

# Rare Action Network State Legislative Tracker

Spring 2017

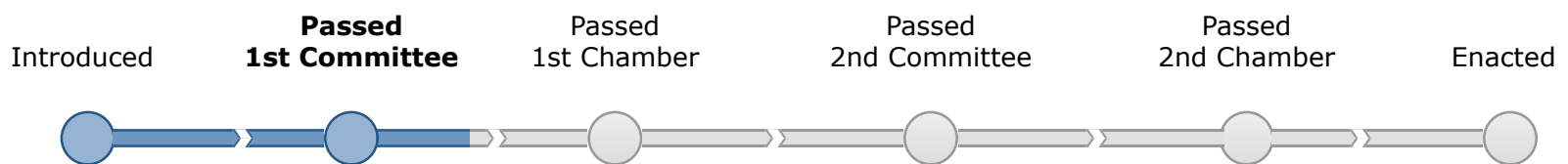
For more information, contact the NORD policy team at [action@rarediseases.org](mailto:action@rarediseases.org)



Join the conversation on Twitter by following @rareaction

## Alaska

### 1. AK S 32



**Title:** Biological Products

**Summary:** Relates to biological products; relates to the practice of pharmacy; relates to the Board of Pharmacy.

**NORD:** NORD supports. Actions: Submitted written testimony and constituent messages

**Disposition:** Pending

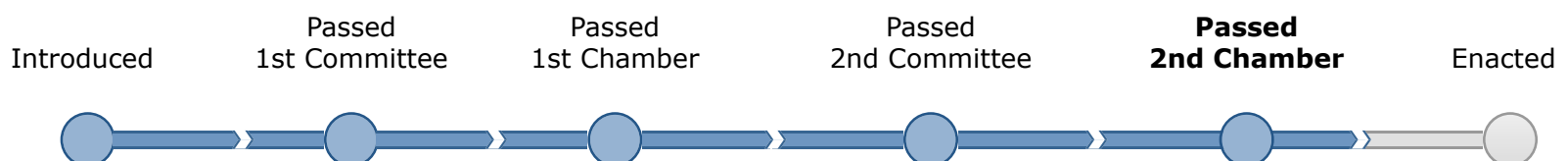
**Introduced:** 01/23/2017

**Author:** Hughes (R)

**Status:** 03/15/2017 From SENATE Committee on LABOR AND COMMERCE: Do pass. (5-0)  
03/15/2017 To SENATE Committee on FINANCE.

## Alabama

### 2. AL HJR 115



**Title:** Rare Disease Advisory Council

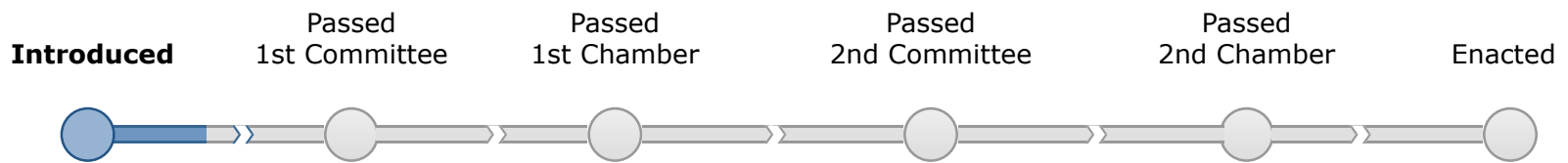
**Summary:** Establishes the Alabama rare disease advisory council.

**NORD:** NORD supports. Actions: Submitted written testimony and constituent messages. In-person legislative visits during Rare Disease Day.

**Disposition:** To Governor  
**Introduced:** 03/02/2017  
**Author:** Weaver (R)  
**Status:** 03/15/2017 From SENATE Committee on RULES: Reported favorably.  
03/15/2017 Passed SENATE.  
03/15/2017 Eligible for GOVERNOR'S desk.  
03/15/2017 \*\*\*\*\*To GOVERNOR.

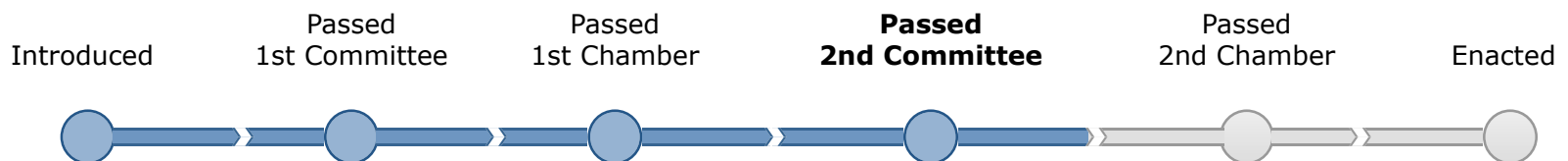
## Arkansas

### 3. AR H 1204



**Title:** Biological Product Substitutions by Pharmacists  
**Summary:** Allows pharmacists to make biological product substitutions; relates to pharmacy records, electronically accessible pharmacy records and pharmacy benefit management systems; requires a label showing the trade name or the proper name of the biological product.  
**NORD:** NORD Supports  
**Disposition:** Pending  
**Introduced:** 01/18/2017  
**Author:** Magie (D)  
**Status:** 03/23/2017 WITHDRAWN by Author.

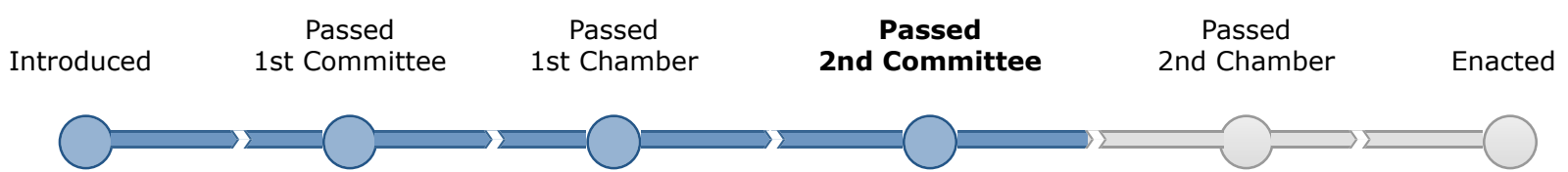
### 4. AR H 1900



**Title:** Health Insurance Coverage  
**Summary:** Amends the requirements for health insurance coverage for medically necessary foods used in the treatment of inborn errors of metabolism.  
**Disposition:** Pending  
**Introduced:** 03/03/2017  
**Author:** Bentley (R)  
**Status:** 03/28/2017 From SENATE Committee on INSURANCE AND COMMERCE: Do pass as amended.

## Arizona

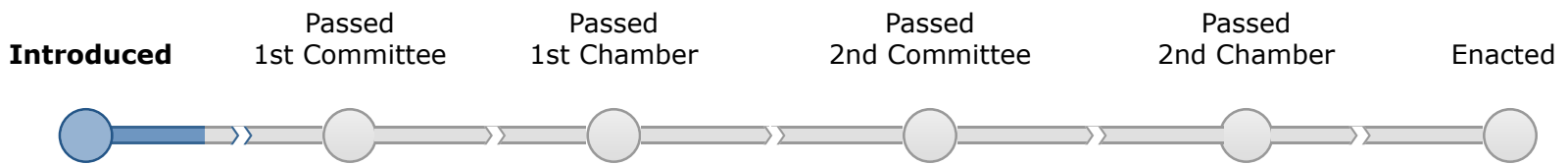
### 5. AZ S 1368



**Title:** Newborn Screening and Fees  
**Summary:** Relates to newborn screening; relates to fees.  
**NORD:** NORD Supports  
**Disposition:** Pending  
**Introduced:** 01/26/2017  
**Author:** Allen (R)  
**Status:** 03/09/2017 From HOUSE Committee on HEALTH: Do pass. (9-0)

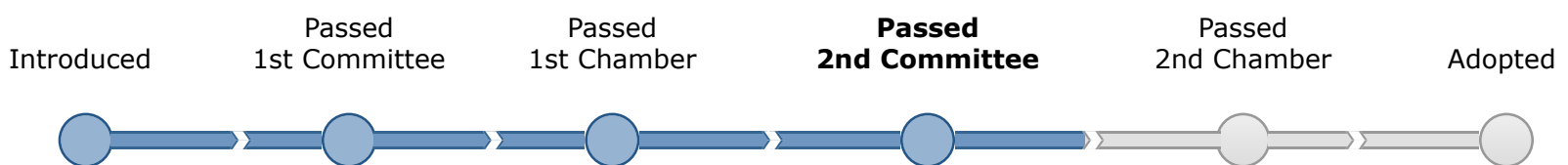
**California**

**6. CA A 1353**



**Title:** Health Care Coverage: Prescription Drugs: Continuity  
**Summary:** Requires a health care service plan and health insurer that provides coverage for outpatient prescription drugs to establish an expeditious process by which enrollees and insureds or prescribing providers may obtain an exception to any prior authorization process or any other utilization management or medical management practices. Requires coverage for certain medically necessary nonformulary drugs.  
**NORD:** NORD Supports  
**Disposition:** Pending  
**Introduced:** 02/17/2017  
**Author:** Waldron (R)  
**Status:** 03/23/2017 From ASSEMBLY Committee on HEALTH with author's amendments.  
 03/23/2017 In ASSEMBLY. Read second time and amended. Re-referred to Committee on HEALTH.

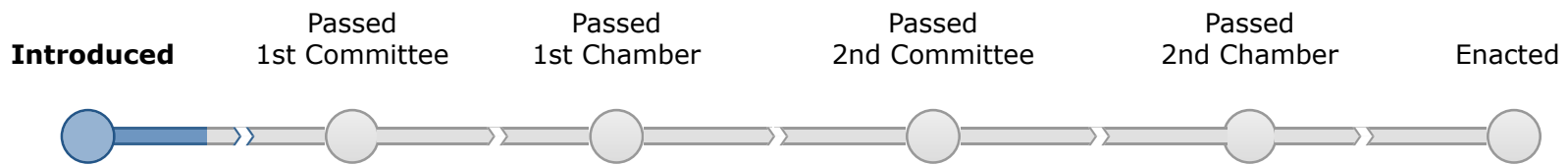
**7. CA ACR 14**



**Title:** Rare Disease Day  
**Summary:** Proclaims February 28, 2017, as Rare Disease Day in California and provides for the recognition of Rare Disease Day in subsequent years.

**Disposition:** Pending  
**Introduced:** 01/23/2017  
**Author:** Nazarian (D)  
**Status:** 03/28/2017 In SENATE. Ordered to SENATE SPECIAL CONSENT CALENDAR.

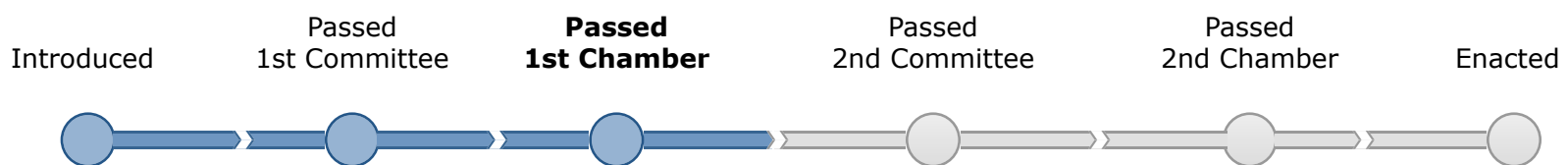
## 8. CA S 643



**Title:** Duchenne Muscular Dystrophy  
**Summary:** Adds Duchenne muscular dystrophy to the list of medical conditions eligible for the Holden-Mosccone-Garamendi Genetically Handicapped Persons Program.  
**NORD:** NORD Supports. Actions: Submitted written testimony to health committee and participating in coalition in support of the bill.  
**Disposition:** Pending  
**Introduced:** 02/17/2017  
**Author:** Pan (D)  
**Status:** 03/02/2017 To SENATE Committee on HEALTH.

## Colorado

## 9. CO S 203



**Title:** Prohibit Carrier From Requiring Alternative Drug  
**Summary:** Concerns the prohibition against a carrier requiring a covered person to undergo step therapy when the covered person has already tried a step-therapy required drug.  
**NORD:** NORD Supports. Actions: Submitted written testimony.  
**Disposition:** Pending  
**Introduced:** 02/28/2017  
**Sponsor:** Todd (D)  
**Status:** 03/23/2017 To HOUSE Committee on HEALTH, INSURANCE, & ENVIRONMENT.

## Connecticut

## 10. CT H 6009





**Title:** Rare Disease Advisory Council

**Summary:** Establishes a rare disease advisory council; makes recommendations on legislation concerning the rare disease community.

**NORD:** NORD supports. Actions: Submitted written testimony and constituent messages. In-person legislative visits during Rare Disease Day.

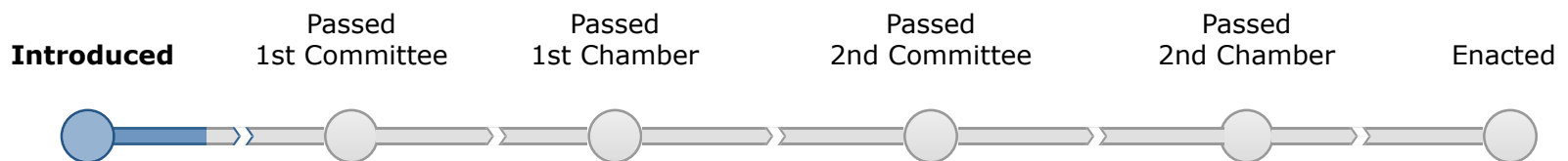
**Disposition:** Pending

**Introduced:** 01/19/2017

**Introducer:** Rose (D)

**Status:** 02/17/2017 Public Hearing Scheduled 0222.

## 11. CT H 6622



**Title:** Changes to Health Insurer Prescription Drug Formularies

**Summary:** Limits changes to health insurers' prescription drug formularies; limits when health insurance policies may change prescription drug formularies during a policy term.

**NORD:** NORD Supports

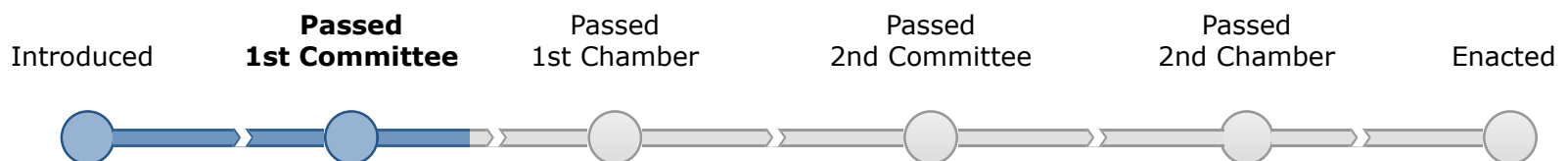
**Disposition:** Failed

**Introduced:** 01/24/2017

**Introducer:** Cook (D)

**Status:** 03/16/2017 Failed Joint Favorable deadline.

## 12. CT H 7118



**Title:** Biological Products

**Summary:** Concerns biological products; adds biological products to existing law regarding substitution of generic drugs.

**NORD:** NORD supports. Actions: Submitted written testimony and constituent messages. In-person legislative visits during Rare Disease Day.

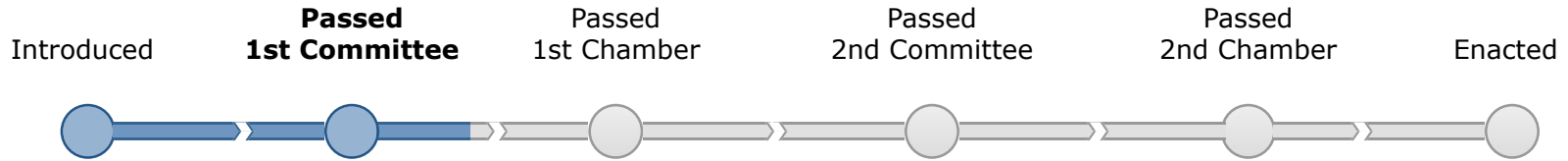
**Disposition:** Pending

**Introduced:** 02/22/2017

**Introducer:** Joint Committee on General Law

**Status:** 03/23/2017 Committee Substitute reported out of Legislative Commissioner's Office.  
03/23/2017 HOUSE Calendar No. 158.  
03/23/2017 Reissued by Legislative Commissioner's Office with File No. 189.

### 13. CT S 22



**Title:** Cost Sharing for Prescription Drugs

**Summary:** Concerns cost-sharing for prescription drugs; assists citizens with prescription drug costs; imposes a coinsurance, copayment, deductible or other out-of-pocket expense that exceeds a specified sum for a covered prescription drug.

**NORD:** NORD Supports this legislation.

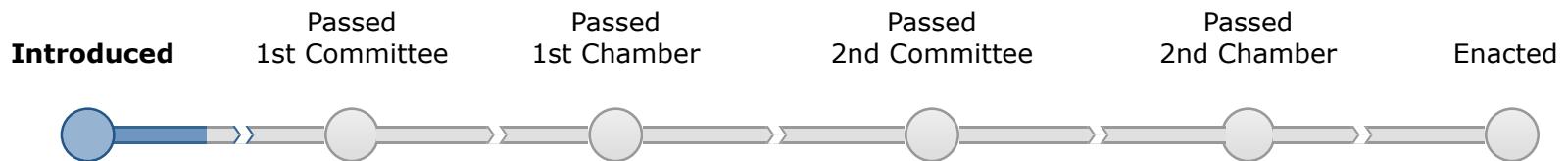
**Disposition:** Failed

**Introduced:** 01/09/2017

**Introducer:** Looney (D)

**Status:** 03/16/2017 Failed Joint Favorable deadline.

### 14. CT S 545



**Title:** Step Therapy Drug Regimens for Cancer Patients

**Summary:** Concerns a study of requests by health care providers to override step therapy drug regimens for certain cancer patients; requires a study and report on the processes that insurance companies, hospital service corporations, medical service corporations, health care centers and other entities that use step therapy for prescription drugs employ in assessing requests made by treating health care providers to override the use of step therapy drug regimens for insureds diagnosed with metastatic cancer.

**Disposition:** Failed

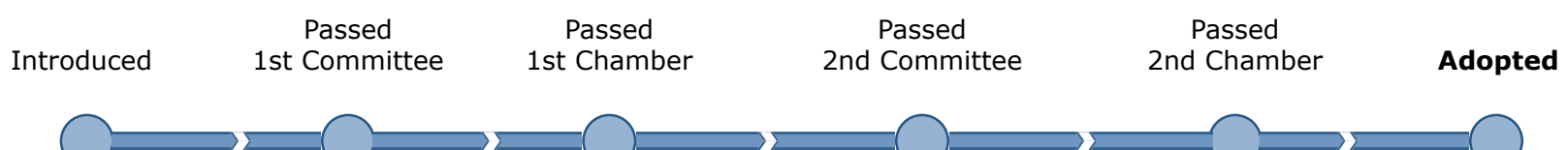
**Introduced:** 01/23/2017

**Introducer:** Kennedy (D)

**Status:** 03/16/2017 Failed Joint Favorable deadline.

## Delaware

### 15. DE HCR 13



**Title:** Rare Disease Day Resolution

**Summary:** Recognizes March 22, 2017, as "Rare Disease Day" in Delaware.

**Disposition:** Adopted

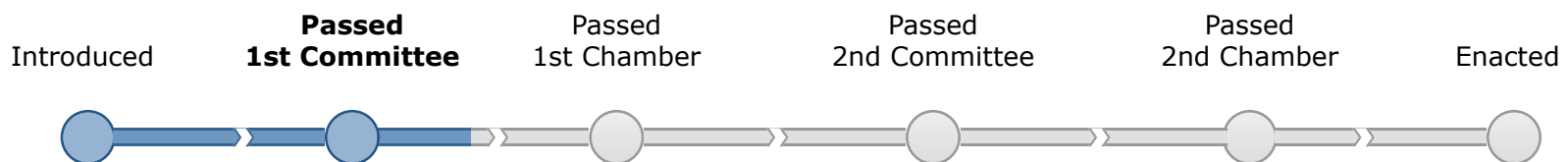
**Introduced:** 03/22/2017

**Primary Sponsor:** Baumbach (D)

**Status:** 03/22/2017 INTRODUCED.  
03/22/2017 Passed HOUSE. \*\*\*\*\*To SENATE.  
03/22/2017 Passed SENATE. (19-0)

## Florida

### 16. FL H 95



**Title:** Nonmedical Changes To Prescription Drug Formularies

**Summary:** Relates to consumer protection from nonmedical changes to prescription drug formularies; limits changes to prescription drug formularies during health insurance policy or HMO contract year; provides applicability; exempts state group insurance program; requires small employer carriers to limit changes to prescription drug formularies under certain circumstances; changes to a health maintenance contract prescription drug formulary during a contracted year.

