



Department of Health

Mike DeWine, Governor
Jon Husted, Lt. Governor

Bruce Vanderhoff, MD, MBA, Director

RDAC Minutes 03/10/22

Patrick Londergan called the meeting to order and welcomed everyone to the meeting.
Patrick Londergan called the roll.

In attendance:

Senator Steve Huffman
Senator Hearcel Craig
Representative Beth Liston
Jennifer Voit
Patrick Londergan
Kate Barrett
Annie Ross Womack
Kelly Maynard
Kim Dedino
Kim Wallis
Randi Clites
Sheila Hiddleston
Tiffany Sammons

December West
Joshua Hahn
Dr. Manickam
Dr. Pena
Eileen Sullivan
Dr. Ahuja
Anne Clark
Daniel Bradford
Andrea Hoffman
Edward Pauline
Angela Snyder
Gretchen Blazer Thompson

Not Present: Dr. Kopp, Dr. Moncrief, Amista Lipot

A quorum is established.

Guests: Renata Staff, ODH Staff Attorney, Kimberly Mathews, ODH Parent Consultant (taking minutes).

Members shared a brief introduction and provided their experience related to rare diseases.

Patrick Londergan provided a high-level overview of the CMH program.

Patrick Londergan provided the Council information regarding RDAC:

<https://codes.ohio.gov/ohio-revised-code/section-103.60> The purpose of the council is to

advise the general assembly regarding research, diagnosis, and treatment efforts related to rare diseases across the state.

Randi Clites presented a [PowerPoint](#) to the Council.

Tiffany Sammons presented a [PowerPoint](#) to the Council.

Patrick shared that RDAC members are welcome to also provide presentations during the meetings.

Election of Chairperson/Co-Chairperson:

- Patrick Londergan opened a discussion to help identify a chair/co-chair. Patrick shared that ODH staff will be supportive with background assistance – minutes, meeting notices, agendas, file sharing, etc.
- Nominations: Tiffany Sammons nominated Randi Clites, Dr. Ahuja seconded, Kelly Maynard also nominated and Patrick Londergan second. Vote taken: Unanimous yes. Congratulations to Randi!

Randi graciously accepted and began to lead the meeting. She thanked everyone for being a part of the RDAC.

Sub Workgroups: Randi opened the discussion about how RDAC might work within sub workgroups: **Research, Diagnosis, Treatment.**

Patrick Londergan shared that related to federal funding:

- Ohio is in the Region V.
- Ohio is well known as a state that has many government programs to help individuals who prove to be eligible.
- Ohio is recognized as a leader in helping families and children.

Kelly Maynard asked, “If you had a magic wand, what would you do?” She provided information related to the SMA diagnosis referring to the earlier the treatment, the better the outcome.

- Wish list:
 - Diagnosis.
 - Data Collection – what actually is the state of OH spending on orphan drugs compared to overall drug spend?
 - Improved access reducing the delay between approval and dosing.

Dr. Ahuja asked for the specifics of the RDAC. Lisa Griffin shared: <https://codes.ohio.gov/ohio-revised-code/section-103.60>.

Randi Clites shared - What are the issues around diagnosis? How can RDAC help with be more supporting early diagnoses around rare diseases? How do we make sure we have the treatments that rare disease patients need in Ohio? Access issues in Ohio: Randi referenced

patients are waiting for durable medical equipment (DME) and ancillary supplies due to: Ohio contracts with out of state vendors. She suggested this be brought back to Ohio providers – this delays access to care. If we work on this, quicker access to care keeps patients out of emergency rooms and keep patients away from longer term care issues. Research – Let's share through RDAC with the Legislature what is happening with research here in Ohio.

December West – Awareness for rare diseases is definitely needed. For her daughter, the diagnosis pathway was difficult – they had to go through three separate possible diagnosis situations, which was not the correct diagnosis. They had to go out of state for final diagnosis. More access to medications.

Loren Pena – In genetics here in Ohio it is becoming easier to diagnosis because the state of Ohio now covers compressive testing for anybody. What she is seeing now is for fairly common disorders, there is limited information on long term longitudinal natural history so there is very little information on end points. There are treatments available, but insurance companies are setting their own expectations for when to initiate and when to continue approvals. It would be a very powerful tool if we could all put our heads together as to how we can promote longitudinal understandings of rare disorders. This may be partnering and funding with family organizations with a lead clinician – someway where to advocate for patients and help educate insurance companies on what treatment is indicated, why it is indicated, and where the data is to support starting treatment and continuing treatment.

Randi Clites – if anyone is interested and willing to step up and lead the subgroups, please alert me.

Dr. Manickam - referenced for a relatively common disorder such as Down Syndrome, his understanding is there is no means of getting statewide data as to incidence.

- Randi asked - is there a way this can be tracked through the CMH program?

Kim Wallis shared that it would be good to track access as to how to get the patient to the correct medical providers.

