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

**REMOTE MEETING:    Thursday, September 21th, 9:00-11:00 AM**

<https://us06web.zoom.us/j/84568557355?pwd=WUdrTzJYSlZjbngySzJBd0huNDVMQT09>

* **Welcome**
* **Roll Call**
* **Guest Speaker: Access to social services and resources for children and families with a rare disease**
  + **Pamela Chamorro, MSW, LICSW**

**Director of Social Services**

**Boston Children’s Hospital**

* **Guest Speaker: Creating a structure for an annual report to the state legislature and developing impactful recommendations**
  + **Barbara L’Italien**

**Executive Director of the Massachusetts Disability Law Center**

**(former State Representative and State Senator)**

* **RDAC Virtual Town Hall October 21st, 2023** 
  + **Questions**
  + **Logistics**
  + **Marketing and Recruiting (Flyer)**

**Workgroup 1 update – Dr. David Miller, Chair**

**Presentation of Final Draft of Prevalence Paper**

**VOTE:** to approve the paper

**Workgroup 2 & 3 update – Jen McNary, W2 Chair**

**Discussion of Final Survey Tool, marketing, and outreach**

**VOTE**: to approve the 7/20/23 meeting minutes

**Announcements**

**NEXT FULL COUNCIL MEETING: November 16th, 2023, 9:00 am – 11:00 am**