**NORD:** NORD supports this legislation.

**Disposition:** Pending

**Introduced:** 03/07/2017

**Author:** Massullo (R)

**Status:** 03/07/2017 INTRODUCED.  
03/07/2017 To HOUSE HEALTH INNOVATION SUBCOMMITTEE.  
03/07/2017 Referred to HOUSE INSURANCE AND BANKING SUBCOMMITTEE.  
03/07/2017 Referred to HOUSE Committee on APPROPRIATIONS.  
03/07/2017 Referred to HOUSE HEALTH AND HUMAN SERVICES.  
03/07/2017 In HOUSE. On Committee agenda 02/22/17.  
03/07/2017 From HOUSE HEALTH INNOVATION SUBCOMMITTEE: Reported favorably with substitute.  
03/07/2017 In HOUSE. Pending review of Committee Substitute under Rule 7.18(c).  
03/07/2017 Withdrawn from HOUSE Committee on APPROPRIATIONS.  
03/07/2017 Referred to HOUSE Committee on HEALTH AND HUMAN SERVICES.  
03/07/2017 To HOUSE INSURANCE AND BANKING SUBCOMMITTEE.

### 17. FL H 787



**Title:** Health Insurance Coverage for Enteral Formulas

**Summary:** Relates to health insurance coverage for enteral formulas.

**NORD:** NORD supports this legislation.

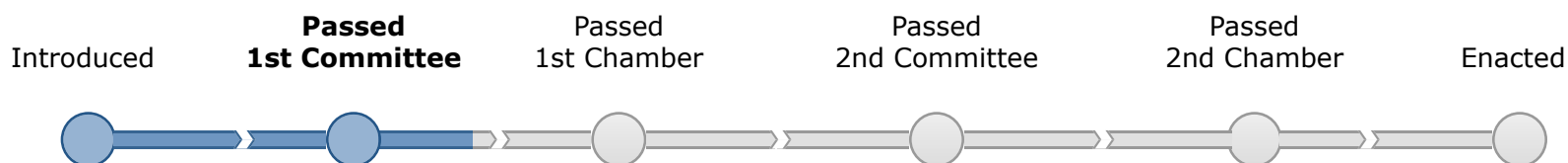
**Disposition:** Pending

**Introduced:** 03/07/2017

**Author:** Slosberg E (D)

**Status:** 03/07/2017 INTRODUCED.  
03/07/2017 To HOUSE HEALTH INNOVATION SUBCOMMITTEE.  
03/07/2017 Referred to HOUSE Committee on APPROPRIATIONS.  
03/07/2017 Referred to HOUSE HEALTH AND HUMAN SERVICES.

## 18. FL H 963



**Title:** Newborn Screenings

**Summary:** Relates to newborn screenings; requires the Department of Health, upon the advice of the Genetics and Newborn Screening Advisory Council, to expand within a specified period the statewide screening of newborns to include any condition on the federal Recommended Uniform Screening Panel; requires the council to determine whether a condition should be included in the state's screening program within a specified period after its addition to the federal panel.

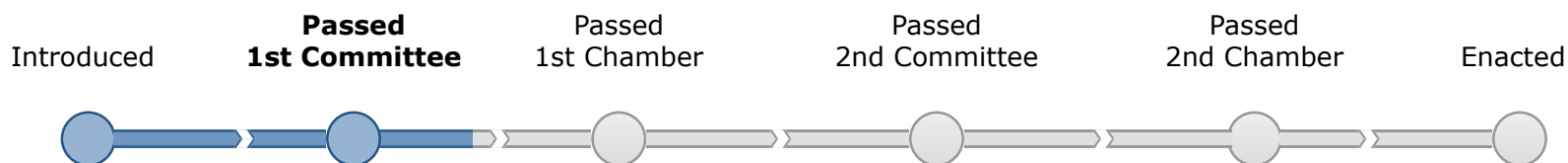
**Disposition:** Pending

**Introduced:** 03/07/2017

**Author:** Fitzenhagen (R)

**Status:** 03/23/2017 To HOUSE HEALTH CARE APPROPRIATIONS SUBCOMMITTEE.

## 19. FL S 182



**Title:** Prescription Drug Formularies

**Summary:** Relates to consumer protection from nonmedical changes to prescription drug formularies; limits changes to a health insurance policy prescription drug formulary during a policy year; requires small employer carriers to provide continuity of care for certain patients with respect to prescription drug coverage; limits changes to a health maintenance contract prescription drug formulary during a contract year.

**NORD:** NORD supports this legislation. Actions: Submitted written testimony.



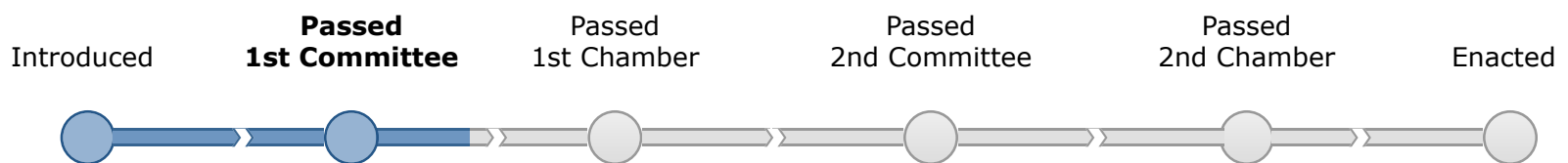
**Disposition:** Pending

**Introduced:** 03/07/2017

**Author:** Mayfield D (R)

**Status:** 03/07/2017 INTRODUCED.  
 03/07/2017 To SENATE Committee on BANKING AND INSURANCE.  
 03/07/2017 Referred to SENATE Committee on HEALTH POLICY.  
 03/07/2017 Referred to SENATE Committee on RULES.  
 03/07/2017 In SENATE. On Committee agenda 02/07/17.  
 03/07/2017 From SENATE Committee on BANKING AND INSURANCE: Reported favorably with substitute.  
 03/07/2017 In SENATE. Pending reference review under Rule 4.7(2).  
 03/07/2017 To SENATE Committee on HEALTH POLICY.  
 03/07/2017 Referred to SENATE Committee on APPROPRIATIONS.  
 03/07/2017 Referred to SENATE Committee on RULES.  
 03/07/2017 To SENATE Committee on HEALTH POLICY.  
 03/07/2017 In SENATE. On Committee agenda 02/21/17.  
 03/07/2017 From SENATE Committee on HEALTH POLICY: Reported favorably with substitute.  
 03/07/2017 In SENATE. Pending reference review under Rule 4.7(2).  
 03/07/2017 To SENATE Committee on APPROPRIATIONS.

## 20. FL S 1124



**Title:** Newborn Screenings

**Summary:** Relates to newborn screenings; requires the Department of Health, upon the advice of the Genetics and Newborn Screening Advisory Council, to expand within a specified period the statewide screening of newborns to include any condition on the federal Recommended Uniform Screening Panel.

**NORD:** NORD supports this legislation. Actions: Submitted written testimony.

**Disposition:** Pending

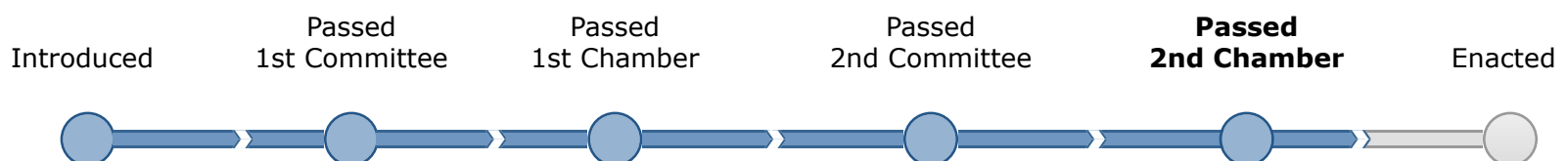
**Introduced:** 03/07/2017

**Author:** Book (D)

**Status:** 03/28/2017 In SENATE. Pending reference review under Rule 4.7(2).

## Georgia

## 21. GA H 241



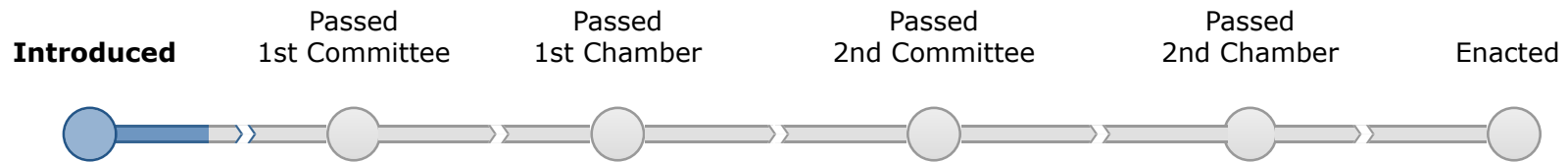
**Title:** Krabbe Disease

**Summary:** Relates to control of hazardous conditions; add Krabbe disease to the list of metabolic and

genetic conditions for which newborn screening may be conducted pursuant to the Department of Public Health; provides for the screening at the option of the parent or parents; provides for payment of fees directly to the laboratory; provides for a short title; provides for related matters; repeals conflicting laws.

**NORD:** NORD supports this legislation  
**Disposition:** To Governor  
**Introduced:** 02/02/2017  
**Author:** Hawkins (R)  
**Status:** 03/24/2017 In SENATE. Read third time. Passed SENATE. (54-0)  
03/24/2017 Eligible for GOVERNOR'S desk.

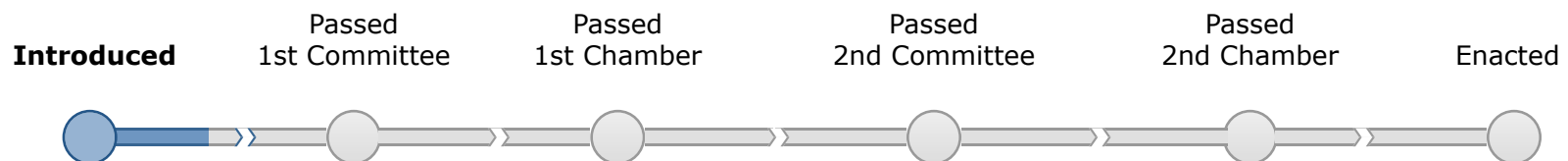
## 22. GA H 519



**Title:** Health Benefit Insurance Provisions  
**Summary:** Relates to insurance generally, so as to require health benefit plans to utilize certain clinical review criteria to establish step therapy protocols; provides for a step therapy override determination process; provides for definitions; provides for statutory construction; provides for rules and regulations; provides for applicability; provides for related matters; repeals conflicting laws.  
**Disposition:** Pending  
**Introduced:** 02/28/2017  
**Author:** Cooper (R)  
**Status:** 03/03/2017 In HOUSE: Read 2nd time.

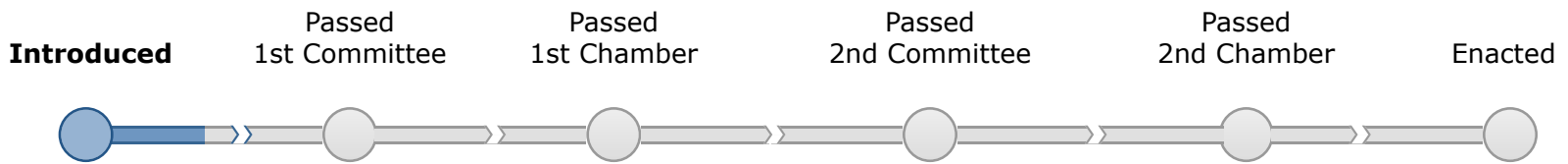
## Hawaii

## 23. HI H 1289



**Title:** Health Insurance  
**Summary:** Establishes requirements for step therapy protocols to ensure patient access to the particular prescription drugs prescribed by health care providers; establishes insurance coverage requirements and standards for appeal of coverage determinations.  
**Disposition:** Pending  
**Introduced:** 01/24/2017  
**Author:** Belatti (D)  
**Status:** 03/09/2017 Failed First Crossover Deadline - First Year of Biennium.

## 24. HI H 1525



**Title:** Prospective Review

**Summary:** Specifies procedural, disclosure, notice, and other requirements for prospective reviews required by health carriers or utilization review organizations prior to certification of coverage for health care services.

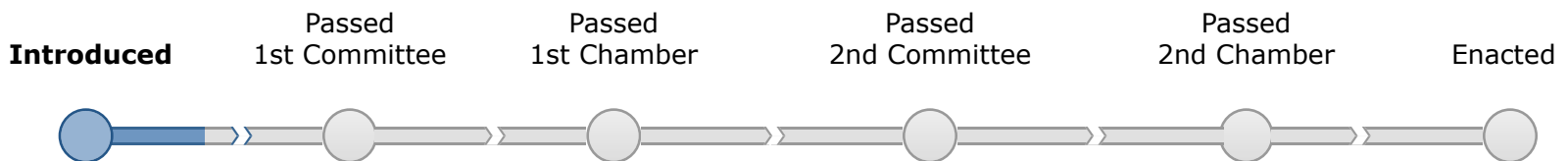
**Disposition:** Pending

**Introduced:** 01/25/2017

**Author:** McKelvey (D)

**Status:** 03/09/2017 Failed First Crossover Deadline - First Year of Biennium.

## 25. HI S 727



**Title:** Rare Disease Advisory Board

**Summary:** Establishes the rare disease advisory board within the Department of Health to provide education about rare diseases and encourage the funding of research in the development of new treatments for rare diseases; describes duties of the advisory board, members of the board, and the board's obligation to coordinate with local and national groups conducting similar research and advocacy for persons with rare diseases.

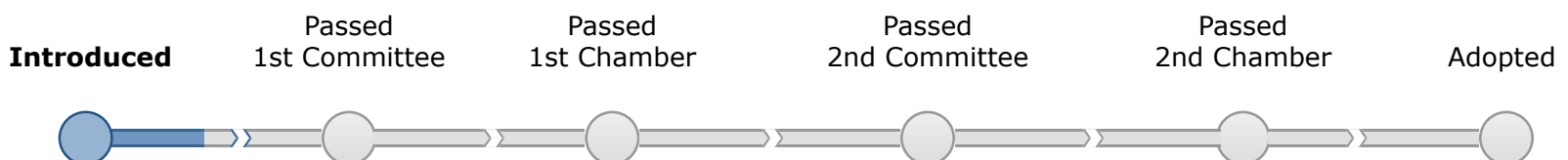
**Disposition:** Pending

**Introduced:** 01/20/2017

**Author:** Green (D)

**Status:** 03/09/2017 Failed First Crossover Deadline - First Year of Biennium.

## 26. HI SCR 37



**Title:** Rare Disease Task Force

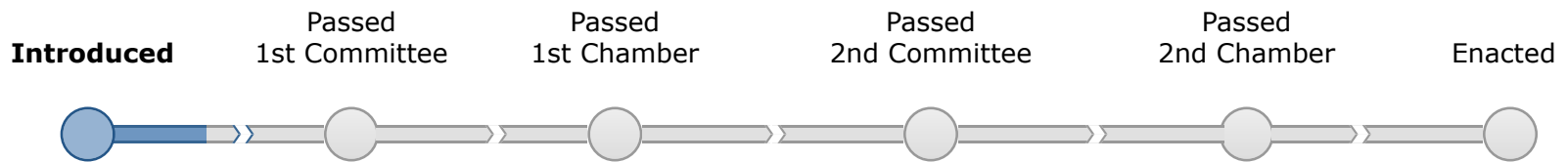
**Summary:** Urges the establishment of a rare disease task force.

**Disposition:** Pending

**Introduced:** 01/24/2017  
**Author:** Green (D)  
**Status:** 03/15/2017 In Committee: Measure Deferred.

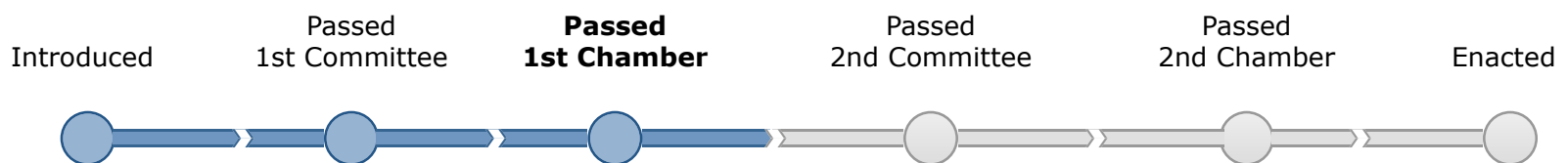
## Iowa

### 27. IA H 31



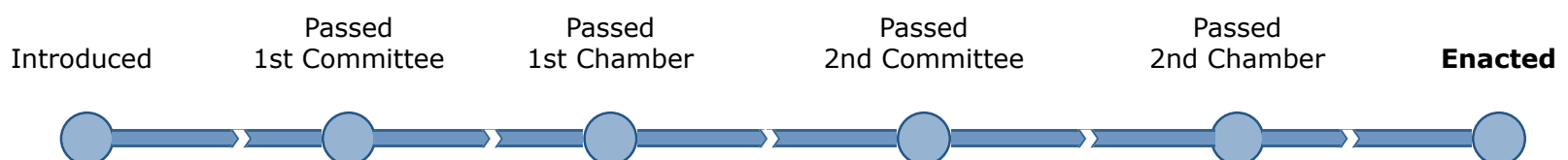
**Title:** Storing of Residual Newborn Screening Specimens  
**Summary:** Relates to the storing of residual newborn screening specimens; includes effective date provisions.  
**Disposition:** Pending  
**Introduced:** 01/18/2017  
**Author:** Jones (R)  
**Status:** 01/24/2017 In HOUSE Committee on HUMAN RESOURCES: Subcommittee assignments: R. Taylor, Chair, Bergan, Mascher.

### 28. IA H 233



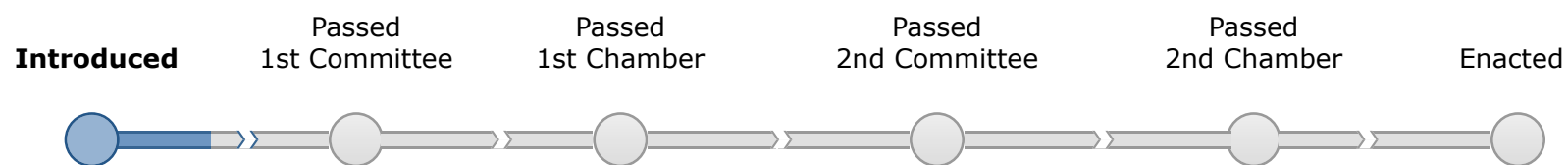
**Title:** Step Therapy Protocols  
**Summary:** Relates to the use of step therapy protocols for prescription drugs by health carriers, health benefit plans, and utilization review organizations; includes applicability provisions.  
**Disposition:** Pending  
**Introduced:** 02/06/2017  
**Author:** House Human Resources Committee  
**Status:** 03/27/2017 In HOUSE. Filed Amendment No. H-1239.  
03/27/2017 In HOUSE. Adopted Amendment Nos. H-1239, H-1235.  
03/27/2017 Passed HOUSE. \*\*\*\*\*To SENATE. (98-0)

### 29. IA H 305



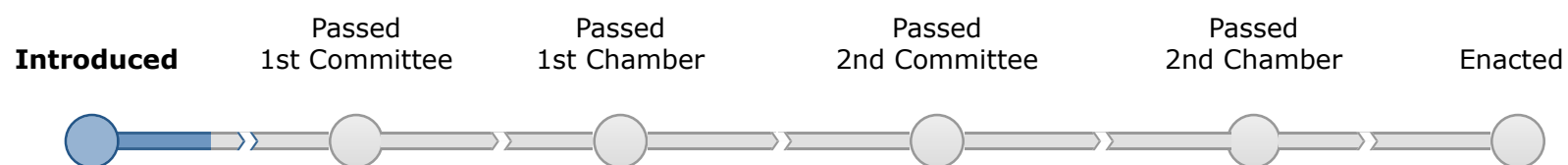
**Title:** Prescribing of Biological Products  
**Summary:** Relates to the prescribing of biological products; makes penalties applicable.  
**Disposition:** Enacted  
**Introduced:** 02/14/2017  
**Author:** House Human Resources Committee  
**Status:** 03/10/2017 Signed by GOVERNOR.

