research there is about her disease it makes treatments very difficult.

I cannot work due to frequent hospital stays, therapies, specialist appointments, and since the disease is unknown there are no facilities trained to take care of her with all the complexities she has.

This disease is often referred to as a ticking time bomb. and as far as we know as of now Jemma is the only child with this disease in the oklahoma metro, and they believe the state. The other known child with it in oklahoma died last year.

DIAGNOSTIC JOURNEY	SPECIALISTS	OUT OF STATE FOR CARE?
14 months	**7**	**Yes ✓**

THE VICK FAMILY

My name is Karisha Vick and I'm a mother of 7. My two children Nevaeh (8) and Legend (5) were both born with Sickle Cell. Throughout their lives they have been in and out the hospital for sickle cell crisis, surgeries, and other health related issues due to their illness. As a single mother, it is very overwhelming for me, especially when we have to travel to Tulsa (St. Francis Hospital). I always think to myself no one understands what I deal with on a day to day basis.

The costs that I have endured over the years for both children has taken a toll on me financially. I have applied for state benefits for my children on several occasions and have gotten denied; I have no help other than they help I receive from Supporters of Families with Sickle Cell Disease. As of right now, my children and I are looking for a place to call home as our apartment was lost due to a fire. ***The burden is very heavy and stressful, however, I can't give up.***

TRAVELED OUT OF STATE FOR CARE?

Yes ✓

MARLEE'S MIRACLES

OKSD 40

Born with a rare CHD, being abandoned and given no chance to survive to being adopted, THRIVING 8 years later.

Marlee has had 4 open heart surgeries. She always has a smile on her face.

Impact:

This has had a financial impact on our family through taking time off or work, travel costs, equipment not covered by insurance.

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DIAGNOSTIC JOURNEY	SPECIALISTS	OUT OF STATE FOR CARE?
3 days	14	Yes ✓

RENEE KAPLAN

OKSD 39
OKHD 67

I do not believe that it is possible to get a correct diagnosis of cicatricial pemphigoid in Oklahoma, so I assume that there are some undiagnosed cases in this state. I have never met any health care professional in Oklahoma who had any experience with cicatricial pemphigoid, so how would they know how to treat this disease?

It is unfortunate that Oklahoma residents often must travel out of state at their own expense to get diagnosed and treated for rare diseases.

I began to get multiple severe blisters in my mouth following a dental procedure in 2019. My dentist said that it was the worst case of gingivitis that he had ever seen. After the rinses and medications that my dentist prescribed had not helped, I visited a periodontist. The periodontist wrote in his note that his clinical impression was cicatricial pemphigoid. He did an incisional biopsy of my gums for which he charged me $500, and he sent the specimen to a dental pathologist in Edmond, OK. The pathologist reported that there was no disease, only inflammation. The periodontist wrote in his note that inflammation did not explain the condition of my mouth, but he was not interested in spending any more time on my oral blisters. The periodontist instructed me to return to my dentist.

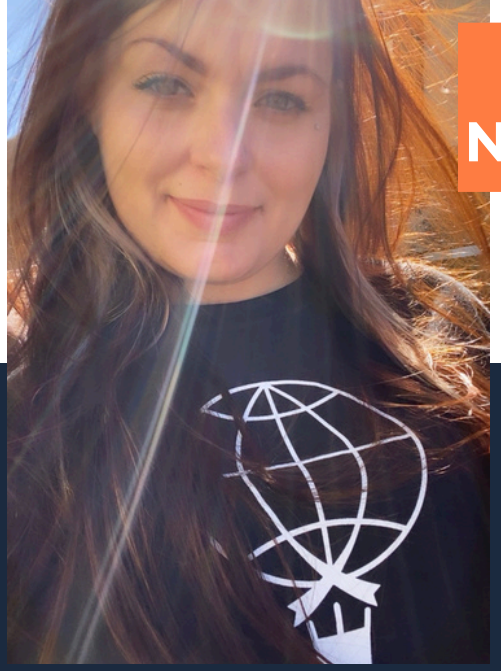
I was not satisfied with the periodontist's answer. I searched the Internet, and I read a story about a woman with symptoms similar to mine. I traveled to Baltimore, MD, to see a dermatologist at Johns Hopkins Hospital who was one of the world's leading experts on oral blistering diseases. He did a biopsy, and the pathology confirmed cicatricial pemphigoid. He told me that the Tulsa periodontist had not done the biopsy correctly and that the Edmond dental pathologist was not qualified to do the pathology for cicatricial pemphigoid. I have not been able to find a dermatologist in Oklahoma who has any experience with this rare disease, so I have traveled to Baltimore for my care since 2019.

