MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 2643**	DATE: **3/9/2026**
COMMITTEE: **Emerging Issues**	

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **AIDAN EVERETT WAGNER**		PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS:			
CITY:		STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **3/9/2026 8:09 AM**	

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

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 2643**	DATE: **3/9/2026**
COMMITTEE: **Emerging Issues**	

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **ARNIE C. "HONEST-ABE" DIENOFF-STATE PUBLIC ADVOCAT**		PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS:			
CITY:		STATE:	ZIP:
EMAIL:	ATTENDANCE: **In-Person**	SUBMIT DATE: **3/9/2026 11:55 PM**	

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

I am in Favor of this Bill and Access to Invenstigational Treatment.

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 2643**	DATE: **3/9/2026**
COMMITTEE: **Emerging Issues**	

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **BILL MUNDHAUSEN**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:

EMAIL:	ATTENDANCE:	SUBMIT DATE: **3/9/2026 12:00 AM**

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

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 2643**	DATE: **3/9/2026**
COMMITTEE: **Emerging Issues**	

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

WITNESS NAME

REGISTERED LOBBYIST:

WITNESS NAME: **CAMELLIA PETERSON**		PHONE NUMBER: **417-726-9475**	
REPRESENTING: **AMERICANS FOR PROSPERITY**		TITLE: **LEGISLATIVE DIRECTOR**	
ADDRESS: **PO BOX 94**			
CITY: **JEFFERSON CITY**		STATE: **MO**	ZIP: **65102**
EMAIL: **cpeterson@afphq.org**	ATTENDANCE: **In-Person**	SUBMIT DATE: **3/9/2026 8:45 PM**	

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

Every Missouri patient at the end of their treatment options should have the freedom to work with their doctor to have access to individualized treatment regardless of FDA approval. We encourage the committee to pass this out unanimously.

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 2643**	DATE: **3/9/2026**
COMMITTEE: **Emerging Issues**	

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

WITNESS NAME

BUSINESS/ORGANIZATION:

WITNESS NAME: **DAVID TIPTON**	PHONE NUMBER: **601-857-5532**	
BUSINESS/ORGANIZATION NAME: **NACLC/UPCI (WELDON SPRING, MO)**	TITLE: **VICE PRESIDENT, APOSTOLIC ACTION NETWORK**	
ADDRESS: **PO BOX 1188**		
CITY: **RAYMOND**	STATE: **MS**	ZIP: **39154**
EMAIL: **supt@msupci.com**	ATTENDANCE: **Written**	SUBMIT DATE: **3/7/2026 1:35 PM**

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

Chairman Christ and Members of the Committee:

I am writing to express my strong support for the Hope for Missouri Patients Act (HB 2643), sponsored by Rep. Melanie Stinnett. I am vice president of the Apostolic Network with the National Apostolic Christian Leadership Conference (NACLC). We are the public policy arm of the United Pentecostal Church International (UPCI), headquartered in Weldon Spring, Missouri.

The NACLC represents churches and people of Faith, both in Missouri and nationwide. I write today, not in my official capacity, but on a more personal basis.

As a cancer survivor, I have benefitted from individualized therapy and treatment offered in Germany. I could not obtain such care in my home state of Mississippi, so I travelled to Europe to get it. Subsequently, my home state passed similar legislation. Under this bill, such options would be available in Missouri. This would bring healing and hope to many families.

