



January 3, 2024

The Honorable Senator Jean Breaux
Indiana State Senate
200 W. Washington St.
Indianapolis, IN 46204

Re: Support for Senate Bill 43 (Breux) - Amending the Membership of the Indiana Rare Disease Advisory Council (RDAC)

Dear Senator Breaux,

The National Organization for Rare Disorders (NORD) writes today in support of [Senate Bill 43 \(Breux\)](#), legislation that would amend the membership of Indiana's Rare Disease Advisory Council (RDAC).

The National Organization for Rare Disorders is a federation of non-profits and health organizations dedicated to improving the health and wellbeing of people living with rare diseases. We have over 330+ member organizations which represent patients and caregivers living with any of over 7,000 rare diseases. For forty years, we have been at the forefront of advocacy for policies and programs such as the creation of State Rare Disease Advisory Councils that aim to improve the health and well-being of individuals living with rare diseases and their families. Through [Project RDAC](#), NORD is working to establish an effective RDAC in every state in the country. To date, there are 27 Councils nationwide.

On May 1, 2023, Governor Eric Holcomb signed [House Bill 1201](#), sponsored by Representative Cindy Ledbetter, into law (Public Law 129), officially establishing a Rare Disease Advisory Council in Indiana. NORD thanks you for your co-sponsorship of that bill in the Senate and your support to ensure Senate passage last session. Fortunately, appointments to the Council were made well ahead of their statutory deadline of September 1, 2023, and the Council met for the first time on [September 26, 2023](#). In fact, appointments were made so quickly that NORD was able to welcome two appointed members to the Indiana RDAC to our first ever in-person meeting of RDAC Members from across the country this past October! At that meeting, Indiana's RDAC appointees had the opportunity to meet RDAC members from other Councils nationwide and take-home great lessons that will benefit Indiana's RDAC as it gets started.

Currently, Indiana's RDAC is made up of a diverse group of members, including patients, health care providers, researchers, and representatives of the pharmaceutical industry. Current law requires the Indiana RDAC to be made up of fifteen total members; three *ex officio* voting members and 12 appointed voting members. Senate Bill 43 amends the membership of Indiana's RDAC to expand Council membership by one voting appointed member and specifies they must be a physician who specializes in treating children with a rare disease. Right now, current law requires one physician member with experience treating rare diseases, in general. The bill also contains changes NORD considers to be

1779 MASSACHUSETTS AVENUE NW, SUITE 500
WASHINGTON, DC 20036
T 202-588-5700 ■ F 202-588-5701

7 KENOSIA AVENUE
DANBURY, CT 06810
T 203-744-0100 ■ F 203-263-9938

1900 CROWN COLONY DRIVE, SUITE 310
QUINCY, MA 02169
T 617-249-7300 ■ F 617-249-7301

rarediseases.org ■ orphan@rarediseases.org

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technical in nature such as increasing the quorum count from eight members present to nine and striking the deadline for appointments.

Having more than one physician member is not uncommon among other RDACs nationwide. For example, Minnesota¹, Tennessee², and Massachusetts³ RDACs have two physician members and Pennsylvania⁴ and Maine⁵ require three physician members. Additionally, many rare diseases are found only in children. In fact, according to the National Cancer Institute (NCI), all pediatric cancers are considered rare⁶. Thus, the perspective of a physician who works within the rare disease space for children would be of benefit to the Council and Indiana's rare community.

It has been exciting to see how quickly Indiana got their RDAC operational. Thank you for your sponsorship in 2023 and your continued support as you seek to improve the Council this legislative session. We hope you consider NORD a resource for you as this bill moves through the legislative process and look forward to working with you and your staff to improve the lives of rare disease patients and their families living in Indiana.

Thank you for your service to Indiana.

Sincerely,



Carolyn G Sheridan, MPH
State Policy Manager, Eastern Region
National Organization for Rare Disorders®

CC:

Rachel Gray, Legislative Assistant for Senator Jean Breaux
Shenetha Shepard, Media Contact for Senator Jean Breaux

¹ [MINN. STAT. 256.4835 \(2019\)](#)

² [Tenn.Code Ann. §71-7-102\(1\)\(C\)](#)

³ [Mass. Gen. Laws. 111 § 241\(b\)](#)

⁴ [35 P.S. § 6263\(b\)](#)

⁵ [22 M.R.S.A. § 1700-B \(1\)](#)

⁶ [National Cancer Institute, *Rare Cancers of Childhood Treatment*](#)