### 30. IA HSB 26



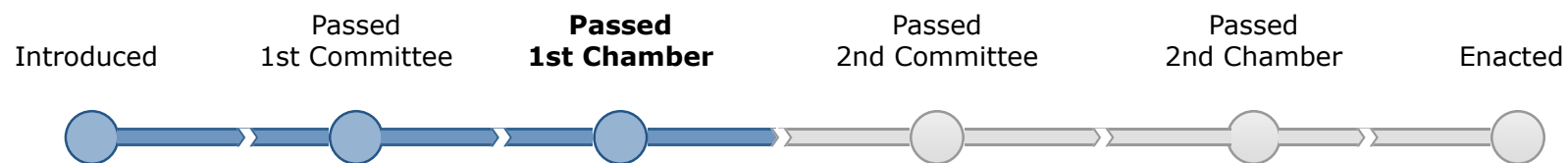
**Title:** Step Therapy Protocols for Prescription Drugs  
**Summary:** Relates to the use of step therapy protocols for prescription drugs by health carriers, health benefit plans, and utilization review organizations; includes applicability provisions.  
**NORD:** NORD supports this legislation. Actions: Submitted written testimony.  
**Disposition:** Pending  
**Introduced:** 01/23/2017  
**Author:** House Human Resources Committee  
**Status:** 02/06/2017 In HOUSE. Becomes HOUSE File 233.

### 31. IA HSB 38



**Title:** Prescribing of Biological Products  
**Summary:** Relates to the prescribing of biological products; makes penalties applicable.  
**Disposition:** Pending  
**Introduced:** 01/24/2017  
**Author:** House Human Resources Committee  
**Status:** 02/14/2017 In HOUSE. Becomes HOUSE File 305.

### 32. IA S 51



**Title:** Testing of Newborns

**Summary:** Relates to a cytomegalovirus public health initiative and the testing of newborns for congenital cytomegalovirus.

**NORD:** NORD supports this legislation

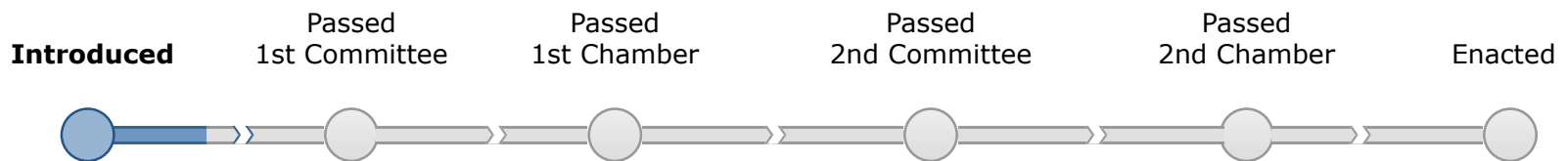
**Disposition:** Pending

**Introduced:** 01/11/2017

**Author:** Zaun (R)

**Status:** 03/27/2017 In HOUSE Committee on COMMERCE: Subcommittee assignments: Cownie, Chair, Best, Forbes.

### 33. IA S 326



**Title:** Prescribing of Biological Products

**Summary:** Relates to the prescribing of biological products; makes penalties applicable.

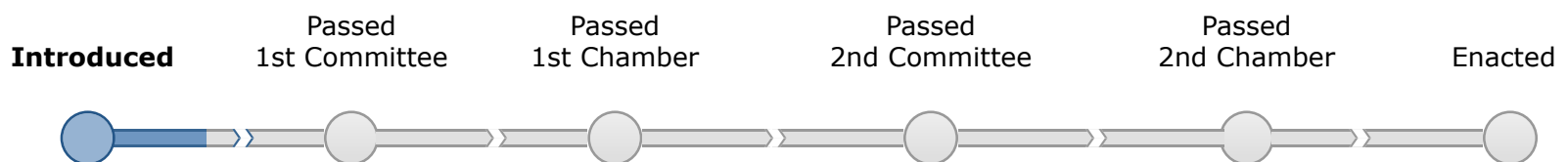
**Disposition:** Failed

**Introduced:** 02/22/2017

**Author:** Senate Human Resources Committee

**Status:** 03/01/2017 Withdrawn from further consideration.

### 34. IA S 436



**Title:** Step Therapy Protocols for Prescription Drugs

**Summary:** Relates to the use of step therapy protocols for prescription drugs by health carriers, health benefit plans, and utilization review organizations; includes applicability provisions.

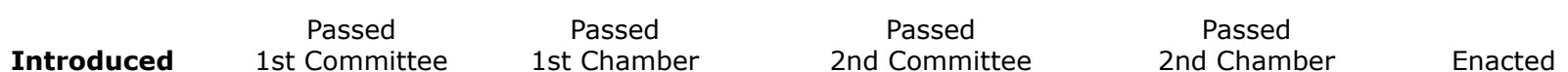
**Disposition:** Pending

**Introduced:** 03/03/2017

**Author:** Senate Human Resources Committee

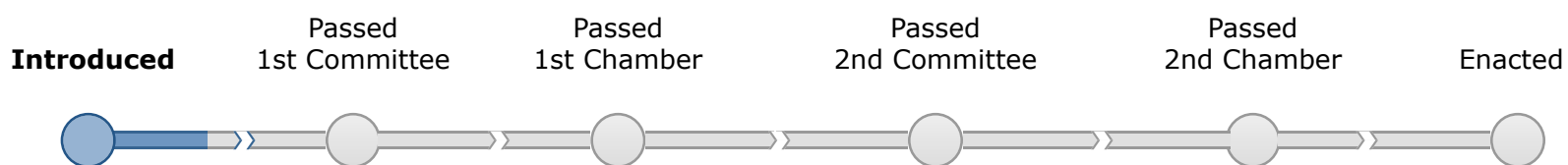
**Status:** 03/03/2017 INTRODUCED.

### 35. IA SSB 1029



**Title:** Biological Products  
**Summary:** Relates to the prescribing of biological products; makes penalties applicable.  
**Disposition:** Pending  
**Introduced:** 01/27/2017  
**Author:** Senate Human Resources Committee  
**Status:** 02/22/2017 In SENATE. Becomes SENATE File 362.

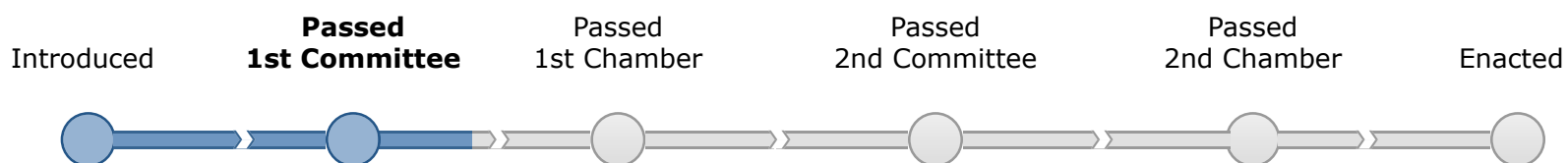
## 36. IA SSB 1072



**Title:** Step Therapy Protocols  
**Summary:** Relates to the use of step therapy protocols for prescription drugs by health carriers, health benefit plans, and utilization review organizations; including applicability provisions.  
**Disposition:** Pending  
**Introduced:** 02/08/2017  
**Author:** Senate Human Resources Committee  
**Status:** 02/21/2017 In SENATE Committee on HUMAN RESOURCES: Passed subcommittee.

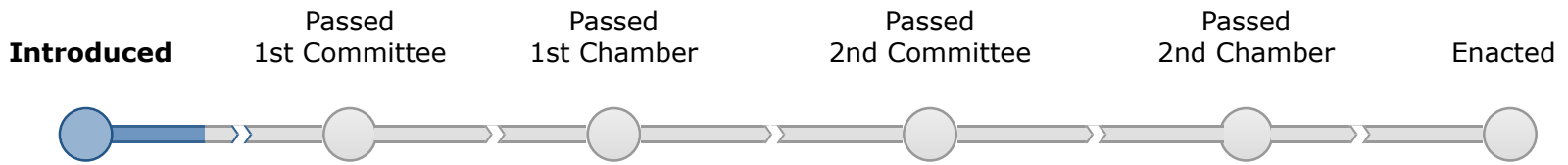
## Illinois

## 37. IL H 311



**Title:** Network Adequacy and Transparency  
**Summary:** Creates the Network Adequacy and Transparency Act; provides that administrators and insurers, prior to going to market, must file with the Department of Insurance for review and approval a description of the services to be offered through a network plan, with certain criteria included in the description; provides that the network plan shall demonstrate to the Department, prior to approval, a minimum ratio of full-time equivalent providers to plan beneficiaries and maximum travel and distance standards.  
**NORD:** NORD supports this legislation. Actions: Submitted written testimony  
**Disposition:** Pending  
**Introduced:** 01/11/2017  
**Sponsor:** Halbrook (R)  
**Status:** 03/15/2017 In HOUSE. Placed on Short Debate Calendar Second Reading.

## 38. IL H 2694



**Title:** Managed Care Reform and Patient Rights

**Summary:** Amends the Managed Care Reform and Patient Rights Act; in provisions concerning transition of services, provides that the health care plan shall not modify an enrollee's coverage of a drug during the plan year if the drug has been previously approved for coverage by the plan for a medical condition, the plan's prescribing provider continues to prescribe the drug for the medical condition, and the patient continues to be an enrollee of the health care plan.

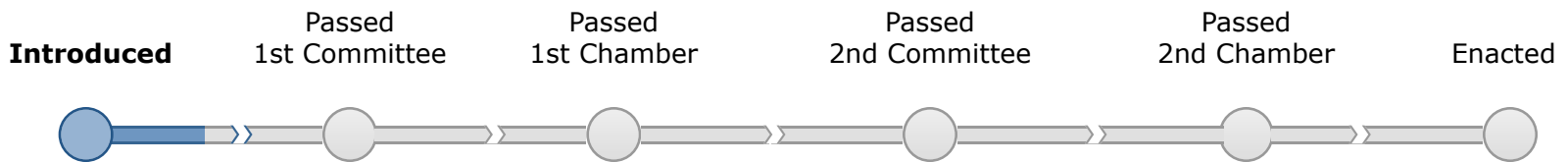
**Disposition:** Pending

**Introduced:** 02/08/2017

**Sponsor:** Williams A (D)

**Status:** 02/22/2017 To HOUSE Committee on HUMAN SERVICES.

## 39. IL S 70



**Title:** Network Adequacy and Transparency

**Summary:** Creates the Network Adequacy and Transparency Act; provides that administrators and insurers, prior to going to market, must file with the Department of Insurance for review and approval a description of the services to be offered through a network plan, with certain criteria included in the description; provides that the network plan shall demonstrate to the Department, prior to approval, a minimum ratio of full-time equivalent providers to plan beneficiaries and maximum travel and distance standards.

**Disposition:** Pending

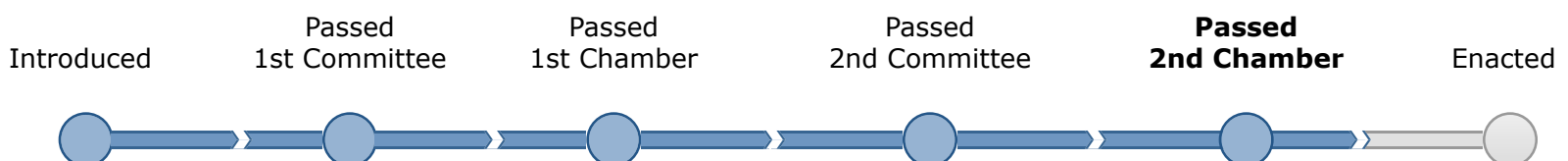
**Introduced:** 01/11/2017

**Sponsor:** Bush (D)

**Status:** 03/17/2017 In SENATE. Rule 2-10 Committee/3rd Reading Deadline Established As April 7, 2017.

## Indiana

## 40. IN S 73





**Title:** Electronic Authorization for Prescription Drugs

**Summary:** Relates to electronic authorization for prescription drugs; requires certain health plans to accept and respond to electronic prior authorization requests according to a particular electronic transaction standard.

**NORD:** NORD Supports this legislation.

**Disposition:** Pending

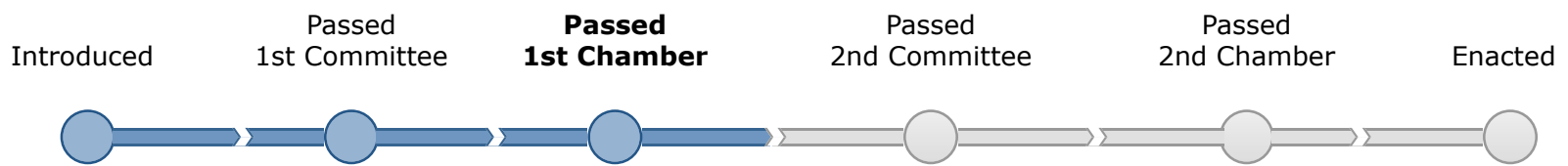
**Introduced:** 01/03/2017

**Author:** Grooms (R)

**Status:** 03/21/2017 Passed HOUSE. \*\*\*\*\*To SENATE for concurrence. (94-2)

## Kansas

### 41. KS H 2107



**Title:** Biological Product Inclusion and the Pharmacy Act

**Summary:** Relates to inclusion of biological products in the pharmacy act of the state of Kansas.

**NORD:** NORD supports. Actions: Submitted written testimony and constituent messages. In-person legislative visits during Rare Disease Day.

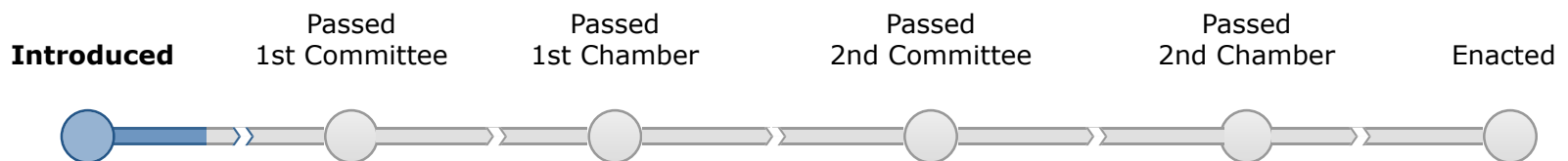
**Disposition:** Pending

**Introduced:** 01/19/2017

**Author:** House Health and Human Services Committee

**Status:** 03/08/2017 Senate Hearing: Thursday, March 16, 2017, 09:30 AM Room 118-N.

### 42. KS H 2151



**Title:** Health Insurance Use of Step Therapy Protocols

**Summary:** Establishes restrictions on health insurance use of step therapy protocols.

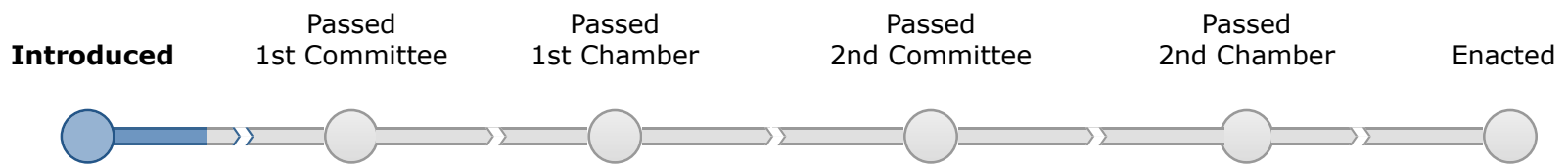
**Disposition:** Pending

**Introduced:** 01/25/2017

**Author:** House Health and Human Services Committee

**Status:** 01/26/2017 To HOUSE Committee on HEALTH AND HUMAN SERVICES.

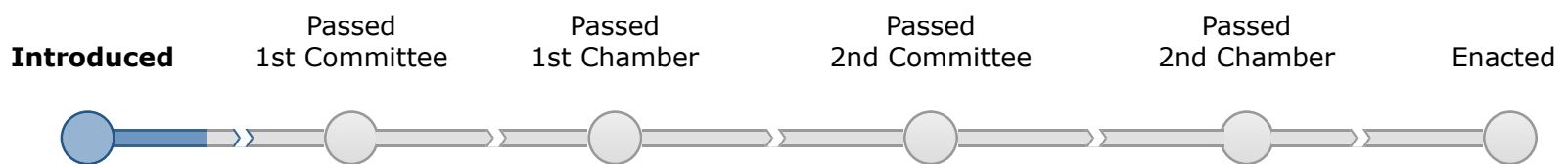
### 43. KS S 82



**Title:** Health Insurance Restrictions on Step Therapy Protocols  
**Summary:** Establishes restrictions on health insurance use of step therapy protocols.  
**NORD:** NORD supports. Actions: Submitted written testimony and constituent messages. In-person legislative visits during Rare Disease Day.  
**Disposition:** Pending  
**Introduced:** 01/25/2017  
**Author:** Senate Public Health and Welfare Committee  
**Status:** 02/08/2017 Senate Hearing: Monday, February 13, 2017, 09:30 AM Room 118-N.

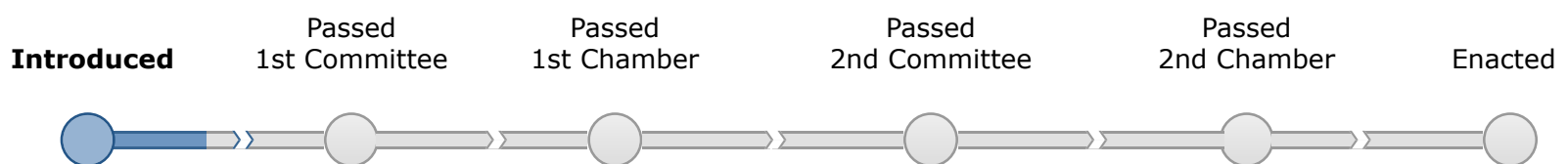
## Massachusetts

### 44. MA H 491



**DOCKET** 1498  
**Title:** Transparency and Access in Healthcare  
**Summary:** Relates to transparency and access in healthcare.  
**NORD:** NORD supports. Actions: Submitted written testimony and constituent messages. In-person legislative visits during Rare Disease Day.  
**Disposition:** Pending  
**Introduced:** 02/23/2017  
**Author:** Benson (D)  
**Status:** 02/27/2017 To JOINT Committee on FINANCIAL SERVICES. Dated 1/23/2017.

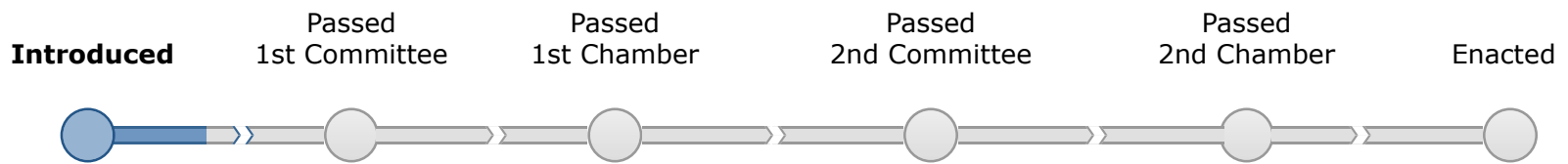
### 45. MA H 492



**DOCKET** 1503  
**Title:** Management of Medications  
**Summary:** Relates to management of medications.  
**Disposition:** Pending

**Introduced:** 02/23/2017  
**Author:** Benson (D)  
**Status:** 02/27/2017 To JOINT Committee on FINANCIAL SERVICES. Dated 1/23/2017.

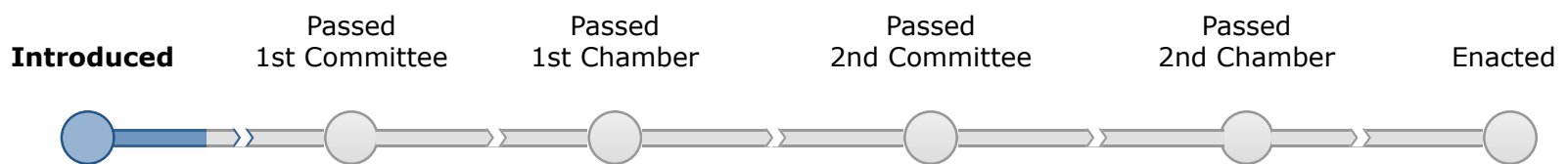
## 46. MA H 1171



**DOCKET** 1591  
**Title:** Rare Disease Advisory Council  
**Summary:** Establishes a rare disease advisory council.

**Disposition:** Pending  
**Introduced:** 01/23/2017  
**Author:** Heroux (D)  
**Status:** 02/27/2017 To JOINT Committee on PUBLIC HEALTH. Dated 1/23/2017.

