



RareAction[™] State Legislative Tracker

September/October 2016

For More information, please contact Tim Boyd at tboyd@rarediseases.org

ARIZONA

1. AZ H 2310

Title: **Biological Products**

Allows a pharmacist to substitute a biological product for a prescribed biological if certain conditions are met, including a **Summary:**

requirement that the pharmacy inform the patient of the substitution and a requirement that the pharmacy retain a specified record; requires notification of any price difference; provides for labeling requirements; requires a list to be maintained on a

website regarding interchangeable products; includes such products in the worker's compensation statute.

Disposition: Enacted **Introduced:** 01/14/2016

Status: 05/17/2016 Chapter No. 293

H 2310 ensures that pharmacists communicate "" to a patient's prescribing physician "" any and all dispensations of a **Commentary:**

substitute biological product for another biologic drug. NORD supports this bill and submitted written testimony.

Cobb (R) **Author:**

CALIFORNIA

2. CA A 2400

Title: Prescription Drug Coverage: Prior Authorization

Summary: Specifies that an external exception request may be file in lieu of a grievance with a health care service plan or health insurer

regarding nonformulary drugs, following an adverse benefit determination. Requires any plan or insurer grievance system process or a plan or insurer internal process to require the resolution of grievances or complaints that involve the disapproval

of a request for a formulary drug within a specified time period for both nonurgent and exigent circumstances.

Disposition: Failed - Adjourned

Introduced: 02/18/2016

Status: 05/27/2016 In ASSEMBLY Committee on APPROPRIATIONS: Held in committee.

Commentary: NORD supports this bill and submitted written testimony.

Author: Nazarian (D)

3. CA S 1095

Title: Newborn Screening Program

Summary: Requires the Department of Public Health to expand statewide screening of newborns to include screening for any disease

that is detectable in blood samples as soon as the disease is adopted by the federal Recommended Uniform Screening Panel. Provides for the Genetic Disease Testing Fund. Includes cystic fibrosis, biotinidase, severe combined immunodeficiency (SCID), and adrenoleukodystrophy (ALD). Exempts the expansion of contracts for this purpose from certain provisions of the

Public Contract Code.

Disposition: Enacted **Introduced:** 02/17/2016

Status: 09/16/2016 Signed by GOVERNOR.

09/16/2016 Chaptered by Secretary of State. Chapter No. 393

Commentary: NORD supports SB 1095 and submitted written testimony to the Senate Health Committee

Author: Pan (D)

CONNECTICUT

4. CT H 5132

Title: Newborn Screening for Pompe Disease

Summary: Adds Pompe disease to the list of testing to be administered to newborn infants.

Disposition: Failed

Introduced: 02/09/2016

Status: 03/23/2016 Failed Joint Favorable deadline.

Commentary: NORD supports this bill and submitted written testimony.

Introducer: Joint Committee on Public Health

5. CT H 5517

Title: Cost Sharing for Prescription Drugs

Summary: Concerns cost-sharing for prescription drugs; limits coinsurance, copayments, deductibles or other out-of-pocket expenses

imposed on insureds for prescription drugs.

Disposition: Failed

Introduced: 03/02/2016

Status: 03/17/2016 Failed Joint Favorable deadline.

Commentary: NORD is part of a CT-based coalition supporting this bill and provided in-person and written testimony.

Introducer: Joint Committee on Insurance and Real Estate

6. CT S 313

Title: Biological Products

Summary: Relates to biological products and interchangeable biological products; provides for the definitions of biological product and

interchangeable; provides that, except under certain circumstances or unless the purchaser instructs otherwise, the pharmacist may substitute a biological product for a prescribed biological product if certain conditions exist; requires pharmacists to inform patients of the substitution; provides for related signage and certain related recordkeeping and

maintenance requirements.

Disposition: Failed - Adjourned

Introduced: 02/25/2016

Status: 03/24/2016 Reported out of Legislative Commissioner's Office.

03/24/2016 Senate Calendar No. 188.

03/24/2016 Reissued by Legislative Commissioner's Office with File No. 218.

Commentary: Sb 313 ensures that pharmacists communicate "" to a patient's prescribing physician "" any and all dispensations of a

substitute biological product for another biologic drug. NORD supports this bill and submitted written testimony.

Introducer: Joint Committee on General Law

DISTRICT OF COLUMBIA

7. DC B 32

Title: Specialty Drug Copayment Limitation

Summary: (Permanent Law) Imposes a limit on the amount that a person must pay in copayment or coinsurance through a health benefit

plan for a prescription for a specialty drug.

