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

**Workgroup 3 Subcommittee Meeting**

Monday, February 13th, 2023

10:00 AM – 11:00 PM

**MEETING MINUTES-Approved 4.3.23**

**Welcome-** Lena Joseph, Chair welcomed all to the meeting at 10:02

She then conducted a roll call

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| **Subcommittee member** | **Present** |
| Lena Joseph (Chair) | X |
| Glenda Thomas | X |
| Shivang Patel | X |
| Jenn McNary | - |
| Charlotte Boney | - |
| Hannah Kane | X |
| Robert Shultz | X |
| Asma Rashid | X |
| Michael Green | - |
| Michael Sherman | X |

**L Joseph** asked all membersto introduce themselves and express how they would like to contribute to the workgroup. She started by letting everyone know that she is a nurse who works at the Cystic Fibrosis program at Boston Children’s Hospital. She got involved with the RDAC as a way to advocate for her patients and their families.

**M Sherman** introduced himself as the chief medical officer at Harvard Pilgrim Health Care. He is concerned about access and affordability. As a payer, we are concerned about the demand for drugs that are not FDA-approved but have high demand. He looks forward to working with the group to figure out some of the challenges that people with rare disease face.

**Rep Kane** introduced herself as a legislator that comes to the RDAC with a desire to make things better for those with a rare condition. She stated that her daughter has two chronic conditions, and although neither condition is rare, it is rare to have these two conditions.

**R Schultz** introduced himself as a life science entrepreneur and professor at Babson College, Northeastern University, and the Massachusetts College of Pharmacy and Health Sciences, who is interested in how health plans look at value. Thinking about how to pay for it. He is interested in understanding how health plans decide what to pay for.

**S. Patel** introduced himself as a pharmacist who owns several pharmacies. He enjoys helping people pay for their prescriptions. Working with patient assistance programs to help his clients.

**G Thomas** introduced herself as a patient with a rare disease. She has Myasthenia Gravis (MG). She works with the national board of MG and is the New England MG support group leader. She also collaborates with pharmacies to educate people about rare diseases.

**A Rashid** introduced herself as a genetic counselor at Boston Children’s Hospital. She enjoys working one-on-one with the patients and families but is excited to work on the RDAC to help more people.

**L Joseph** referred the group to the legislation guiding our work. She asked all to review the legislative charges and read the following;

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| “Coordinate the performance of the rare disease advisory council's duties with those of other rare disease advisory bodies, community-based organizations and other public and private organizations with the commonwealth for the purpose of ensuring greater cooperation regarding the research, diagnosis, and treatment of rare diseases” |
| “Receive and consider reports and testimony from expert individuals, the department, community-based organizations, voluntary health organizations, health care providers, and other public and private organizations recognized as having expertise in rare disease care, to learn about their contributions to rare disease care and possibilities for the improvement of rare disease care in the commonwealth” |

**L Joseph** asked the group how do we identify the stakeholders. Would our first goal be to identify the stakeholders?

**Rep Kane** stated that she didn’t want to limit where we get our information. She suggested we consider asking others, including patients, providers, caregivers, etc. She thought a good starting point might be to create categories and identify stakeholders in each category. We should start with the list in the legislation. In developing the legislation, we put a lot of thought into who should be represented. We should start with that list.

**A Rashid** asked if we should start with the groups we know and that are represented in this group. What if we look at genetic counselors? There is a national group of genetic counselors. I could ask them for a list of those in Massachusetts.

**L Joseph** asked if we could identify categories.

A Rashid offered to look into dietician groups also

**Rep Kane** asked if we should also identify secondary roles that people when to talk to stakeholders. We may want to ask a group about specific questions. We may want to hold a focus group with one of the stakeholders to ask what issues or challenges they see for people with a rare disease. We should know why we list someone as a stakeholder.

**L Joseph** asked how we want to divide up the work

**A Rashid** suggested that we need to know what are looking for before we can start working.

**G Thomas** suggested focusing on identifying the categories first; then we could divide up the work.

**Rep Kane** asked with we could all think more strategically. We need to think about the end goal of fostering communication and collaboration. How are we going to do that? If we start with listing all the stakeholders, what will we do with it? Are we going to survey them? We need to think about why we need them as stakeholders.

**L Joseph** asked if we could bring the group back to the question, How do we even find these stakeholders?

**Rep Kane** suggested starting with the list identified by the legislation. Like;

Legislators, pharmacists, providers, nurses, health plans, etc.

**S Patel** suggested that once we come up with a list, we could divide up the work by county if that helps. We have 14 counties. I could work on finding out about provider groups.

**R Schultz** suggested that we could find out a lot on rare disease day on the 28th. People interested in the rare disease community will be there. I will be there.

**A Rashid** stated that Children’s has a rare disease day also; she would attend and gather as much information as she could.

**R Schultz** said that he would gather as much as possible at Rare Disease Day at the statehouse on the 28th. He also stated that we should be conscious of companies that are not in it for the right reasons. We may not want to work with all of these.

**L Joseph** asked how we could decide what group to work with and which ones were not in it for the right reasons. We would have to defer to others that know.

**R Schultz** offered to gather information about the biotechs and life science companies at Rare Disease Day. He also stated that NORD would be there and they may have information too.

L Joseph stated that this would be a great first step. If we can develop a master list before the next meeting, we could then decide how to reach out to them and what to ask. Is everyone ok working in a google doc to enter the information you collect?

All agreed

**L Joseph** then asked if there was a better time for all to meet. When no one responded, she suggested that Mary Lou would send out a doodle poll with some options for meetings every other month. She would also send information about the google docs.

L Joseph let everyone know that it was close to 11. Was there a motion to adjourn?

S Patel made a motion to adjourn.

L Joseph seconded. The meeting was adjourned at 11:00 am.