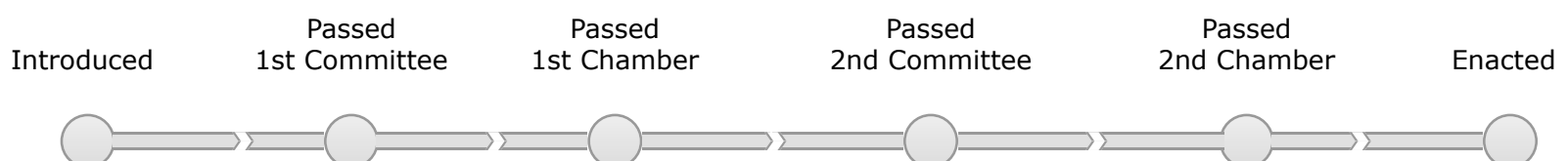
## 47. MA H 1650



**DOCKET** 330  
**Title:** Rare Disease Day Proclamation  
**Summary:** Relates to the annual issuance of a proclamation by the Governor designating the last day of February as Rare Disease Day.

**Disposition:** Pending  
**Introduced:** 02/24/2017  
**Author:** Ashe (D)  
**Status:** 02/27/2017 Filed as House Docket 330  
02/27/2017 To JOINT Committee on STATE ADMINISTRATION AND REGULATORY OVERSIGHT. Dated 1/23/2017.

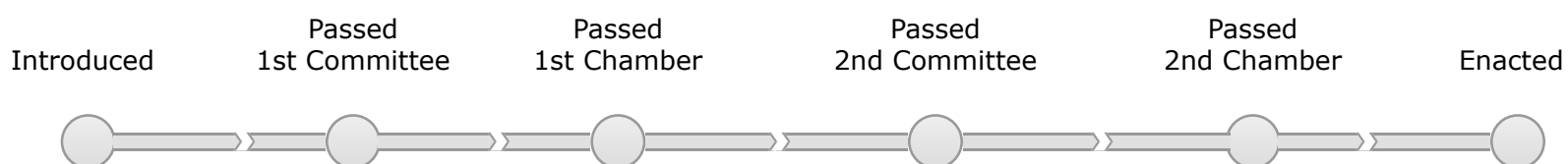
## 48. MA HD 390



**DOCKET** 1167

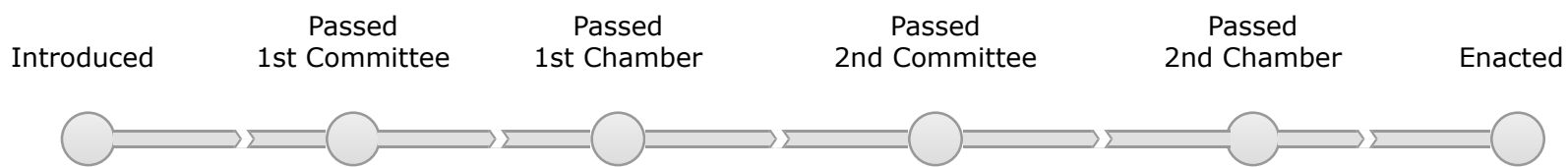
**Title:** Krabbe Disease in Newborn Screening  
**Summary:** Includes Krabbe Disease in newborn screening.  
**NORD:** NORD supports this legislation  
**Disposition:** Pending  
**Author:** Garry (D)  
**Status:** 02/24/2017 Assigned House Bill No. 1167

## 49. MA HD 1591



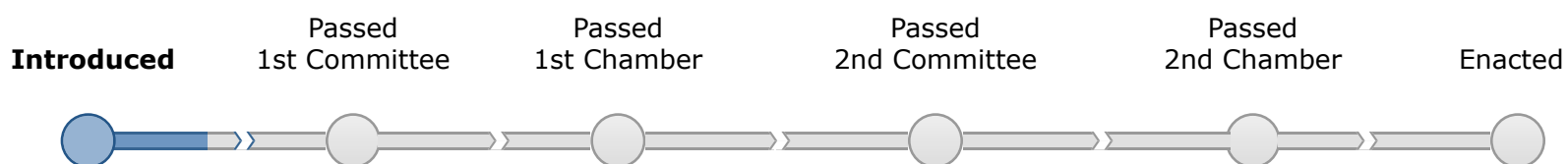
**DOCKET** 1171  
**Title:** Rare Disease Advisory Council  
**Summary:** Creates a Massachusetts Rare Disease Advisory Council.  
**Disposition:** Pending  
**Author:** Heroux (D)  
**Status:** 02/24/2017 Assigned House Bill No. 1171

## 50. MA HD 3712



**Title:** Rare Disease Advisory Council  
**Summary:** Creates a Massachusetts Rare Disease Advisory Council.  
**Disposition:** Pending  
**Author:** Heroux (D)  
**Status:** 01/25/2017 FILED.

## 51. MA S 516



**DOCKET** 1341  
**Title:** Prescription Drug Coverage

**Summary:** Relates to out-of-pocket expenses for prescription drug coverage.

**NORD:** NORD supports this legislation. Actions: submitted written testimony.

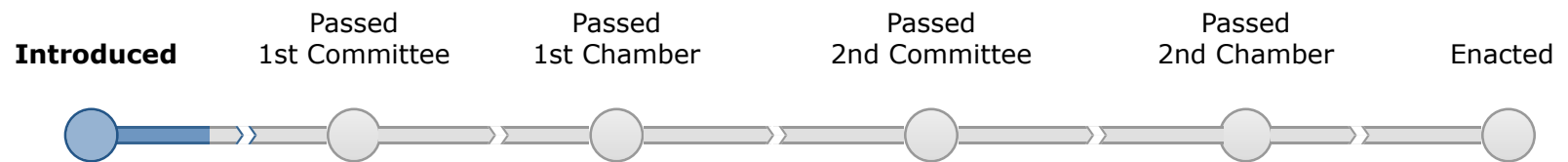
**Disposition:** Pending

**Introduced:** 02/22/2017

**Author:** DiDomenico (D)

**Status:** 02/27/2017 To JOINT Committee on FINANCIAL SERVICES. Dated 1/23/2017.

## 52. MA S 542



**DOCKET** 1029

**Title:** Prescription Drug Coverage Out of Pocket Expenses

**Summary:** Makes out-of-pocket expenses for prescription drug coverage more affordable.

**NORD:** NORD supports this legislation. Actions: Submitted written testimony.

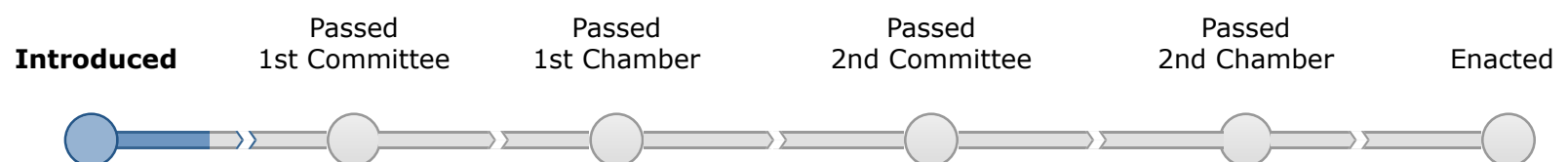
**Disposition:** Pending

**Introduced:** 02/22/2017

**Author:** Lesser (D)

**Status:** 02/27/2017 To JOINT Committee on FINANCIAL SERVICES. Dated 1/23/2017.

## 53. MA S 551



**DOCKET** 376

**Title:** Improved Medication Management

**Summary:** Reduces health care costs through improved medication management.

**NORD:** NORD supports. Actions: Submitted written testimony and constituent messages. In-person legislative visits during Rare Disease Day.

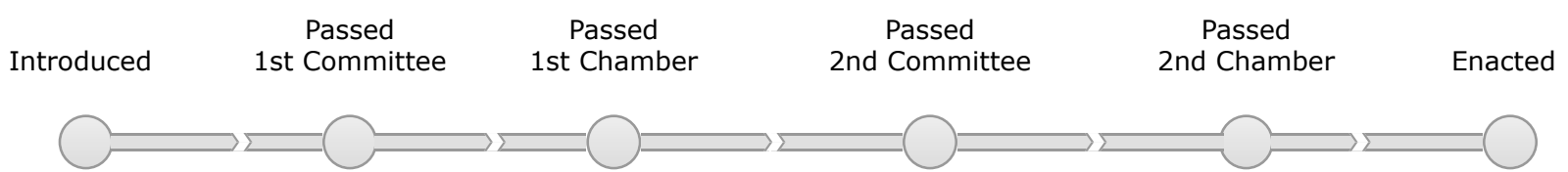
**Disposition:** Pending

**Introduced:** 02/22/2017

**Author:** L'Italien (D)

**Status:** 02/27/2017 To JOINT Committee on FINANCIAL SERVICES. Dated 1/23/2017.

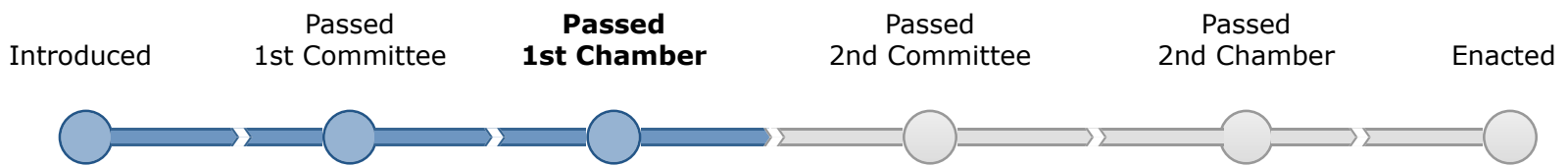
## 54. MA SD 1341



**DOCKET**                    516  
**Title:**                      Prescription Drug Coverage Out of Pocket Expenses  
**Summary:**                Concerns out of pocket expenses for prescription drug coverage.  
**Disposition:**            Pending  
**Author:**                    DiDomenico (D)  
**Status:**                    02/24/2017 Assigned Senate Bill No. 516

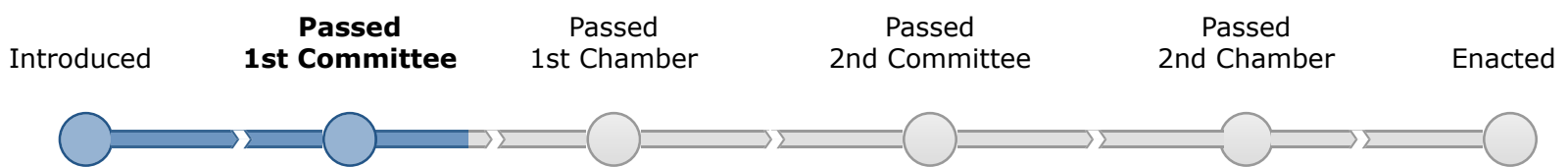
**Maryland**

55. **MD H 740**



**Title:**                      Cancer Treatment Access Act  
**Summary:**                Prohibits a specified insurer, nonprofit health service plan, or health maintenance organization from imposing a step therapy or fail-first protocol on an insured or an enrollee for a specified prescription drug used in the treatment of a specified cancer under specified circumstances.  
**Disposition:**            Pending  
**Introduced:**            02/02/2017  
**Author:**                    Angel (D)  
**Status:**                    03/16/2017 To SENATE Committee on FINANCE.  
                                   03/16/2017 Hearing Scheduled 3/30 at 1:00 p.m.

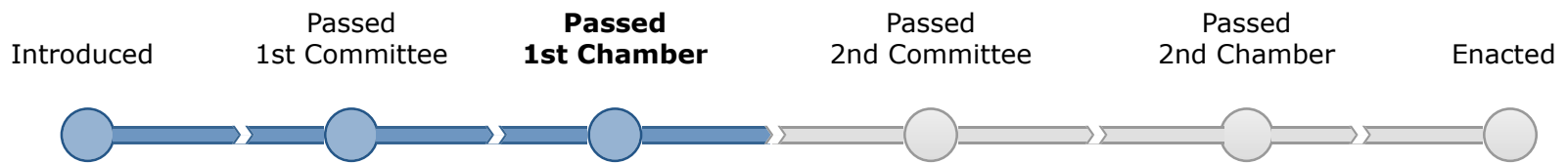
56. **MD H 1128**



**Title:**                      Prescription Drugs  
**Summary:**                Prohibits insurers, nonprofit health service plans, and health maintenance organizations from making specified formulary changes during a plan year and the open enrollment period that precedes the plan year; applies the Act to all policies, contracts, and health benefit plans issued, delivered, or renewed in the State on or after the specified date.  
**Disposition:**            Failed  
**Introduced:**            02/09/2017

**Author:** Kelly A (D)  
**Status:** 03/14/2017 From HOUSE Committee on HEALTH AND GOVERNMENT OPERATIONS:  
Reported unfavorably. (22-0)  
03/14/2017 Withdrawn from further consideration.

## 57. MD H 1273



**Title:** Pharmacists Substitution

**Summary:** Authorizes a pharmacist to substitute an interchangeable biological product for a prescribed product under specified circumstances; requires a pharmacist or the pharmacist's designee, except under specified circumstances, to inform specified consumers of the availability of an interchangeable biological product and the approximate cost difference as compared to a specified drug; requires the State Board of Pharmacy to maintain on its Web site a link to specified lists of biological products.

**NORD:** NORD supports this legislation.

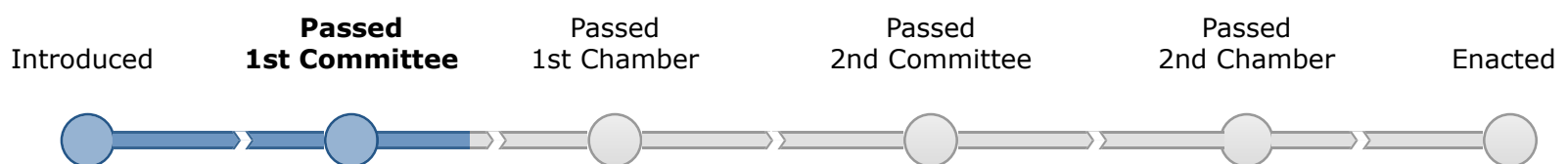
**Disposition:** Pending

**Introduced:** 02/10/2017

**Author:** Cullison (D)

**Status:** 03/20/2017 Passed HOUSE. \*\*\*\*\*To SENATE. (138-0)  
03/20/2017 To SENATE Committee on EDUCATION, HEALTH AND ENVIRONMENTAL AFFAIRS.

## 58. MD S 768



**Title:** Health Insurance

**Summary:** Prohibits insurers, nonprofit health service plans, and health maintenance organizations from making specified formulary changes during the plan year and the open enrollment period that precedes the plan year; applies the Act to all policies, contracts, and health benefit plans issued, delivered, or renewed in the State on or after October 1, 2017.

**Disposition:** Failed

**Introduced:** 02/03/2017

**Author:** Feldman (D)

**Status:** 03/13/2017 From SENATE Committee on FINANCE: Reported unfavorably. (11-0)  
03/13/2017 Withdrawn from further consideration.

## 59. MD S 997

Passed Passed Passed Passed

Introduced 1st Committee 1st Chamber 2nd Committee **2nd Chamber** Enacted



**Title:** Pharmacists Substitution

**Summary:** Authorizes a pharmacist to substitute an interchangeable biological product for the prescribed product under specified circumstances; requires a pharmacist or the pharmacist's designee, except under specified circumstances, to inform specified consumers of the availability of an interchangeable biological product and the approximate cost difference as compared to a specified drug; requires the State Board of Pharmacy to maintain on its Web site a link to a specified list of biological products.

**NORD:** NORD supports this legislation. Actions: Submitted written testimony.

**Disposition:** To Governor

**Introduced:** 02/03/2017

**Author:** Conway J (D)

**Status:** 03/28/2017 Passed HOUSE.  
03/28/2017 Eligible for GOVERNOR'S desk.

## Maine

### 60. ME H 198

Introduced Passed 1st Committee Passed 1st Chamber Passed 2nd Committee Passed 2nd Chamber Enacted



**LD** 265

**Title:** Lysosomal Storage Disorders Newborn Screening

**Summary:** Requires the Department of Health and Human Services to amend its rules in Chapter 283 relating to the newborn screening program by January 1, 2018 to add to the program the lysosomal storage disorders known as Krabbe, Pompe, Gaucher, Fabry and Niemann-Pick diseases. It directs the department to explore options to enter into contracts with other states to test samples collected for lysosomal storage disorders.

**NORD:** NORD supports this legislation

**Disposition:** Pending

**Introduced:** 01/27/2017

**Author:** Johansen (R)

**Status:** 01/31/2017 HOUSE refers to JOINT Committee on HEALTH AND HUMAN SERVICES.  
01/31/2017 SENATE refers to JOINT Committee on HEALTH AND HUMAN SERVICES in concurrence.

### 61. ME LR 1195

Introduced Passed 1st Committee Passed 1st Chamber





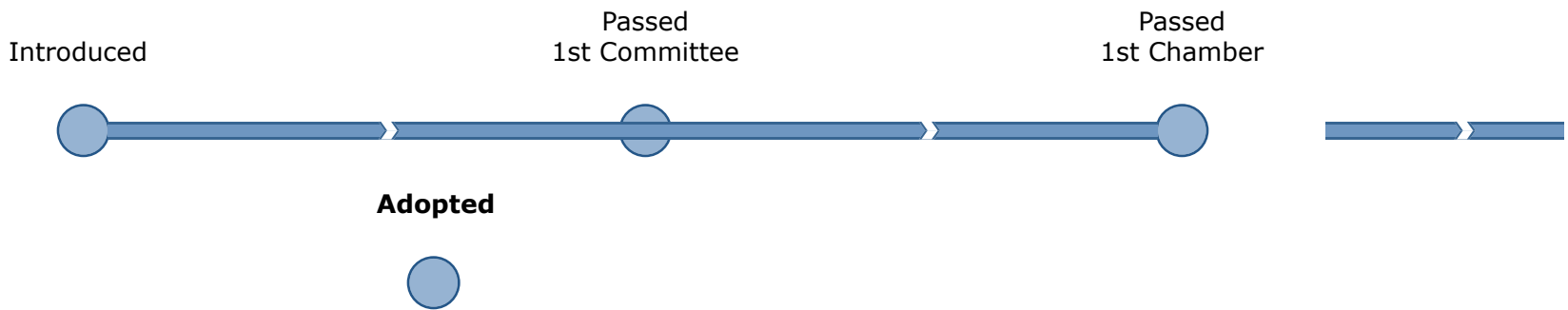
Enacted



**Title:** Prescription Drug Step Therapy  
**Summary:** Regards prescription drug step therapy.  
**Disposition:** Pending  
**Author:** Senator Rosen  
**Status:** 01/10/2017 FILED.

## Michigan

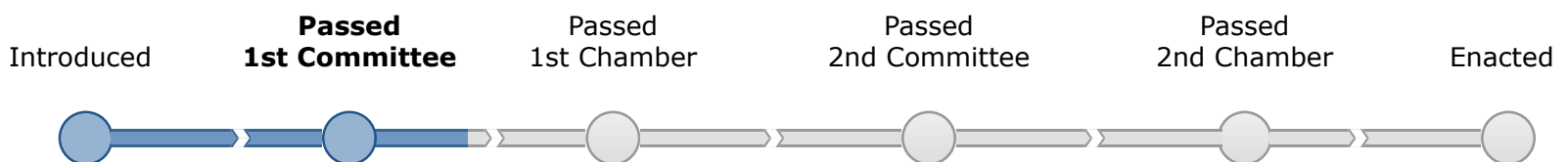
### 62. MI HR 28



**Title:** Rare Disease Day Resolution  
**Summary:** Declares February 28, 2017, as Rare Disease Day in the state of Michigan.  
**Disposition:** Adopted  
**Introduced:** 02/28/2017  
**Sponsor:** Faris (D)  
**Status:** 02/28/2017 INTRODUCED.  
 02/28/2017 In HOUSE. Passed HOUSE.

