

REGULAR CALENDAR

February 3, 2022

HOUSE OF REPRESENTATIVES

REPORT OF COMMITTEE

**The Committee on Judiciary to which was referred HB
1013,**

**AN ACT relative to meetings of the New Hampshire rare
disease advisory council. Having considered the same,
report the same with the following resolution:**

RESOLVED, that it is INEXPEDIENT TO LEGISLATE.

Rep. Michael Sylvia

FOR THE COMMITTEE

COMMITTEE REPORT

Committee:	Judiciary
Bill Number:	HB 1013
Title:	relative to meetings of the New Hampshire rare disease advisory council.
Date:	February 3, 2022
Consent Calendar:	REGULAR
Recommendation:	INEXPEDIENT TO LEGISLATE

STATEMENT OF INTENT

This bill would make a special provision for one public body, the Rare Disease Advisory Council, to meet remotely. The majority of the committee believes that RSA 91-A should apply uniformly with respect to all public bodies. Having a variety of differing laws for public bodies would be chaotic and make it difficult to maintain transparency.

Vote 15-6.

Rep. Michael Sylvia
FOR THE COMMITTEE

Original: House Clerk
Cc: Committee Bill File

REGULAR CALENDAR

Judiciary

HB 1013, relative to meetings of the New Hampshire rare disease advisory council. **INEXPEDIENT TO LEGISLATE.**

Rep. Michael Sylvia for Judiciary. This bill would make a special provision for one public body, the Rare Disease Advisory Council, to meet remotely. The majority of the committee believes that RSA 91-A should apply uniformly with respect to all public bodies. Having a variety of differing laws for public bodies would be chaotic and make it difficult to maintain transparency. **Vote 15-6.**

HOUSE COMMITTEE ON JUDICIARY

EXECUTIVE SESSION on HB 1013

BILL TITLE: relative to meetings of the New Hampshire rare disease advisory council.

DATE: February 3, 2022

LOB ROOM: 206-208

MOTIONS: INEXPEDIENT TO LEGISLATE

Moved by Rep. Sylvia

Seconded by Rep. McLean

Vote: 15-6

CONSENT CALENDAR: NO

Statement of Intent: Refer to Committee Report

Respectfully submitted,

Rep Kurt Wuelper, Clerk



2021 SESSION

Judiciary

Bill #: 1013 Motion: ITL AM #: _____ Exec Session Date: 2-3-22

<u>Members</u>	<u>YEAS</u>	<u>Nays</u>	<u>NV</u>
Gordon, Edward M. Chairman	✓		
McLean, Mark Vice Chairman	✓		
Sylvia, Michael J.	✓		
Wuelper, Kurt F. Clerk	✓		
Alexander, Joe H.	✓		
Rice, Kimberly A. EDWARDS	✓		
Silber, Norman J. MERNER	✓		
Greene, Bob J.	✓		
Kelley, Diane E.	✓		
Tausch, Lindsay ANDRUS	✓		
Trottier, Douglas R.	✓		
Smith, Marjorie K.	✓		
Berch, Paul S. woods		✓	
Horrigan, Timothy O.		✓	
DiLorenzo, Charlotte I.	✓		
Chase, Wendy	✓		
Kenney, Cam E.	✓		
Langley, Diane M.	✗	✓	
McBeath, Rebecca Susan		✓	
Paige, Mark		✓	
Simpson, Alexis		✓	

Handwritten signature

15

6

HOUSE COMMITTEE ON JUDICIARY

PUBLIC HEARING ON *HB 1013*

BILL TITLE: relative to meetings of the New Hampshire rare disease advisory council.