Disposition: Pending **Introduced:** 01/20/2015

Status: 09/20/2016 Re-referred to the COUNCIL Committee of the WHOLE, Subcommittee on Consumer Affairs.

Sponsor: Cheh (D)

8. DC B 142

Title: Medical Foods Insurance Coverage

Summary: (Permanent Law) Establishes a law requiring health insurance policies to provide coverage for certain medical foods.

Disposition: Pending **Introduced:** 03/17/2015

Status: 09/20/2016 Re-referred to the COUNCIL Committee of the WHOLE, Subcommittee on Consumer Affairs.

Sponsor: Evans (D)

DELAWARE

9. **DE S 58**

Title: Newborn Screening Program

Summary: Creates the Newborn Screening Program; provides screening for metabolic, hematologic, endocrinologic, immunologic and

structural disorders; relates to blood specimens and consent; clarifies that genetic information may be retained for a specified time; establishes a Newborn Screening Advisory Committee; provides for confidentiality of test results; requires parental and physician notification; provides for billing; provides that no newborn shall be denied testing because of parental

inability to pay.

Disposition: Enacted **Introduced:** 04/15/2015

Status: 07/15/2015 Signed by GOVERNOR.

07/15/2015 Chapter Number 96

Primary Sponsor:

Hall-Long (D)

GEORGIA

10. GA H 875

Title: Health Benefit Policies Information and Processes

Summary: Relates to insurance generally; requires issuers of health benefit policies provide certain information to enrollees and establish

certain processes and limits relating to specialty drugs; provides for a short title; defines terms; provides specific requirements

for issuers; provides for related matters; repeals conflicting laws.

Disposition: Failed - Adjourned

Introduced: 01/28/2016

Status: 02/02/2016 In HOUSE: Read 2nd time.

Author: Hawkins (R)

HAWAII

11. **HI H 254**

State ID CD1

Title: Biosimilars

Summary: Regulates biosimilar medicines; transfers the board of drug product selection's duties of creating the list of substitutable

generic drug products and biological products to the director of health; requires labeling when dispensing an interchangeable biological product; requires an electronic medical records system to notify the practitioner of products supplied to the patient;

requires pharmacist posting regarding availability of generic or interchangeable biological products.

Disposition: Enacted

Introduced: 01/22/2015

Status: 07/12/2016 Signed by GOVERNOR.

07/12/2016 Act No. 242

Commentary: H 254 ensures that pharmacists communicate "" to a patient's prescribing physician "" any and all dispensations of a substitute

biological product for another biologic drug. NORD supports this bill and submitted written testimony.

Author: Evans (D)

12. HI HR 76

Title: Statewide Rare Disease Task Force

Summary: Requests the convening of a statewide rare disease task force.

Disposition: Failed - Adjourned

Introduced: 03/11/2016

Status: 03/14/2016 To HOUSE Committee on HEALTH.

03/14/2016 Subsequent referral set for: HOUSE Committee on FINANCE.

Commentary: NORD supported the creation of a Rare Disease Task Force as part of its Rare Disease Day event in Hawaii.

Author: Kong (D)

IOWA

13. **IA H 14**

Title: Screening of Newborns for Lysosomal Storage Disorders

Summary: Directs the Center for Congenital and Inherited Disorders with the assistance of the Department of Public Health to adopt rules

to require the screening of newborns for the six specified lysosomal storage disorders as part of the newborn metabolic screening; provides that the LSDs specified are: Globoid cell leukodystrophy, Fabry, Pompe, Niemann-Pick, Gaucher, and

Hurler syndrome.

Disposition: Failed - Adjourned

Introduced: 01/15/2015

01/20/2015 In HOUSE Committee on HUMAN RESOURCES: Subcommittee assignments:Forristall, Bacon, and Wessel-Kroeschell. Status:

Author: Ruff (D)

ILLINOIS

14. IL H 2790

Title: Newborn Metabolic Screening Act

Summary: Amends the Newborn Metabolic Screening Act; requires the Department of Public Health to provide all newborns with

screening tests for the presence of adrenoleukodystrophy; provides that testing shall begin within a certain number of months following the occurrence of various events, including the development and validation of a reliable methodology, the availability of any necessary reagents, and the establishment of relevant performance specifications; specifies a base fee for newborn

screening services.

Disposition: Enacted Introduced: 02/20/2015

Status: 08/19/2015 Signed by GOVERNOR.