## Minnesota

### 63. MN H 712

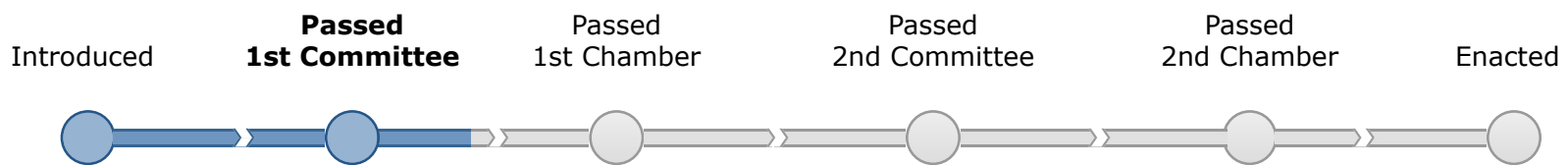


**Title:** Standards of Biological Products Substitution  
**Summary:** Relates to health; modifies and adds definitions; establishes standards for the substitution of biological products.  
**NORD:** NORD supports this legislation  
**Disposition:** Pending  
**Introduced:** 02/01/2017

**Author:** Albright (R)

**Status:** 03/08/2017 From HOUSE Committee on HEALTH AND HUMAN SERVICES REFORM: Do pass as amended.  
03/08/2017 In HOUSE. Second Reading.

## 64. MN S 1184



**Title:** Biological Product Substitutions

**Summary:** Relates to health; modifies and adds definitions; establishes standards for the substitution of biological products.

**Disposition:** Pending

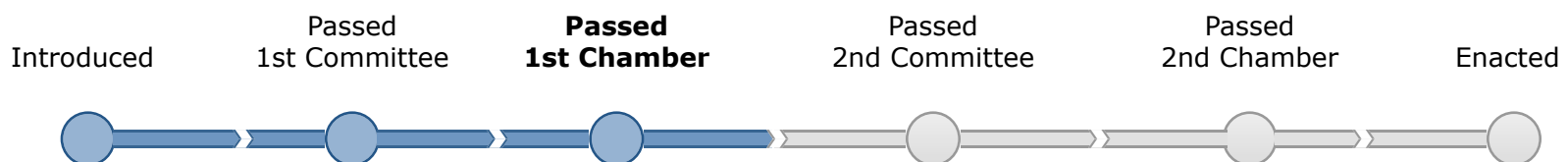
**Introduced:** 02/20/2017

**Author:** Nelson C (R)

**Status:** 03/15/2017 From SENATE Committee on HEALTH and HUMAN SERVICES FINANCE and POLICY: Do pass as amended.  
03/15/2017 In SENATE. Second Reading.

## Missouri

## 65. MO H 66



**Title:** Newborn Screening Requirements

**Summary:** Expands the newborn screening requirements to include spinal muscular atrophy (SMA) and Hunter syndrome.

**NORD:** NORD supports this legislation

**Disposition:** Pending

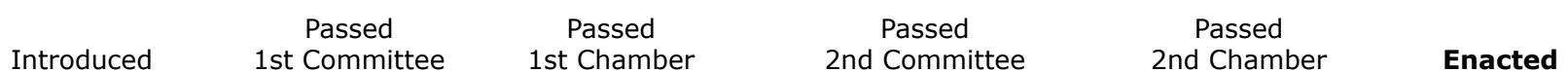
**Introduced:** 01/04/2017

**Sponsor:** Ruth (R)

**Status:** 03/08/2017 Executive Session Held.  
03/08/2017 In SENATE Committee on SENIORS, FAMILIES AND CHILDREN: Voted do pass as substituted.

## Montana

## 66. MT H 233





**Title:** Drug Product Selection Act

**Summary:** Revises drug product selection laws to include biological products; provides definitions; requires reporting of drug product selection.

**NORD:** NORD supports this legislation. Actions: Submitted written testimony.

**Disposition:** Enacted

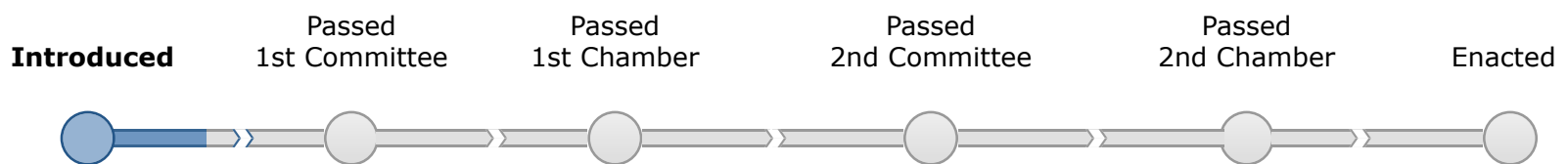
**Introduced:** 01/12/2017

**Author:** Ehli (R)

**Status:** 02/22/2017 Chaptered. Chapter No. 42

## North Carolina

### 67. NC H 270



**Title:** Newborn Screening

**Summary:** Directs the commission for public health to adopt rules to add a screening test for Pompe disease, Mucopolysaccharidosis Type I, and X-linked Adrenoleukodystrophy to the newborn screening program; increases the fee for newborn screening tests; appropriates funds to the Department of Health and Human Services, division of public health, to purchase necessary equipment and upgrades at the state laboratory of public health for newborn screening and all other laboratory operations.

**NORD:** NORD supports this legislation

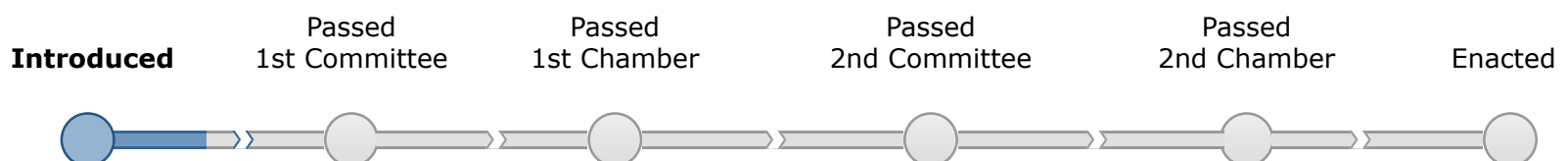
**Disposition:** Pending

**Introduced:** 03/08/2017

**Author:** Lambeth (R)

**Status:** 03/08/2017 INTRODUCED.  
03/08/2017 To HOUSE Committee on HEALTH.

### 68. NC S 190



**Title:** Newborn Screening

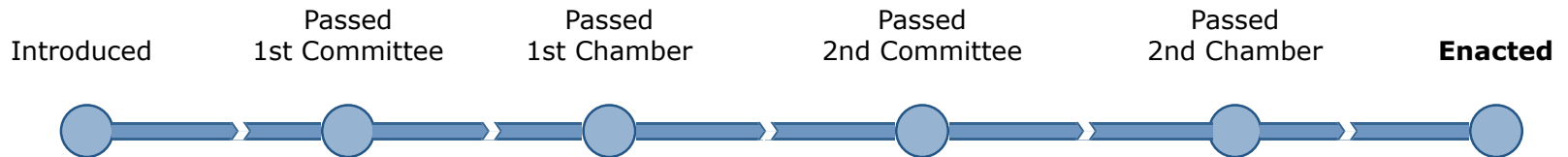
**Summary:** Directs the commission for public health to adopt rules to add a screening test for Pompe disease, Mucopolysaccharidosis Type I, and X-linked Adrenoleukodystrophy to the newborn screening program; increases the fee for newborn screening tests; appropriates funds to the Department of Health and Human Services, division of public health, to purchase necessary

equipment and upgrades at the state laboratory of public health for newborn screening and all other laboratory operations.

**Disposition:** Pending  
**Introduced:** 03/07/2017  
**Author:** Davis D (D)  
**Status:** 03/07/2017 INTRODUCED.  
03/07/2017 To SENATE Committee on RULES AND OPERATIONS OF THE SENATE.

## North Dakota

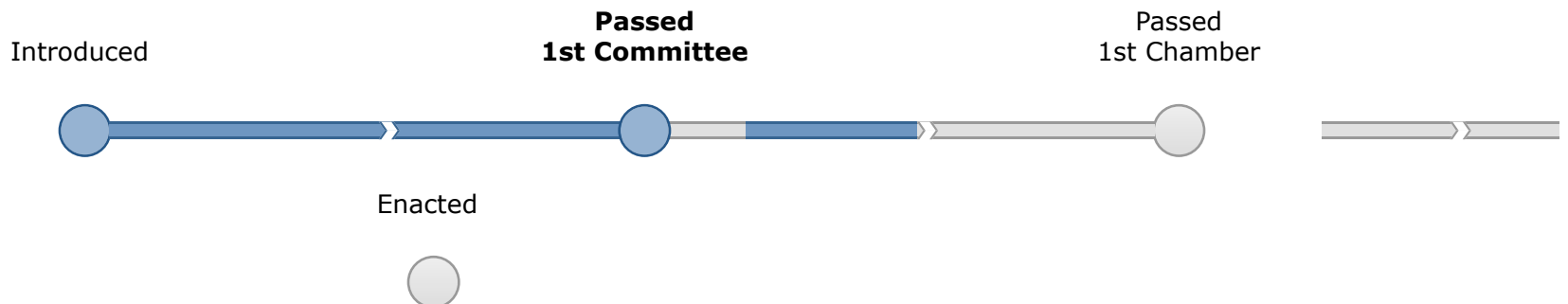
### 69. ND H 1187



**Title:** Medical Food Program for Phenylketonuria  
**Summary:** Relates to the medical food program for phenylketonuria or maple syrup urine disease; relates to treatment for a positive diagnosis; provides for a registry of cases of metabolic diseases; provides for medical food for persons under a specified age regardless of income; relates to low-protein modified food products; provides for reimbursement from any government program that provides coverage to that individual for the treatment services provided by the department.  
**NORD:** NORD supports this legislation  
**Disposition:** Enacted  
**Introduced:** 01/09/2017  
**Author:** Delmore (D)  
**Status:** 03/21/2017 Signed by GOVERNOR.

## Nebraska

### 70. NE L 481

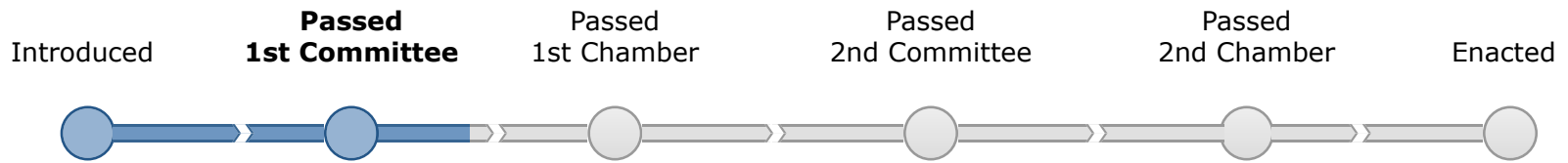


**Title:** Interchangeable Biological Products Drug Selections  
**Summary:** Provides for drug product selection for interchangeable biological products.  
**NORD:** NORD supports this legislation. Actions: Submitted written testimony.  
**Disposition:** Pending

**Introduced:** 01/17/2017  
**Author:** Kuehn (NP)  
**Status:** 02/24/2017 From LEGISLATIVE Committee on HEALTH AND HUMAN SERVICES: Placed on General File. (7-0)

## New Hampshire

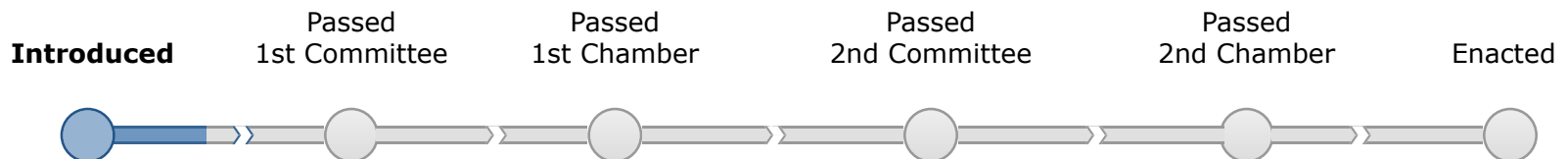
### 71. NH H 443



**Title:** Prescription Drug Manufacturers  
**Summary:** Prohibits prescription drug manufacturers from offering to pay or reimburse an individual for his or her insurance copayment.  
**Disposition:** Failed  
**Introduced:** 01/05/2017  
**Author:** Kurk (R)  
**Status:** 03/08/2017 Failed to pass HOUSE.

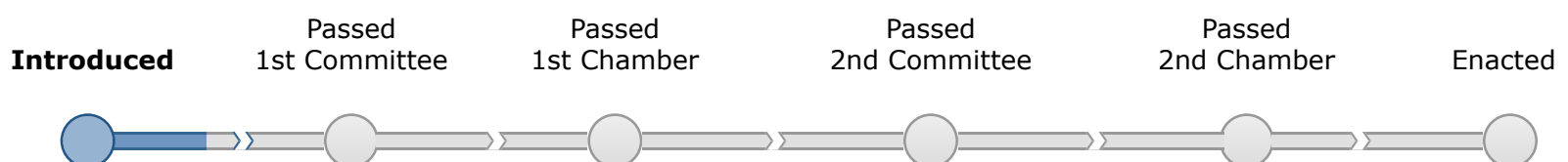
## New Jersey

### 72. NJ A 817



**Title:** Disorders in Newborn Screening Program  
**Summary:** Expands number of disorders included in newborn screening program.  
**NORD:** NORD supports this legislation  
**Disposition:** Pending  
**Introduced:** 01/27/2016  
**Sponsor:** Jimenez (D)  
**Status:** 01/27/2016 INTRODUCED.  
01/27/2016 To ASSEMBLY Committee on WOMEN AND CHILDREN.

### 73. NJ A 902



**Title:** Newborn Screening Specimen Disposal

**Summary:** Requires Department of Human Services (DHS) to dispose of newborn screening specimens within 60 days after testing.

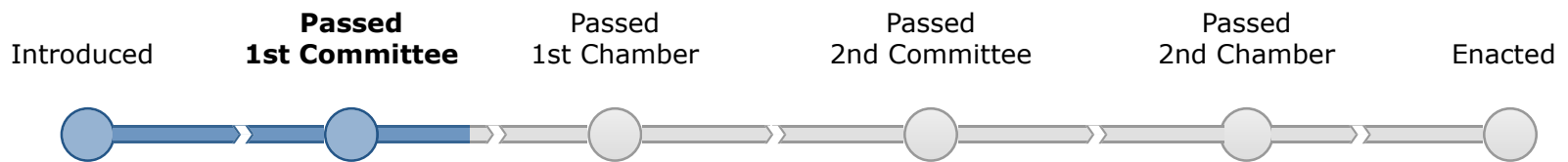
**Disposition:** Pending

**Introduced:** 01/27/2016

**Sponsor:** Vainieri Huttle (D)

**Status:** 01/27/2016 INTRODUCED.  
01/27/2016 To ASSEMBLY Committee on WOMEN AND CHILDREN.

## 74. NJ A 2337



**Title:** Patient Cost Sharing

**Summary:** Requires health insurers to limit patient cost-sharing and provide appeal process concerning certain prescription drug coverage.

**NORD:** NORD supports this legislation and provided in-person testimony and constituent visits during Rare Disease Day.

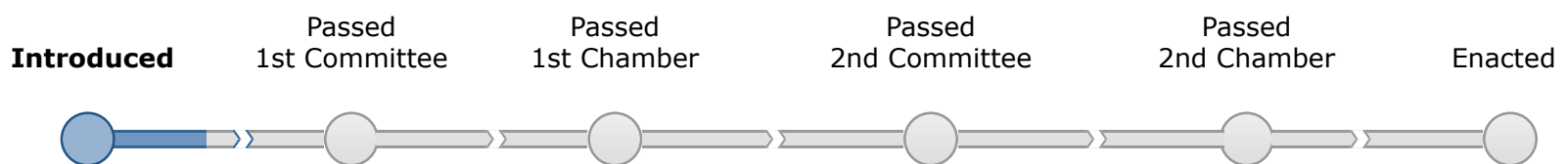
**Disposition:** Pending

**Introduced:** 02/04/2016

**Sponsor:** Benson (D)

**Status:** 10/06/2016 From ASSEMBLY Committee on FINANCIAL INSTITUTIONS AND INSURANCE. (10-0)

## 75. NJ A 3137



**Title:** Rare Disease Advisory Council

**Summary:** Establishes the New Jersey Rare Disease Advisory Council.

**Disposition:** Pending

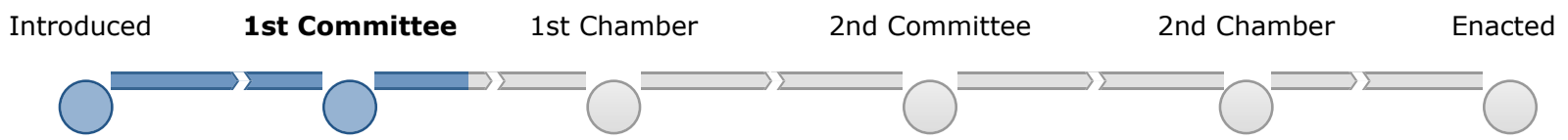
**Introduced:** 02/22/2016

**Sponsor:** Dancer (R)

**Status:** 02/22/2016 INTRODUCED.  
02/22/2016 To ASSEMBLY Committee on HEALTH AND SENIOR SERVICES.

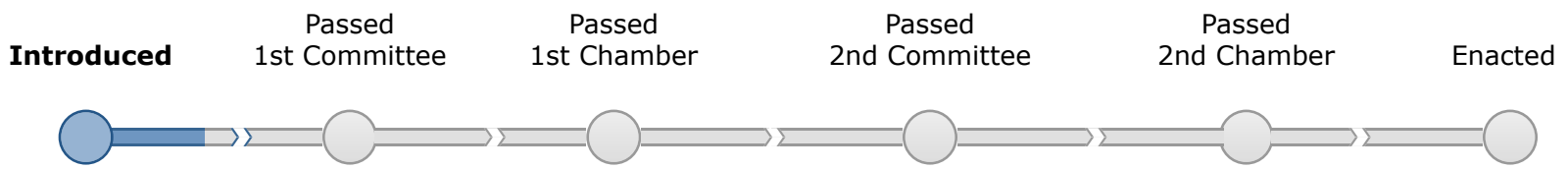
## 76. NJ S 814

**Passed**      Passed      Passed      Passed



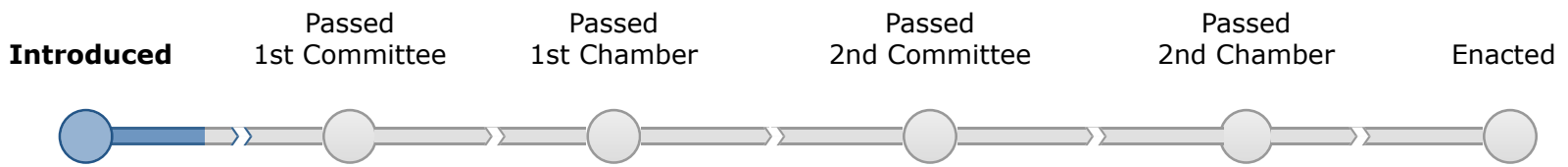
**Title:** Health Insurers to Limit Patient Cost Sharing  
**Summary:** Requires health insurers to limit patient cost-sharing and provide appeal process concerning certain prescription drug coverage.  
**Disposition:** Pending  
**Introduced:** 01/12/2016  
**Sponsor:** Weinberg (D)  
**Status:** 12/15/2016 From SENATE Committee on BUDGET AND APPROPRIATIONS. (10-1)

77. **NJ S 1283**



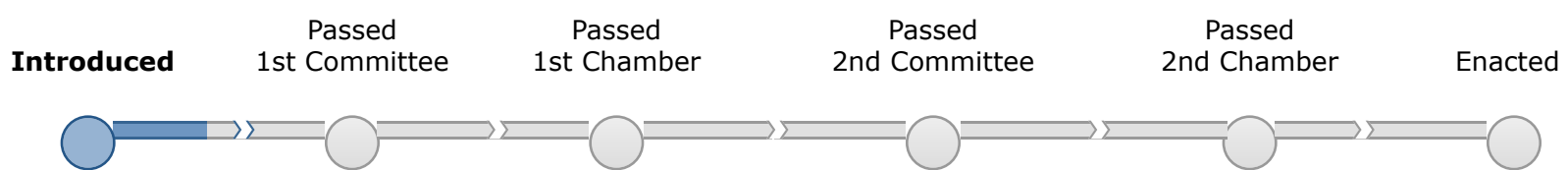
**Title:** Newborn Screening Program  
**Summary:** Revises Newborn Screening program in Department of Health.  
**Disposition:** Pending  
**Introduced:** 02/08/2016  
**Sponsor:** Vitale (D)  
**Status:** 02/08/2016 INTRODUCED.  
 02/08/2016 To SENATE Committee on HEALTH, HUMAN SERVICES AND SENIOR CITIZENS.