Sincerely, Rev. David Tipton

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 2643**	DATE: **3/9/2026**
COMMITTEE: **Emerging Issues**	

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **DONNA PATTY**		PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS:			
CITY:		STATE:	ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: **3/9/2026 12:00 AM**	

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

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 2643**	DATE: **3/9/2026**
COMMITTEE: **Emerging Issues**	

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **ELIJAH STACY**		PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS:			
CITY:		STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **3/8/2026 11:31 PM**	

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

March 8th, 2026
Chairman Representative Brad Christ
House Emerging Issues Committee
RE: Vote Yes on HB 2643
Dear Chairman Chairman Representative Brad Christ and Members of the House Emerging Issues Committee,
My name is Elijah Stacy. I am 24 years old, and for as long as I can remember, I have been fighting an uphill battle against
Duchenne Muscular Dystrophy (DMD), a progressive and fatal genetic disorder. At just six years old, I was diagnosed with this
disease that would come to define my daily struggles but not my spirit. By 11, I lost my ability to walk. Today, I am fully
dependent on a power wheelchair and face the relentless challenges of this disease every moment of my life.
DMD is a thief. It steals the ability to run, walk, hug loved ones, and eventually even to breathe. It is a disease that robs
individuals of their independence and families of precious time. I have watched my own body weaken over the years, losing my
ability to lift my arms and perform simple tasks. Despite this, I have worked tirelessly to defy expectations, founding a nonprofit
called Destroy Duchenne at the age of 15 to fight for patients like me.
But my fight is personal in ways that words can hardly convey. I've lived through the devastation of this disease, not just in my
body but in my family. My younger brother Max passed away from DMD at the age of 14. My youngest brother is now 17,
battling the same relentless condition. I've watched my parents pour everything they have—physically, emotionally, and
financially—into supporting us while dealing with the unbearable pain of knowing the future DMD typically holds.
My journey is filled with moments of profound grief and resilience. It's also marked by hope. As a biotech consultant and
someone deeply involved in the field of medical innovation, I see the incredible advances being made in personalized medicine.
Treatments now in development hold the potential to preserve muscle function and fundamentally change the trajectory of rare

diseases like DMD. But hope for patients like me and my brother is often trapped in the bureaucratic red tape of the FDA's outdated regulatory system.

Time is a luxury I don't have. The average lifespan for someone with Duchenne is 25. My muscles continue to waste away, and every day brings the possibility of losing more function. Many other patients face even greater urgency—some are mere days or weeks away from losing their fight. That is why I urge you to support the Right to Try for Individualized Treatments Act (Right to Try 2.0).

This legislation would give patients with life-threatening or severely debilitating illnesses access to investigational treatments customized to their genetic makeup when all approved options have been exhausted. It empowers patients and their doctors to make critical decisions without unnecessary government barriers. It is about giving people like me a fighting chance.

Imagine watching your body deteriorate while knowing that promising therapies exist but are inaccessible due to years-long regulatory processes. I don't want to spend my last years hoping—I want to spend them living. With Right to Try 2.0, patients like me can gain timely access to these treatments, potentially preserving muscle function, extending our lives, and improving the quality of every day we have left.

Please understand that this is not just about me. It's about the 30 million Americans living with rare diseases, 95% of whom have no FDA-approved treatment options. It's about the families, the caregivers, and the loved ones who fight alongside us. This legislation has already been passed in six states, and it's time for Kansas to lead in this life-saving effort.

I ask you to vote yes on HB 2643 and give patients like me the opportunity to fight for our lives. We don't want pity; we want a chance. A chance to pursue hope. A chance to live.

Thank you for your time and consideration.

Sincerely,

Elijah Stacy

Founder, Destroy Duchenne

Bestselling Author and Patient Advocate

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 2643**	DATE: **3/9/2026**
COMMITTEE: **Emerging Issues**	

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **FRANK GILLHAM**		PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS:			
CITY:		STATE:	ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: **3/9/2026 12:00 AM**	

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

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 2643**	DATE: **3/9/2026**
COMMITTEE: **Emerging Issues**	

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **GRETCHEN PETERS**		PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS:			
CITY:		STATE:	ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: **3/9/2026 12:00 AM**	

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

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 2643**	DATE: **3/9/2026**
COMMITTEE: **Emerging Issues**	

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **JENNIFER REINHARDT**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **3/6/2026 8:39 PM**

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

Dear Representative,

Thank you for considering running the Access to Individualized Investigational Treatment bill. I am blessed to be able to talk to you and have a happy ending to my story. I went to Oregon from my home state in 2017 to get a treatment for my terminally ill daughter, because they were one of a few states that were allowed to do international medicine through the individualized treatments bill. It would be amazing if we could have that law here in Missouri and Maya's story could help someone else, like the people who came before us in Oregon helped her. The Right to Try bill in Oregon helped save Maya's life. I am happy to testify, or meet with you, or anyone to help give someone else the opportunity Maya was given.