08/19/2015 Public Act No. 403

Sponsor: Fine (D)

15. IL H 3519

Title: Pharmacy Practice Act

Summary: Amends the Pharmacy Practice Act; provides that a pharmacist may substitute a biological product only if the product has

been determined to be interchangeable, the physician does not designate that substitution is prohibited, the pharmacy informs the patient of the substitution, and the selected biological product that will be used as the substitution has a specified unit

price; requires a link on a specified website to the current list of interchangeable biological products.

Disposition: Pending - Carryover

Introduced: 02/26/2015

Status: 04/24/2015 Rereferred to HOUSE Committee on RULES.

Commentary: NORD supports this bill and submitted written testimony.

Sponsor: Harris D (R)

16. IL H 3605

Title: Insurance Code

Summary: Amends the Insurance Code; provides that insurers that issue individual and group accident and health policies that provides

coverage for prescription drugs shall ensure that any required copayment or coinsurance applicable to drugs and rated as platinum, gold, or silver under federal regulations does not exceed \$100 per month for up to a 30-day supply of any single drug, and \$200 for plans rated as bronze level under federal regulations, and a beneficiary's annual out-of-pocket expenditures

for/.

Disposition: Pending **Introduced:** 02/26/2015

Status: 04/22/2016 Rereferred to HOUSE Committee on RULES.

Commentary: NORD submitted written testimony.

Sponsor: Andrade (D)

17. IL H 4576

Title: Rare Disease Commission Act

Summary: Creates the Rare Disease Commission Act; provides for the creation of the Rare Disease Commission; provides that initial

appointments shall be made by a specified date; provides required criteria and considerations for appointees and nominations to the Commission; provides for terms and vacancies; provides that the Commission shall coordinate with the Genetic and

Metabolic Diseases Advisory Committee.

Disposition: Enacted **Introduced:** 01/28/2016

Status: 08/12/2016 Signed by GOVERNOR.

08/12/2016 Public Act No. 773

NORD and a coalition of rare advocates (including many of our Illinois-based member organizations) have strongly supported

H 4676 and submitted letters and testimony to the House and Senate.

Sponsor: Harper (D)

18. **IL H 5928**

Title: Managed Care Reform and Patient Rights Act

Summary: Amends the Managed Care Reform and Patient Rights Act; applies the medical exemptions process to all entities licensed in

the State to sell a policy of group or individual accident and health insurance or health benefits plan; provides certain exceptions upon which a step therapy override will always be provided; sets clinical review criteria that must be used to

establish step therapy protocols.

Disposition: Pending **Introduced:** 02/11/2016

Status: 04/08/2016 Rereferred to HOUSE Committee on RULES.

Commentary: NORD supports this bill and submitted written testimony.

Sponsor: Fine (D)

19. IL S 1359

Title: Insurance Code

Summary: Amends the Insurance Code; provides that a health plan that provides coverage for prescription drugs shall ensure that any

required copayment or coinsurance applicable to drugs on a specialty tier does not exceed \$100 per month for up to a 30-day supply of any single drug and a beneficiary's annual out-of-pocket expenditures for prescription drugs are limited to no more than fifty percent of the dollar amounts in effect under specified provisions of the federal Patient Protection Affordable Care

Act.

Disposition: Pending **Introduced:** 02/18/2015

Status: 07/31/2016 Rule 3-9(b) / Re-referred to ASSIGNMENTS Committee.

Commentary: NORD supports this bill and submitted written testimony.

Sponsor: Holmes (D)

20. **IL S 3037**

Title: Managed Care Reform and Patient Rights Act

Summary: Amends the Managed Care Reform and Patient Rights Act; applies the medical exemptions process to all entities licensed in

the State to sell a policy of group or individual accident and health insurance or health benefits plan; provides certain exceptions upon which a step therapy override will always be provided; sets clinical review criteria that must be used to

establish step therapy protocols.

Disposition: Pending **Introduced:** 02/18/2016

Status: 07/31/2016 Rule 3-9(b) / Re-referred to ASSIGNMENTS Committee.

Commentary: NORD supports this bill and submitted written testimony.

Sponsor: Morrison (D)

INDIANA

21. IN S 41

Title: Pharmacy Benefits

Summary: Relates to pharmacy benefits; requires the State Employee Health Plan, an accident and sickness insurer, and a health

maintenance organization to make available a procedure for a covered individual's use in requesting an exception to a step therapy protocol used by such entities with respect to coverage for certain prescription drugs, including time frames for a

determination concerning an exception and reasons for granting an exception.

Disposition: Enacted **Introduced:** 01/05/2016

Status: 03/23/2016 Public Law No. 19-2016

Commentary: NORD supports this bill and submitted written testimony.