Cicatricial can affect the eyes and cause blindness. I had symptoms in my eyes in 2022, so I called my Tulsa ophthalmologist. Without seeing me or talking to me, he assumed that I had a routine eye infection, and he sent a prescription to my pharmacy. Several weeks later, my Johns Hopkins dermatologist would diagnose me with ocular cicatricial pemphigoid and prescribe appropriate treatment. I am now under the care of an ophthalmologist at Johns Hopkins.

DIAGNOSTIC JOURNEY
7 MONTHS
AFTER ONSET OF SYMPTOMS

SPECIALISTS
2

TRAVELED OUT OF STATE FOR CARE?
Yes ✓



JUSTINE
NARCOLEPSY MAMA

OKHD 35 OKSD 20

Hello, I'm Justine Bennett from Pawnee, Oklahoma. I live with narcolepsy with cataplexy, a rare condition that causes sudden sleep attacks and muscle weakness triggered by strong emotions. This condition affects my daily life and requires constant management and support from my family. Raising awareness and improving support for rare diseases like mine can significantly enhance the quality of life for those affected. **Your attention and action can make a real difference in our lives.**

DIAGNOSTIC JOURNEY

11 YEARS

SPECIALISTS

3

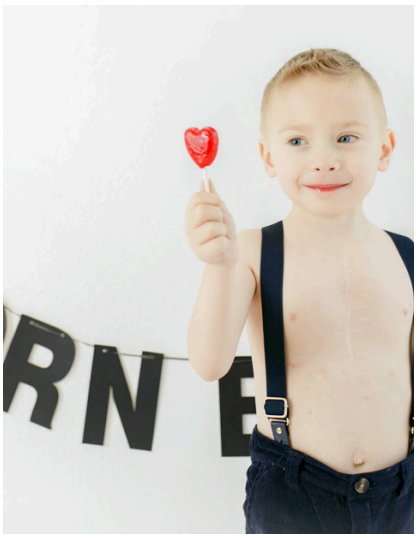
Narcolepsy with cataplexy can lead to several health issues beyond the primary symptoms. These include:

1. Mental Health Challenges: Many individuals experience anxiety and depression due to the unpredictability of sleep attacks and cataplexy episodes, which can affect social interactions and overall well-being.
2. Sleep Disorders: People with narcolepsy often have disrupted nighttime sleep, leading to further fatigue and exacerbating daytime sleepiness.
3. Increased Risk of Accidents: The sudden onset of sleep can lead to dangerous situations, especially while driving or operating machinery, increasing the risk of accidents.
4. Obesity: Some individuals may experience weight gain due to decreased physical activity and the potential side effects of medications used to manage symptoms.
5. Cardiovascular Issues: Research suggests a potential link between narcolepsy and increased cardiovascular risks, although more studies are needed to fully understand this connection.

Addressing these health issues requires a holistic approach, including medical treatment, lifestyle changes, and support from family and friends. Raising awareness about these challenges is crucial for improving the lives of those affected.

ELI DRABEK

OKSD 24
OKHD 53



My son Eli was **born brave**. In 2018, doctors took him early at 33 weeks, after diagnosing him during an anatomy scan with tetralogy of Fallot (toF) with pulmonary atresia, a complex congenital heart defect (CHD) at the extreme end of the spectrum. With an estimated incidence of 0.7 per 10,000 live births, toF is considered a critical CHD accounting for just 2% of all CHD cases.

