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

**Workgroup 2 Subcommittee Meeting**

Wednesday, February 8th, 2023

11:00 AM – 12:00 PM

**MEETING MINUTES – Approved 4.12.23**

**Welcome-Jenn McNary, workgroup chair, welcomed all to the meeting at 11:02, then conducted a roll call.**

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| --- | --- | --- | --- |
| **First Name** | **Last Name** | **Email** | **Present** |
| Jenn | McNary | [jenn@jmcnaryconsulting.com](mailto:jenn@jmcnaryconsulting.com) | X |
| Lisa | Deck | [lisadeck@gmail.com](mailto:lisadeck@gmail.com) | X |
| Guadalupe | Hayes-Mota | [guadamota@gmail.com](mailto:guadamota@gmail.com) | - |
| Diane | Lucente | [dlucente@partners.org](mailto:dlucente@partners.org) | X |
| Michele | Rhee | [michele.rhee@gmail.com](mailto:michele.rhee@gmail.com) | - |
| Ross | Zafonte | [rzafonte@mgh.harvard.edu](mailto:rzafonte@mgh.harvard.edu) | - |
| Janis | Creedon | [janiscreedon@gmail.com](mailto:janiscreedon@gmail.com) | - |
| Jay | Livingstone | [jay.livingstone@mahouse.gov](mailto:jay.livingstone@mahouse.gov) | X |

**J. McNary opened the meeting by asking all to give a short introduction and how they think they can contribute to this workgroup. She started the introductions by letting everyone know that she is a mother of 3 children who have a rare disease. Two of them are now adults and they have had significant challenges transitioning from pediatric care to adult care with a rare disease. She can contribute information related to patients and caregivers impacted by a rare disease.**

**L Deck introduced herself as an adult patient with a rare disease. She stated that she could contribute as a patient. She also stated that she has held many volunteer roles on various nonprofits and has learned a lot about the types of supports available to those with a rare disease.**

**D. Lucente introduced herself as a genetic counselor who works at Massachusetts General Hospital (MGH). She works mostly with patients who have neurodegenerative disorders. She added that she knows that MGH offers many supports and she hopes to contribute to the group in any way that is helpful.**

**Rep. J. Livingstone introduced himself as the vice chair of the healthcare finance committee. He stated that he represents the 8th district, and in his role on the healthcare finance committee he is involved in all healthcare legislation. He is available to help with any type of legislation that will support the committee's mission.**

**J. McNary started the meeting by showing the group the legislative charges for their workgroup. She asked all if they had any questions related to these charges. Below are the charges as presented;**

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| (iv) | Develop methods to publicize the profile of the social and economic burden of rare disease in the commonwealth to ensure that the public and health care providers are sufficiently informed of the most effective strategies for recognizing and treating rare disease |
| (v) | Determine the human impact and economic implications of early treatment of rare diseases versus delayed or inappropriate treatment of rare disease as it pertains to the quality of care, the quality of patients" and their families" lives and the economic burdens, including insurance reimbursements, rehabilitation, hospitalization, and related services on patients, families, and the commonwealth |
| (vi) | Evaluate the current system of rare disease treatment and available public resources to develop recommendations to increase rare disease survival rates, improve quality of life and prevent and control risks of co-morbidities for rare disease based on available scientific evidence |
| (viii) | Examine the feasibility of developing a rare disease information and patient support network in the commonwealth to aid in determining any genetic or environmental contributors to rare diseases |

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

**J McNary asked if the group had any thoughts on a mission statement for the workgroup. No one had a comment so she offered to draft a mission statement and send to the group for review.**

**D Lucente stated that we first need to know what supports are out there. She thinks that the first activity should be to audit and list any and all supports available to Massachusetts residents. Once we know what is available, we can better assess where the gaps are.**

**She summarized by saying that she thinks we should organize our work into three parts.**

**1. Audit for social supports in Massachusetts**

**2. Elicit information from the public about what resources are available and what they think is missing or hard to access.**

**3. Then, we can make recommendations based on our gathered information.**

**J McNary asked if the audit's goal was to find out what social supports exist for rare disease patients in Massachusetts.**

**All agreed**

**J. McNary then summarized by asking the group if our goal should be to have a comprehensive list of social support resources.**

**All agreed.**

**J McNary then asked if the group could think about what objectives would help us reach that goal. She wondered if we should also find out how accessible a resource is. She thought that sometimes a resource is available, but it’s either hard to access or people don’t know it’s available.**

**D. Lucente stated that she thought that our first step should be to identify the resources then maybe in phase 2, look at access issues. It may be too much to do all of this at once.**

**L Deck added that she thought there might be lists out there, and we could use those lists as a starting point. She offered to find the list she was thinking about.**

**J McNary asked the group to think about places, like hospitals or other places where we could find some of these lists. She thought that maybe NORD had a list on their website. She offered to check into that.**

**D Lucente offered to check with the Director of Caregiver Support at MGH. She thought that may be a good place to start.**

**J McNary asked how the group wanted to start gathering this information. Where can we find these lists and whom should we talk to ?**

**L Deck thought that we should talk to patient advocacy groups.**

**J McNary asked if it would be a good plan first to gather all the information about resources, then survey those resources to get more information about how to access them, etc.**

**She asked if people thought that a survey monkey would be a good tool to use for gathering this info?**

**D Lucente asked if we should survey patients, caregivers, and providers too?**

**J McNary asked if people thought that we should ask for contact information from the person answering the survey. We could ask if they want to get involved with the RDAC. She then asked the group how they thought we could share this information with the public.**

**L Deck stated that she thought that our information would be a great resource for patients and caregivers.**

**Rep Livingstone added that he and his staff would be happy to compile this information for the group. He thought maybe a google doc might be the best way to start collecting lists and resources. Maybe everyone on the committee could send the information to Audrey (on my staff) and she can organize the information for all to review at the next meeting.**

**D Lucente added that it is great to gather all the information about resources, but information changes often. We should think about a maintenance plan. Someone will need to check the resource list on a regular basis to see if they are still valid.**

**J McNary stated that a maintenance plan could be one of our recommendations. The resources we list will only be helpful if they are actually available when someone needs to access them.**

**J. McNary then summarized the discussion. So, we first need to audit information about social support resources that are available in Massachusetts, then we need to develop a survey that could be sent to those on our list to gather more information about the resource, then we need to send out the survey, and gather the responses and report on the results.**

**L Deck offered to help organize the information.**

**J McNary ended by letting everyone know that she would meet with Audrey from Rep Livingstone’s office to figure out how to organize the information and get back to everyone about next steps.**

**She then stated that it was 11:58, was there any questions?**

**No one responded so she asked if there was a motion to adjourn.**

**D Lucente made a motion to adjourn**

**L Deck seconded the motion**

**J McNary adjourned the meeting at 11:59**