

State of Connecticut  
GENERAL ASSEMBLY



PUBLIC HEALTH COMMITTEE  
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**Task Force to Study Rare Diseases**

Meeting Summary

September 8, 2017

Dr. Gulati convened the meeting at 1:10 PM with introductions of the Task Force members and the presentations.

Members Present: Dr. Cathleen Lutz, Dr. Joseph Tucker, Dr. Lynne Sherman, Dr. Mridu Gulati, Nancy Dupont, John Morthanos, Michele Spencer-Manzon, Lesley Bennett, Nancy Dupont, Paul Pescatello, Representative Kim Rose, and Senator Somers.

Others Present: Tracy Wodatch, David Marro and Maryann May.

Dr. Gulati announced that the next meetings will be held on October 20<sup>th</sup> and November 17<sup>th</sup>, 2017, and that as speakers are confirmed she will inform members of the agendas.

Presentations

Lynne Sherman presented on Pediatric Specialty Centers.



Lynne Sherman  
YNHCH upd rare dise:

Lesley Bennett asked what diseases are being looked at now.

Lynne Sherman stated that the focus is on a specific pediatric demographic that is susceptible to genetic disorders but have not been diagnosed on traditional test.

Lesley Bennett asked if Lynne was collaborating with the National Institute of Health undiagnosed program.

Lynne Sherman responded that not officially and added that YNHCH have similar type research taking place and that this center is really designed to help family seeking

answers that have been on the diagnostic odysseys trying to get their child diagnosed and help.

Lesley Bennett asked if Lynne knew the operational cost of this center.

Lynne Sherman stated that the research portion is free and that there is a regular charge that goes to insurance for clinical testing. She added that they try to get reimbursement.

Lesley Bennett stated that it is important that families are made aware of Pediatric Centers and the resources they offer.

Dr. Gulati asked if confirmatory testing must be done before a patient is seen.

Dr. Michelle Spencer-Manzon stated that if it is a critical newborn screening they are seen immediately. Otherwise confirmatory testing is done before seeing a patient because 90% of tests are false positives. She added it can take 24 hours to 7 days to get a child in the center and receiving care.

Dr. Tucker stated that Dr. Spencer-Manzon's procedures are very similar to his practices and protocols and added that confirmatory testing is typically coordinated through the patient's primary care provider.

Dr. Gulati asked what the gap is between initial testing and confirmatory testing. She also asked if community pediatricians are well equipped to give families information between that processes.

Dr. Spencer-Manzon stated that the gap depends on the type of test and the speed of the test. She added that sometimes it can be 24 hours, and other times it can be weeks. It is not the quickest process by any means.

Dr. Tucker agreed with Dr. Spencer-Manzon and stated that in an ideal world he would meet with every patient on that same day. He added that with the current number of positive screens and the limited amount of resources it is impossible to meet with everyone and often times communicating with the families is done via telephone.

Dr. Gulati asked what contributed to the increase in volume that specialty centers are experiencing and how are the centers handling this growing volume.

Lynne Sherman stated that it is a challenge to have enough specialty physicians available at the centers to meet demand. She added that when they are evaluating a site performance they look at how many referrals are made, the next available appointments, demographics of the area and what services are needed on hand daily; Pediatricians, Endocrinologist, Gastroenterologist, or respiratory physician etc. She expressed the need to have comprehensive specialists need to be available for appointments and added that there are also telemedicine options available to improve the efficiency of limited resources.

Dr. Gulati asked how social work and palliative care are distributed.

Lynne Sherman stated that they have these resources available but they do not have enough of them.

Lesley Bennett asked how many of the 1000 plus metabolic disorders how many are being screened for at these facilities.

Dr. Spencer-Manzon stated that the number being screened for is less than 60 and added that newborn screening looks for more common disorders that are amenable to current treatments and cures.

Lesley Bennett asked if patients are ever referred to Boston or New York City.

Dr. Spencer-Manzon stated that she will refer patients to any place in the country that is doing something her center is not doing in hopes of helping the patient.

Lesley Bennett thinks it is important to get the scope of the problem in front of people and it is difficult for centers to try and keep up with 1,000 different disorders and to deal with testing right away.

Dr. Spencer-Manzon stated that testing is not so much the issue. She added that the nice thing about metabolic disorders is that the community is small enough and as a result there is not one national expert you cannot get on the phone. She stated that she will often times co-manage a patient with other sub-specialty centers around the country and in that case she will provide the day-to-day management of the patient and the sub-specialty center will do yearly or bi-yearly checkups.

Lesley Bennett explained that the one stated a problem patients and their families are experiencing are that they are running out of doctors that can help them.

Dr. Gulati asked what areas the state can be of assistance in.

Lynne Sherman stated that 55% of children in hospitals are Medicaid patients and those with complex issues account for 40% of spending that would be an area that the state could assist with.

