



State of Connecticut

Task Force to Study Rare Diseases

Co-Chairs

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Agenda



1. Convene Task Force Meeting
2. Remarks by the Chairs
3. Medical Waiver Programs in Connecticut—Kathi Bruni
4. Task Force Discussion
 - Next Meeting Dates
 - Review of Prior Meetings
 - Goals Through December 2017/Establishment of Possible Subcommittees
5. Public Comments

PA 15-242, Sec 35



- June 2015—Public Health Co-Chairs— Representative Ritter and Senator Gerratana amendment added to HB6987 (PL15-242) creating a rare Disease Task Force
 - Under Section 35 (a) of Public Act 15-242 Sec. 35. (*Effective from passage*) (a) There is established a task force to study rare diseases. The task force shall:
 - (1) examine research, diagnoses, treatment and education relating to rare diseases, and
 - (2) make recommendations for the establishment of a permanent group of experts to advise the Department of Public Health on rare diseases.



Section35 Public
Act 15-242

Proposed Bill 6009



Proposed Bill No. 6009

January Session, 2017

LCO No. 2605

02605

Referred to Committee on PUBLIC HEALTH

Introduced by:

REP. ROSE, 118th Dist.

AN ACT ESTABLISHING A RARE DISEASE ADVISORY COUNCIL.

Be it enacted by the Senate and House of Representatives in General Assembly convened:

That title 19a of the general statutes be amended to **establish an advisory council** comprised of researchers, **geneticists**, physicians, hospital administration and patient advocates for the purpose of making recommendations to the joint standing committee of the **General Assembly** having cognizance of matters relating to public health concerning the rare disease community.

Statement of Purpose:

To make recommendations on legislation concerning the rare disease community.

Status of recent bill?



Rare Disease Task Force

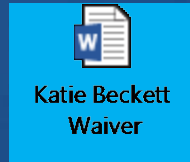
Not appointed:

- Internal Medicine
- Emergency Medicine
- Cardiovascular

Waivers



- DSS Waivers
 - Connecticut Home Care Program for Elders
 - <http://www.ct.gov/dss/cwp/view.asp?a=2353&q=305170>
 - (Eligibility):
<https://www.ascendami.com/CTHomeCareForElders/default/HomeCareForEldersInstructions.aspx>
 - Katie Beckett Waiver
 - Personal Care Attendant
- DDS Waivers (Department of Developmental Disabilities Waivers)
 - <http://www.ct.gov/dds/cwp/view.asp?q=332294>



Next Meeting Date



- Survey Results (not all responding)
 - Friday afternoons
- Proposed Dates
 - July 21, 2017 1:00PM-2:30 PM
 - September 8, 2017 1:00PM-2:30PM
 - October 20, 2017 1:00PM-2:30 PM
 - November 17, 2017 1:00 PM-2:30 PM
- Calendar invites will be sent out as well
 - Will call in number be the same?
 - Goto meeting/Video conferencing

Prior Meetings Discussions



● Meeting 1 (2/24/2017)

● Goals

- Community outreach provider (medical education/awareness of community resources)
- Community outreach patients/caregivers
- Improving access to services
- Enhancing newborn screening
 - Adding tests
- Improving the “flow” of newly identified patients
 - Partnership /Collaboration/between Centers and Community
 - Improving timeliness

Meeting 2: March 31, 2017





- Medicaid Presentation
- Medical homes
 - <http://www.ct.gov/dss/cwp/view.asp?a=4769&q=587210>
- Waivers
- Financial support of specialty centers (block grants)
- Mental Health Providers
- Long term data on patients identified to newborn screening
- Quality metrics

Meeting 3 (Newborn Screening)

- Newborn Screening
 - Adding or Removing Screening tests
 - Improving contact from pediatrician to parent
 - Improving educational material for patients and providers
 - Updates to webpage
 - <http://www.ct.gov/dph/cwp/view.asp?a=3122&q=387742> (CT)
 - Other states:
 - <http://www.oregon.gov/oha/PH/LABORATORYSERVICES/NEWBORNSCREENING/Pages/facts.aspx> (Oregon)
 - <https://www.wadsworth.org/programs/newborn/screening>

Future Topics/Meetings



- Identifying Challenge for Individual Community Providers (Working with CT American Academy of Pediatrics) regarding Rare Diseases?
 - ?Survey? (ie. Lupus Survey)
 - Ongoing medical education  Lupus Survey
 - Timely access to subspecialty services for patients  Lupus Survey Questions
 - Access to supportive services for patients/Knowledge of existing services
- Identifying Challenges for Rare Disease Providers/Centers
 - ?Survey
 - Presentation by Specialty Centers
- Provider Outreach/Education Including around Screening
 - Enhancing existing materials on website re: diseases (ie. Newborn Screening)
 - Presentation/Presence at Local Hospital/meetings
 - Contact local Provider Organizations (ie. CT-AAP, local hospitals)
 - Email blasts from Departments
- Improving information regarding State based Services to Community Providers
 - Collaboration with local hospital/CT American Academy of Pediatrics
- Newborn Screening
 - Enhancing testing (Adding tests)

Next Steps



- Recurring invitations to Task Force Meetings from which departments?
- Creation of subcommittees?
 - How many subcommittees?
 - Advisors to subcommittees?
- Topic choices for next few meetings
 - (Specialty Centers)