Here is our story.

My daughter, Maya was born in 2001 with a heart defect as a blue baby. She had to have open heart surgery at 3 days old after being on a ventilator. After surgery, she got sepsis and was not growing. She almost died. At this point, her newborn screen came back positive for cystic fibrosis. After a series of miracles and a few months of hospitalizations, Maya was stabilized, and we were then dealing with the cystic fibrosis. CF does not have a cure.

Cystic Fibrosis is a life threatening genetic rare disease. Maya's body could not fight common bacteria that caused infections, and she could not digest her food. Eventually, we were told she would be diabetic, and she may have liver issues as her disease progressed. The median age for someone with cystic fibrosis when Maya was born was around 30, however together with her heart issue no one knew how long she would live. The surgery to save her heart was new and so there were no old people with her shunt. The CF gene is recessive. My uncle died of CF when he was 2, which made Maya's diagnosis particularly terrifying for my mom's side of the family. My grandma cried and cried. I didn't know that Maya was sick until she was born, as they didn't do gene screening for mothers in 2001. My ultrasounds were normal, and the baby's heart valves don't open until birth so Maya grew ok until she was born.

It was a full-time job raising Maya, and so instead of going to graduate school for social work, I got into real estate so I could make a living working part time and have flexible hours. I was only 23. I researched all the alternative medicines, and which doctors in which states had higher life expectancies. We flew to Minnesota to meet with Dr Warwick, a pioneer in cystic fibrosis. Maya got on inhaled NAC, because in Minnesota the median life expectancy was 16 years higher than Denver and that is what they did there. Through a private dietitian, we got Maya on an anti-inflammatory diet. The hospital was giving her Ensure (a mix of corn syrup and canola oil through their contract with Nestle) to gain weight. Once she was off of that, she started to get less sick. I reached out to a man in his 50s in California with CF who was also a doctor. 50 is old for CF. He said that she had to run, that the

pounding in her chest and coughing would help dislodge her mucus. So, I sent Maya to taekwondo, crying. For years. She would spar and cry as her Cuban teacher told her that "crying don't fix nothing". The running made her tough and even though she hated it, we were trying to buy time until a treatment for CF came out. The doctors in thought it would be 10 years, for a gene therapy. Dr Accurso at Children's hospital oversaw CF gene therapy research, and he was Maya's doctor. One day it would be like asthma instead of a death sentence, he said. So we kept fighting. I think with a dying child, without hope, you can't keep moving. As long as I had something to fight for, I kept going.

Her daily schedule all her childhood was to wake up, do a nose wash, get hooked up to a vest that shook her for 30 minutes with a nebulizer, and go to school with another nebulizer in the car on the way to downtown. She needed pills to digest her food, and was on a schedule of a month on, a month off, of strong antibiotics to keep her infections at bay. They made her nauseous, so she had a room to lay down in the nurse office and a private bathroom. Although I lived by the airport, I drove her downtown to a charter school as she needed a special school and had an IEP. The schools by us were very poorly rated and I didn't have a lot of extra money to go to private school. I am grateful there was a charter option to drive to. After school, Maya did more treatments at night. Maya jokes she spent her life plugged into a wall until she got better. The nebulizer and vest had to be plugged in, so she couldn't move around. She got good at art and writing because she could do that while plugged in and worked around the vest shaking her little body.

