MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 1756**	DATE: **2/4/2026**
COMMITTEE: **Special Committee on Tourism**	

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **ANNA BUSER**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **2/4/2026 9:49 AM**

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

I support the June's Week bill as a way to raise awareness of rare pediatric diseases. This recognition is a simple way to show support and understanding for the Missouri children and families affected by rare conditions.

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 1756**	DATE: **2/4/2026**

COMMITTEE:
Special Committee on Tourism

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **ARNIE C. AC DIENOFF-STATE PUBLIC ADVOCATE**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **In-Person**	SUBMIT DATE: **2/4/2026 11:42 PM**

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

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 1756**	DATE: **2/4/2026**

COMMITTEE:
Special Committee on Tourism

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **CARI LEE**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **2/4/2026 8:30 AM**

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

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 1756**	DATE: **2/4/2026**

COMMITTEE:
Special Committee on Tourism

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **DAVID REZNACK**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **2/4/2026 9:01 AM**

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

Finally!

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 1756**	DATE: **2/4/2026**

COMMITTEE:
Special Committee on Tourism

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **HAILEY STEINMEYER**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **2/4/2026 7:18 AM**

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

Chair and members of the committee,

My name is Hailey Steinmeyer and I am here as a parent.

I am asking you to support “June’s Week” because behind every statistic about rare pediatric disease is a family living a nightmare they never saw coming—and discovering far too quickly how little attention, research, and urgency exists for children who are sick.

Walking through serious illness with a child is terrifying in a way that is hard to put into words. As a parent, your job is to protect your child. But when the disease is rare, you learn that there are not enough studies, not enough treatment options, and not enough experts whose full-time work is focused on saving children like yours. You hear phrases like “there just isn’t enough data” or “research funding is limited,” and you realize how small your child’s world feels to the system meant to help them.

Pediatric cancer is often labeled “rare,” but when you are living it, it does not feel rare at all. It feels everywhere. It feels urgent. It feels unacceptable that children—who have done nothing wrong—are fighting diseases that lack cures simply because there is not enough investment or visibility.

Someone has to fight for these kids. Children cannot advocate for themselves. Families are exhausted, scared, and often isolated. Awareness matters because awareness leads to funding, research, and people choosing to dedicate their brilliance to pediatric medicine instead of more profitable paths.

“June’s Week” is not just symbolic. It is a statement that Missouri sees these children and these families. It says that our state is willing to stand up and acknowledge that rare pediatric diseases deserve attention, urgency, and hope. It tells Missouri families walking this road that they are not invisible.

Missouri should be the state that honors its families by saying: we care, we recognize your fight, and we believe children’s lives are worth investing in. Supporting this bill is a small but meaningful step toward a future where fewer parents have to hear that there simply isn’t enough research to save their child.

I urge you to support “June’s Week” and help give a voice to children who cannot speak for themselves and families who desperately need hope.

Thank you for your time and for considering this important bill.

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 1756**	DATE: **2/4/2026**

COMMITTEE:
Special Committee on Tourism

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **JESSICA HORNER**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **2/4/2026 8:22 AM**

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

June is a friend of my son. Throughout the journey she and her family are navigating they have faced many scary and uncertain situations. No child and family should receive a diagnosis alongside with the news there isn’t much research. Children are our future and we owe proactive efforts to each and every one to support their health and chance to grow into change makers in their communities.

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 1756**	DATE: **2/4/2026**

COMMITTEE:
Special Committee on Tourism

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **JESSICA STEINMEYER**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **2/3/2026 2:56 PM**

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

Chair and Members of the Subcommittee,

Thank you for the opportunity to submit testimony in support of House Bill 1756.

My name is Jessica Steinmeyer. I am a Missouri resident and one of two very lucky parents of a brave little girl named June. June was diagnosed with an atypical teratoid rhabdoid tumor (ATRT), a rare pediatric brain tumor. She has completed treatment and recently received a clear brain scan. She will continue to be monitored closely in the months and years ahead.

House Bill 1756 designates the first full week in September as “June’s Week” and “Rare Pediatric Disease Week” in Missouri. This designation matters not only to our family, but to the many Missouri families affected by rare pediatric diseases - conditions that are often difficult to diagnose and limited in treatment options.

Awareness and early recognition can make a meaningful difference, yet families facing rare diagnoses often do so with little public understanding or visibility. By encouraging appropriate events and activities during this designated week, the bill creates space for education, awareness, and recognition of the children and families affected.

At the heart of this designation are the children themselves. June, like so many brave children across our state, has shown strength and resolve far beyond her years. She has endured challenges that would test even the strongest adults, and she has met them with determination and grace. Children like her are a quiet beacon - showing us how to face uncertainty, persist through hardship, and keep moving forward.

This legislation does not mandate action or funding. It simply acknowledges an issue that too often goes unseen and honors the children and families navigating rare pediatric diseases during treatment and long after it ends.

I respectfully ask the committee to support House Bill 1756.

Thank you for your time and consideration.

Respectfully,

Jessica Steinmeyer

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 1756**	DATE: **2/4/2026**

COMMITTEE:
Special Committee on Tourism

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **JOHN RUTH**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: **2/4/2026 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 1756**	DATE: **2/4/2026**

COMMITTEE:
Special Committee on Tourism

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **KATIE KEVER**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **2/4/2026 8:14 AM**

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

I am in support of June’s Week because families navigating rare pediatric diseases deserve greater awareness, increased research, and stronger support. Dedicating time to recognize these conditions encourages research, and reminds families that they are not alone.