Author: Long (R)

22. **IN S 164**

Title: Newborn Screening for Lysosomal Storage Disorders

Summary: Adds the following lysosomal storage disorders to the newborn screening requirements Krabbe disease; Pompe disease;

Niemann-Pick disease; Gaucher disease; Fabry disease; Hurler syndrome.

Disposition: Failed - Adjourned

Introduced: 01/05/2016

Status: 01/05/2016 INTRODUCE D.

01/05/2016 To SENATE Committee on HEALTH AND PROVIDER SERVICES.

Commentary: NORD supports this bill and submitted written testimony.

Author: Miller Pa (R)

23. IN SR 47

Title: State Department of Health Study

Summary: Urges the state department of health to study the fiscal impact of additional newborn screening.

Disposition: Adopted **Introduced:** 02/29/2016

Status: 03/08/2016 Passed SENATE. (50-0)

Commentary: NORD supports this bill and submitted written testimony.

Author: Miller Pa (R)

KANSAS

24. KS H 2239

Title: Newborn Screening for Congenital Heart Disease

Summary: Relates to newborn screening for critical congenital heart disease.

Disposition: Failed - Adjourned

Introduced: 02/04/2015

Status: 02/18/2015 Withdrawn from HOUSE Committee on HEALTH AND HUMAN SERVICES.

02/18/2015 To HOUSE Committee on APPROPRIATIONS.

Commentary: NORD supports this bill and submitted written testimony.

Author: House Judiciary Committee

25. **KS S 341**

Title: Step Therapy for Medicaid Patients

Summary: Allows step therapy for Medicaid patients; relates to the medical assistance program and the electronic claims management

system; provides for a report detailing the amount of money saved.

Disposition: Failed - Adjourned

Introduced: 01/20/2016

Status: 03/03/2016 House Hearing: 03/10/2016, 1:30PM Room 546-S

Commentary: NORD supports this bill and submitted written testimony.

Author: Senate Public Health and Welfare Committee

KENTUCKY

26. KY S 134

Title: Biological Products

Summary: Defines biological product and interchangeable biological product and to re-order other definitions; requires lower-priced

biological products to be dispensed when appropriate unless notified otherwise and require labeling and notification of

biological product substitutions; adds biological products to inspection requirements.

Disposition: Enacted

Introduced: 01/28/2016

Status: 04/09/2016 Signed by GOVERNOR.

04/11/2016 Act No. 73

Commentary: NORD supports this bill and submitted written testimony.

Sponsor: Alvarado (R)

LOUISIANA

27. LA SCR 3

Title: Newborn Screening

Summary: Directs the Department of Health and Hospitals to submit a report on the health benefits and health care costs of adding

Adrenoleukodystrophy (ALD) to the newborn screening panel; provides that the costs reported on shall include costs to the state lab operated through the Office of Public Health and also include a detailed financial analysis of how those costs would

be reimbursed by Medicaid and to the extent determinable, by commercial insurance.

Disposition: Adopted **Introduced:** 03/14/2016

Status: 05/19/2016 Passed HOUSE. (77-0)

Author: Mills (R)

MASSACHUSETTS

28. MA H 791

DOCKET 1671

Title: Prescription Drug Coverage and Step Therapy Protocols

Summary: Relates to requiring certain requirements and restrictions for prescription drugs coverage and step-therapy protocols.

Disposition: Pending **Introduced:** 03/11/2015

Status: 06/23/2016 From JOINT Committee on HEALTH CARE FINANCING: Ought to pass.

Author: Benson (D)

29. MA H 976

DOCKET 2708

Title: Substitution of Interchangeable Biosimilars

Summary: Relates to the substitution of interchangeable biosimilars.

Disposition: Pending **Introduced:** 03/11/2015

Status: 06/20/2016 From HOUSE Committee on STEERING, POLICY AND SCHEDULING. Reported for consideration by HOUSE.

06/20/2016 In HOUSE. Rules suspended. 06/20/2016 In HOUSE. Read second time. 06/20/2016 In HOUSE. Ordered to third reading.

Author: Cusack (D)

30. MA H 1894

DOCKET 2672

Title: Retail Pharmacy Discounts and Co Pay Assistance

Summary: Relates to retail pharmacy discounts and co-pay assistance.

Disposition: Pending **Introduced:** 03/11/2015

Status: 09/21/2016 From JOINT Committee on PUBLIC HEALTH: Accompanied Study Order H 4638.