78. **NJ S 1929**



**Title:** Insurance Coverage for Elemental Formula  
**Summary:** Requires health insurance coverage for amino acid-based elemental formula.  
**Disposition:** Pending  
**Introduced:** 03/10/2016  
**Sponsor:** Lesniak (D)  
**Status:** 03/10/2016 INTRODUCED.  
 03/10/2016 To SENATE Committee on COMMERCE.

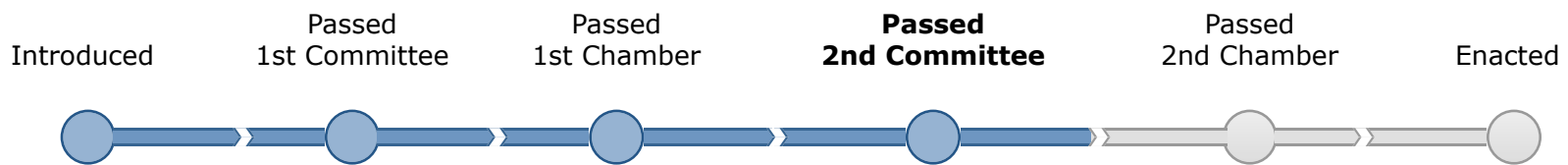
79. **NJ SJR 33**



**Title:** Rare Disease Awareness Day  
**Summary:** Designates last day of February of each year as Rare Disease Awareness Day in New Jersey.  
**Disposition:** Pending  
**Introduced:** 02/11/2016  
**Sponsor:** Bucco AR (R)  
**Status:** 02/11/2016 INTRODUCED.  
 02/11/2016 To SENATE Committee on HEALTH, HUMAN SERVICES AND SENIOR CITIZENS.

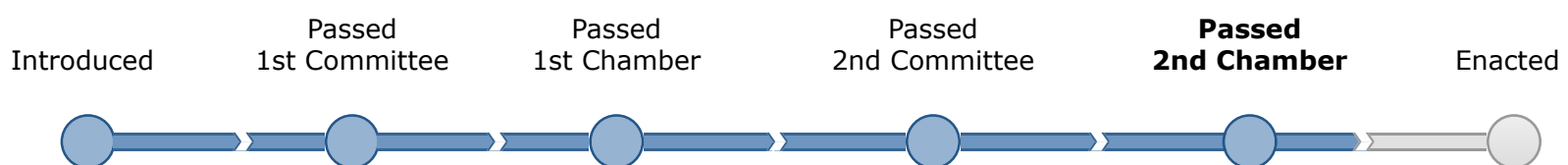
## New Mexico

### 80. NM H 244



**Title:** Prescription Drug Coverage Step Therapy  
**Summary:** Relates to health coverage; enacts new sections of the health care purchasing act, the public assistance act, the New Mexico insurance code, the health maintenance organization law and the nonprofit health care plan law to establish guidelines relating to step therapy for prescription drug coverage.  
**NORD:** NORD supports this legislation. Actions: Submitted written testimony.  
**Disposition:** Failed - Adjourned  
**Introduced:** 01/25/2017  
**Author:** Thomson (D)  
**Status:** 03/11/2017 From SENATE Committee on CORPORATIONS AND TRANSPORTATION: Do pass as amended.

### 81. NM H 260

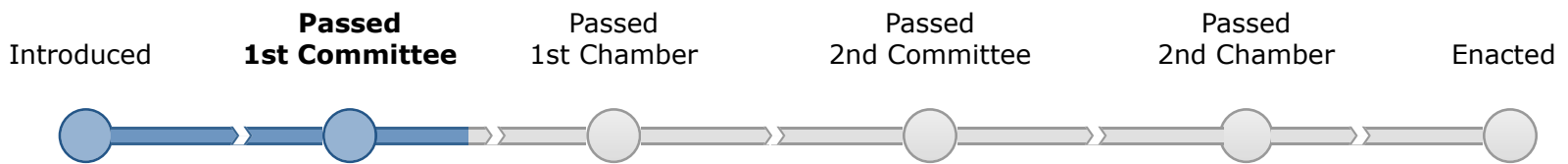


**Title:** Regulation of Biosimilar Products  
**Summary:** Relates to health; amends the Drug, Device and Cosmetic Act to provide for regulation of biosimilar products.  
**Disposition:** To Governor  
**Introduced:** 01/26/2017



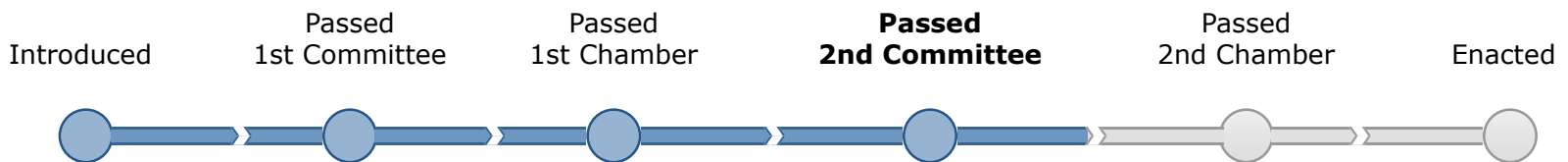
**Author:** Armstrong (D)  
**Status:** 03/13/2017 Passed SENATE. (35-0)

## 82. NM S 179



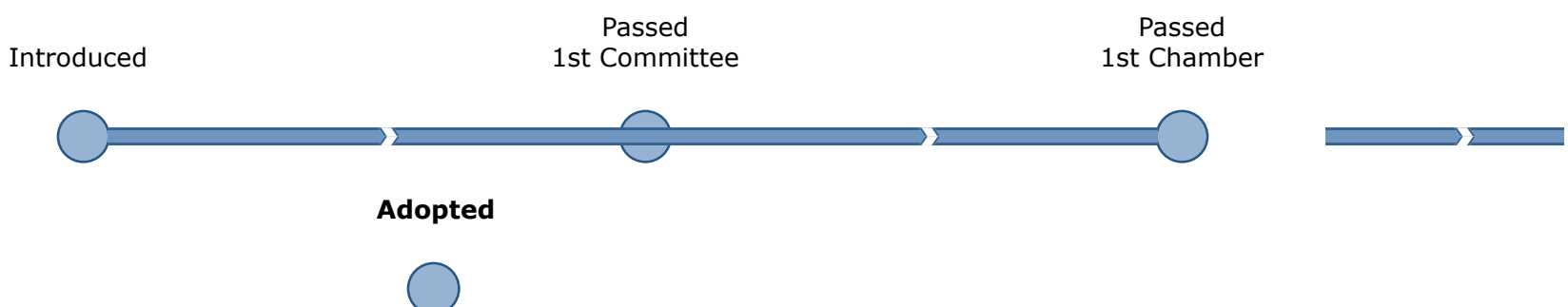
**Title:** Prescription Drug Coverage Step Therapy  
**Summary:** Relates to health coverage; enacts new sections of the health care purchasing act, the public assistance act, the New Mexico insurance code, the health maintenance organization law and the nonprofit health care plan law to establish guidelines relating to step therapy for prescription drug coverage.  
**Disposition:** Failed - Adjourned  
**Introduced:** 01/25/2017  
**Author:** Stefanics (D)  
**Status:** 03/01/2017 From SENATE Committee on CORPORATIONS AND TRANSPORTATION: Do pass as amended.  
03/01/2017 Re-referred to SENATE Committee on FINANCE.

## 83. NM S 180



**Title:** Regulation of Biosimilar Products  
**Summary:** Relates to health; amends the New Mexico drug, device and cosmetic act to provide for regulation of biosimilar products.  
**Disposition:** Failed - Adjourned  
**Introduced:** 01/25/2017  
**Author:** Ortiz y Pino (D)  
**Status:** 03/11/2017 From HOUSE Committee on BUSINESS AND INDUSTRY: Do pass.

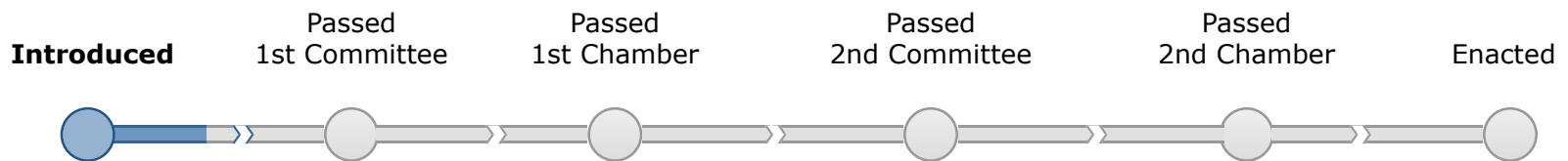
## 84. NM SM 108



**Title:** World Rare Disease Day  
**Summary:** Declares February 28, 2017 World Rare Disease Day in the Senate.  
**Disposition:** Adopted  
**Introduced:** 02/27/2017  
**Author:** Rodriguez (D)  
**Status:** 02/28/2017 In SENATE. Withdrawn from table.  
02/28/2017 Passed SENATE. (42-0)

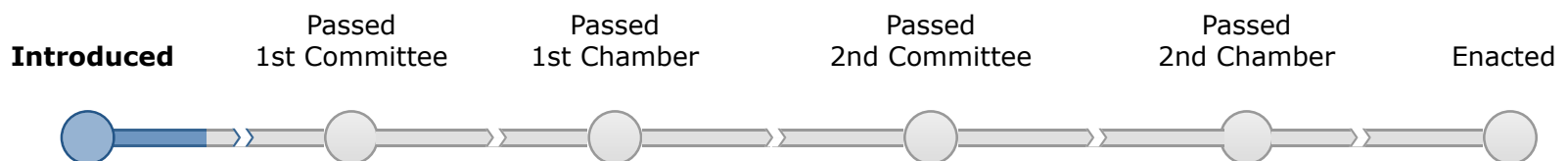
## Nevada

### 85. NV A 245



**Title:** Dispensing of Biological Products  
**Summary:** Enacts provisions governing the dispensing of biological products and interchangeable biological products.  
**Disposition:** Pending  
**Introduced:** 02/27/2017  
**Author:** Benitez-Thompso (D)  
**Status:** 02/27/2017 INTRODUCED.  
02/27/2017 To ASSEMBLY Committee on COMMERCE AND LABOR.

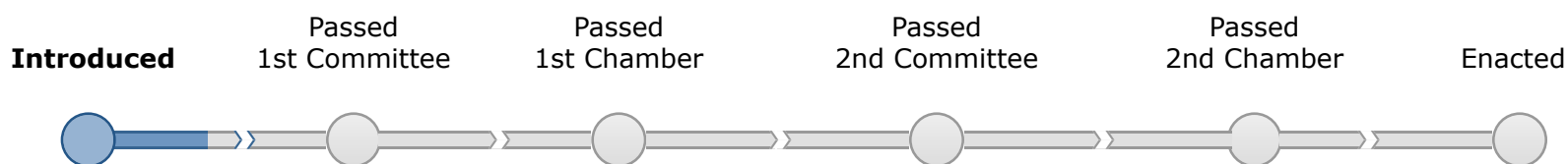
### 86. NV S 265



**Title:** Prescription Drugs  
**Summary:** Revises provisions relating to prescription drugs.  
**NORD:** NORD opposes this legislation because it put onerous requirements on non-profits and applies provisions that could impact rare disease research.  
**Disposition:** Pending  
**Introduced:** 03/14/2017  
**Author:** Cancela (D)  
**Status:** 03/14/2017 INTRODUCED.  
03/14/2017 To SENATE Committee on HEALTH AND HUMAN SERVICES.

## New York

## 87. NY A 1076



**Title:** DNA Testing for Newborns

**Summary:** Requires hospitals to provide parents of newborns with the option to have a DNA test performed on their child or have a blood sample taken from the child and preserved for future DNA testing.

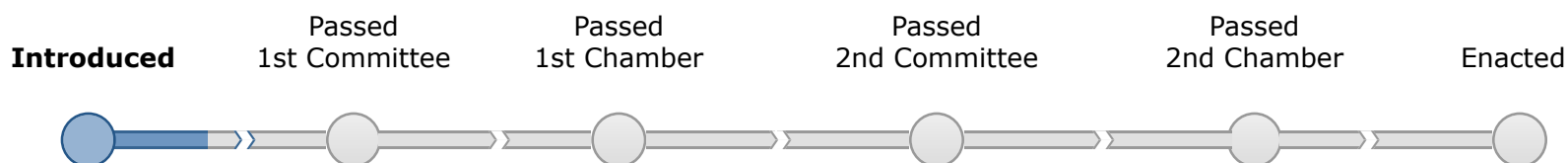
**Disposition:** Pending

**Introduced:** 01/10/2017

**Sponsor:** Pretlow (D)

**Status:** 01/10/2017 INTRODUCED.  
01/10/2017 To ASSEMBLY Committee on HEALTH.

## 88. NY S 4788



**Title:** Interchangeable Biological Products

**Summary:** Relates to interchangeable biological products; enacts provisions relating to substitutions of biological products by pharmacists.

**NORD:** NORD supports this legislation.

**Disposition:** Pending

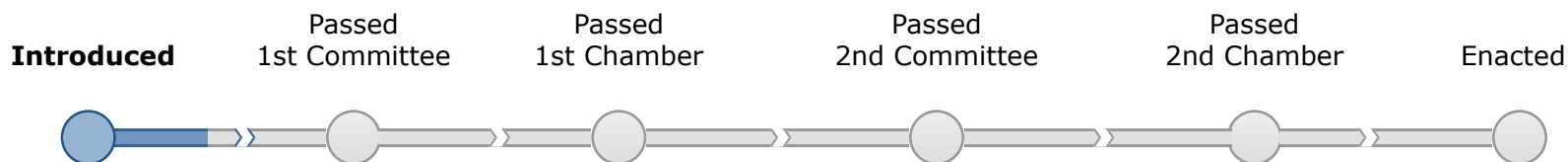
**Introduced:** 03/01/2017

**Sponsor:** Hannon (R)

**Status:** 03/01/2017 INTRODUCED.  
03/01/2017 To SENATE Committee on HIGHER EDUCATION.

## Ohio

## 89. OH H 72



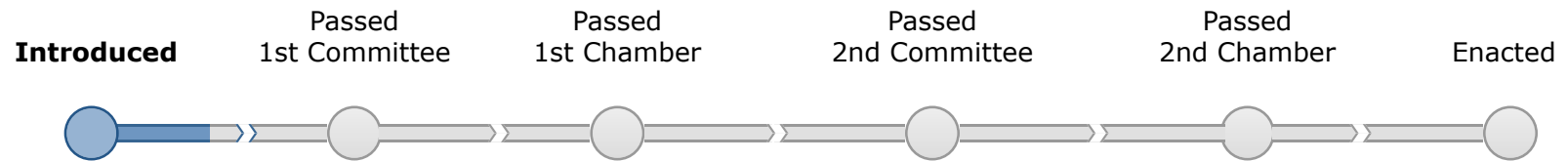
**Title:** Step Therapy Protocol Requirements

**Summary:** Adopts requirements related to step therapy protocols implemented by health plan issuers and the Department of Medicaid.

**Disposition:** Pending

**Introduced:** 02/21/2017  
**Sponsor:** Johnson (R)  
**Status:** 02/28/2017 From HOUSE Committee on RULES AND REFERENCE: Recommended referral.  
02/28/2017 In HOUSE. To second reading. Read a second time.  
02/28/2017 To HOUSE Committee on HEALTH.

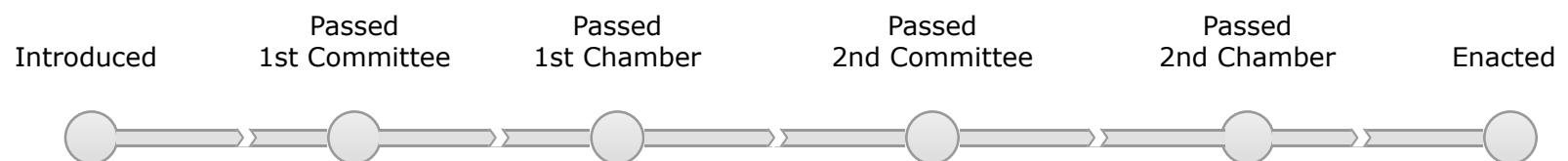
## 90. OH S 56



**Title:** Step Therapy Protocols  
**Summary:** Adopts requirements related to step therapy protocols implemented by health plan issuers and the Department of Medicaid.  
**NORD:** NORD supports. Actions: Submitted written testimony and constituent messages. In-person legislative visits during Rare Disease Day.  
**Disposition:** Pending  
**Introduced:** 02/14/2017  
**Sponsor:** Lehner (R)  
**Status:** 02/15/2017 From SENATE Committee on RULES AND REFERENCE: Recommended referral.  
02/15/2017 In SENATE. To second reading. Read a second time.  
02/15/2017 To SENATE Committee on HEALTH, HUMAN SERVICES, AND MEDICAID.

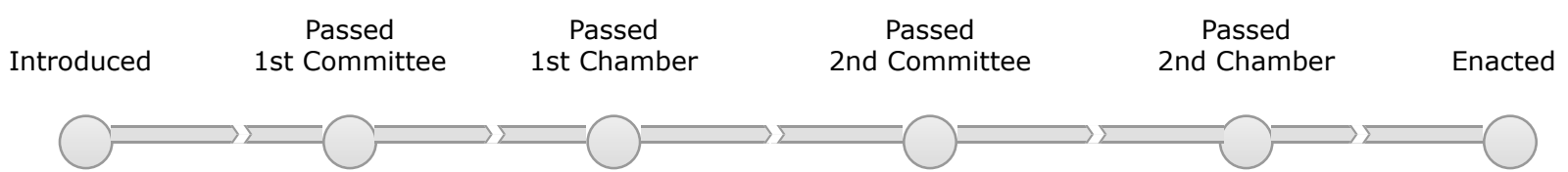
## Oregon

## 91. OR D 1255



**Title:** Health Authority  
**Summary:** Directs Oregon Health Authority to establish and operate statewide database for collection and dissemination of orders for rare disease emergency response medical treatment for the purpose of ensuring safe treatment of individuals with rare diseases in emergency situations; creates Oregon ORDER Database Advisory Committee to advise authority on establishment, operation and evaluation of database.  
**NORD:** NORD supports this legislation. Actions: provided in-person testimony and legislative visits as part of Rare Disease Day  
**Disposition:** Pending  
**Author:** Senate Committee on Education and General Government  
**Status:** 02/01/2017 Assigned SENATE Bill No. 215

## 92. OR D 1743



**Title:** Prescription Drug Formulary for Insurance Code

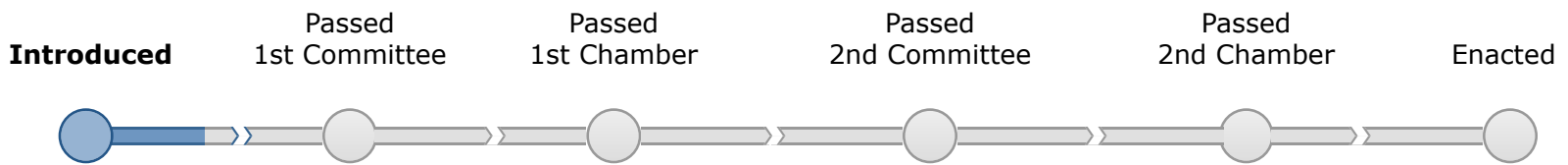
**Summary:** Defines prescription drug formulary for purposes of Insurance Code; requires carrier offering health benefit plan to small employers, groups or individuals to make specified information about prescription drug formularies available on carrier's website and through toll-free telephone number; prohibits carrier from making changes to prescription drug formulary more than once every specified period unless based on alert issued by United States Food and Drug Administration.

**Disposition:** Pending

**Author:** Senate Committee on Health Care

**Status:** 12/12/2016 FILED.

### 93. **OR S 237**



**Title:** Group Health Benefit Plans

**Summary:** Requires at least 25 percent of carrier's individual and group health benefit plans within each metal level of coverage to have copayment-only cost sharing requirements.