Dr. Tucker stated that in following up with new born screening requires a lot of resources and there is no way to be reimbursed and that he offers a lot of his free time to remedy this issue.

Dr. Spencer-Manzon affirmed Dr. Tucker's statements and added that the lack of state support is an issue, along with the shortage of social workers. She stated that she also spends a lot of time fighting with insurance companies to pay for certain things and that she wants the state to mandate that insurers cover certain procedures and testing.

Lesley Bennett asked Spencer-Manzon if she was aware of complex services through DSS for her patients.

Dr. Spencer-Manzon stated she was not aware of it.

Lesley Bennett agreed to follow up with her about it at a later point.

Tracy Wodatch presented on Home Healthcare providers.



Tracy wodatch  
Palliative Care and Hc

Dr. Gulati asked about access to palliative care, the definition of a palliative care provider and how is that integrated with other practices.

Tracy Wodatch stated that said she does not have all the answers but that the goal of the Palliative Care Advisory Council is to develop standards and benchmarks for the profession. The DPH website more or less describes Palliative care as a team approach, not just a consult but looks at an overall approach to managing that person's care. Palliative care is often associated with cancer patients but they only account for only 36-37%. The other ones are rare diseases, kidney failure, and Alzheimer's etc. She stated that the states goal is to improve the knowledge base of providers in the state.

Dr. Gulati asked how independent providers like herself can access palliative care providers in the outpatient setting.

Tracy Wodatch stated that there are not enough palliative care programs available for inpatient and outpatient care. She added that in the year past the Joint Commission just approved an accredited community based palliative care program. Nationally the support is still not there yet but that is expected to change as the palliative care community becomes stronger and offers proven outcomes.

Lynne Sherman stated that the presentation is raising a lot of awareness for her and she has to do further background reading of her own on the matter. She added that Palliative is another level of specialty that many providers are struggling to provide themselves because they are not aware of the help that is available to them.

Dr. Spencer-Manzon stated that half her patients could benefit from palliative care. She asked how she can access palliative services for her younger patients, what services are provided exactly and how useful is it in certain settings.

Tracy Wodatch suggested that she access palliative care through Yale Hospital first and that then her office and the palliative care services can work collaboratively when caring for the patient.

Dr. Spencer-Manzon asked Tracy Wodatch what palliative care offers that she herself doesn't.

Tracy Wodatch explained that a good palliative care team will look at the entirety of the patient's situation and consider all of the factors when accessing each patient's needs. Palliative care teams offers solutions outside of treating just symptoms with traditional medicine.

Dr. Spencer- Manzon Inaudible

David Marro presented on Durable Medical Equipment.

**A copy of his Presentation was not provided. We contacted him to provide a copy.**

Dr. Gulati asked that Dave explain C-Map certification.

David Amaro stated that a doctor can be licensed in the state and have an NPI number and that in order to prescribe durable equipment the doctor must also be C-Map certified. He added it that it stops the referral process to send a patient home because a doctor that is C-Map certified must be found.

Tracy Wodatch explained that Medicaid enrolled program and the doctor must be enrolled as a certified prescriber, orderer or referrer in order to participate.

Dr. Gulati asked what are some of ways it can be made easier for patients to receive oxygen equipment.

David Marro stated that patients should get oxygen covered and added that its supplemental with a retest in 30 days. If a patient is not using the equipment after a checkout then a leave a note and the supplier will pick it up.

Dr. Gulati asked if an appropriate assessment of durable medical assessment is actually happening upon a patients discharge from a hospital and where does Dave see room for improvement.

David Marro stated that home assessments would be vital and that too many times he sees a home that is not ADA complaint or that there is a potential fire and electrical hazards.

Dr. Gulati asked how to make home assessments be made mandatory.

David Marro stated that more time needs to be given to suppliers when durable equipment is required. This allows the supplier to conduct a proper assessment of the patient's home and make sure everything is to standard. A lot of times he is given supply request and only has 15 minutes or 30 minutes to turn it around.

Tracy Wodatch expressed her concern about competitive bidding because it makes specialty equipment tough to get. She stated that as most in-state suppliers do not carry certain equipment on hand because it is expensive and the reimbursement rate is not great. Additionally it is not uncommon for patient equipment request to be supplied by several suppliers.

David Marro stated that the face-to-face requirement between a physician and nurse for prescribing certain durable equipment is incredible strict and time consuming.

Tracy Wodatch Inaudible

Dr. Gulati asked how Medicaid plays a role in this.

Tracy Wodatch stated Medicaid will provide the equipment but it is a time consuming and lengthy process.

Paul Pescatello presented on CT Bioscience Growth Council.



Maryann May presented on the CT Hemophilia Society.

**A copy of her Presentation was not provided. We contacted her to provide a copy.**

Dr. Gulati adjourned the meeting at 3:25 PM.