Maya was hospitalized several times, and we did several clinical trials. One trial called the Inspire Tiger trail, they had to hold her down and put IVs in her body while she yelled. She was around 7. It was very hard. And it didn't work. We kept going, because there was no other option.

Dr Accurso at Children's Hospital warned us that once Maya got a bacteria called pseudomonas, that she would decline rapidly as the antibiotics would not work. It is found in standing water, and hard to not get as there is water everywhere outside. I washed our clothes in borax, put our toothbrushes through the dishwasher, and changed our shower heads to prevent getting it. I kept researching how to keep it away. Eventually, she still got it, at around 13 years old. For 3 years, we were controlling it with essential oil washes and special herbs from the naturopaths. I took Maya to special doctors in the mountains and Boulder. Then, when she was 16, nothing worked. Her infection was raging despite 2 months of cipro antibiotics. Her sinuses were full of mucus, and she was dizzy, along with being sick from being on antibiotics for 2 months. The hospital offered to do sinus surgery to get rid of some of the mucus, but I chose not to since the mucus was full of super bacteria, and I didn't want it in her blood stream again. I was afraid of sepsis. The antibiotics did not work against her bacteria, because the bacteria protected itself with a bubble called a biofilm. The medicine didn't touch the bacteria, so Maya kept getting sicker.

I think this part is important, because if she had not gotten this sick, or if there was a treatment that worked in our state we would not have gone to extreme measures to try to save her. I knew that people with cf with these bacteria could die in their teens.

My mom is a nurse, and she sent me an article from Prevention Magazine, on how there was a treatment for antibiotic resistant infections in Tbilisi, Georgia. The Georgia by Russia, not the Atlanta kind of Georgia. Here is the article she sent me.

https://www.prevention.com/health/a20447787/the-cure-for-antibiotic-resistance/

The problem of antibiotic resistance isn't just for people with cystic fibrosis. Because of antibiotic overuse in the United States, especially for meat production, a lot of bacteria don't respond to antibiotics. 35,000 people in the US die every year, according to the CDC.

Through my research I learned that it is hard to patent something that is alive, like the phage who eat bacteria in nature. If pharma doesn't see money in it, they don't bring it to the United States. Phage Therapy has been around for a century in Tbilisi, it isn't new, and it isn't expensive. One treatment at the time cost around $60. You just couldn't legally get it in our state, and the doctors at Children's hospital would not help me because it was not FDA approved. To get a treatment through the FDA, it takes around 10 years and 1.3 Billion dollars. Sadly, I did not have 10 years and a billion dollars.

One thing about me is that I am a fighter too. I raised Maya and my little son as a full-time sole parent. The only way I could do this was because I work in real estate and have flexible hours (and enough money) to travel all over and time to research and connect to other people doing the same thing which is trying to save themselves and their families.

I pulled all the research papers on the bio phage and cystic fibrosis through the health journals. One of my client's cousins was in the NIH. My friend from church's husband was a pulmonary surgeon. I asked them if this was a good idea. They both said that it was a real medicine, but just international and couldn't be used here. Well, if there was a treatment, I was going to try to get it for my child. That wasn't ok, that she would just die because of geography.

The next steps were to find someone who used it. I looked online, and through all the CF message

boards. I found a guy that had used it in Oregon. He connected me with a doctor in Oregon. The doctor was busy for a few months. I kept calling, and calling. Finally I got an appointment. Part of the law was that she had to see us in person. This was difficult. My son was little and in school. I was single and working. My family couldn't help me in Colorado with the timing of the appointment. So I reached out to my cousins in Seattle. I had to fly to Seattle with my kids, Maya really sick. I left my son in Seattle and rented a car and drove Maya to see Dr Ambrose in Oregon.

Dr Ambrose could now get Maya the treatment, but it had to be ordered from Tblisi. It has to go through the FDA and Federal right to try laws and clear customs in Detroit. It is not easy, even with the laws, to get the medicine.

Because Maya was so sick, Dr Ambrose figured out how to get us one box of medicine while the other ones were on order.