Commentary: This bill is currently up for consideration as Budget Amendment #364. NORD provided written testimony and submitted

constituent emails in support of the bill and amendment.

Author: Bradley (D)

31. MA HD 945

DOCKET 1977

Title: Massachusetts Rare Disease Advisory Council

Summary: Creates a Massachusetts Rare Disease Advisory Council.

Disposition: Pending - Carryover

Status: 03/11/2015 Assigned HOUSE Bill No. 1977

Author: Heroux (D)

32. MA HD 1090

DOCKET 1967

Title: Krabbe Disease in Newborn Screening

Summary: Includes Krabbe disease in newborn screening.

Disposition: Pending - Carryover

Status: 03/11/2015 Assigned HOUSE Bill No. 1967

Commentary: NORD supports this bill and submitted written testimony.

Author: Garry (D)

33. MA S 541

DOCKET 1172

Title: Out of Pocket Expenses for Prescription Drug Coverage

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

Disposition: Pending **Introduced:** 04/15/2015

Status: 06/06/2016 From JOINT Committee on FINANCIAL SERVICES: Accompanied Study Order S 2318.

NORD is a members of the Mass Patients for Prescription Access coalition. Our work on S 541 has included multiple rounds of

Commentary: legislative visits, 300 constituent generated emails, and in-person and written testimony. We are supporting the PFPA coalition

in pursuing the bill as a budget amendment (A# 644 to H 4200).

Author: Petruccelli (D)

34. MA S 1145

DOCKET 1301

Title: Lysosomal Storage Disorders in Infants

Summary: Relates to Lysosomal Storage Disorders in infants.

Disposition: Pending

Introduced: 04/15/2015

Status: 03/28/2016 From JOINT Committee on PUBLIC HEALTH: Accompanied Study Order S 2199.

Commentary: NORD supports this bill and submitted written testimony.

Author: Fattman (R)

MAINE

35. ME LR 586

Title: Screening of Newborns for Lysosomal Storage Disorders

Summary: Concerns screening of newborns for lysosomal storage disorders.

Disposition: Failed - Adjourned **Status:** 01/14/2015 FILED.

01/14/2015 Assigned Senate Paper number 32 and LD 84.

Author: Senator Haskell

36. ME S 32

LD 84

Title: Screening of Newborns for Lysosomal Storage Disorders

Summary: Requires the Department of Health and Human Services to amend its rules in Chapter 283 by January 1, 2016 to add to the

newborn screening program the lysosomal storage disorders known as Krabbe, Pompe, Gaucher, Fabry and Niemann-Pick diseases. It authorizes the department to explore options to enter into contracts with other states to test samples collected for

lysosomal storage disorders.

Disposition: Failed

Introduced: 01/14/2015

Status: 05/06/2015 HOUSE adopts Majority Committee Report: Ought not to pass.

05/06/2015 SENATE adopts Majority Committee Report: Ought not to pass.

05/06/2015 In SENATE. Placed in Legislative File (DEAD).

Author: Haskell A (D)

MICHIGAN

37. MI H 4812

Title: Interchangeable Biological Drug Products

Summary: Provides the FDA-designated interchangeable biological drug products pharmacists are allowed to dispense.

Disposition: Pending **Introduced:** 08/18/2015

Status: 02/18/2016 From SENATE Committee on HEALTH POLICY: Recommended as substituted (S-1). (10-0)

02/18/2016 In SENATE. To second reading.

H 4812 ensures that pharmacists communicate "" to a patient's prescribing physician "" any and all dispensations of a **Commentary:**

substitute biological product for another biologic drug. NORD supports this bill and submitted written testimony.

Sponsor: Bizon (R)

38. MI S 354

Title: Prescription Drugs

Summary: Regulates tiered formulary for prescription drugs.

Disposition: Pending **Introduced:** 05/27/2015

Status: 05/27/2015 INTRODUCED.

05/27/2015 To SENATE Committee on INSURANCE.

Sponsor: Robertson (R)

MINNESOTA

39. MN S 693

Title: Health

Summary: Relates to health; adds a disorder to the lists of disorders to be tested for in the newborn screening program.

Disposition: Failed - Adjourned

Introduced: 02/06/2015

Status: 02/09/2015 To SENATE Committee on HEALTH, HUMAN SERVICES AND HOUSING.

Author: Miller (R)

MISSOURI

40. MO H 1366

Title: Laws Regarding Substitution By a Pharmacist

Summary: Changes the laws regarding the substitution by a pharmacist of an interchangeable biological product for a prescribed product.