DATE: 1-19-22

LOB ROOM: 206/8

Time Public Hearing Called to Order: 9:00 AM

Time Adjourned: 9:32

Committee Members: ~~Gordon, McLean, Wuelper, Sylvia, Alexander Jr., Notter, Merner, Greene, D. Kelley, Andrus, Trottier, M. Smith, Borch,~~ **Horrigan, DiLorenzo, Chase, Kenney, Langley, McBeath, Paige and Simpson**

Bill Sponsors:

Rep. Marsh, Carr. 8; Rep. Woods, Merr. 23; Rep. Deshaies, Carr. 6; Rep. Weber, Ches. 1; Rep. Simpson, Rock. 36; Sen. Rosenwald, Dist 13; Sen. Sherman, Dist 24

TESTIMONY

* Use asterisk if written testimony and/or amendments are submitted.

Rep Woods Carr 8 Sponsor Supports Our board has a real problem meeting in person as over half the board is immune compromised which, with a physical quorum require under 91-A.

Q Sylvia: This is a new commission? Ans: Yes, since the 2019 session. Q I assume other boards have had similar issues, how are you different? Ans: With covid the situation is significantly worse. Q Are members so incapacitated they don't do regular stuff? Ans: Yes. Many barely leave their homes: groceries are delivered, utilize telemedicine, etc.

Q Horrigan: Should we restore the remote meetings as under the emergency orders? Ans: We have very specific needs and don't want to represent everyone

*Rep Marsh See my written testimony

Q Sylvia: When was this authorized by the board? Ans: It wasn't "officially" but they asked for it over the phone.

Q: **Gordon** Was this a quorum before Covid? Ans: No and we have been close to a quorum at times since.

Dr Saichela Dept of HHS Support We want to be very flexible to support this group a large part of whom are immunocompromised. Q **Sylvia:** Q Prior to this council how did HHS track needs like this? Ans: we had no formal way. We consulted with health care providers and other groups.

***Laurie Ortalano:** RTKNH Opposed We do not support HB 1013. While we are sympathetic a physical location is necessary for public meetings. Very often after such a meeting citizens meet the board members and have communication with them spontaneously. Remote access does not capture all the non-verbal part of the communication in a room. While we are sympathetic to this special body, we still support the physical quorum requirement as in the current law. For remote participation the current law requirements should be maintained. I am curious that they could meet before the pandemic and question why they can't return to that status. Q **Sylvia:** I didn't like the delays between speaking and hearing in remote participation. Is that a serious concern? Ans: Definitely. The lag time is only one thing. There are other tech issues that cause

problems as well. Q **Simpson**: Is the ancillary contact you mentioned in 91-A? Ans: No. Q Has your group discussed the difference between an advisory board like this as compared to a regular public body? Ans: No. We consider it just as the law does. No distinctions are made there or by us. Q **Horrigan**: Doesn't the post-meeting communication conflict with 91-A? Ans: Not at all. 91-A controls communication among the board members, not between the members and the public. I came in and asked questions of the members who were here, but that isn't subject to 91-A. Many times, the communication may not be related to the current agenda but offers a chance to input toward future actions. Q **DiLorenzo**: As a stroke survivor, it sounds like many members of this board have mobility issues as I do. Ans: I don't disagree with you. We support remote participation by the public and even board members, but we strongly believe that a physical location is critical. Maybe they should add a member or five so they can make a quorum. Q **Langley**: Would you consider a hybrid model at the Chair's discretion? Ans: I would have to discuss with the group, and I will.



Rep Kurt Wuelper

House Remote Testify

Judiciary Committee Testify List for Bill HB1013 on 2022-01-19

Export to Excel

<u>Name</u>	<u>City, State</u> <u>Email Address</u>	<u>Title</u>	<u>Representing</u>	<u>Position</u>	<u>Testifying</u>	<u>Non-Germane</u>	<u>Signed Up</u>
WOODS, GARY	BOW, NH gw pops054@gmail.com	An Elected Official	Myself	Support	No	No	1/14/2022 12:17 PM
Rosenwald, Cindy	Concord, NH cindy.rosenwald@leg.state.nh.us	An Elected Official	SD 13	Support	No	No	1/14/2022 12:26 PM
Smith, Julie	Nashua, NH cantdog@comcast.net	A Member of the Public	Myself	Oppose	No	No	1/16/2022 9:31 PM
Hughes, Corry	Jefferson, NH corryhughes@gmail.com	A Member of the Public	Myself	Support	No	No	1/17/2022 4:21 PM
Gilbert, Krista	KEENE, NH 1666freedom@gmail.com	A Member of the Public	Myself	Support	No	No	1/19/2022 1:10 AM
Donnelly, Ryan	Hudson, NH rdonnelly@gsil.org	A Member of the Public	Granite State Independent Living	Support	No	No	1/19/2022 8:40 AM
Sherman, Senator Tom	SD 24, NH jennifer.horgan@leg.state.nh.us	An Elected Official	SD24	Support	No	No	1/19/2022 9:28 AM

