MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 3457**

DATE: **3/26/2026**

COMMITTEE: **Health and Mental Health**

TESTIFYING: ☑ IN SUPPORT OF ☐ IN OPPOSITION TO ☐ FOR INFORMATIONAL PURPOSES

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **ALYSSA JANELLE LEE**

PHONE NUMBER:

BUSINESS/ORGANIZATION NAME:

TITLE:

ADDRESS:

CITY:

STATE:

ZIP:

EMAIL:

ATTENDANCE: **Written**

SUBMIT DATE: **3/24/2026 7:07 AM**

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

My name is Alyssa Lee, and I am writing this testimony in support of HB 3457 - Byrnes, concerning medically complex pediatric patients.

I have had the privilege of calling Madeline Grace Aumman my best friend for over a decade, ever since we met in second grade at Immanuel Lutheran Wentzville. From the very beginning of our friendship, Maddie and I could talk about everything. we are both very medically complex people in our own ways.

With my complex medical history, I have often been ignored or dismissed when seeking emergency care. There have been times when doctors have misdiagnosed me, doubted my experiences, or even accused me of faking my pain.

The earliest instance I can recall happened when I was in sixth grade. For a long time, I had been experiencing significant knee pain. Eventually, it became so severe that my mom took me to see a doctor affiliated with St. Louis Children's Hospital. After hearing my symptoms, the doctor quickly concluded that I simply had hip weakness and recommended physical therapy. Deep down, I knew this diagnosis didn't fit what I was experiencing.

Luckily, my mom had already scheduled a second opinion with another doctor later that same day. As soon as I described my symptoms, the second doctor immediately recognized the seriousness of my condition and recommended emergency surgery to reposition my kneecaps, warning that leaving things untreated could cause major problems in the future. As it turned out, I have faced many orthopedic issues since then. Just this past April, during my senior year of high school, I fully dislocated my kneecap and tore several ligaments. Multiple doctors have since told me that much of this could have been avoided if my original doctor had listened to me, rather than dismissing my symptoms.

Another difficult experience from sixth grade involved a condition I have called hemangiomas—masses that my body develops and sometimes requires surgical removal. After one such surgery on my lower left leg, I woke up in the recovery room in excruciating pain. Despite my distress, the nurse told me she couldn't give me more pain medication because it might make me fall asleep. That experience left me feeling not only in pain but also unheard and unsupported.

When I was a junior in high school, I decided to try out for the dance team. On the second day of tryouts, while marking the dance in the corner, I took a step on my right leg and completely dislocated my kneecap. I had to be transported to the ER by ambulance. The fire department had managed to put

my kneecap back in place before I arrived, but I was still in intense pain and unable to move my leg. Despite visible swelling and bruising, the ER doctor—who was not an orthopedic specialist—accused me of faking my injury and dismissed my pain.

These experiences have made me painfully aware of how easy it is for patients—especially young ones—to be misunderstood, dismissed, or even accused of exaggerating their symptoms. My hope is that by sharing these experiences, I can bring attention to the importance of truly listening to patients, no matter their age or how unlikely their stories may seem.

thank you
alyssa janelle lee

MISSOURI HOUSE OF REPRESENTATIVES

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COMMITTEE: **Health and Mental Health**			

TESTIFYING: ☑ IN SUPPORT OF ☐ IN OPPOSITION TO ☐ FOR INFORMATIONAL PURPOSES

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **ANGELA SWEIS**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: **3/26/2026 12:00 AM**

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MISSOURI HOUSE OF REPRESENTATIVES

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COMMITTEE:
Health and Mental Health

TESTIFYING: ☑ IN SUPPORT OF ☐ IN OPPOSITION TO ☐ FOR INFORMATIONAL PURPOSES

WITNESS NAME

BUSINESS/ORGANIZATION:

WITNESS NAME: **ARNIE C. AC DIENOFF**	PHONE NUMBER: **314-440-9000**	
BUSINESS/ORGANIZATION NAME: **STATE PUBLIC ADVOCACY**	TITLE: **STATE PUBLIC ADVOCATE**	
ADDRESS: **P O. BOX #1535**		
CITY: **O' FALLON**	STATE: **MO**	ZIP: **63366**
EMAIL: **ArnieDienoff@Mail.Com**	ATTENDANCE: **In-Person**	SUBMIT DATE: **3/26/2026 11:53 PM**

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

I Support this Bill

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 3457**	DATE: **3/26/2026**

COMMITTEE:
Health and Mental Health

TESTIFYING: ☑ IN SUPPORT OF ☐ IN OPPOSITION TO ☐ FOR INFORMATIONAL PURPOSES

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **CHRISTINE AUMANN**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: **3/26/2026 12:00 AM**

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MISSOURI HOUSE OF REPRESENTATIVES

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Health and Mental Health

TESTIFYING: ☑ IN SUPPORT OF ☐ IN OPPOSITION TO ☐ FOR INFORMATIONAL PURPOSES

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **DAVID BARNES**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: **3/26/2026 12:00 AM**

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MISSOURI HOUSE OF REPRESENTATIVES

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COMMITTEE:
Health and Mental Health

TESTIFYING: ☑ IN SUPPORT OF ☐ IN OPPOSITION TO ☐ FOR INFORMATIONAL PURPOSES

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **HERMAN SMITH**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **In-Person**	SUBMIT DATE: **3/24/2026 7:46 PM**

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please schedule me to speak in favor of house bill 3457 in person on 03/26/26.

