State of Connecticut

Task Force to Study Rare Diseases

Co-Chairs

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Jackson Laboratory

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Section of Pulmonary, Critical Care and Sleep Medicine
Yale School of Medicine
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
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.
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.
Rare Disease Task Force

Not appointed:
• Internal Medicine
• Emergency Medicine
• Cardiovascular
Waivers

DSS Waivers
  Connecticut Home Care Program for Elders
    (Eligibility):
    https://www.ascendami.com/CTHomeCareForElders/default/HomeCareForEldersInstructions.aspx

Katie Beckett Waiver
  Personal Care Attendant

DDS Waivers (Department of Developmental Disabilities Waivers)
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
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
Medicaid Presentation
Medical homes
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:
- https://www.wadsworth.org/programs/newborn/screening
Identifying Challenge for Individual Community Providers (Working with CT American Academy of Pediatrics) regarding Rare Diseases?

- Survey? (ie. Lupus Survey)
- Ongoing medical education
- Timely access to subspecialty services for patients
- 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)
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)