Advising the legislature and DHHS on rare diseases in NH

2020

The RDAC discussed relevant legislation, including SB690 relative to drug formulary changes and SB685 relative to a drug importation program. The language of these bills was incorporated into HB1280, which was signed into law. The council also discussed HB1623, relative to telemedicine, which was signed into law.

2021

The council discussed relevant legislation, including HB600 relative to funding the newborn screening panel, which was signed into law. It discussed HB191, relative to prior authorizations and patient transfers under managed care group health insurance policies, which is retained in House Commerce. The group discussed HB62, relative to continued in-network access to certain health care providers, which was tabled by the House. The group discussed two LSRs for 2022 – one by Rep. Woods regarding an ALS registry, and a second by Rep. Marsh, allowing the council to hold remote meetings

Coordinating with Rare disease advisory councils, community based organizations, public and private organizations to improve cooperation between state and federal activities regarding the research, diagnosis and treatment of rare diseases.

2020

The council met with a member of the North Carolina Rare Disease Advisory Council.

Dr. Stommell contacted multiple people in Massachusetts with the goal of either joining their ALS registry or establishing a NH registry. This is an ongoing goal.

Rep. Marsh discussed HB1623 at the National Organization for Rare Disease annual summit. Our bill is being used as a model for other states.

The New Hampshire Rare Disease Advisory Council, worked in collaboration with the New Hampshire Rare Action Network and the New Hampshire Council for Youth with Chronic Conditions to create a survey to assess the needs of families and individuals in New Hampshire National and state-wide patient organizations and government programs encouraged participation through their social media and email lists. A report of the findings includes information about respondents' diagnosis, insurance coverage, access to providers, transportation, prescription medication and treatment, in-home supports, awareness of legislation affecting the rare community, and quality of life. Recommendations to address the needs of families and individuals with rare disorders in NH are also included.

2021

Several council members participated in the National Organization for Rare Disorders Project RDAC training series.

The RDAC has continued to develop relationships with other organizations including the Council for Youth with Chronic Conditions, the New Hampshire Occupational Therapy Association, the NH Council on

Developmental Disabilities, the NH Rare Disorders Association, the NH Rare Action Network, and the Youth and Sudden Death Committee.

Review data on rare diseases in New Hampshire collected by DHHS

2020

DHHS expanded the newborn screening program in NH

2021

The council was contacted frequently by rare disease patients about the lack of insurance coverage for prescription medications, including low dose naltrexone. The council gathered data regarding reimbursement for low dose naltrexone in New Hampshire by insurance providers. Low dose naltrexone is not covered by Medicare. It is not covered by private carriers without prior authorization. Few prior authorization requests have been completed in the last year. There is no mechanism in place to gather data about Medicaid reimbursement.

Council members were contacted by individuals and families in crisis. There is a state-wide staffing shortage of direct support professionals and in-home support providers. This impacts the quality of life for people with rare disorders. It places limitations on the individuals and their families/caregivers in terms of their ability to work, to care for themselves, and to remain living in the community. COVID has further reduced the workforce. Many individuals and families have been faced with the difficult choice of leaving their job to care for their loved one or placing them in a facility.

Raise public awareness regarding rare diseases in New Hampshire

2020

In cooperation with the NH Rare Action Network the RDAC hosted two Rare Disease Day events.