Disposition: Failed - Adjourned

Introduced: 01/06/2016

Status: 04/20/2016 Executive Session Held.

04/20/2016 In SENATE Committee on GOVERNMENTAL ACCOUNTABILITY AND FISCAL OVERSIGHT: Voted do pass.

Commentary: H 1366 ensures that pharmacists communicate "" to a patient's prescribing physician "" any and all dispensations of a

substitute biological product for another biologic drug. NORD supports this bill and submitted written testimony.

Sponsor: Hubrecht (R)

41. MO H 1387

Title: Newborn Screening Requirements

Summary: Expands the newborn screening requirements to include severe combined immunodeficiency, also known as bubble boy

disease.

Disposition: Failed - Adjourned

Introduced: 01/06/2016

Status: 04/21/2016 Public Hearing held.

04/21/2016 Executive Session Held.

04/21/2016 In SENATE Committee on VETERANS' AFFAIRS AND HEALTH: Voted do pass.

Commentary: NORD supports this bill and submitted written testimony.

Sponsor: Roeber (R)

42. MO H 2029

Title: Step Therapy for Prescription Drugs

Summary: Changes the laws regarding step therapy for prescription drugs; states that if coverage of a prescription drug for the treatment

of any medical condition is restricted for use by a health carrier, health benefit plan, or utilization review organization via a step therapy protocol, the patient and prescribing practitioner shall have access to a readily accessible process to request a step

therapy override exception determination; provides definitions.

Disposition: Enacted **Introduced:** 01/06/2016

Status: 06/08/2016 Signed by GOVERNOR.

Commentary: NORD submitted written testimony

Sponsor: Hoskins D (R)

NORTH CAROLINA

43. NC H 821

Title: Proper Administration of Step Therapy Protocols

Summary: Ensures the proper administration of step therapy protocols for prescription drugs; defines clinical practice guidelines as a

systematically developed statement to assist health care providers and patient decisions about appropriate health care for specific clinical circumstances and conditions; relates to written screening procedures, decision abstracts, clinical protocols, and practice guidelines used by an insurer, health plan, or utilization review organization; relates to step therapy protocol.

Disposition: Failed - Adjourned

Introduced: 04/15/2015

Status: 04/30/2015 Withdrawn from calendar.

04/30/2015 Re-referred to HOUSE Committee on RULES, CALENDAR, AND OPERATIONS OF THE HOUSE.

Commentary: NORD supports this bill and submitted written testimony.

Lewis (R) Author:

NEBRASKA

44. NE L 979

Title: Interchangeable Biological Products

Provides for selection of interchangeable biological products by pharmacists. **Summary:**

Disposition: Failed - Adjourned

Introduced: 01/14/2016

02/19/2016 From LEGISLATIVE Committee on HEALTH AND HUMAN SERVICES: Placed on General File as amended. (5-0) **Status:**

Kuehn (NP) **Author:**

NEW HAMPSHIRE

45. NH LSR 623

Title: Krabbe Leukodystrophy Newborn Screening

Relates to newborn screening for Krabbe Leukodystrophy. **Summary:**

Disposition: Failed - Adjourned

Status: 01/20/2015 Assigned Bill Number: S 200.

Office of Sam Cataldo Author:

NEW JERSEY

46. **NJ A 817**

Title: Disorders in Newborn Screening Program

Summary: Expands number of disorders included in newborn screening program.

Disposition: Pending **Introduced:** 01/27/2016

Status: 01/27/2016 INTRODUCED.

01/27/2016 To ASSEMBLY Committee on WOMEN AND CHILDREN.

Sponsor: Jimenez (D)

47. NJ A 3137

Title: Rare Disease Advisory Council

Summary: Establishes the New Jersey Rare Disease Advisory Council.

Disposition: Pending **Introduced:** 02/22/2016

Status: 02/22/2016 INTRODUCE D.

02/22/2016 To ASSEMBLY Committee on HEALTH AND SENIOR SERVICES.

Sponsor: Dancer (R)

48. **NJ S 1283**

Title: Newborn Screening Program

Summary: Revises Newborn Screening program in Department of Health.

Disposition: Pending **Introduced:** 02/08/2016

Status: 02/08/2016 INTRODUCED.

02/08/2016 To SENATE Committee on HEALTH, HUMAN SERVICES AND SENIOR CITIZENS.

Sponsor: Vitale (D)

NEW YORK

49. **NY A 5174**

Title: Prescription Drug Coverage

Summary: Amends the Insurance Law; requires prescription drug coverage to include such supplements and vitamins, medical foods,

and other medications as shall be deemed necessary to mitigate or treat the symptoms of mitochondrial disease.

