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

**Community Engagement Workgroup Meeting**

Monday, February 5, 2024

10:30 AM – 11:00 AM

Meeting Minutes (approved 5.6.24)

**REMOTE MEETING:**

<https://us06web.zoom.us/j/82330321289?pwd=TOdbT9eCd8RbbRSNuXE2OPDm15av3R.1>

**Welcome – Chair Jenn McNary** welcomed all to the group and thanked the guests for the time. She began by asking all to introduce themselves.

**Present on the call:**

Dr. Dylan Tierney, Chair of the RDAC

Mary Lou Woodford, Coordinator of the RDAC

Casey Hall, RDAC support

Shivang Patel, RDAC member

Glenda Thomas, RDAC member

Lena Joseph, RDAC member

Joan Chambers, guest

Melissa Daley, guest

Paul Joseph, guest

**J McNary** started the meeting by summarizing the work of the RDAC and it’s workgroups. She stated that the RDAC has been meeting since mid-2021. Two workgroups were formed in 2023 to help the RDAC better understand its stakeholders. Who is the rare community in Massachusetts? We also want to collect information about what resources people in the rare community are using and find most useful as well as what resources are not working or missing. Our ultimate goal is to present some recommendations for change to the governor and the state legislature. We know that we need to increase awareness about the RDAC. People just don’t know that we exist. We created a survey to collect some of this data but we have had a very poor response rate. We think because people just don’t know about it. We also held a virtual town hall to gather public feedback and that was poorly attended as well. I’m asking all of you for help about how to increase awareness of the RDAC with no budget.

**M Daley** added that she felt that social media would be a great start to get people talking about the RDAC. She asked if the RDAC could have a linked in, FB, and Instagram account?

**J McNary** stated that we had discussed this in the past however were unsure about how to proceed when we don’t have a staff person to manage the accounts.

**D Tierney** added that we are a legislative council that is managed by the Department of Public Health (DPH). We have some constraints about what we can and cannot do. He stated that he had met with the media advisory group at DPH and they let us know that there are other templates we could use. He added that he felt that our primary focus is finding the close to 700,000 people impacted by a rare disease in Massachusetts. We estimate that up to 10% of the population in Massachusetts may be living with a rare disease. How to we reach them to better understand their needs.

**M Daley** added that social media is an inexpensive way to increase awareness.

**P Joseph** agreed with M Daley and added that social media is a good vehicle to start to increase awareness for the RDAC. He added that this is something that could be done simultaneously with updating our website and working on a marketing plan. They can all be done concurrently. He recommended creating social media pages to get people talking. The council member can use their social media accounts to drive traffic to the RDAC. We should also update the website and make sure the survey is available and visible when the go to the RDAC website.

**J Chambers** added that she reviewed the RDAC website and thought it needed some warms and more content. People need to get something out of going to a website. She recommended a two pronged approach as Paul recommended. We create social media pages at the same time we are updating the website. The next step would be to send targeted messages through social media to drive people back to the website. You could also start working on a marketing strategy for content creation.

**M Daley** added that using rare disease month or day as a jump off point would be great. She added that maybe we could utilize other rare disease organizations to help. We post something for them and they reciprocate, increasing traffic.

**J Chambers** stated that the website re-design should include a sense of representation from the rare disease community. You want people to see themselves on the page. Adding pictures will add warmth.

**G Thomas** asked if we could have a statement or short story from RDAC members.

**D Tierney**  stated that he had talked with DPH media person and there are other templates that we could use. Mary Lou will look into that. He added that we had discussed partnering with other organizations but we thought it would be hard to monitor which ones we should support and which ones that we shouldn’t so we decided to stay away from this strategy.

**J McNary** thanked everyone for their time and stated that we were quickly approaching 11:00. She asked each person to please send her any ideas on re-designing our website. Send me anything that you think will increase our image and show representation.

**P Joseph** added in the chat that he recommended adding a section on “who we are” based on Glenda’s recommendation. Each RDAC member could have a picture and a statement or short story about why they are on the RDAC or why it’s important to them.

**J McNary** thanked everyone and adjourned the meeting at 11:02.