

State of Connecticut  
GENERAL ASSEMBLY



PUBLIC HEALTH COMMITTEE  
LEGISLATIVE OFFICE BUILDING, ROOM 3000  
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**Task Force to Study Rare Diseases**

Meeting Summary

November 17, 2017

Dr. Gulati convened the meeting at 1:30 PM with introductions of the Task Force members and the presentations.

Members Present: Dr. Tucker, Dr. Pober, Dr. Sherman, Dr. Gulati, Nancy Dupont, John Morthanos, Michelle Cotton, Dr. Spencer Manzon, Lesley Bennett, Paul Pescatello, Rep. Kim Rose.

Others Present: Paul Lombardo, Gerard O'Sullivan, Eileen McMurrer, John Frassinelli, Bryan Klimkiewicz, Dr. Mustafa Khokha, Laura Stefon and Stephanie Knutson.

Paul Lombardo and Gerard O'Sullivan presented on The Connecticut Department of Insurance.



External\_Appeal\_Consumer\_Guide.pdf

Lesley Bennett asked if the State offers continuous insurance for an adult dependent disabled child.

Paul Lombardo stated that he has to check for an answer. He further stated that under the Affordable Care Act dependents are covered until age 26, but again stated he would need to check on an answer and get back to her.

Gerard O'Sullivan stated that if any member received pushed back on an issue to contact the Insurance Department or himself directly for assistance.

Dr. Gulati asked what percentage of the population the Insurance Department has purview over.

Paul Lombardo stated the total number is decreasing daily as most large employers are moving to the self-funded market and small employers are using stop loss coverage. He

further stated that large employers (51 employees or more) are about 60 and 65 percent self-funded and that he expects the small group market to grow more in the future. He also added that the individual market is fully funded at this point.

Dr. Gulati asked how well informed are the families and patients about the appeals process for denied claims.

Gerard O'Sullivan stated that insurance companies are required to provide patients upon denial information regarding their appeal rights and the assistance that they can receive from the Insurance Department or The Office of The Health Care Advocate.

Dr. Pober asked how denials for genetic testing are handled by the External Review Committee.

Paul Lombardo stated that the External Review Committee is required to assign the appeal to a clinical peer that has expertise over that particular test or test that was denied.

Dr. Mustafa Khokha asked how new diagnostic procedures can be added to the list of approved procedures that are covered by insurance companies in a more timely fashion.

Gerard O'Sullivan stated that the process can be hastened if doctors jointly state that these "experimental" tests are now the standard of care for medicine and to update medical protocols. This will result in insurance companies covering those tests.

Lesley Bennett asked if co-insurance payments are based on the list price of the drug or the actual cost of the drug.

Paul Lombardo stated that the co-insurance payment is based on the list price at the pharmacy.

Lesley Bennett asked how often the formularies change for insurance plans as they can change without notice thus causing patients a financial burden.

Paul Lombardo stated that formularies are updated no more than twice a year per state statute.

Dr. Gulati asked what tools are available for patients to use to determine what their health insurance plans do and do not cover.

Gerard O'Sullivan stated that the exchange website offers enhanced information about what the plans cover and the out of pocket cost to the patient.

Dr. Gulati asked what can be done to reduce the time required to file appeals to make the life of providers and patients easier.

Gerard O'Sullivan recommended that providers speak with the company directly and if that does not work to reach out to the Insurance Department for assistance.

Dr. Gulati asked for the Department's perspective on palliative care and symptom management.

Gerard O'Sullivan stated that going forward it is reasonable to see more consistent coverage of palliative care by insurers as it becomes more common practice.

Dr. Pober asked what resources are available to help individuals with disabilities navigate all the available resources.

Gerard O'Sullivan stated that the insurance department does the best they can to accommodate people however they can. He further stated that the information is provided via website, internet, and phone and that there is even a language line available as well.

Eileen McMurrer presented on the Office of Early Childhood



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Michelle Cotton asked how Short Chain Acyl CoA Dehydrogenase Deficiency (SCAD) could be added to a referral system for Birth to Three programs.

Eileen McMurrer stated the established conditions list is fluid and SCAD can certainly be added to that list going forward.

Michelle Cotton asked if information can be provided during the transition meeting pertaining to an IEP and a 504 plan.

Eileen McMurrer stated that if parents have accepted support services, IEP and 504 plans are always provided at these meetings.

Lynne Sherman what are the types of interventions provided by the Office of Early Childhood to patients and their families.

Eileen McMurrer stated the Office works to model the trainings with the caregiver and parents present. She further stated that the office will teach the parents and caregiver how to properly position the child in a high chair for snack time. She further stated that the goal is to provide the involved parties with some strategies and techniques to make life easier and manage the patient's disorder best.

Dr. Spencer-Manzon asked if there is a way to close the gap for the Birth-To-Three program for families that cannot afford the cost.

Eileen McMurrer stated that do to the current economic reality the Birth-To-Three program is no longer free, however parents have the option to accept services at no cost. She further stated that these services include initial evaluation and assessment, and transition planning but does not include the more costly physical therapy.

John Frassinelli and Bryan Klimkiewicz presented on the State Department of Education.

John Morthanos asked if there is a way to train the parents and school staff to deal with students that are suffering from a rare disease.

Bryan Klimkiewicz stated that many times the parent of the child is the expert when it comes to dealing with their child and he further stated that when developing an IEP or a 504 plan education of the school staff is a key component.

Dr. Gulati asked how much access the Department of Early Childhood has to information about the various rare diseases.

Stephanie Knutson stated that the Department has plenty of access to information regarding rare diseases and the internet has been a big factor in increasing access.

Michelle Cotton asked if there are better safeguards in place nowadays to ensure that school districts are properly informed when a child with a rare disease enters the district.

Stephanie Knutson stated that there are safeguards in place and the level of communication between all involved parties is the key in ensuring that a child receives the appropriate attention.

Bryan Klimkiewicz further added that every school and every district depending on its size has a staff member that is a 504 Plan coordinator who is responsible for providing patient families with all the information they need for their child.

Dr. Spencer-Manzon asked what are the legal mandates for private schools, how are the quality of special education services ensured across the state and asked the Department to speak on the practice of “Mainstreaming” students with disabilities.

Bryan Klimkiewicz stated that Mainstreaming is practiced to avoid ostracizing students with disabilities from their peers and a plan is developed to place them in a general classroom setting.

Dr. Spencer-Manzon asked if the outcomes of students with mental disabilities who are placed in general education environments are being monitored.

Bryan Klimkiewicz stated it is the responsibility of the schools PPP teams to assess the effectiveness of mainstreaming and if it is in the student’s best interest. He further stated that the Department continually monitors the progress of all students while enrolled in schools and actually leads the country at monitoring the outcomes of young adults from ages 18-24.

Mustafa Khokha presented on Genomic testing.

**Presentation was not provided-requested copy**

Lesley Bennett asked if the rates of positive X-some sequencing are increasing as the technology becomes more advance.

Mustafa Khokha stated that if the rate is going up it means that not enough test is being done. He further stated that if enough patients are being tested regularly then the rate of positives should hold steady implying that providers are a doing good job at identifying which patients should be screened.

Lesley Bennett stressed the importance of the Rare Disease community informing insurers how impactful Genomic testing is for patients and urged that it be covered by the insurance company.

Mustafa Khokha stated the X-some sequencing cost about \$300 at Yale and Whole Genomic sequencing cost about \$2000 and these costs do not include interpretation of the

results. He further stated that the community needs to come together and have conversations with the insurance companies about the importance of covering these test.

Dr. Gulati adjourned the meeting at 4:10 PM.