

#### MISSOURI HOUSE OF REPRESENTATIVES

#### WITNESS APPEARANCE FORM

BILL NUMBER: HB 407				DATE: <b>2/21/2023</b>		
COMMITTEE: Professional Registration and Licensing						
TESTIFYING:	✓ IN SUPPORT OF	☐ IN OPPOSITION TO	☐FOR INFO	RMATIONAL PURPOSES		
		WITNESS NAME				
BUSINESS/ORG	ANIZATION:					
WITNESS NAME: ALLISON HERRITY	1			NUMBER: 12-4743		
BUSINESS/ORGANIZATIONAL ORGAN	N NAME: NIZATION FOR RARE DI	SORDERS	TITLE: POLIC	Y ANALYST		
ADDRESS:						
CITY: WASHINGTON			STATE: <b>DC</b>	ZIP: <b>20036</b>		
EMAIL: aherrity@raredisea	ases.org	ATTENDANCE: Written		MIT DATE: <b>1/2023 10:20 AM</b>		

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

Dear Chair Coleman and Vice Chair Parker. On behalf of the one-in-ten individuals in Missouri living with one of the over 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for your consideration of HB 407 during today's hearing, HB 407, if passed, would allow Missouri to join the Interstate Medical Licensure Compact (IMLC), an agreement between participating U.S. states to work together to significantly streamline the medical licensing process for physicians who want to practice in multiple states, therefore making it possible to improve patient access to medical specialists using telehealth. NORD urges you to support HB 407 and pass it favorably out of this Committee. NORD is a unique federation of voluntary health organizations dedicated to helping people with rare diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services. We believe that all individuals with a rare disease should have access to quality and affordable health care that is best suited to meet their medical needs. In the United States, a rare disease is defined as any disease, disorder, illness, or condition affecting fewer than 200,000 people. Unfortunately, there are often very few specialists who have expertise in any given rare disease. As a result, patients frequently travel significant distances, often across state lines, to see a medical specialist qualified to provide appropriate treatment for their condition. In a survey of rare disease patients conducted by NORD in 2019, almost 40% of respondents reported traveling 60 miles or greater to see a medical specialist with expertise in their rare condition. While rare disease patients faced serious barriers to care even before the COVID-19 pandemic, these barriers increased significantly within the rare disease community as the pandemic shocked the U.S. and global health care systems. In a survey of rare disease patients and caregivers conducted by NORD in the summer of 2020, 79% of respondents reported experiencing a canceled medical appointment due to COVID-19. Fortunately, 88% of survey respondents reported being offered a telehealth appointment, and 92% who accepted the offer of a telehealth visit reported having a positive experience with telehealth, Looking ahead, many patients and providers have signaled that they appreciate and have benefitted from the expanded use of telehealth and want to see its permanent integration into our health care system. As mentioned previously, rare disease patients are often required to travel long distances, including across state lines, to access necessary and appropriate medical care. Currently, many state's licensure laws create barriers to care by limiting providers ability to see patients across state lines. This not only complicates access for patients, but also creates additional burdens for clinicians who want to see outof-state patients who lack access to appropriate care closer to home. This barrier to care can prove insurmountable for some due to the significant costs associated with travel and lodging, among other expenses. HB 407 would streamline the process for providers in other states to obtain licensure in Missouri, allowing those providers to see patients located in Missouri via telehealth. This would not

only expand access to out-of-state medical specialists for individuals with diagnosed rare diseases living in Missouri, but also to diagnostics, potentially cutting down the often-extensive diagnostic odyssey patients go through to obtain an accurate diagnosis. In passing HB 407, Missouri would join 37 other U.S. states, the District of Columbia, and the Territory of Guam as participants in the Interstate Medical Licensure Compact. Once again, on behalf of the Missouri rare disease community, we thank you for your consideration of HB 407 and urge its swift passage. For any questions, please feel free to contact Allison Herrity at aherrity@rarediseases.org. Sincerely, Alyss Patel State Policy Manager, Western Region National Organization for Rare Disorders



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TESTIFYING:	☑ IN SUPPORT OF	☐ IN OPPOSITION TO	☐FOR INFORM	ATIONAL PURPOSES
		WITNESS NAME		
REGISTERED LO	OBBYIST:			
WITNESS NAME: BILL ANDERSON			PHONE NUME <b>573-893-3</b>	
REPRESENTING: MISSOURI HOSPIT	TAL ASSOCIATION		TITLE:	
ADDRESS: 4712 COUNTRY CI	LUB DRIVE			
CITY: JEFFERSON CITY			STATE: <b>MO</b>	ZIP: <b>65102</b>
EMAIL:		ATTENDANCE:	SUBMIT 0 2/21/20	DATE: 123 12:00 AM
THE INFORMA	TION ON THIS FOR	M IS PUBLIC RECOR	D UNDER CHA	PTER 610. RSMo.