Disposition: Pending **Introduced:** 02/12/2015

Status: 01/19/2016 Amended in ASSEMBLY Committee on INSURANCE.

Commentary: NORD submitted written testimony

Sponsor: McDonald J (D)

50. NY S 3250

Title: Prescription Drug Coverage

Summary: Amends the Insurance Law; requires prescription drug coverage to include such supplements and vitamins, medical foods,

and other medications as shall be deemed necessary to mitigate or treat the symptoms of mitochondrial disease; include coverage for the cost of such supplements and vitamins, medical foods, and other medications; includes coverage may be

subject to such annual deductibles and coinsurance.

Disposition: Pending **Introduced:** 02/03/2015

Status: 01/15/2016 Amended in SENATE Committee on INSURANCE.

Commentary: NORD submitted written testimony

Sponsor: Little (R)

51. NY S 6311

Title: Interchangeable Biological Products

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

pharmacists.

Disposition: Pending **Introduced:** 01/06/2016

Status: 01/06/2016 INTRODUCE D.

01/06/2016 To SENATE Committee on HEALTH.

Sponsor: Hannon (R)

OHIO

52. OH H 505

Title: Regulation of Biological Products

Summary: Regards the regulation of biological products and the substitution of interchangeable biological products when dispensed by

pharmacists; provides definitions; makes clarifying changes.

Disposition: Pending **Introduced:** 04/04/2016

Status: 05/17/2016 From SENATE Committee on RULES AND REFERENCE: Recommended referral.

05/17/2016 In SENATE. To second reading. Read a second time.

05/17/2016 To SENATE Committee on HEALTH AND HUMAN SERVICES.

Commentary: NORD submitted written testimony

Sponsor: Huffman S (R)

53. **OH S 14**

Title: Krabbe Disease Newborn Screening

Summary: Requires that Krabbe disease be included in the Newborn Screening Program.

Disposition: Pending - Carryover

Introduced: 02/02/2015

Status: 02/04/2015 From SENATE Committee on RULES AND REFERENCE: Recommended referral.

02/04/2015 In SENATE. To second reading. Read a second time.

02/04/2015 To SENATE Committee on HEALTH AND HUMAN SERVICES.

Sponsor: Lehner (R)

54. **OH S 135**

Title: Rare Disease Drug Health Care Coverage

Summary: Limits the out-of-pocket cost to an individual covered by a health plan for drugs used to treat rare diseases.

Disposition: Pending - Carryover

Introduced: 03/25/2015

Status: 04/14/2015 From SENATE Committee on RULES AND REFERENCE: Recommended referral.

04/14/2015 In SENATE. To second reading. Read a second time.

04/14/2015 To SENATE Committee on INSURANCE.

Commentary: NORD is a member of the Ohio Out-of-Pocket coalition.

Sponsor: Cafaro (D)

55. OH S 243

Title: Step Therapy Protocols

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

provides for clinical review criteria, utilization review organizations, rate filing documents, public information and electronic

insurance records.

Disposition: Pending - Carryover

Introduced: 11/17/2015

Status: 12/09/2015 From SENATE Committee on RULES AND REFERENCE: Recommended referral.

12/09/2015 In SENATE. To second reading. Read a second time.

12/09/2015 To SENATE Committee on MEDICAID.

Sponsor: Lehner (R)

OKLAHOMA

56. **OK H 1503**

Title: Pharmacies

Summary: Relates to pharmacies; defines certain terms; permits pharmacists to dispense substitute biological product under certain

conditions; requires State Board of Pharmacy to maintain certain list on its website; provides for codification; provides an

effective date.

Disposition: Failed - Adjourned

Introduced: 02/02/2015

Status: 02/11/2015 Withdrawn from HOUSE Committee on PUBLIC HEALTH.

02/11/2015 To HOUSE Committee on RULES.

Commentary: NORD supports this bill and submitted written testimony.

Author: Virgin (D)

57. **OK H 1504**

Title: Insurance

Summary: Relates to insurance; defines terms; limits certain copayments and costs for certain prescription and specialty drugs; requires

certain health plans to implement an exceptions process; provides that certain denials shall be subject to certain external review; prohibits certain health plan from placing certain drugs on a specialty tier; requires the Insurance Commissioner to

promulgate certain rules; construes provisions; provides for codification; provides an effective date.

Disposition: Failed - Adjourned

Introduced: 02/02/2015

Status: 02/03/2015 To HOUSE Committee on INSURANCE.

