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

**Full Council Meeting**

**AGENDA**

**REMOTE MEETING:    Thursday, May 22, 2025 9:00-11:00 AM**

[**https://zoom.us/j/94240082040?pwd=O9fi9XlWJHEST8uI6aPeKCrRc3nT2G.1**](https://zoom.us/j/94240082040?pwd=O9fi9XlWJHEST8uI6aPeKCrRc3nT2G.1)

**Welcome**

**Introduce new member- Olaide Adekanbi**

**Roll Call**

**Vote to approve minutes from the last full council meeting (March 27, 2025)**

**Guest Speaker: Rare Disease Speaker Nicole Johnson**

**Transitions from pediatric care to adult care for those with a rare disease – Andrew Dwyer**

**Panel Discussion**

* **Nathan Grant**
* **Lena Joseph, MSN, RN, CPN,** Nurse Manager of Boston Children’s Hospital Cystic Fibrosis Program
* **Margaret McManus,** President of The National Alliance to Advance Adolescent Health and co-Director of Got Transition/Center for Health Care Transition Improvement
* **Erica Barnes,** Executive Director of the Minnesota Rare Disease Advisory Council

**Update on the impact of the discontinuation of the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) – Dr. Olaf Bodamer**

**Subcommittee Updates**

* **Policy Subcommittee- Glenda Thomas**
* **Research Subcommittee – Tai Pasquini**
* **Steering Subcommittee – Dylan Tierney**

 **RDAC membership engagement survey results – Tai Pasquini**

**Announcements**

**Adjourn**

**NEXT FULL COUNCIL MEETING: Scheduled for July 24, 2025.**