NORD®
National Organization
for Rare Disorders

Alone we are rare. Together we are strong.®

May 14, 2024

The Honorable Jim Burgin
Chair
Committee on Health Care
North Carolina Senate
Legislative Office Building
300 N. Salisbury St.
Raleigh, NC 27603

The Honorable Kevin Corbin
Chair
Committee on Health Care
North Carolina Senate
Legislative Office Building
300 N. Salisbury St.
Raleigh, NC 27603

The Honorable Joyce
Krawiec
Chair
Committee on Health Care
North Carolina Senate
Legislative Office Building
300 N. Salisbury St.
Raleigh, NC 27603

Re: NORD Supports HB681, An Act Relative to the Interstate Medical Licensure Compact (IMLC)

Dear Chair Burgin, Chair Corbin, Chair Krawiec, and Members of the Senate Committee on Health Care,

On behalf of the one-in-ten individuals in North Carolina living with one of the over 10,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for your consideration of HB681. HB681, if passed, would allow North Carolina 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 HB681 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 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 via telehealth. This not only complicates access for patients, but also creates additional burdens for clinicians who want to see out-of-state patients who lack access to appropriate care closer to home.

HB681 would streamline the process for physicians in other states to obtain licensure in North Carolina, allowing those providers to see patients located in North Carolina via telehealth. This would not only expand access to out-of-state medical specialists for individuals with diagnosed rare diseases living in North Carolina, but also help cut down the often-extensive diagnostic odyssey patients go through to obtain an accurate diagnosis. In passing HB681, North Carolina would join 39 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 North Carolina rare disease community, we thank you for the opportunity to share NORD's support for HB681. For any questions, please feel free to contact Allison Herrity at aherrity@rarediseases.org or Carolyn Sheridan at csheridan@rarediseases.org.

Sincerely,

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National Organization for Rare Disorders®

Allison Herrity, MPH
Senior Policy Analyst
National Organization for Rare Disorders®

CC:
Representatives Kristin Baker, Timothy Reeder, Donny Lambeth, and Larry Potts, Primary Sponsors HB681
Christie Darling, Legislative Assistant for Sen. Jim Burgin
Cindy Hobbs, Legislative Assistant for Sen. Kevin Corbin
Debbie Lown, Legislative Assistant for Sen. Joyce Krawiec