



MISSOURI HOUSE OF REPRESENTATIVES
WITNESS APPEARANCE FORM

BILL NUMBER: HCR 46		DATE: 2/13/2024	
COMMITTEE: Special Committee on Tourism			
TESTIFYING: <input checked="" type="checkbox"/> IN SUPPORT OF <input type="checkbox"/> IN OPPOSITION TO <input type="checkbox"/> FOR INFORMATIONAL PURPOSES			
WITNESS NAME			
INDIVIDUAL:			
WITNESS NAME: ANTHONY CLEMONS		PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS:			
CITY:		STATE:	ZIP:
EMAIL:	ATTENDANCE:		SUBMIT DATE: 2/13/2024 12:00 AM
THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.			



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WITNESS NAME		
INDIVIDUAL:		
WITNESS NAME: ARNIE C. AC "HONEST-ABE" DIENOFF		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:		TITLE:
ADDRESS:		
CITY:		STATE: ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: 2/13/2024 12:00 AM
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WITNESS NAME		
INDIVIDUAL:		
WITNESS NAME: BRENDA S WALKER		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:		TITLE:
ADDRESS:		
CITY:		STATE: ZIP:
EMAIL: bswalker3330@gmail.com	ATTENDANCE: Written	SUBMIT DATE: 2/9/2024 9:01 AM

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

Please support this terrible disease. People do not talk about this enough so people are not getting treatment because it's a disease that no one knows about. By the time you're diagnosed it's usually too late. we need support and medication and more research. If we have a day designated for this disease people will be more aware of it and support people who are diagnosed



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WITNESS NAME		
INDIVIDUAL:		
WITNESS NAME: BRETT SPERRY, MD		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:		TITLE:
ADDRESS:		
CITY:		STATE: ZIP:
EMAIL: bsperry@saint-lukes.org	ATTENDANCE: Written	SUBMIT DATE: 2/12/2024 8:31 PM

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

I am writing this in support of HB2591 and HCR46 to designate May 8th as Amyloidosis Awareness Day. Amyloidosis is an underrecognized condition that can be deadly and lead to heart and kidney failure. Only in about the last 10 years has this disease been recognized more frequently, and there has been a major push in the medical scientific community to improve awareness. There has also been major investment from pharmaceutical companies in developing new breakthrough treatments for this condition. This condition particularly affects people of African ancestry, putting them at risk for reduced longevity. For example, Tiny Archibald (former Kansas City Kings and NBA Hall of Fame basketball player) went public about having amyloidosis and needing a heart transplant for it in 2018. As hereditary amyloidosis affects about 3.5% of the black population in the United States, over 1.6 million individuals in our country may carry this risk which may affect them significantly later in life. The key to tackling this disease is early diagnosis and awareness. The earlier the disease is diagnosed, the more treatment options are available that can slow the progression and improve quantity and quality of life. It is for this reason that I am petitioning the house to support the designation of May 8 in the state of Missouri as Amyloidosis Awareness Day. Thank you for your support!



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WITNESS NAME		
INDIVIDUAL:		
WITNESS NAME: DANIEL HARTMAN		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:		TITLE:
ADDRESS:		
CITY:		STATE: ZIP:
EMAIL: dhartman4299@gmail.com	ATTENDANCE: Written	SUBMIT DATE: 2/10/2024 6:52 PM
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I would like to urge the committee to vote to pass this bill and help create awareness for this terrible disease in hopes we can help Missouri families and save lives



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WITNESS NAME		
INDIVIDUAL:		
WITNESS NAME: ELIZABETH NEGRELLI		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:		TITLE:
ADDRESS:		
CITY:		STATE: ZIP:
EMAIL: ednegrelli4@gmail.com	ATTENDANCE: Written	SUBMIT DATE: 2/13/2024 10:37 AM
THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.		