MISSOURI HOUSE OF REPRESENTATIVES

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COMMITTEE: **Health and Mental Health**	

TESTIFYING: ☑ IN SUPPORT OF ☐ IN OPPOSITION TO ☐ FOR INFORMATIONAL PURPOSES

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **JEAN BAIRD**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **3/25/2026 3:49 PM**

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Having had the pleasure of knowing Maddie and her family, I wholeheartedly support Maddie’s Law. This legislation is both necessary and long overdue in the medical field. I truly believe that, had it already been in place, many lives could have been saved.

It is heartbreaking that it took the loss of such a young, sweet, and beautiful life to bring about this change. Maddie will always hold a special place in my heart.

MISSOURI HOUSE OF REPRESENTATIVES

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COMMITTEE: **Health and Mental Health**	

TESTIFYING: ☑ IN SUPPORT OF ☐ IN OPPOSITION TO ☐ FOR INFORMATIONAL PURPOSES

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **JEFF AUMANN**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: **3/26/2026 12:00 AM**

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MISSOURI HOUSE OF REPRESENTATIVES

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DATE: **3/26/2026**

COMMITTEE: **Health and Mental Health**

TESTIFYING: ☑ IN SUPPORT OF ☐ IN OPPOSITION TO ☐ FOR INFORMATIONAL PURPOSES

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **JENNIFER RAE MEEHAN**

PHONE NUMBER:

BUSINESS/ORGANIZATION NAME:

TITLE:

ADDRESS:

CITY:

STATE:

ZIP:

EMAIL:

ATTENDANCE: **Written**

SUBMIT DATE: **3/25/2026 6:54 PM**

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

As a Special Education Teacher for medically complex students, I strongly recommend the passing of HB 3458 Medically Complex Pediatric Patients, Maddie’s Law as it will help many families and children. The passing of this bill will ensure pediatric patients’ voices are heard by doctors therefore improving diagnostic accuracy and protecting medically complex children. Doctors need to listen to what the patient and parents are reporting as symptoms, and then treat those symptoms. In Maddie’s case, this did not happen. Maddie shared with me in great detail several times how she would describe her pain to her team of doctors and she was disregarded. Maddie also shared with me that she was made to feel like she was exaggerating the severity of her pain and then to be left untreated for hours. For Maddie, proper treatment was withheld resulting in her condition declining and then leading to her death. I feel with all my heart with more accurate diagnosis and proper medical care, Maddie would still be here with us today. Maddie was very aware of her fate and very adamant that this medical neglect ever happen to another person. She shared her story hoping to make the needed changes to protect medically complex patients and to save lives. If HB 3458 is passed, Maddie’s wish would become reality. Medical professionals would be held accountable to listen and treat their patients accordingly.

MISSOURI HOUSE OF REPRESENTATIVES

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COMMITTEE:
Health and Mental Health

TESTIFYING: ☑ IN SUPPORT OF ☐ IN OPPOSITION TO ☐ FOR INFORMATIONAL PURPOSES

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **JULEE MITSLER**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: **3/26/2026 12:00 AM**

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Health and Mental Health

TESTIFYING: ☑ IN SUPPORT OF ☐ IN OPPOSITION TO ☐ FOR INFORMATIONAL PURPOSES

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **KELI STONE**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: **3/26/2026 12:00 AM**

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WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **MARSHA GOGGIN**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: **3/26/2026 12:00 AM**

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WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **MARTHA SMITH**		PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS:			
CITY:		STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **3/25/2026 7:02 PM**	

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We support the Maddies Law and all medically complex kids who face the obstacles of advocating in emergency departments and general inpatient situations.

Representative Melissa Schmidt knows Tommy and will be summarizing his story. Thank you

MISSOURI HOUSE OF REPRESENTATIVES

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Health and Mental Health

TESTIFYING: ☑ IN SUPPORT OF ☐ IN OPPOSITION TO ☐ FOR INFORMATIONAL PURPOSES

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **NATALIE BRAVO**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: **3/26/2026 12:00 AM**

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MISSOURI HOUSE OF REPRESENTATIVES

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TESTIFYING: ☑ IN SUPPORT OF ☐ IN OPPOSITION TO ☐ FOR INFORMATIONAL PURPOSES

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **NATALIE MCBRIDE**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **3/24/2026 12:12 AM**

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

As a parent of a medically complex child, visits to the emergency room are often. Doctors have no clue what my child has. A blueprint already on the record will guide them to save a life and clue them in. This is a great idea. Our children matter.