**NORD:** NORD supports. Actions: Submitted written testimony and constituent messages. In-person legislative visits during Rare Disease Day.

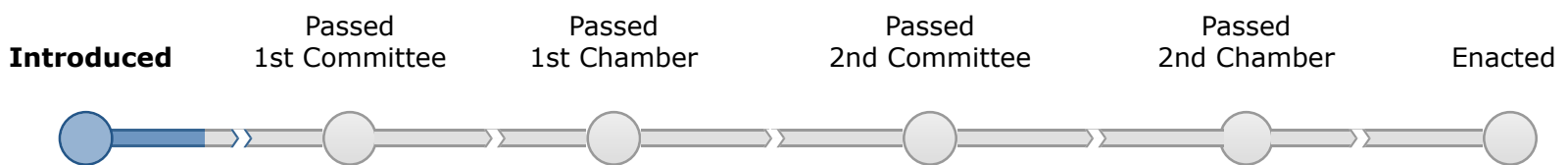
**Disposition:** Pending

**Introduced:** 02/01/2017

**Author:** Joint Interim Human Services and Early Childhood Development

**Status:** 03/21/2017 Public Hearing held.

### 94. **OR S 526**



**Title:** Step Therapy Protocol Imposed by Insurer

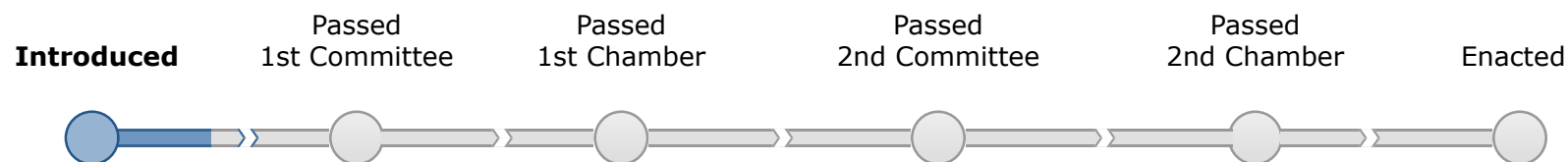
**Summary:** Modifies requirements applicable to step therapy protocol imposed by insurer; allows patient to appeal insurer's denial of step therapy override.

**NORD:** NORD supports. Actions: Submitted written testimony and constituent messages. In-person legislative visits during Rare Disease Day.

**Disposition:** Pending

**Introduced:** 02/01/2017  
**Author:** Kruse (R)  
**Status:** 02/21/2017 Public Hearing held.

## 95. **OR S 808**



**Title:** Health Testing Service

**Summary:** Provides that with respect to health screen testing for newborns, Oregon Health Authority shall specify that health testing service may conduct tests for conditions listed on Most Recent edition of Recommended Uniform Screening Panel by United States Department of Health and Human Services; establishes Review Committee on Health Screen Testing for Newborns for purposes of studying, evaluating and making proposals related to health screen testing of newborns.

**NORD:** NORD supports. Actions: Submitted written testimony and constituent messages. Conducted in-person legislative visits.

**Disposition:** Pending

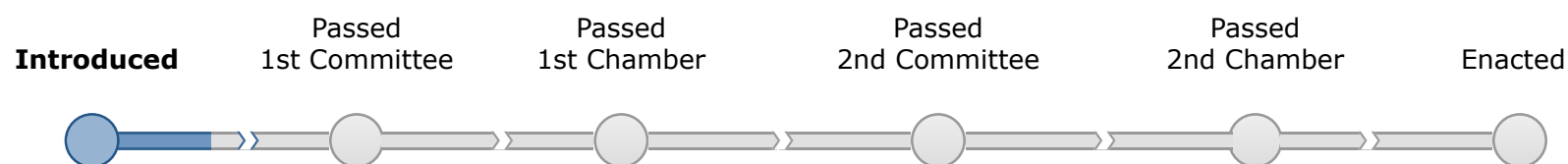
**Introduced:** 02/16/2017

**Author:** Boquist (R)

**Status:** 03/24/2017 Public Hearing Scheduled 04/06/2017.

## Pennsylvania

## 96. **PA H 239**



**PN** 261

**Title:** Rare Disease Advisory Council

**Summary:** Establishes the Rare Disease Advisory Council and providing for its powers and duties; provides for duties of the Department of Health, the Insurance Department, the Department of Human Services and the Department of Education.

**NORD:** NORD supports this legislation. Actions: Submitted written testimony. Planning in-person legislative visits during Rare Disease Day in May.

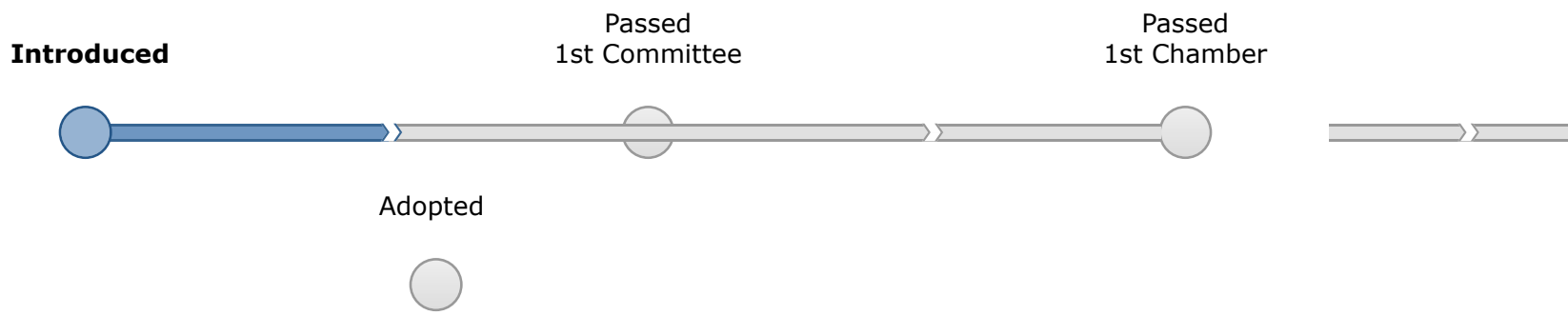
**Disposition:** Pending

**Introduced:** 02/01/2017

**Author:** Toepel (R)

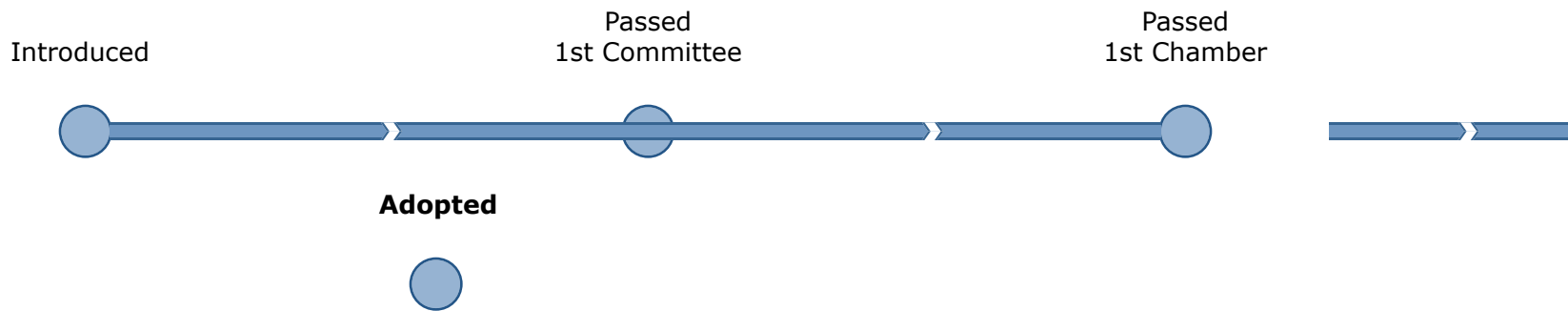
**Status:** 02/01/2017 INTRODUCED.  
02/01/2017 To HOUSE Committee on HEALTH.

## 97. PA HR 55



**PN:** 277  
**Title:** Rare Disease Day  
**Summary:** Recognizes March 14, 2017, as "Rare Disease Day".  
**Disposition:** Pending  
**Introduced:** 02/02/2017  
**Author:** Toepel (R)  
**Status:** 03/20/2017 To HOUSE Committee on RULES.

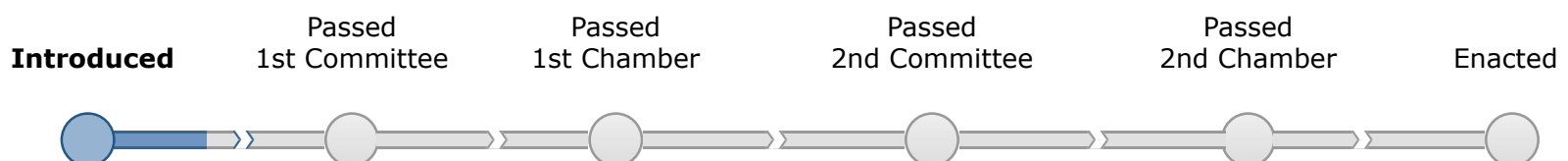
## 98. PA SR 29



**PN:** 308  
**Title:** Rare Disease Day  
**Summary:** Recognizes February 28, 2017, as Rare Disease Day.  
**Disposition:** Adopted  
**Introduced:** 02/08/2017  
**Author:** Costa J (D)  
**Status:** 02/08/2017 FILED.  
02/08/2017 INTRODUCED.  
02/08/2017 Passed SENATE.

## Rhode Island

## 99. RI H 5636



**Title:** Insurance Step Therapy Protocols

**Summary:** Would require health insurers, nonprofit hospital service corporations, nonprofit medical service corporations and health maintenance organizations that issue policies that provide coverage for prescription drugs and use step therapy protocols, to base step therapy protocols on appropriate clinical practice guidelines or published peer review data developed by independent experts with knowledge of the condition or conditions under consideration; that patients be exempt from step therapy protocols/.

**NORD:** NORD supports this legislation. Actions: Submitted written testimony.

**Disposition:** Pending

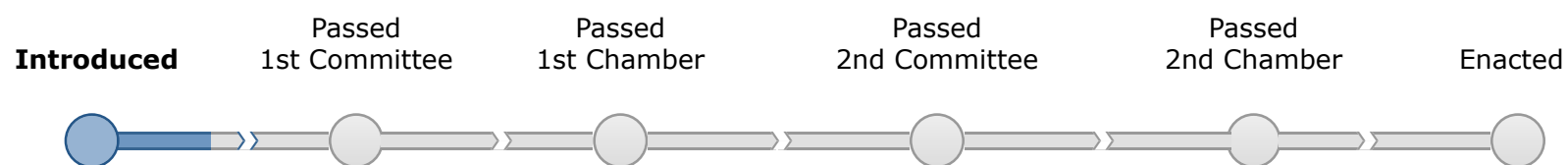
**Introduced:** 03/01/2017

**Author:** Blazejewski (D)

**Status:** 03/25/2017 Committee meeting postponed 03/28/2017.

## South Carolina

### 100. SC H 3323



**Title:** Payment of Insurance Premiums

**Summary:** Allows the payment of insurance premiums and other cost sharing by third parties on behalf of individuals insured by qualified health plans.

**NORD:** NORD supports. Actions: Submitted written testimony and constituent messages. Conducted in-person legislative visits during Rare Disease Day.

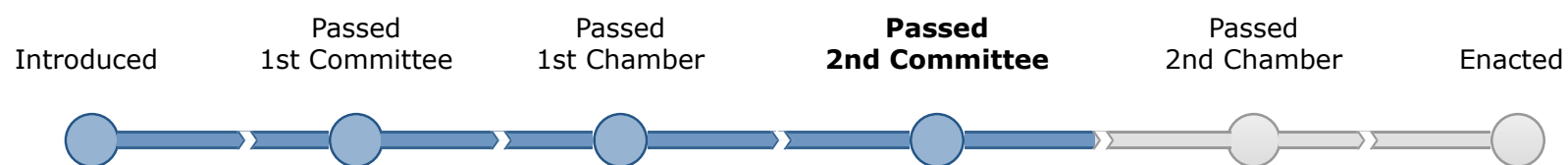
**Disposition:** Pending

**Introduced:** 01/10/2017

**Author:** Stringer (R)

**Status:** 01/10/2017 INTRODUCED.  
01/10/2017 To HOUSE Committee on LABOR, COMMERCE AND INDUSTRY.

### 101. SC H 3438



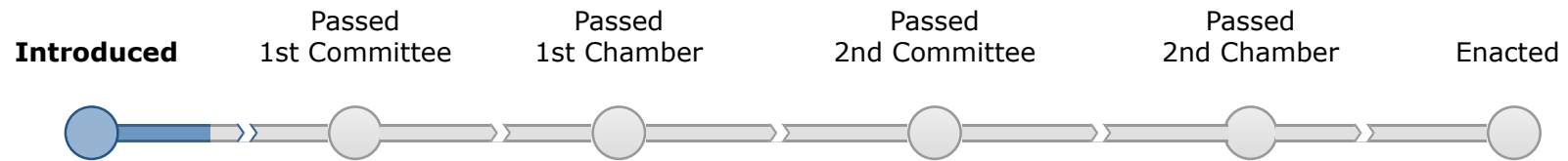
**Title:** Drug Product Selection Act

**Summary:** Relates to definitions in the Drug Product Selection Act; includes interchangeable biological products in the definition of substitute; relates to the substitution of equivalent drugs; allows pharmacists to substitute interchangeable biological products when appropriate; relates to label requirements for prescriptions so as to include interchangeable biological products; requires pharmacies to keep records of dispensed biological products; requires a database for all approved biological products.



**NORD:** NORD supports this legislation. Actions: Submitted written testimony.  
**Disposition:** Pending  
**Introduced:** 01/12/2017  
**Author:** Henderson (R)  
**Status:** 03/23/2017 Committee amendment adopted on SENATE floor.

## 102. SC S 299



**Title:** Drug Product Selection Act

**Summary:** Relates to definitions in the Drug Product Selection Act; includes interchangeable biological products; relates to the substitution of equivalent drugs; allows a pharmacist to substitute an interchangeable biological product for a specific biological product; relates to the substitution of prescriptions by pharmacists; allows pharmacists to substitute interchangeable biological products when appropriate; relates to definitions in the pharmacy practice act; adds definitions for biological product.

**Disposition:** Pending

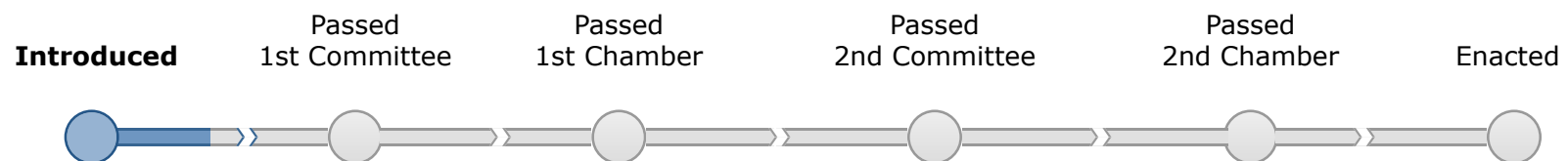
**Introduced:** 01/24/2017

**Author:** Bryant (R)

**Status:** 01/24/2017 INTRODUCED.  
01/24/2017 To SENATE Committee on MEDICAL AFFAIRS.

## Tennessee

## 103. TN S 1138



**Title:** Pediatric Rare Disease Treatment Information Act

**Summary:** Relates to Children; enacts the Access to Pediatric Rare Disease Treatment Information Act; provides for sharing of essential treatment information for children with cancer among certain health care institutions.

**Disposition:** Pending

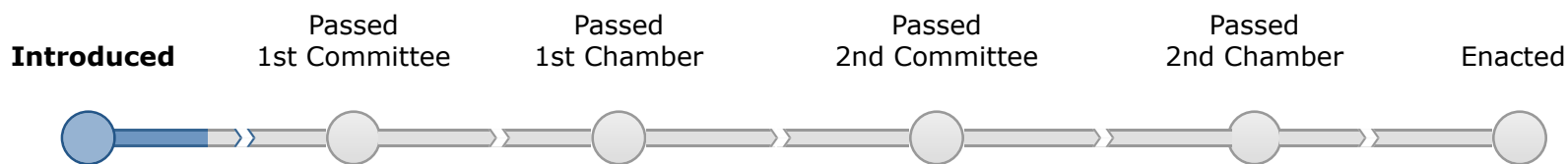
**Introduced:** 02/09/2017

**Author:** Kyle (D)

**Status:** 02/13/2017 To SENATE Committee on HEALTH AND WELFARE.

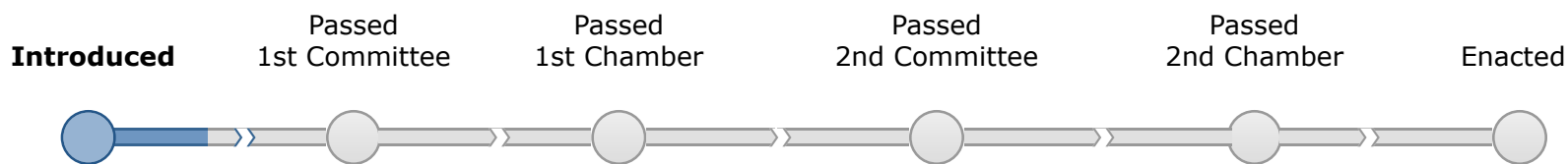
## Texas

## 104. TX H 1067



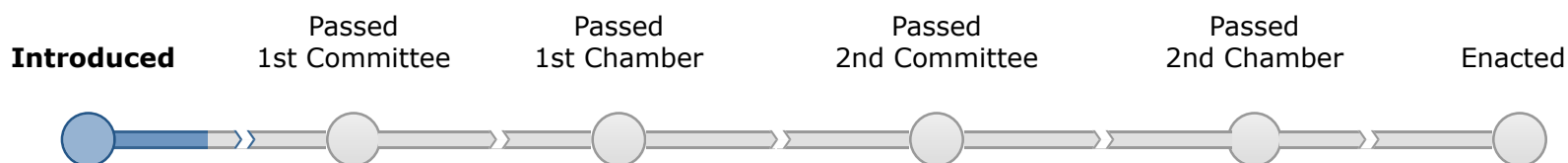
**Title:** Newborn Screening Tests for Adrenoleukodystrophy  
**Summary:** Relates to newborn screening tests for adrenoleukodystrophy.  
**NORD:** NORD supports this legislation.  
**Disposition:** Pending  
**Introduced:** 01/17/2017  
**Author:** Meyer (R)  
**Status:** 03/07/2017 Considered in public hearing.  
03/07/2017 Testimony taken in committee.  
03/07/2017 Left pending in committee.

## 105. TX H 1464

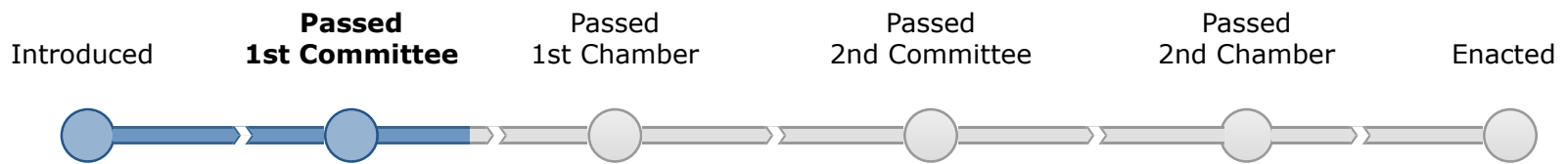


**Title:** Step Therapy Protocols for Health Benefit Plans  
**Summary:** Relates to step therapy protocols required by a health benefit plan in connection with prescription drug coverage.  
**Disposition:** Pending  
**Introduced:** 02/01/2017  
**Author:** Bonnen G (R)  
**Status:** 03/07/2017 To HOUSE Committee on INSURANCE.

## 106. TX H 1937



**Title:** Newborn Screening Tests for Adrenoleukodystrophy  
**Summary:** Relates to newborn screening tests for adrenoleukodystrophy.  
**Disposition:** Pending  
**Introduced:** 02/15/2017  
**Author:** Villalba (R)

107. **TX S 680**

**Title:** Health Benefit Plan Step Therapy Protocols

**Summary:** Relates to step therapy protocols required by a health benefit plan in connection with prescription drug coverage; provides definitions; relates to clinical practice guidelines and clinical review criteria.

