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

**Workgroup 3 Subcommittee Meeting**

Monday, April 3rd , 2023

10:00 AM – 11:00 PM

**Meeting Minutes**

**Approved June 5, 2023**

**Welcome – Chair Lena Joseph** welcomed all to the meeting at 10:02. She made a short announcement welcoming all to the call and asked if anyone from the public was listening that they mute their microphone and turn off their camera. She thanked everyone for their interest in the RDAC. She then conducted a roll call.

**Roll Call**

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| **First Name** | **Last Name** | **Email**  | **PRESENT** |
| Lena | Joseph | ljoseph66@gmail.com | X |
| Glenda | Thomas | gethomas@rcn.com | X |
| Shivang  | Patel | spatel@metrowestpharmacy.com | X |
| Jenn | McNary | jenn@jmcnaryconsulting.com | X |
| Charlotte | Boney | charlotte.boney@baystatehealth.org | - |
| Hannah | Kane | hannah.kane@mahouse.gov | X |
| Robert | Schultz | schultz.robert@gmail.com | X |
| Asma | Rashid | asma.rashid@childrens.harvard.edu | X |
| Paul  | Feeney | paul.feeney@masenate.gov | Staff Maya Rabinovitz joined at 10:05 |

**L Joseph –** asked if allreceived the minutes from the last meeting. All responded yes. She then asked if there was a motion to accept the minutes as sent.

**Rep Kane** made a motion to accept the minutes as sent

**G Thomas** made a second

**L Joseph** then conducted a roll call vote to accept the minutes

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| **First Name** | **Last Name** | **Email**  | **Accept** |
| Lena | Joseph | ljoseph66@gmail.com | X |
| Glenda | Thomas | gethomas@rcn.com | X |
| Shivang  | Patel | spatel@metrowestpharmacy.com | X |
| Jenn | McNary | jenn@jmcnaryconsulting.com | X |
| Charlotte | Boney | charlotte.boney@baystatehealth.org | - |
| Hannah | Kane | hannah.kane@mahouse.gov | X |
| Robert | Schultz | schultz.robert@gmail.com | X |
| Asma | Rashid | asma.rashid@childrens.harvard.edu | X |
| Paul  | Feeney | paul.feeney@masenate.gov | abstained |

**L Joseph** opened the meeting by thanking all for their participation in the workgroup. She stated that the google doc which was the collection tool used to collect stakeholder information had been sparsely populated. She asked if all thought that this was the best way to collect information. She asked if anyone had thoughts about the process we created.

**R Shultz** stated that he was disappointed that Rare Disease Day was canceled as he hoped to gather a lot of the information on that day.

**J McNary** Asked if we were looking to add individuals or organizations to the list.

**L Joseph** responded by stating that we are looking for any and all stakeholders at this point. The entry could be an individual, and individual associated with a company or a company. We did get a list of organizations from NORD, we just need to add them to the list.

**J McNary** stated that some people may be a little intimidated by the google spreadsheet so was there another way to gather this information.

**R Shultz** stated that he thought we should be careful about adding biotech and pharmaceutical companies to our list. He said some companies might want to be on our list so that they can lobby us.

**Rep Kane** stated that she thought that we should not limit who goes on the list at this point. She thinks that we should also solicit feedback from the public. It would be helpful to ask the public about stakeholders we may now know about.

**J McNary** asked if we could send a request to MassBio. She thinks that we should be as inclusive as possible at this point. Include any and all possible stakeholders. If we can push out a survey tool to collect contact information, it may be helpful.

**G Thomas** stated that she went to NORD website to download the list of stakeholders and has been trying to locate any Massachusetts-based organizations, but it’s been difficult. She asked if we wanted just Massachusetts-based organizations for our list.

**L Joseph** stated that she was thinking that the workgroup could start by creating a list, then create a survey tool to gather information to help the group respond to the legislative charges, then we would collect the data from the survey and develop a report with recommendations for the legislature. She asked if all we in favor of this plan.