I am a patient with amyloidosis I saw 9 different specialists and almost died because of lack of awareness of this - not so rare- disease This disease needs awareness in order to save lives of future patients. Many more individuals have this disease than previously thought and increasing awareness will allow for accurate diagnosis and initiation of treatment which is necessary for survival. These patients don't have to die because of lack of awareness



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WITNESS NAME		
INDIVIDUAL:		
WITNESS NAME: ELIZABETH SIMPSON		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:		TITLE:
ADDRESS:		
CITY:		STATE: ZIP:
EMAIL: easimpson78@comcast.net	ATTENDANCE: Written	SUBMIT DATE: 2/10/2024 2:13 PM

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

2 1/2 years ago my husband Rick was an active MO small business owner. He began losing weight and had a chronic cough among many other symptoms. He saw multiple physicians including his primary care physician and multiple specialists. Finally after 2 years, 80 lbs of weight loss and preventable severe heart and nerve damage, a simple genetic blood test found the diagnosis of Amyloidosis. The delay in treatment worsened his permanent damage from this disease. I am a recently retired pediatrician. I would like to use the excuse that children with the genetic form of amyloidosis do not have symptoms until adulthood for my lack of knowledge of the disease prior to Rick's diagnosis. However, I find my adult colleagues are also not aware of the symptoms of Amyloidosis. Treatment for this disease has expanded greatly in the last few years and most physicians and mid-level providers do not have sufficient knowledge of this disease to consider the diagnosis. Early identification is easy to do if the medical professional has the awareness to suspect it. Early treatment is key to stabilizing the disease and stopping the otherwise fatal trajectory. Please support the establishment of an Amyloidosis awareness day. Increasing awareness will truly save lives!



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WITNESS NAME		
INDIVIDUAL:		
WITNESS NAME: JO LYNN LANE		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:		TITLE:
ADDRESS:		
CITY:		STATE: ZIP:
EMAIL: jolynn@heartlandsalespromo.com	ATTENDANCE: Written	SUBMIT DATE: 2/8/2024 11:25 PM
THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.		

I want to express my firm support for this bill to pass. Amyloidosis is a rare disease with no cure but with early detection through awareness can be managed and prolong lives and improve the quality of life for people suffering from it. Awareness is the pathway to saving lives and we all need to recognize the urgent need to raise awareness of this for all out citizens. Thank you.



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WITNESS NAME		
INDIVIDUAL:		
WITNESS NAME: JOSHUA JAMES BROWNLEE		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:		TITLE:
ADDRESS:		
CITY:		STATE: ZIP:
EMAIL: camobrownlee@gmail.com	ATTENDANCE: Written	SUBMIT DATE: 2/10/2024 8:24 PM
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I believe we need this to bring awareness to the cause



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WITNESS NAME		
INDIVIDUAL:		
WITNESS NAME: LARRY R KENT		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:		TITLE:
ADDRESS:		
CITY:		STATE: ZIP:
EMAIL: larrykent@me.com	ATTENDANCE: Written	SUBMIT DATE: 2/11/2024 11:30 AM

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I support this bill because we need to address the rare Amyloidosis disease.



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WITNESS NAME		
INDIVIDUAL:		
WITNESS NAME: LYNDA LARIMER		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:		TITLE:
ADDRESS:		
CITY:		STATE: ZIP:
EMAIL: Lyndalarimer@gmail.com	ATTENDANCE: Written	SUBMIT DATE: 2/10/2024 7:35 PM
THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.		

Greetings to the committee. I apologize for not being able to attend in person. However this bill is very important to me. I am very familiar with Amyloidosis and the serious effects it can have if not diagnosed in a timely matter. Making people aware is critically important in saving lives. Please vote to make this pass. Thank you.



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WITNESS NAME			
INDIVIDUAL:			
WITNESS NAME: MICHAEL LANE		PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS:			
CITY:		STATE:	ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: 2/13/2024 12:00 AM	
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WITNESS NAME		
INDIVIDUAL:		
WITNESS NAME: MIKE MITCHELL		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:		TITLE:
ADDRESS:		
CITY:		STATE: ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: 2/13/2024 12:00 AM
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WITNESS NAME		
INDIVIDUAL:		
WITNESS NAME: SIERRA KINI		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:		TITLE:
ADDRESS:		
CITY:		STATE: ZIP:
EMAIL: sierra.kini04@gmail.com	ATTENDANCE: Written	SUBMIT DATE: 2/10/2024 7:22 PM
THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.		

I would like to voice my support with this amazing bill rare disease needs to be recognized in awareness conceive lives in our state of Missouri. We need to make everybody aware of the potential dangers of this disease. Please vote to pass this bill. Thank you



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WITNESS NAME		
INDIVIDUAL:		
WITNESS NAME: WILLIAM RITCHIE		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:		TITLE:
ADDRESS:		
CITY:		STATE: ZIP:
EMAIL: ritchie.montana@gmail.com	ATTENDANCE: Written	SUBMIT DATE: 2/13/2024 11:05 AM

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The main difficulty in getting early detection of this disease is lack of awareness of its existence. Early detection will allow for much better outcomes.