Eileen Sullivan – XLH Rare Disease in NE Ohio. Rare disease monitoring program. Rare Disease emergency care needing acute treatment – there is lack of knowledge for treatment

Anne Clark – Diagnosis is a huge program. There are huge delays in timely diagnoses. Her son's rare disease is 1 in 100 worldwide. There are lot of things being missed, unfortunately. There is no research for my son's rare disease. There is a huge need for awareness.

Tiffany Sammons – facial recognition scans can now help with diagnosing six rare syndromes – this technology scans dysmorphic features. How do we get this implemented here in Ohio? How do we get insurances to recognize and cover this type of testing here in Ohio?

- Randi replied - Ohio is now aligned with the national [RUSP](#). Patient organizations are still working to get ALD and SMA recognized.

Angela Snyder - Ohio has a plethora of research institutes. Is this something that ODH can help with to data dump and gather information? How do we get to the basics for data research? Is there an organization that does this sort of data gathering?

- Tiffany Sammons shared there is a research team at NORD. She can ask if someone from this team can join for a meeting if this would be helpful.
- Randi Clites – there are other patient led groups around the country that are doing this work. [RDI](#) may be a group to look at. As well as [NORD](#) and [Every Life Foundation](#). Is there someone who would like to step up and lead this workgroup?

Andrea Hoffman – The cystic fibrosis (CF) community may be a model to look at for diagnosis awareness, education, and advocacy with policy makers. CF looks a lot different than it did 20 years ago. Care for CF is now taking a more holistic approach, including mental health and nutrition.

- Randi shared that whoever is taking the lead of the Treatment subgroup – this is definitely something to look at. Hemophilia is looking at wellness, swimming, yoga, golf, etc. These are important things to also look at.

Renata Staff, ODH Staff Attorney joined to share with the RDAC important information related to the Ohio Public Meetings law - <https://codes.ohio.gov/ohio-revised-code/section-121.22>.

- There must be a pre-arranged gathering of a majority of members to discuss public business.
- A notice must be given in advance to include date/time/location of the meeting.
- Until June 2022, the law allows bodies to meet remotely or other virtual means.
- Minutes must be kept.
- Meetings must be open to the public – no closed-door meetings unless there is an executive session.
 - o Executive session – private meeting with just the members of the public body to discuss the following: personnel matter, purchase/sale of property, collective bargaining matters, pending or imminent court action, security/trade secrets, and confidential business information.
- All requirements apply to main committee and subcommittee meetings.
- Email: discussions/decisions violate the law – this is not a prearranged discussion.
 - o The public records act is in place.
- Serial/Round Robin Meetings violate the law – there is not a Quorum.
- Patrick Londergan asked question re: subgroups.
 - o What constitutes a quorum? Are these public meetings? Answer: A majority of subcommittee members are present. All subcommittee meetings are considered public meetings and all the above apply under the Ohio Public Meetings law.
- Randi Clites asked: Are the meetings available to the public via the ODH website? Answer: Notices will be listed on the ODH website through Comms. All virtual meetings will be recorded and made available to the public and send out to RDAC members.
- Loren Pena asked: What constitutes as a quorum? Answer: The majority – one half plus one.

- Shelia Hiddleston asked: For virtual meetings, is it required that prior notice be given so the public can have the opportunity to watch while the meeting is occurring? Does putting up the link afterwards meet requirements for a public meeting? Is there a more secure link to share with the public for “view only” vs. meetings being “hacked”?
Answer: Public notice will include a virtual MS Teams link where all can view the meeting.
- Andrea Hoffman asked: When discussing confidential hospital information, does this require an executive session? Answer: Unless the topic pertains to the Executive Session requirements, the meeting must be held publicly.
 - Follow up question from Rep. Liston: What happens when patient stories are discussed? Answer: There is not an allowance for this in the open meetings act.
 - How does this support HIPAA laws? Answer: This is something to consider when having discussions. There are limited allowances for Executive sessions (see above).
- Angela Snyder asked if there will be a landing page on ODH website for RDAC? This would help provide a one stop location to share with those who are asking about the committee. Answer: Patrick Londergan will look into this and get back with the committee. Randi Clites will add this topic to the next meeting agenda.
- Randi Clites and Patrick Londergan thanked Renata Staff for attending the meeting to provide information and answer questions.

Subgroup Interest –

Sheila Hiddleston – Incidence/Data collection.

Loren Pena – Therapeutics.

Dr. Ahuja – Therapeutics/Research.

Upcoming meetings: Virtual meeting allowances are in place until July 1, 2022. Randi Clites shared that RDAC committee member appointments are approved until April 23, 2023.

Meeting agenda items:

- RDAC webpage.
- Patient stories (Andrea Hoffman, Kelly Maynard, Eileen Sullivan).

Upcoming Meetings:

May 5, 2022, 1 – 3 p.m.

June 23, 2022, 1 – 3 p.m.

Randi Clites thanked everyone for their time and being involved as a RDAC member. She also thanked everyone for the support as Chair of the RDAC. The meeting ended at 3:08 p.m.