Maya nebulized the phage and also we put it in her nose, for her sinus infection. The infection finally drained and she got better.

Now this wasn't a cure. I learned to facetime the doctors in Tbilisi, and how to get Maya better. Each time Maya got an infection that didn't respond to antibiotics, we had to do this. When her window leaked and the water from the leaves got into her space, she was sick. It was a constant struggle to keep her healthy. She was sick over and over again. The phage also didn't not help her organs impacted by cystic fibrosis other than her lungs. But the lung failure is what will kill you.

Maya's lungs healed with the phage and her lung function got back up into the 100s. She has 100% lung function of a healthy person, sometimes 125% lung function of a healthy person (PFTs or pulmonary function test). People with CF lose lung function as they age until they die. I was able to keep Maya's lungs undamaged until a better treatment came out. The cystic fibrosis foundation was working on a medicine. I was watching it in the pipeline.

Then in December 2019 Trikafta came out, and since then she has not had a lung infection. She could stop taking her insulin. Her lung function is 115-125% of a healthy person.

Trikafta is a drug that corrects the CFTR defects in her cells, and it is super effective. It gives her close to a normal life expectancy if taken daily. Since Trikafta, she hasn't had to take the phage because she hasn't gotten that sick.

Without the bio-phage, I don't know if we would have made it to 2019. I don't know how bad the infection would have gotten and if she would have come back from it. Once the lungs are damaged, you can't fix them. Also she was starting to have to take insulin in 2019. It felt crushing, the amount of work needed to keep her alive. As a single parent I was starting to break down.

I am not a rare disease advocate by trade, I am a real estate broker. I got involved because we don't want to go back to Maya being sick, it would take over our lives. Maya will die if she loses access to Trikafta.

I think everyone should have the right to try medicines if they have a life threatening disease. It doesn't hurt anyone else, and a lot of the medicines are not expensive. Most importantly, you need hope. Without hope, there is no reason to keep going. I needed to keep going for myself and my son even if the worst had happened. I don't know why Maya was saved and so many people die of rare diseases. But I can use my voice and say, let other people have the right to try different medicines, so they have hope until their miracle drug comes out too.

Thank you for listening to my story.

Here is a movie on a family's journey who's story is similar to ours. They had to jump through so many hurdles in the United States to get the medicine, whereas I went directly to the Tbilisi clinic's supply to save Maya. But the movie is like watching my own experience with Maya. It is very well done. Please watch it if you have time. 10% of people with CF still do not have a treatment like Trikafta, as it is based on genotype. The rare disease community matters and has a voice. https://www.youtube.com/watch?v=aGxCjASgMB8&t=960s

We want people to make it and have hope. Please cut the red tape out of Missouri, as so many people don't have the resources or experience to navigate the complex bureaucratic systems. Especially if they are sick. In 2017 I didn't know about the "Access to Individualized Treatments" law in Oregon. I was so blessed there were others that thought about it before me and paved a road for me to travel on.

Please pass this law and pray for the nations sick children, to have hope for a treatment and eventual cure.

Jennifer Reinhardt 303-514-8491

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 2643**	DATE: **3/9/2026**
COMMITTEE: **Emerging Issues**	

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **KAREN SEARS**		PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS:			
CITY:		STATE:	ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: **3/9/2026 12:00 AM**	

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

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 2643**	DATE: **3/9/2026**
COMMITTEE: **Emerging Issues**	

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **KENDRA D RILEY**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **3/8/2026 2:49 PM**

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

Rep. Brad Christ,

Thank you for the opportunity to share my family's story and why this bill is important to myself and other families with children who have rare diseases. My name is Kendra Riley, and I am the mother to three children, two of which were diagnosed with a rare genetic disorder called Metachromatic Leukodystrophy (or MLD) in 2020.