Author: Virgin (D)

58. **OK H 2607**

Title: Education and Newborn Screening Program

Summary: Relates to public safety; relates to an education and newborn screening program; requires State Board of Health to expand

program to include adrenoleukodystrophy; provides an effective date.

Disposition: Failed - Adjourned

Introduced: 02/01/2016

Status: 02/02/2016 To HOUSE Committee on APPROPRIATIONS AND BUDGET.

Author: McDaniel J (D)

OREGON

59. OR H 4105

Title: Biological Product Dispenses

Summary: Requires a pharmacy or pharmacist that dispenses a biological product to communication the specific product dispensed to

the patient, including the name and manufacturer of the product, by making an entry into an electronic system that the

prescribing practitioner can access electronically that meets specified requirements; provides others methods of

communicating with the practitioner.

Disposition: Enacted **Introduced:** 02/01/2016

Status: 03/14/2016 Chaptered. Chapter No. 43

Commentary: NORD supports this bill and submitted written testimony.

Author: House Health Care Committee

PENNSYLVANIA

60. PA S 514

PN 1970

Title: Powers and Duties of the Department of Health

Summary: Amends the Generic Equivalent Drug Law; provides for definitions, for substitutions, for posting requirements, for powers and

duties of Department of Health and for immunity of pharmacists under certain circumstances; provides procedures for the

substitution of a biological product by a pharmacist.

Disposition: Enacted **Introduced:** 02/19/2015

Status: 07/20/2016 Signed by GOVERNOR.

07/20/2016 Act No. 95

Author: Vance (R)

61. **PA S 841**

PN 963

Title: Requirements for Insurers and Prescription Drugs

Summary: Provides requirements for insurers relating to prescription drug coverage; confers powers and imposing duties on the

Insurance Department.

Disposition: Pending - Carryover

Introduced: 05/28/2015

Status: 05/28/2015 FILED.

05/28/2015 INTRODUCE D.

05/28/2015 To SENATE Committee on BANKING AND INSURANCE.

Commentary: NORD submitted written testimony and conducted legislative visits as part of our Rare Disease Day event. NORD is a member

of Medication Access Pennsylvania.

Author: Mensch (R)

RHODE ISLAND

62. RI H 7816

Title: Pharmacy Dispensed Biological Product Regulation

Summary: Adds biological products and interchangeable biological products to the medications pharmacies may dispense; regulates

procedures for dispensing and substitution.

Disposition: Enacted **Introduced:** 03/02/2016

Status: 06/28/2016 Signed by GOVERNOR.

06/28/2016 Public Law No. 2016-193

Author: Serpa (D)

TENNESSEE

63. **TN H 33**

Title: Health Care

Summary: Relates to Health Care; requires that every newborn be tested for lysosomal storage disorders, including Krabbe, Fabry,

Gaucher, Pompe, Hurler Syndrome, Niemann-Pick, and others as determined by the department of health as screenings for

such become available.

Disposition: Failed - Adjourned

Introduced: 01/14/2015

Status: 04/21/2015 From HOUSE Committee on FINANCE, WAYS AND MEANS: Recommend passage with amendment.

04/21/2015 To HOUSE Committee on CALENDAR AND RULES.

04/21/2015 Placed on Regular Calendar.

04/22/2015 In HOUSE. Substituted on HOUSE floor by S 44

64. TN S 44

Title: Lysosomal Storage Disorder Newborn Testing

Summary: Requires that every newborn be tested for lysosomal storage disorders, including Krabbe, Fabry, Gaucher, Pompe, Hurler

Syndrome, Niemann-Pick, and other genetic, metabolic, or other heritable conditions; provides for fees.

Disposition: Enacted **Introduced:** 01/14/2015

Status: 05/20/2015 Public Chaptered. Chapter No. 436

65. TN S 2084

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: Failed - Adjourned

Introduced: 01/21/2016

Status: 03/16/2016 In SENATE Committee on GOVERNMENT OPERATIONS: Referred to General Subcommittee.

VIRGINIA

66. VAH 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: Pending - Carryover

Introduced: 01/13/2016

Status: 02/02/2016 In HOUSE Committee on COMMERCE AND LABOR: Continued to 2017.

Author: Davis (R)

WISCONSIN

67. **WIS 39**

Title: Newborn Screening

Summary: Relates to newborn screening for certain lysosomal storage disorders.

Disposition: Failed

Introduced: 02/19/2015

Status: 04/13/2016 Failed to pass pursuant to Senate Joint Resolution 1.

Author: