**MASSACHUSETTS RARE DISEASE ADVISORY COUNCIL (RDAC)**

**Full Council Meeting**

**REMOTE MEETING:    Thursday, July 18th, 2024 9:00-11:00 AM**

<https://us06web.zoom.us/j/88428432880?pwd=wzFyn6p9g9wDKxBoKIJBdYOFzlcddH.1>

* **Welcome**
* **Roll Call**
* **VOTE to approve minutes from the last full council meeting (May 16, 2024)**
* **Guest Speaker: Lesa Brackbill,** Mom, Author and Advocate
* **Guest Speaker – Dr. Olaf Bodamer,** a physician-scientist and geneticist
  + Boston Children’s Hospital, Rare Disease Center of Excellence
* **Massachusetts Newborn Screening Program Panel**

**Panelists include:**

* + **Dr. Karen McAlmon, MD** Chair, Massachusetts Newborn Screening Advisory Committee
  + **Anne Marie Comeau, PhD** Deputy Director, UMass New England Newborn Screening Program*;* Professor of Pediatrics, UMass Chan Medical School
  + **H. Dawn Fukuda, ScM** Assistant Commissioner, Director of the Bureau of Infectious Diseases and Laboratory Sciences
  + **Jim Ballin, Esq** Deputy General Council, Massachusetts Department of Public Health
* **Q & A and Discussion**
* **Update on the healthcare bill – Representative Jay Livingstone**

**NEXT FULL COUNCIL MEETING: Scheduled for September 19, 2024.**

**Adjourn**