This rare and very aggressive genetic disorder attacks the brain and then the nervous system. Within 90 days of my daughter Olivia being diagnosed at almost 2 years old she lost the ability to walk, then talk, she is now tube fed, no longer has control of her limbs, experiences 1-2 grand mal seizures per week, takes 10 medications a day to stay pain free and relies on us for everything.

A few months after her diagnosis, our youngest daughter, Keira, was diagnosed with the same genetic disorder. But unlike her older sister, Keira was a newborn and had not yet begun to show symptoms. Catching Keira's diagnosis early gave us the opportunity to try to save her life, since there was a cutting-edge gene therapy treatment that was showing promising results in non-symptomatic MLD patients.

Unfortunately, since Olivia was already showing symptoms, this treatment could not help her and we were given an estimated lifespan of 6 years old. But it could potentially save Keira's life if we moved quickly. There was only one issue – this personalized gene therapy which would be tailored to Keira based on her DNA was not available in the United States due to the FDA's outdated drug approval process.

In order to get Keira this very promising individualized treatment, we were able to raise the hundreds of thousands of dollars needed – in one months' time no less – to move our entire family to Italy for 5 months during the pandemic to get our baby girl there in time to receive this treatment before it was too late. Other families are not so lucky.

This is why HB 2643 is so important to families like ours. As genetic testing allows doctors to catch rare diseases earlier and personalized medicine advances, I fear more parents will face situations like ours.

Keira's individualized treatment was a life-saving success. She was the 32nd child in the world to receive this treatment and is now a vibrant child who loves gymnastics, swimming and singing like

Taylor Swift…whereas her sister Olivia was already in hospice at this age. None of Keira's every day, "normal" abilities would be possible without her receiving the treatment in Italy. A treatment she should have been able to have access to here in the U.S.

This bill, which creates a right to try for individualized treatments for patients with life-threatening or severely debilitating diseases, can help prevent other families from facing the same situation we faced. The bill would give families the option to seek investigational personalized therapies right here in Missouri rather than having to drop everything and move overseas.

Please keep in mind the approximately 600,000 Missouri residents who are estimated to be living with a rare disease. That's 600,000 friends, neighbors, and family members who could potentially have a chance at living a normal life. So I ask that you please protect the right to try by supporting HB 2643.

Kendra Riley
Mother of Eva, Olivia & Keira

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 2643**	DATE: **3/9/2026**
COMMITTEE: **Emerging Issues**	

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **MADISON STEPHENS**		PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS:			
CITY:		STATE:	ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: **3/9/2026 12:00 AM**	

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

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 2643**	DATE: **3/9/2026**
COMMITTEE: **Emerging Issues**	

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

WITNESS NAME

BUSINESS/ORGANIZATION:

WITNESS NAME: **RICH DEAUGUSTINIS**	PHONE NUMBER: **404-547-8153**	
BUSINESS/ORGANIZATION NAME: **THE MYOSITIS ASSOCIATION**	TITLE: **CHAIR OF THE BOARD**	
ADDRESS: **3599 VANET RD**		
CITY: **ATLANTA**	STATE: **GA**	ZIP: **30341**
EMAIL: **deaugustinis@myositis.org**	ATTENDANCE: **Written**	SUBMIT DATE: **3/7/2026 9:38 AM**

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

My name is Rich DeAugustinis. I am Chair of the Board for The Myositis Association and previously served on the board of the Mesothelioma Foundation.

Thank you for allowing me to testify today in support of Missouri House Bill 2643, Access to Individualized Investigational Treatments. This is a very important bill.

Given my personal journey and my nonprofit involvements, I am very qualified to authoritatively speak on this issue.

I am testifying today on behalf of my father Augie and my late wife Tara. One is living with a rare disease, and one had her life shortened by one.
My father Augie was diagnosed with Inclusion Body Myositis in 2008.

IBM, as it's called, is a rare neurodegenerative disease that slowly wastes away all of the muscles in your body.