Archived: Wednesday, March 16, 2022 10:39:06 AM
From: [Laura Colquhoun](#)
Sent: Monday, January 17, 2022 11:03:42 AM
To: [~House Judiciary Committee](#)
Subject: I do not support HB1013
Importance: Normal

Dear Honorable of the House Judiciary Committee;

My name is Laura Colquhoun and I live in Nashua NH. I do not support HB1013 relative to changing the format of meetings of the New Hampshire rare disease advisory council.

While I am sympathetic with members of the Board that are autoimmune compromised, I believe a physical location must be provided for all public meetings. This new paragraph amendment to RSA 126-A:79 allows no physical location to be available. Additionally, if only electronic means are provided, this may limit the attendance of some members of the public in remote areas that do not have access to technology.

In Nashua, the physical location is a critical component of our public meetings. Very often before the start of the meeting and after adjournment, members of the public engage their ward representatives in dialog on the business of the board. Not all members of the public are comfortable speaking in public and participating in the meetings where they have to address officials. Some chose a more personal, face-to-face approach to discuss city matters after the meeting was concluded. These social connections are an important part of doing business and a physical location provides a means for this to happen.

Additionally, conducting business and negotiating, which is often happening with new legislation, consists of verbal and non-verbal cueing. The body language of our board members signals messages on voting positions. This type of communication can only be captured when meetings maintain physical locations. Remote access through video means does not always capture the room and telephonic remote access completely eliminates all interpersonal connections and non-verbal communication. Seeing and hearing the entire elected body is an important part of public meetings.

For these reasons, I do supports public meetings to include:

1. A physical location must be provided.
2. The quorum of the board present in the physical location must be defined by the committee.
3. Board members participating remotely must give a reason why remote participation is being done.

4. Any member participating via video should identify the location from which the person is participating from and if any other persons are present at that location with them.
5. Virtually access, either telephonic or video, must be provided in the meeting notice required to be posted under RSA 91-A:2
6. Each member participating electronically or otherwise shall be able to simultaneously hear each other and speak to each other during the meeting, and shall be audible or otherwise visible to the public in attendance at the meeting.
7. The public must have a means to notify the committee if they cannot access the meeting.
8. The meeting must be adjourned if the public is unable to access the meeting.

Please oppose HB1013 which would permit fully remote public meetings.

Very truly yours,
Laura Colquhoun
30 Greenwood Dr
Nashua, NH 03062

Online testimony submission

HB 1013 Relative to meetings of the New Hampshire Rare Disease Advisory Council

This bill would allow the NH Rare Disease Advisory Council (RDAC) to meet remotely.

I am a member of the New Hampshire RDAC, appointed as a parent representative. I am submitting this written testimony on my own behalf. My son Jordan and I both have rare disorders.

The Advisory Council serves four critical functions

1. Advising the legislature and DHHS on rare diseases in NH
2. Coordinating with rare disease advisory councils and other organizations regarding research, diagnosis and treatment of rare diseases.
3. Review data on rare diseases in NH collected by DHHS
4. Raise public awareness regarding rare diseases in New Hampshire.

The RDAC meets once a month. While under the emergency order, the council continued to meet regularly with the use of the zoom video conferencing. Rare disease patients, caregivers, and their allies could attend meetings to gather and share valuable information. Communication between participants was easily understood. Accessibility was improved for all individuals, including those with rare disorders and disabilities. The ability to attend remotely removes barriers that may interfere with or prohibit participation in in-person meetings. This includes functional impairments (vision, hearing, mobility or communication) as well as fear of exposure to COVID-19 or other illnesses.

When the emergency order expired, the council meetings were put on pause until a suitable meeting location could be found. The council has resumed in-person meetings as required under current law. Zoom video conferencing is also available. Most council members are phoning in or video-conferencing in. Communication and understanding of information is quite difficult. The members who are attending in person are wearing masks and maintaining social distancing protocols. Even with the caption feature turned on from the zoom platform, I often cannot understand the information that is being shared.

