

New Hampshire Governor's Rare Disease Advisory Council

Minutes 9/18/20

Prepared by Laura Landerman-Garber Ph.D.

-Chairman, Representative William Marsh read the NH State Guidelines for official NH meetings during the COVID-19 Pandemic , including the parameters for meetings held via tele-technology

-Attendance: Present-Chairman Representative William Marsh, Representative Richard Osborne, Dr. Sai Cherala, Dr. Mary Beth Dinulos, Dr. Elijah Stommel, Dr. Laura Landerman-Garber, Ms. Krista Gilbert. Absent: Dr. Richard Lefluer, Dr. Angela Shepard, Senator Cindy Rosenwald. Guests: Dr Margaret Clifford, Dr. Jonathan Ballard, Tyler Brennen (NHID), Ms. Abby Rogers, Ms. Elizabeth Shannon, Ms. Paula Minnehan, Ms. Courtney Tanner.

-Minutes from Meeting (18 September 2020) were reviewed and accepted.

Guests:

-Mr. Brennen (NHID)

—Discussed the issues related to both health insurance coverage as well as services for rare disease. Reasonable time frame as well as distance traveled is important in terms of Network Adequacy. Additionally, services are to be provided within reason within New England region.

—Two years ago, coverage was updated to include telehealth and given current pandemic, telehealth coverage and services are to be more broad-based.

—Mr. Brennan was asked what would happen to a person with a RD who chose a Plan based on specific Providers who were expert with

their RD. He discussed that most Networks in NH are very robust in that regard despite some being initially limited in 2014. No policy can guarantee to keep those specific Providers for that subscriber's contract year but do try to be both transparent and are in fact required to obtain a Provider of "equal" expertise.

—Mr. Brennan was asked if there are specific contacts within insurance companies that are designated for subscribers who have RD. He discussed that case managers are the ones to contact but that there are not necessarily designated RD contacts. He did recommend that frustrated subscribers can always call the NHID Consumer Department.

-Dr. Clifford (Pharmacy)

—Dr. Clifford was asked what individuals who have a RD should do if they need to get their medications out-of-state. She reported that if the need is to be long-term, then that pharmacy will have to become enrolled in the pharmacy network. If, however, the need for out-of-state medications is short term or a one time event, then adjustments can be made.

—Dr Clifford discussed that participants can change their Doctor for "Cause" one time per calendar year.

—Specialty Pharmacy Issues

-Ms. Gilbert discussed concerns of consistency of access to Specialty Pharmacies. This issue arose from reviewing the RD Survey that she dispensed in NH to individuals and families with RD. For example, Compassionate use Medications require a physician who has an expert on that condition and medication

-Ms. Shannon discussed frustration with Prior-Authorizations and Utilization Reviews for medications. She has to review her medications every three months and inquired whether there is a way to avoid doing so.

-Mr. Brennan reported that Insurance Carriers must respond within 48 hours on Prior-Authorization issues, especially for those medications not on a formulary.

The NHID enforces that there is not discrimination practice against patients in this regard but acknowledged that it is hard to track/monitor.

-Dr. Clifford agreed that the reviews must be done within a specific designated time frame and if the Physician/Provider is not available , then a 72 hour emergency dose is given .

-Representative Osborne noted that as a physician , he is aware that these challenges happen all too often and believes that providers should get more training in dealing with insurance companies .

-It was asked rhetorically of our guests and to be later discussed amongst Council Members, if RD patients could be involved with the NH Medical Society to help to train physicians.

-Chairman Marsh thanked our invited guests Dr Clifford and Mr. Brennan for attending and engaging in an informative discussion

Data Base:

-Dr. Stommel reported that he is currently writing a grant and that he will report back to us at the next meeting as to any advances in the topic of a Data Base (ALS and/or RD)

Legislation:

-Chairman Marsh

—Submitted Bill for Legislation that if an insurance carrier has a provider at the time of contract, that said carrier is to keep provider at original rates

—Submitted Bill for Legislation to change funding for Newborn Screenings, It is currently too expensive. Change may in fact be how it is billed and not in how it is funded?

–Dr. Cherala addressed funding and concern of sustainability of Newborn Screening. There is not only a need to continue the current screenings but also to continue to develop new tests.

–Ms. Minnehan discussed the issue of how difficult it is to sustain the funding for the Newborn Screenings. It is very costly for the hospitals to sustain/manage these costs

–Chairman Marsh discussed the need to be more equitable and fair in who is paying for the screenings, such as hospitals vs insurance carriers.

–Chairman Marsh reported that he recently met a constituent who benefited greatly from a life saving treatment after a newborn screening. (SMA)

Newborn Screening:

–Dr. Cherala discussed that three new screening tests began on 8/26/20. Newborn screenings are crucial in helping families in terms of treatment and support.

–Dr. Stommel raised the question of how to possibly publicize the success stories in terms of these screening which in turn may educate Granite Staters about how to seek out screenings and what to ask for in this regard. The issue of HIPPA was raised and will be further discussed.

Ms. Gilbert:

–NORD Summit October 8/9, 2020. Chairman Marsh will be speaking about telehealth. Dr. Cherala will also be presenting and

will be discussing newborn screening. Registration is still open and Ms. Gilbert can be contacted to assist with registration.

-Ms. Gilbert discussed a medication that is traditionally used for addiction. This medication (Naltrexone) when used off-label can be possibly helpful in the management and treatment of cancer, Chrons, and Ehlers-Danlos Syndrome. For Ehlers-Danlo, the medication required out-of-pocket payment. Ms. Gilbert is working to see if it might be covered under insurance for those in need of the medication. It was suggested to Ms. Gilbert that Dr. Lefluers may be a good resource with whom to discuss this issue.

-Ms. Gilbert followed up to a discussion from our last meeting regarding the direct support professional position and related possible certification. She is continuing to attempt to gather information about this topic and will follow up with the Council. Chairman Marsh will look into the issue as well and will discuss it further with Ms. Gilbert outside this meeting. It was recommended that Senator Rosenwald be consulted.

-The next meeting is scheduled for 16 October 2020 at 3:00 PM via tele-technology.

-The Meeting was adjourned without objection.

Meeting Minutes respectfully submitted by Laura Landerman-Garber Ph.D on 12 October 2020