My dad is 17 years in, and life for him is now in a wheelchair full time. He can't do much for himself without help. In 2014 he participated in a clinical trial of a gene therapy that promised to rebuild the muscle tissue in his legs. It was a phase 1 trial, which as you know is focused on safety, not efficacy.

Miraculously, it was successful and built muscle in my father's legs. He was able to walk for a few more years. Unfortunately, the researchers could not find financial support for a phase 2 trial and my father couldn't continue to benefit from the gene therapy.

Had this legislation been law at that time, it would have cleared a path for my dad to continue utilizing this effective treatment. It likely would have delayed the further breakdown of his muscles, and extended quality of life for him.

This legislation also could have helped my late wife Tara. She was diagnosed with mesothelioma in early 2016. Meso is a very rare cancer of the lining of the lung, caused by exposure to asbestos. She fought valiantly for 15 months but passed in 2017 at the age of 47, leaving behind me and our 15-year-old daughter.

Meso is considered one of the deadliest cancers in the world. Generally, if you are diagnosed with

meso, it’s a death sentence. It’s not a question of if, but how fast.

Despite that, there are a growing range of experimental treatments that are showing promise with mesothelioma, treatments like CAR-T cell therapy and immunotherapy.

Broader access these treatments and others might just turn mesothelioma into a chronic disease that can be managed, rather than a very painful death sentence.

Simply put, this legislation would have given Tara a chance — and just as importantly given her a chance to try some of these experimental treatments.

There are many people in the great state of Missouri struggling with rare diseases — very likely in every single one of your districts. They need new options to improve their quality of life and to extend their lives. They need HOPE.

There are treatments are out there that Missouri residents can't access. ... Effective treatments that are available in other countries or that could be in clinical trials here in the US.

While this bill won't address every single situation, it will open the door to a lot more opportunities for access to care. It will open the door to HOPE.

Please support this bill and let’s make it law during this legislative session. Do it for Augie and Tara, and countless others in your districts that need it. Thank you.

Rich DeAugustinis
Chair of the Board, The Myositis Association
deaugustinis@myositis.org
404-547-8153

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 2643**	DATE: **3/9/2026**
COMMITTEE: **Emerging Issues**	

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

WITNESS NAME

REGISTERED LOBBYIST:

WITNESS NAME: **TAYLOR WALKER**	PHONE NUMBER: **450-910-5026**	
REPRESENTING: **BARRY GOLDWATER INSTITUTE FOR PUBLIC POLICY RESEARCH**	TITLE:	
ADDRESS: **500 E CORONADO RD**		
CITY: **PHOENIX**	STATE: **AZ**	ZIP: **85004**
EMAIL:	ATTENDANCE:	SUBMIT DATE: **3/9/2026 12:00 AM**

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

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 2643**	DATE: **3/9/2026**
COMMITTEE: **Emerging Issues**	

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **TYLER STILLINGS**		PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS:			
CITY:		STATE:	ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: **3/9/2026 12:00 AM**	

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

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 2643**	DATE: **3/9/2026**
COMMITTEE: **Emerging Issues**	

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **SARAH BERRY**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **3/9/2026 9:31 AM**

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

HB 2643 establishes a state framework for access to individualized investigational drugs, biological products, and devices developed based on a patient's genetic profile.

However, the regulation of investigational drugs is governed primarily by federal law under the Federal Food, Drug, and Cosmetic Act and the FDA's investigational drug approval system.

Creating a parallel state authorization pathway risks conflict with federal regulatory authority and raises significant federal preemption concerns.

The bill also provides broad liability protections for manufacturers and providers while limiting the ability of state officials to intervene, which substantially reduces existing regulatory safeguards surrounding experimental medical treatments.

If the General Assembly intends to expand access to individualized investigational therapies, that expansion should occur within clearly defined federal research and approval pathways rather than through a state statutory structure that may conflict with federal law and weaken existing oversight protections.

For these reasons, HB 2643 warrants careful reconsideration.