Because there are a limited number of council members physically present at the meetings, a quorum cannot be established. I believe that the work of the Rare Disease Advisory Council is critical for the well being of the citizens of New Hampshire. Please review the work that the group has done over the last two years that I've summarized below and I think that you will agree. In order for this group to continue to function effectively, it must be able to meet remotely.

Sincerely,

Krista M. Gilbert

816 C Court Street
Keene, NH 03431

1666freedom@gmail.com

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Raise public awareness regarding rare diseases in New Hampshire

2020

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Archived: Wednesday, March 16, 2022 10:52:07 AM

From: William Marsh

Sent: Wednesday, January 19, 2022 7:10:16 AM

To: ~House Judiciary Committee; Gary Woods

Subject: HB1013

Importance: Normal

Attachments:

HB1013 Committee -- Marsh.pdf  Rare Disease Advisory Council Annual Report Final
2020.pdf  Rare Disease Advisory Council Annual Report 2021.pdf 

Dear House Judiciary:

Attached find my testimony for HB1013.

Rep. Woods will introduce the bill, as I have to introduce another bill before Legislative Administration.

I have also attached the last two annual reports of the Rare Disease Advisory Council for your information.

I will come to your committee after Legislative Administration is done in case you have any questions.

Rep. Marsh

HB 1013 - AS INTRODUCED

2022 SESSION

22-2159

05/08

HOUSE BILL **1013**

AN ACT relative to meetings of the New Hampshire rare disease advisory council.

SPONSORS: Rep. Marsh, Carr. 8; Rep. Woods, Merr. 23; Rep. Deshaies, Carr. 6; Rep. Weber,
Ches. 1; Rep. Simpson, Rock. 36; Sen. Rosenwald, Dist 13; Sen. Sherman, Dist 24

COMMITTEE: Judiciary

ANALYSIS

This bill allows the New Hampshire rare disease advisory council to meet remotely.

Explanation: Matter added to current law appears in ***bold italics***.
Matter removed from current law appears ~~[in brackets and struckthrough.]~~
Matter which is either (a) all new or (b) repealed and reenacted appears in regular type.

STATE OF NEW HAMPSHIRE

In the Year of Our Lord Two Thousand Twenty Two

AN ACT relative to meetings of the New Hampshire rare disease advisory council.

Be it Enacted by the Senate and House of Representatives in General Court convened:

1 1 New Paragraph; New Hampshire Rare Disease Advisory Council; Remote Meetings
2 Authorized. Amend RSA 126-A:79 by inserting after paragraph VII the following new paragraph:

3 VIII. As many people with rare diseases, including several members of this council, are
4 immunocompromised due either to their disease or their treatment, notwithstanding any provision
5 of the law to the contrary, the rare disease advisory council is authorized to meet remotely.

6 (a) If a physical location is provided for a meeting, provision also shall be made to access
7 the meeting telephonically and additional access may be provided by video or other electronic means.

8 (b) If a meeting has no physical location, public access shall be provided to the public by
9 telephone, and additional access may be provided by video or other electronic means.

10 (c) Whether or not a meeting has a physical location, public notice of the meeting, with
11 all information necessary to access the meeting telephonically and by other means, shall be provided
12 pursuant to RSA 91-A:2, II. The meeting shall be adjourned if the public is unable to access the
13 meeting.

14 (d) Each member participating electronically or otherwise shall be able to
15 simultaneously hear each other and speak to each other during the meeting, and shall be audible or
16 otherwise discernable to the public in attendance at the meeting's location, if the meeting has a
17 physical location. Any member participating in such fashion shall identify the location from which
18 the person is participating and the persons present in the location from which the member is
19 participating. No meeting shall be conducted by electronic mail or any other form of communication,
20 including an online chat function, that does not permit the public to hear, read, or otherwise discern
21 meeting discussion contemporaneously at the meeting location specified in the meeting notice.

22 (e) A member participating in a meeting by the means described in this paragraph is
23 deemed to be present at the meeting for purposes of voting. All votes taken during such a meeting
24 shall be by roll call vote.

25 2 Effective Date. This act shall take effect 60 days after its passage.