**Rep Kane** added that the list could be a living document that is updated regularly

**L Joseph** added that she thought dividing the work was the best way to accomplish the first task. She then asked for help in filling the spreadsheet.

**R Shultz** asked if we were just looking for pharma and biotech stakeholders

**L Joseph** responded by saying no, we want any and all stakeholders. They can be pharma or advocacy groups.

**Rep Kane** asked if we could create a google survey that would populate our google spreadsheet.

**L Joseph** thought that was a great idea and asked if anyone knew how to do that.

**G Thomas**  explained that she is a support group leader for Myasthenia Gravis in Massachusetts but they are not a formal organization. Would that be part of the list?

**L Joseph** responded by saying that we wanted to be inclusive at this point and we could add an individual name to the list or an organization. She also added that we could call the national organizations on the list from NORD and ask if they have a Massachusetts chapter.

**J McNary** added that she thought we were on the right track. She added that Sickle Cell had a Massachusetts chapter but they were not a formal 501(c)3. She didn’t think that we needed to have only formal organizations. Anyone, who is a potential stakeholder should be on our list.

**G Thomas** added that she thought that there was still a lot of work to be done to fill in this spreadsheet. Calling all these organizations will be very time-consuming.

**L Joseph** then asked what the group thought we should do with the information once we have it. Does it make sense to survey them about the RDAC?

**G Thomas** asked if it made sense to send a survey tool with a broader reach to the public and the information they send will populate our spreadsheet.

**Rep Kane** added that it was only about collecting contact information at this point. We will survey to collect contact information for any stakeholder of rare disease in Massachusetts. We won’t be surveying with specific questions at this point.

**L Joseph** asked if there was anyone in the group that knew how to develop this type of survey

**S Patel** stated that he knew how to do this. He then asked if we needed to use a HIPAA-protected survey tool. He uses Jot Form for some of the work he does, put it’s a subscription-based tool.

**L Joseph** added that she didn’t think we needed a HIPAA-compliant tool at this point as we were just collecting contact information, of which most is public record.

**S Patel** stated they he could make up the survey tool.

**Rep Kane** asked if we could add to the spreadsheet as we go

**S Patel** stated yes, it can be used multiple times.

**L Joseph** added that it was probably best to use the google survey tool at this point. We don’t have any funds to purchase a subscription service and the information we are collecting is just contact information. She asked S Patel if he was able to create this type of google survey tool that would populate our spreadsheet.

**S Patel** stated that he would work on the survey tool and he could get it done in a couple weeks.

**G Thomas** added that she was willing to help.

**Rep Kane** suggested using a dropdown to identify the type of stakeholder. She recommended using the same categories as were listed in the legislation. She added that we could always add an “other” category for people to fill in if they were not a member of one of our stakeholder groups.

**L Joseph** do you think it would be helpful to ask about their interest in rare diseases? Maybe ask which rare disease they were interested in. She then asked if anyone had any thoughts on what to say in the intro when we send out the survey tool.

**Rep Kane** suggested using our mission in the introduction.

**S Patel** stated that he thought NORD had an example of the introduction. Maybe we could look at that as an example.

**L Joseph** stated that she would summarize the discussion for the day. I think that we made some good decisions today. To summarize:

* **S Patel** will develop a survey tool in the next 2 weeks. **G Thomas** will help.
* **L Joseph** will work on an introduction paragraph to send with the survey tool. Once we have the tool completed, we will send to all council members and ask them to push it out to all of their contacts.
* **L Joseph** will begin working on a survey tool that we will discuss at our next meeting. This is the questionnaire that we will send out to stakeholders to answer our legislative charges.

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|  [https://us06](https://us06web.zoom.us/j/83407469310?pwd=bW1WQlp6MkVCMkhLdGpqU1VaU3FSQT09) |

**L Joseph** Noted that the group had a game plan and did anyone want to make a motion to **Adjourn.**

**S Patel** made a motion to adjourn

**G Thomas** made a second

The meeting was adjourned at 10:46 am