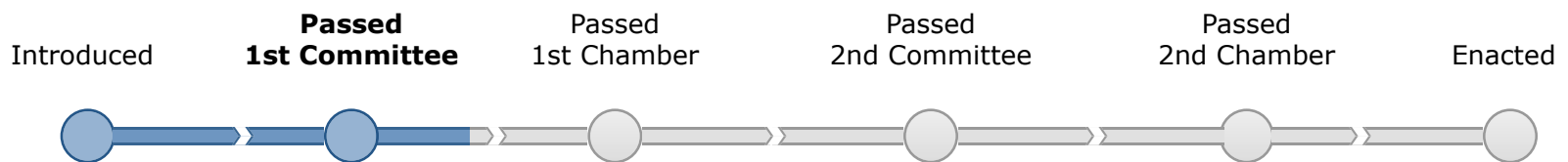
**NORD:** NORD supports. Actions: Submitted written testimony and constituent messages. Conducted in-person legislative visits during and constituent outreach during Rare Disease Day.

**Disposition:** Pending

**Introduced:** 01/31/2017

**Author:** Hancock (R)

**Status:** 03/22/2017 Not again placed on intent calendar.

**Utah**108. **UT H 266**

**Title:** Health Insurance Provisions

**Summary:** Amends health insurance provisions in the Insurance Code; prohibits the use of step therapy for pharmaceuticals unless certain conditions are met; requires a health insurer to authorize bypass of a step drug when certain conditions are met; addresses adverse benefit determinations.

**NORD:** NORD supports this legislation.

**Disposition:** Failed

**Introduced:** 02/01/2017

**Author:** Hutchings (R)

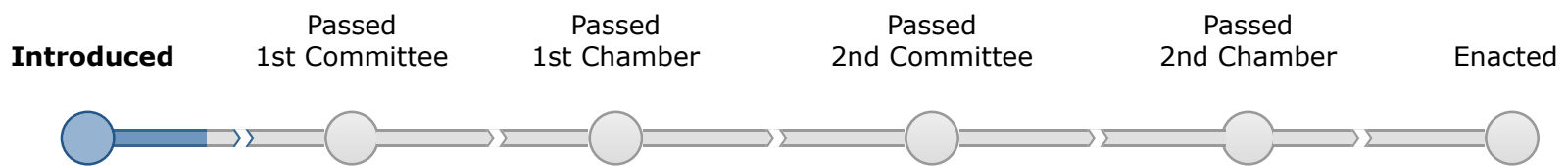
**Status:** 03/09/2017 Enacting clause struck.

**Virginia**109. **VA H 362**



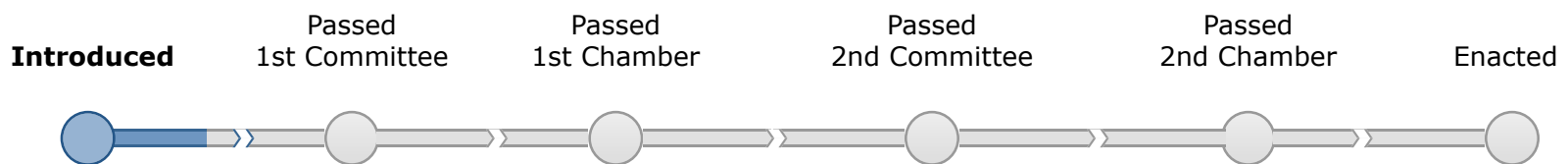
**Title:** Step Therapy Protocols  
**Summary:** Relates to step therapy protocols; relates to disclosures; requires health insurers that limit coverage for prescription drugs through the use of a step therapy protocol to have in place a process for a prescribing provider to request an override of the protocol for a patient.  
**Disposition:** Failed - Adjourned  
**Introduced:** 01/13/2016  
**Author:** Davis (R)  
**Status:** 02/02/2016 In HOUSE Committee on COMMERCE AND LABOR: Continued to 2017.

## 110. VA H 601



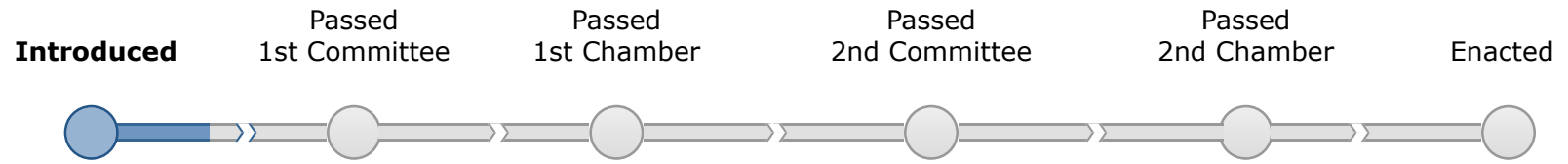
**Title:** Health Insurance  
**Summary:** Relates to health insurance; relates to mandated coverage for treatment of inborn errors of metabolism; requires health carriers to provide coverage for treatment of inborn errors of metabolism that involve amino acid, carbohydrate, and fat metabolism and for which medically standard methods of diagnosis, treatment, and monitoring exist.  
**Disposition:** Failed - Adjourned  
**Introduced:** 01/13/2016  
**Author:** Murphy (D)  
**Status:** 01/26/2016 In HOUSE Committee on COMMERCE AND LABOR: Continued to 2017.

## 111. VA H 1755



**Title:** Step Therapy Protocols  
**Summary:** Relates to step therapy protocols; relates to disclosures; requires health insurers that limit coverage for prescription drugs through the use of a step therapy protocol to have in place a process for a prescribing provider to request an override of the protocol for a patient; provides that a step therapy protocol is a protocol or program that establishes the specific sequence in which prescription drugs for a specified medical condition are medically appropriate for a particular patient.  
**Disposition:** Failed  
**Introduced:** 01/11/2017  
**Author:** Davis (R)

## 112. VA S 331



**Title:** Step Therapy

**Summary:** Relates to step therapy; relates to psychiatric medicines; prohibits a health insurer or other carrier from using step therapy in a manner that results in a denial of or delay in coverage for any psychiatric medication under a health insurance policy or plan; applies only to health insurance policies or plans that provide coverage for prescription drugs on an outpatient basis; provides that if the health benefit plan utilizes a closed drug formulary, the prohibition applies only to psychiatric medications.

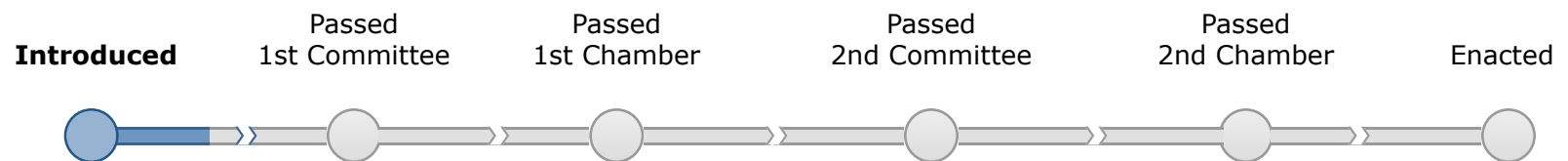
**Disposition:** Failed

**Introduced:** 01/13/2016

**Author:** DeSteph (R)

**Status:** 02/01/2016 In SENATE Committee on COMMERCE AND LABOR: Passed by indefinitely. (15-0)

## 113. VA S 332



**Title:** Step Therapy Protocols

**Summary:** Relates to step therapy protocols; requires health benefit plans that restrict the use of any prescription drug through the use of a step therapy protocol to have a clear, convenient, and expeditious process for a prescribing medical provider to request an override of such restrictions for a patient; requires website posting.

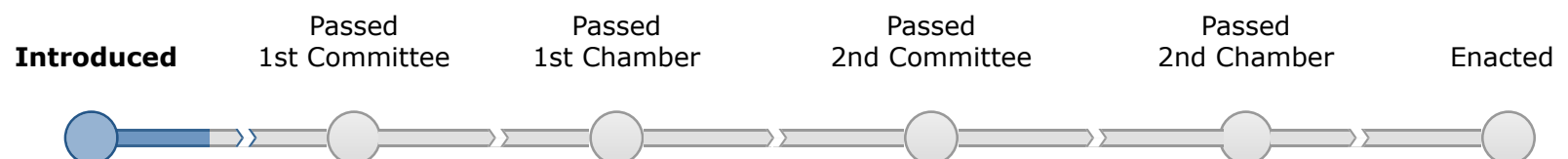
**Disposition:** Failed

**Introduced:** 01/13/2016

**Author:** DeSteph (R)

**Status:** 02/01/2016 In SENATE Committee on COMMERCE AND LABOR: Passed by indefinitely. (15-0)

## 114. VA S 1408



**Title:** Step Therapy Protocols

**Summary:** Relates to step therapy protocols; requires health benefit plans that restrict the use of any prescription drug through the use of a step therapy protocol to have in place a clear, convenient, and expeditious process for a prescribing medical provider to request an override of such restrictions for a patient.

**Disposition:** Failed

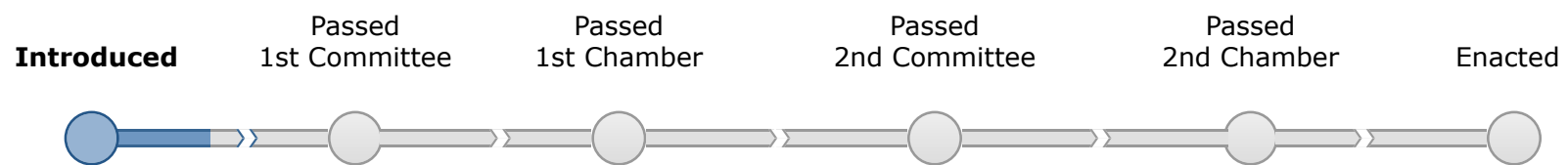
**Introduced:** 01/11/2017

**Author:** DeSteph (R)

**Status:** 01/23/2017 In SENATE Committee on COMMERCE AND LABOR: Passed by indefinitely. (9-6)

## Vermont

### 115. VT H 65



**Title:** Health Coverage for Enteral Formula for Home Use

**Summary:** Relates to health insurance coverage for enteral formula for home use.

**NORD:** NORD supports this legislation.

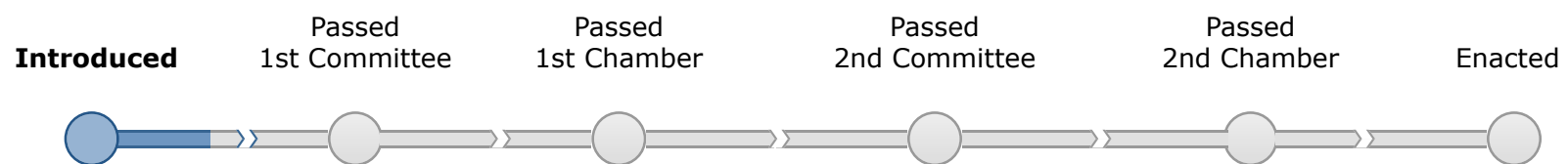
**Disposition:** Pending

**Introduced:** 01/17/2017

**Author:** Weed (D)

**Status:** 01/18/2017 To HOUSE Committee on HEALTH CARE.

### 116. VT H 447



**Title:** Interchangeable Biological Products

**Summary:** Relates to interchangeable biological products.

**NORD:** NORD supports this legislation. Actions: Submitted written testimony.

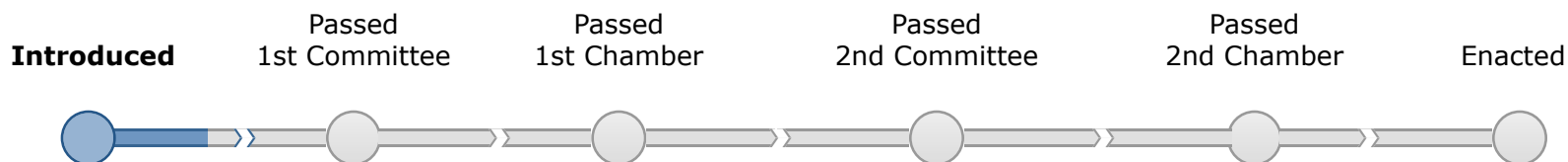
**Disposition:** Pending

**Introduced:** 02/22/2017

**Author:** Copeland-Hanzas (D)

**Status:** 02/23/2017 To HOUSE Committee on HEALTH CARE.

### 117. VT S 19



**Title:** Out of Pocket Limit for Prescription Drugs

**Summary:** Relates to preserving the out-of-pocket limit for prescription drugs in bronze-level Exchange plans.

**NORD:** NORD supports this legislation.

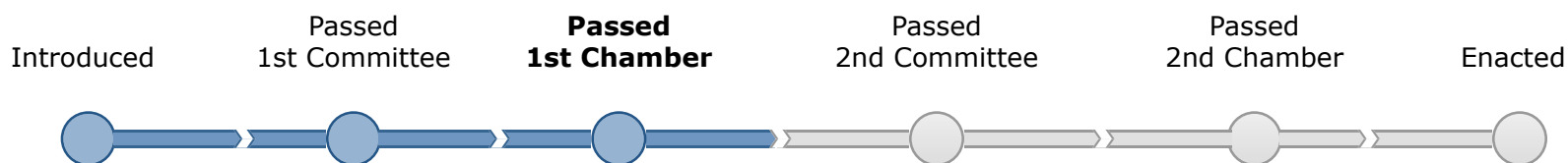
**Disposition:** Pending

**Introduced:** 01/11/2017

**Author:** Ayer (D)

**Status:** 02/14/2017 SENATE Committee on HEALTH AND WELFARE relieved of further consideration.  
02/14/2017 To SENATE Committee on FINANCE.

118. **VT S 92**



**Title:** Interchangeable Biological Products

**Summary:** Relates to interchangeable biological products.

**NORD:** NORD supports this legislation. Actions: Submitted written testimony.

**Disposition:** Pending

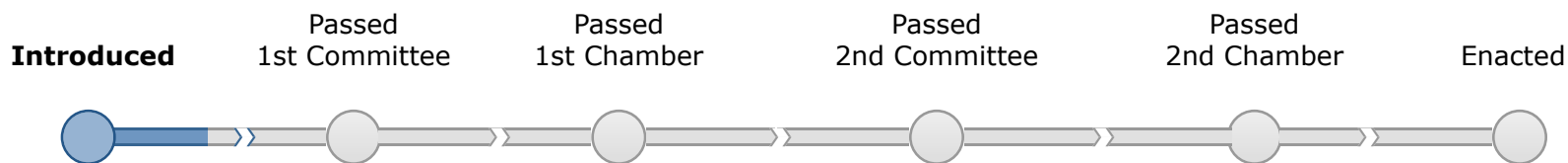
**Introduced:** 02/21/2017

**Author:** Lyons (D)

**Status:** 03/28/2017 To HOUSE Committee on HEALTH CARE.

**Washington**

119. **WA S 5626**



**Title:** Metastatic Cancer

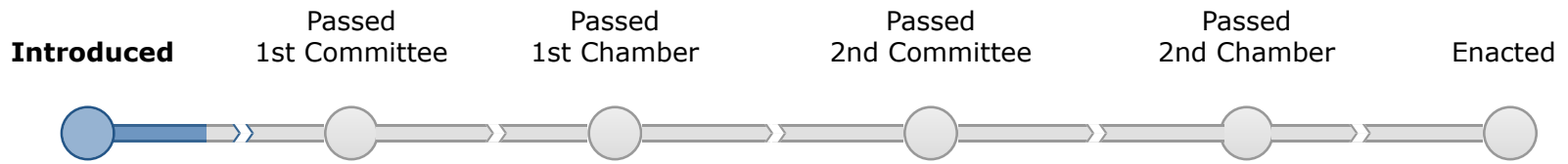
**Summary:** Prohibits the use of step therapy in treatments for stage four advanced, metastatic cancer.

**Disposition:** Pending

**Introduced:** 02/01/2017

**Author:** Miloscia (R)

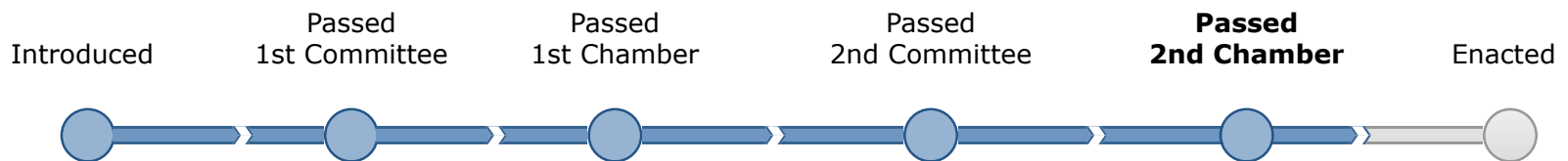
120. **WA S 5757**



**Title:** Step Therapy in Prescription Drug Coverage  
**Summary:** Concerns use of step therapy in prescription drug coverage.  
**Disposition:** Pending  
**Introduced:** 02/08/2017  
**Author:** Rivers (R)  
**Status:** 02/08/2017 INTRODUCED.  
02/08/2017 To SENATE Committee on HEALTH CARE.

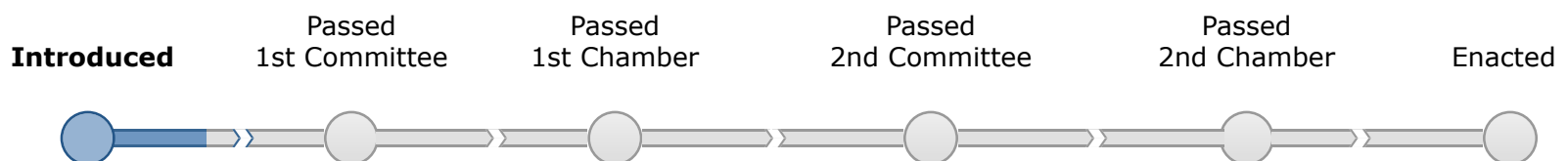
**West Virginia**

121. **WV H 2300**



**Title:** Step Therapy Protocols  
**Summary:** Regulates step therapy protocols in health benefit plans which provide prescription drug benefits; provides that upon the granting of a step therapy override determination, the health plan issuer or utilization review organization shall authorize coverage for the prescription drug prescribed by the patient's treating healthcare provider, provided such prescription drug is a covered prescription drug under such policy or contract.  
**NORD:** NORD supports this legislation. Actions: Submitted written testimony.  
**Disposition:** To Governor  
**Introduced:** 02/09/2017  
**Sponsor:** Kelly (R)  
**Status:** 03/25/2017 \*\*\*\*\*To GOVERNOR.

122. **WV S 49**



**Title:** Drug Benefits Prior Authorization Provisions



**Summary:** Requires provisions for prior authorization of drug benefits by insurers.

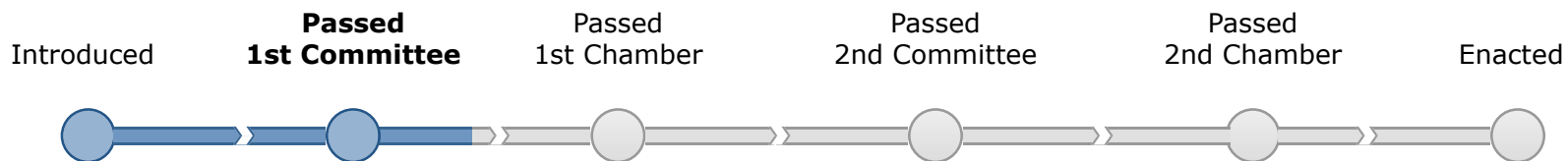
**Disposition:** Pending

**Introduced:** 02/08/2017

**Sponsor:** Ferns (R)

**Status:** 02/08/2017 INTRODUCED.  
02/08/2017 To SENATE Committee on BANKING AND INSURANCE.

## 123. **WV S 526**



**Title:** Insurance Coverage for Inherited Enzymatic Disorders

**Summary:** Relates to mandatory insurance coverage, up to the age of twenty, for certain medical foods for amino acid-based formulas; provides a list of diagnosed conditions for which insurance coverage should extend; provides that coverage extends to medically necessary foods for home use when prescribed by a physician; defines terms; provides for exclusions.

**NORD:** NORD supports this legislation. Actions: Submitted written testimony and conducted constituent outreach to legislators.

**Disposition:** Pending

**Introduced:** 03/07/2017

**Sponsor:** Takubo (R)

**Status:** 03/28/2017 In SENATE: Read 2nd time.

For more information, contact the NORD policy team at [action@rarediseases.org](mailto:action@rarediseases.org)