At the age of 6, Eli has undergone three open heart surgeries, seven heart catheterizations and countless cardiology appointments on the journey to repair his heart. After severe complications from a cath procedure in 2023 that nearly cost him his life, Eli required VV-ECMO life support and spent 28 days in the hospital. That experience led us to seek a second opinion ahead of his third open heart surgery. At the recommendation of another Oklahoma cardiologist, we sought out the pulmonary artery reconstruction (PAR) program offered at Stanford's Lucile Packard Children's Hospital in Palo Alto, California during the summer of 2024. PAR is a surgical procedure pioneered at Stanford that rebuilds arteries and vessels in the lungs to achieve near-normal heart-lung function for improved health and wellness. Surgeons there perform at least one of these surgeries per week.

In addition to PAR, surgeons replaced Eli's conduit connecting his right ventricle to his pulmonary artery as originally planned. The surgery was a success and Eli was discharged from the hospital just six days later to return home to Oklahoma.

Following his recovery, Eli entered Kindergarten this fall and is now expected to reach adulthood before he will require another intervention to manage his CHD.

SPECIALISTS	TRAVELED OUT OF STATE FOR CARE?
5	Yes ✓

THE MAYES FAMILY

OKHD 28 OKSD 28

Blakely is a 6-year-old girl with polymicrogryia and 16p13.11 microdeletion syndrome, both of which cause developmental delays. She is about a year and a half behind in her development. Blakely had her first seizure at the age 1, and by the age 2.5, she was diagnosed with polymicrogryia, followed by the microdeletion syndrome at age 3.

Our family has faced many challenges including frequent doctor visits, hospital stays, and ongoing therapies. **Due to these medical needs, we are a single income household.**

Blakely receives therapy twice a week for an hour each session. Our family has sought additional medical opinions out of state and remains hopeful that, in the coming months, Blakely will be able to stop taking three different seizures medications.

DIAGNOSTIC JOURNEY	3 YEARS
SPECIALISTS	3
TRAVELED OUT OF STATE FOR CARE?	Yes ✓

THE RAYOS FAMILY

OKHD 89
OKSD 44

I believe that my story has the potential to inspire change—whether it's advocating for better healthcare access, supporting research or shaping inclusive policies that recognize the needs of all Oklahomans. Together, I ensure that my story is can be used every where and be a huge impact on the individual that may receives the attention and support they deserve while having a rare disorder and disability.

At the heart of Oklahoma and with being in the disability hispanic community there are unique narratives that often go unheard. My mission is to use the voices of those with rare conditions, having their struggles with a rare condition, having the resilience they embody. By sharing these powerful stories. I aim to understand and using empathy among the policymakers and leaders.

DIAGNOSTIC JOURNEY
4 yrs

SPECIALISTS
2

Dandy-Walker Syndrome

My name is Tamara Rayos
I am 21 years old
I live in south side of Oklahoma city
Senior year in college at the University of Oklahoma

Dandy-Walker Syndrome (DWS) is a congenital brain malformation involving the cerebellum and the fluid-filled spaces around it. It is characterized by an enlargement of the fourth ventricle and cyst formation, leading to various neurological and developmental challenges. The exact cause is not fully understood, but it is believed to arise during early fetal development. I was diagnosed with Dandy-Walker Syndrome when I was a new born and was in the nicu for 4 months
developmental delays, coordination problems, intellectual disability, and motor skill challenges.

Tamara Rayos has a supportive family who is actively involved in my own care and development. I work closely with healthcare professionals to manage my mental health conditions.
Tamara Rayos attends The university of Oklahoma post secondary education and receives special education services, therapies, which help in overcoming learning challenges.

Tamara Rayos enjoys helping others in the disability community and like to organize random things that can look nice which provide an outlet for creativity and social interaction.
Tamara Rayos is known for resilience, determination, and unique perspective on life. I have developed coping strategies that help them navigate challenges effectively.

Tamara Rayos aims to improve the Hispanic disability community and also helping sooner success development motor skills, social interactions and presentations.
in the long term my goal in the future is to work with sooner success and help the disability community and also be a Spanish medical interpreter.

I go to my Regular consultations with a neurologist, physiologist, therapist, are essential for my comprehensive care.
I Participation in support groups and activities that promote awareness and understanding of for other types of different disabilities in Oklahoma city.

Tamara Rayos is a vibrant individual who, despite the challenges posed by Dandy-Walker Syndrome, continues to inspire those around her through the journey of growth and self-discovery. My story is a testament to resilience, hope, and the power of support.