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

**Full Council Meeting**

**AGENDA**

**REMOTE MEETING:    Thursday, July 24, 2025 9:00-11:00 AM**

[**https://zoom.us/j/94560100661?pwd=qyusgbyfTbIcOLAxdy5UjeywzXq1fF.1**](https://zoom.us/j/94560100661?pwd=qyusgbyfTbIcOLAxdy5UjeywzXq1fF.1)

**Welcome**

**Introduce new members- Lisa Jenike, DNP and Nicole Nyberg**

**Roll Call**

**Rare Disease Guest Speakers:**

* Beatriz Fraga, introduced by Isaac Seigel, MBA,MSW,LICSW and supported by her mom, Renata Fraga
* Taina Christina

**Vote** to approve minutes from the last full council meeting (May 22, 2025)

**Transition from Pediatric Care to Adult Care for those with a Rare Disease**

* Guest Speakers, Elaine Gabovitch, retired Director of the Division of Children and Youth with Special Health Needs (DCYSHN) at the Department of Public Health and Beth Bostic, Acting Director of DCYSHN
* Guest Speakers, Dr. Ahmet Uluer and Susan Shanske, LICSW, Boston Children’s Hospital
* Guest Speaker, Nathan Grant

**Discussion**

 **Subcommittee Updates**

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

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

 **Announcements**

 **Adjourn**