MISSOURI HOUSE OF REPRESENTATIVES

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Health and Mental Health

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WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **REBECCA C. GOGGIN**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: **3/26/2026 12:00 AM**

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WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **THOMAS SMITH "TOMMY "**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **3/25/2026 7:15 PM**

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

**Martha Smith
12701 Vista Dr
Lynchburg MO 65543
marthaks760@gmail.com**

**March 12, 2026
Tricia Byrnes
MO House of Representatives
201 West Capitol Avenue
Room 313-3
Jefferson City MO 65101
Dear Representative Byrnes,
Our**

Tommy is alive today because our family refused to stop advocating when the medical system could not immediately recognize the complexity of his condition. That experience is exactly why legislation like Maddie’s Law: The Rare Pediatric Disease Care and Protocol Protection Act matters so deeply to families like ours—because medically complex children should never have to rely on a parent’s persistence alone for life-saving information to be recognized in an emergency.

Tommy lives with Congenital Central Hypoventilation Syndrome (CCHS), a rare disorder affecting the autonomic nervous system that prevents his body from recognizing when oxygen levels drop or when carbon dioxide levels rise. He may not show the visible warning signs most clinicians are trained to look for, yet without proper ventilation his body cannot adequately breathe during sleep, allowing oxygen levels to fall and carbon dioxide to build to dangerous levels. When this is not recognized quickly, it can become life-threatening and may result in brain injury or loss of life. Children with autonomic nervous system disorders like Tommy often do not present with textbook symptoms, meaning a child can be in a life-threatening situation while appearing far more stable than they truly are.

Over the years, our family has experienced multiple emergency room visits where critical aspects of Tommy’s medical complexity were not immediately recognized as a medical emergency. While medical teams work hard to follow standard protocols, children like Tommy do not always fit those protocols. Important information about his rare conditions, equipment needs, and unique presentation can be buried deep within medical records instead of being immediately visible to providers during urgent situations. When this happens, precious time can

be lost and medically fragile children may be placed at unnecessary risk. These gaps in recognition can lead to delays in appropriate care, unnecessary procedures, and additional trauma for children whose bodies are already working harder than most just to stay stable.

Families and immediate caregivers often become the first line of defense in recognizing when something is wrong. We know the subtle warning signs that something is changing long before it may appear obvious in a clinical setting. However, without a system that clearly communicates a child's medical complexity the moment they enter an emergency department, those critical insights can be overlooked or delayed. No family should have to fight for the system to see what is already known about their child.

Maddie's Law offers a simple, practical solution. By allowing hospitals to implement a clearly visible electronic alert within existing medical record systems for medically complex pediatric patients, emergency providers can immediately recognize that a child requires specialized awareness and access the care plan that guides their treatment. This approach does not create unnecessary burden for hospitals, but it can dramatically improve communication, response time, and patient safety.

Children like Tommy cannot rely on typical warning signs to protect them. Their conditions are complex, their symptoms are often subtle, and their safety depends on systems that recognize those differences immediately. When caring for someone's child—especially one whose life depends on precise, informed care—there must be no room for ego or presumption. There must only be collaboration, clarity, and a healthcare system designed to recognize and protect the most vulnerable children among us.

Thank you for your leadership in introducing Maddie's Law and for your commitment to improving care for medically complex children across Missouri. Families like ours deeply appreciate the work being done to ensure that children like Tommy are seen, understood, and protected when they need it most.

Sincerely,
Martha Smith

MISSOURI HOUSE OF REPRESENTATIVES

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COMMITTEE:
Health and Mental Health

TESTIFYING: ☐ IN SUPPORT OF ☐ IN OPPOSITION TO ☑ FOR INFORMATIONAL PURPOSES

WITNESS NAME

REGISTERED LOBBYIST:

WITNESS NAME: **JUSTIN ALFERMAN**	PHONE NUMBER: **636-667-1093**	
REPRESENTING: **SSM HEALTH**	TITLE:	
ADDRESS:		
CITY: **ST. LOUIS**	STATE: **MO**	ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: **3/26/2026 12:00 AM**

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WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **MEGGIE BIESENTHAL**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **3/23/2026 9:31 PM**

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As a parent of a child who was diagnosed with FND at STL Children's in Dec 2024 & successfully treated for it, I am deeply sorry for Maddie's family & am grateful for Rep. Byrnes' interest in this common but little-known illness. I urge lawmakers to require insurance companies to pay for all testing recommended or mandated by this law. We tried to do different levels of genetic testing for our child but only one $5,000 test (that revealed nothing) was covered by our insurance. When faced with another genetic test that cost a few thousand dollars & was not covered by insurance, we spent our money instead on the treatment we had found that was also not covered by insurance but which helped our daughter conquer her condition.

Additionally, FND often occurs in children with anxiety or other similar conditions. My child has severe medical anxiety & using needles on her is nearly impossible. Mandating that doctors perform additional tests on children whose symptoms already lead the doctors, in their medical expertise, to a diagnosis, can result in more trauma to children who are already suffering.

Thank you for your time.