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TASK FORCE TO STUDY RARE DISEASES

Meeting Summary

January 19, 2018

Dr. Gulati convened the meeting at 1:05pm.

Dr. Gulati noted that this is the last meeting, however the task force is exploring the possibility of extending its deadline in order to spend time flushing out some of the recommendations.

Members and guest speakers introduced themselves.

Dr. Gulati announced that the meeting is being televised.

Venice Francis-Churilov, Associate Vice President & Carrie Lebert, Manager, Intensive Care Management, Community Health Network of Connecticut presented:

ICM Rare Disease
Presentation.PPT

Ms. Lynne Sherman noted the impressive work that is being done with patients. She asked what percentages were pediatric versus adult patients.

Ms. Churilov stated that they manage 11,000 members who are engaged, meaning they agreed to participate in the program and have agreed to complete a very detailed assessment of them. While she did not have an exact percentage, she noted that most patients fall occur in the adult population. Those that are in the pediatric route have a team that works specifically to address their needs.

Dr. Gulati commented that as a rare disease provider, very often she is left doing the primary care for rare disease patients and at times is nervous that she will miss another chronic issue because she is focused on the rare disease. She asked how well connected the Network was to specialty practices and asked from whom they receive most of the referrals.

Ms. Churlov stated that they have a connection to specialty practices and deferred to Carrie Lebert to answer the referrals question.

Ms. Lebert noted that they get referrals from Connecticut Children Medical Center, from University of Connecticut Health Center, from sickle cell members and more. They always ask the members if they can share their medical information with their primary care providers and sometimes they say no and to only send it to their chemo doctor or their rare disease doctor.

Dr. Zavoski stated that 47% of members are attributed to a medical home and the attribution methodology makes use of claims so they allow their patients to choose their primary care providers. He added that they attribute close to 80% to a primary site of some sort.

Dr. Gulati said that one of the questions we have been asked is if the rare disease community can do anything to help you with patients such as provide more information that you can bring back to your clinics and urged everyone to do so.

David Guttchen, Director, Connecticut Long-Term Care Planning Committee, Office of Policy and Management presented:

Balancing the
System_2016 Report

CT Rebalancing
Summary 2017_FINA

Long-Term Care Plan
- 2016.pdf

Ted Doolittle, Healthcare Advocate, Office of the Healthcare Advocate presented:

OHA 1-19-2018
Presentation.pdf

Dr. Gulati asked if there are similar issues that come up repeatedly and if rather than dealing with things on a case by case basis there is a system based approach.

Mr. Doolittle answered that in terms of assisting a particular customer it is always on an individual basis. There is a number of rare disease clients with whom they've worked on a continuous basis for many years. In terms of actual case management, there is no strategy to that and it is purely tactical. They try to take a more systemic view in terms of policy and one of the things they have explored and have a strong relationship with is insurance carriers.

They feel that when they are helping someone with insurance issues in the rare disease community, they find that carriers and clients benefit from stronger individualized cassis and that is a systematic improvement that they would like to see.

Ms. Kelly Amato asked if this is Connecticut based or if it's offered nationally in other states.

Mr. Doolittle stated that there aren't many States that have anything similar to their program. There's an Office of Patient Advocate in California but they help with quality rather than representing people who struggle with insurance companies. He added that there is an office in Colorado that may have a similar mission but he is not too familiar with it. He stated that interestingly enough, one of the initiatives of the Affordable Care Act was to have an Office of Healthcare Advocate in every state and there was quite a lot of money for states to set up healthcare advocate offices, which they all did, however, they typically designate an existing office to be the healthcare advocate office. They ran these offices for a couple of years and after that they went back to being what they were before the conversion.

Dr. Gulati asked how his office advocates for the patients since it hasn't had much experience with rare disease.

Mr. Doolittle said that usually his office's financial interest, which is the client's interest, closely aligns with the provider's interest so the providers work with this office and support them in getting the information necessary. They also reach providers who are experts in a certain rare disease and they show them where to look.

Mr. John Morthanos asked how people know about his office.

Mr. Doolittle commented that he wished they had a larger outreach budget. There is a law in Connecticut that when denying a procedure, it requires carriers to include a paragraph about their office. They also get referrals from the legislature because they and their staff turn to them to a certain degree when constituents call and need their help. They get referrals from providers because they are good at dealing with insurers and there is also a fair amount of word of mouth.

Ms. Maryann May said that people have to change insurances from year to year, especially if they're in the Affordable Care Act. In case their treatment center is not on the list, it is not easy for patients to get referrals to see a specialist. She asked if she can direct patients to the Healthcare Advocate.

Mr. Doolittle answered that Ms. May can direct patients to the Healthcare Advocate.

Emily L. Germain-Lee, M.D., Professor, Department of Pediatrics, UConn School of Medicine; Chief, Division of Pediatric Endocrinology and Diabetes, Connecticut Children's Medical Center presented:

legislature_Germain_
Lee_Jan_19_18.pptx

Mary Beth Bobik-Kadylak, Director of Patient Education & Support, Scleroderma Foundation, Tri-State Chapter presented:

PresentationtoCTConPH.pptx

Holly LaPrade, Patient Advocate, International Fibrodysplasia Ossificans Progressiva Foundation presented:

Holly LaPrade Patient Advocate.pdf

Beth Fox, Parent and Volunteer Regional Parent Ambassador, Dravet Syndrome Foundation presented:

Ms. Fox recounted her personal story of raising her nine year old daughter who has been diagnosed with Dravet Syndrome and the challenges her family faces on a daily basis. There is no cure for Dravet Syndrome and it affects approximately one in 16,000 people. There are currently 20,000 people living with the syndrome in the United States and 10 of those live in Connecticut.

Dr. Gulati adjourned the meeting.