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TESTIFYING: ✓IN SUPPORT	OF IN OPPOSITION TO	☐FOR INFORMA	TIONAL PURPOS	SES	
	WITNESS NAME				
REGISTERED LOBBYIST:					
WITNESS NAME: DAVID JACKSON		PHONE NUMBE <b>314-406-29</b>			
REPRESENTING: MISSOURI SOCIETY OF ANESTHESI	OLOGISTS, RAYUS	TITLE:			
ADDRESS: PO BOX 1865					
CITY: JEFFERSON CITY		STATE: MO	ZIP: <b>63005</b>		
EMAIL:	ATTENDANCE:	SUBMIT DA 2/21/202	ATE: 23 12:00 AM		
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		WITNESS NAME		
REGISTERED LO	OBBYIST:			
WITNESS NAME: GRACE NIELSON			PHONE NUMB <b>417-529-2</b> 9	
REPRESENTING: ASSOCIATED STU	DENTS OF THE UNIVE	RSITY OF MISSOURI	TITLE:	
ADDRESS: 105 JESSE HALL				
CITY: COLUMBIA			STATE: MO	ZIP: <b>65211</b>
EMAIL:		ATTENDANCE:	SUBMIT D 2/21/20	ATE: 23 12:00 AM
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TESTIFYING:	☑ IN SUPPORT OF	☐ IN OPPOSITION TO	☐FOR INFORM	ATIONAL PURPOSES
		WITNESS NAME		
REGISTERED LO	OBBYIST:			
WITNESS NAME: HEIDI GEISBUHLE	R SUTHERLAND		PHONE NUME	BER:
REPRESENTING: MISSOURI CHAMBER OF COMMERCE AND INDUSTRY DIRECTOR OF LEGISLATIVE AFFAIRS				
ADDRESS: 428 E CAPITOL				
JEFFERSON CITY			STATE: <b>MO</b>	ZIP: <b>65101</b>
EMAIL: hsutherland@moc	hamber.com	ATTENDANCE: In-Person	SUBMIT 0 2/21/20	DATE: 123 9:28 AM
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TESTIFYING:	<b>☑</b> IN SUPPORT OF	☐ IN OPPOSITION TO	FOR INFORM	ATIONAL PURPOSES	
		WITNESS NAME			
INDIVIDUAL:					
WITNESS NAME: JASON			PHONE NUMI	BER:	
BUSINESS/ORGANIZATIO	ON NAME:		TITLE:		
ADDRESS:					
CITY:			STATE:	ZIP:	
EMAIL: JWhite@MARC.or	g	ATTENDANCE: Written	SUBMIT <b>2/21/20</b>	DATE: <b>)23 10:10 AM</b>	
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Same as with HB 285



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TESTIFYING:	☑IN SUPPORT OF	☐ IN OPPOSITION TO	☐FOR INFORM	ATIONAL PURPOSES
		WITNESS NAME		
REGISTERED LO	BBYIST:			
WITNESS NAME: JESSICA PETRIE			PHONE NUMB <b>573-635-60</b>	
REPRESENTING: BJC HEALTHCARE			TITLE:	
ADDRESS: 124 1/2 E HIGH ST				
CITY: JEFFERSON CITY			STATE: <b>MO</b>	ZIP: <b>65102</b>
EMAIL: jessica@wintonpol	icygroup.com	ATTENDANCE: Written	SUBMIT D 2/21/20	ATE: <b>23 12:35 PM</b>
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TESTIFYING:	☑IN SUPPORT OF	☐ IN OPPOSITION TO		ATIONAL PURPOSES	
		WITNESS NAME			
REGISTERED LO	OBBYIST:				
WITNESS NAME: WILL MARRS			PHONE NUME <b>417-848-8</b>		
REPRESENTING: MERCY			TITLE:		
ADDRESS: 211 E CAPITOL AVE					
CITY: JEFFERSON CITY			STATE: MO	ZIP: <b>65101</b>	
EMAIL: willmarrs@gmail.c	com	ATTENDANCE: Written	SUBMIT 0 2/21/20	OATE: 23 12:12 PM	
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We are facing staffing shortages across the board in health care and we feel that this would greatly help in that process.



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TESTIFYING:	☐ IN SUPPORT OF	☑ IN OPPOSITION TO	☐FOR INFOR	MATIO	NAL PURPOSES		
		WITNESS NAME					
INDIVIDUAL:							
WITNESS NAME: ARNIE C."HONEST-ABE" DIENOFF-STATE PUBLIC ADVOCATE  PHONE NUMBER:							
BUSINESS/ORGANIZATION NAME: TITLE:							
ADDRESS:							
CITY:			STATE:		ZIP:		
EMAIL: arniedienoff@yah	oo.com	ATTENDANCE: Written		T DATE: 2023 1	1:49 PM		
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I am Opposed to this Bill and Move.



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<b>TESTIFYING:</b> □IN SUPPORT OF	✓ IN OPPOSITION TO	FOR INFORMA	TIONAL PURPOSES		
	WITNESS NAME				
REGISTERED LOBBYIST:					
WITNESS NAME: JEFF HOWELL		PHONE NUMBE 573-636-51			
REPRESENTING: MO STATE MEDICAL ASSOCIATION		EXEC VICE	PRESIDENT		
ADDRESS: 113 MADISON STREET, P.O. BOX 1028					
CITY: JEFFERSON CITY		STATE: <b>MO</b>	ZIP: <b>65102</b>		
EMAIL: jhowell@msma.org	ATTENDANCE: Written	SUBMIT DA 2/21/202	ATE: 23 11:57 AM		
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