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 1756**	DATE: **2/4/2026**

COMMITTEE:
Special Committee on Tourism

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **KRIS OHLSON**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **2/4/2026 12:50 PM**

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

I am STRONGLY in support of this bill, not only being a parent of a child that has suffered for 18 years with Chronic Mylogenous Leukemia PH+ and been through 2 Bone Marrow Transplants, but being along side many families while we were inpatient and attending appointments with many kiddos with so many rare illnesses, some continuing their battles, some have won, but unfortunately far too many are now angels because there is not enough awareness or testing done sooner to possibly help find a cure or a reason that these illnesses are occurring. These children are our future and we need to raise awareness.

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 1756**	DATE: **2/4/2026**

COMMITTEE:
Special Committee on Tourism

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **LAUREN SHAW**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **2/4/2026 9:33 AM**

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

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 1756**	DATE: **2/4/2026**
COMMITTEE: **Special Committee on Tourism**	

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **MATT JESSEE**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: **2/4/2026 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 1756**	DATE: **2/4/2026**

COMMITTEE:
Special Committee on Tourism

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **PATRICK SHAW**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **2/4/2026 8:55 AM**

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

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 1756**	DATE: **2/4/2026**

COMMITTEE:
Special Committee on Tourism

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **PHIL AND DONITA HADLEY**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **2/4/2026 8:56 PM**

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

Only people who have had the unfortunate experience of being on a pediatric cancer floor of a hospital can truly relate to the fear, heartbreak and loneliness the a child and their family go through when they receive the "cancer" diagnosis. In 2006 at the age of 4. years old, our grandson was diagnosed with Chronic Myeleogenous Leukemia. 95% of people diagnosed with CML are males over the age of 55. Since children with CML are so few, protocol for treatment was very limited. He was put on a regiment or oral chemo which appeared to control the leukemia. On December 13, 2023, the CML advanced to an advanced stage. Since that time, he has received extensive radiation treatments, various IV chemos, three transplants and numerous hospital stays and checkups. While there appears to be no sign of Leukemia, he is still dealing with the side effects of all the treatments, drugs and transplant side effects. He turns 23 this April.

Over the years, our family has seen children cured but also seen little ones receive there angel wings. We need this week to draw more attention to pediatric cancer, increase awareness and increase additional research and resources.

Thank you for your time.

Phil and Donita Hadley

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 1756**	DATE: **2/4/2026**

COMMITTEE:
Special Committee on Tourism

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **RACHELLE VALENCIA**	PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:	TITLE:

ADDRESS:

CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **2/4/2026 8:12 AM**

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

Children with rare pediatric illnesses deserve the same hope and research as any other child. Increased awareness and funding could reduce the severe side effects they face, including hearing and muscle loss. Supporting June’s Week is about protecting the next generation and ensuring that rarity does not mean neglect.

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 1756**	DATE: **2/4/2026**
COMMITTEE: **Special Committee on Tourism**	

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **REBECCA GILBERT**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **2/4/2026 8:32 AM**

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

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 1756**	DATE: **2/4/2026**
COMMITTEE: **Special Committee on Tourism**	

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **SAMANTHA ULTICAN**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **2/4/2026 12:58 PM**

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

I hope for more awareness.

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 1756**	DATE: **2/4/2026**

COMMITTEE:
Special Committee on Tourism

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **SHERRI FORD-MACKEY**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE: **Written**	SUBMIT DATE: **2/4/2026 11:29 AM**

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

I wholeheartedly support June's week and bringing to light awareness of rare and serious pediatric illnesses and the immediate need for further research of illnesses such as atypical teratoid rhabdoid tumor (ATRT) that June Steinmeyer is bravely battling.

MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **HB 1756**	DATE: **2/4/2026**
COMMITTEE: **Special Committee on Tourism**	

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

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **TOM RACKERS**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: **2/4/2026 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 1756**

DATE: **2/4/2026**

COMMITTEE: **Special Committee on Tourism**

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: **2/3/2026 10:18 AM**

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

I submit this testimony to object to the advancement of House Bill 1756, not out of disrespect for the child or family named, but due to the legislative function and precedent this bill establishes.

Core Objection: Symbolic Legislation Without Legal Effect

House Bill 1756 creates a commemorative designation only.

It:
Creates no enforceable rights
Allocates no funding
Establishes no programs, reporting, or services
Imposes no duties on state agencies
Provides no measurable outcomes

The bill operates solely as a symbolic proclamation encouraging public awareness.

Missouri law already permits awareness campaigns, charitable recognition, and voluntary observances without statutory enactment.

Improper Use of the Statutory Code

Chapter 9, RSMo is increasingly used to codify memorials, honorary weeks, and awareness designations that do not regulate conduct or confer rights.

This practice:
Expands the statutory code with non-operative law
Dilutes legislative clarity
Substitutes symbolism for policy action
Statutes are meant to govern, not merely commemorate.

Precedent & Equity Concern

By naming an awareness week after a specific individual, the bill raises unavoidable equity questions:

Why this child and disease over others?

What criteria govern future designations?

Where is the limiting principle?

Legislating personal memorials invites uneven application, political selection, and emotional prioritization rather than neutral public policy.

Appropriate Alternatives Exist

If the General Assembly wishes to honor June or raise awareness of rare pediatric diseases, existing mechanisms already allow for:
Executive proclamations
Agency-led awareness initiatives
Nonprofit partnerships
Voluntary public recognition

None require statutory amendment.

HB 1756 does not advance public health policy, improve access to care, or allocate resources to affected families.

It places symbolic recognition into statutory law, where enforceable policy should reside.

For these reasons, House Bill 1756 should not advance.