

## NORD Region A Policy & Advocacy Taskforce Meeting Minutes

### Introductions

- Please join me in welcoming our two new Region A Co-Chairs, Melanie Flood and Kellie Herbert!
  - o Melanie is a patient advocate and communications director who lives with NMOSD, which she was not diagnosed with until she was in her 40s. Melanie is based in the Sacramento, CA area.
  - o Kellie is a mother to a son who has a very rare genetic disorder called SLC6A1. Kellie is based in the Denver, CO area.
- Supraja Sowmiyanarayanan has joined NORD's Policy team as Program Assistant. Supraja will be helping with Taskforce communications, so you can expect to see her name in your email inbox in the future!

### NORD Policy Updates

- Colorado Medicaid Step Therapy ([HB 23-1183](#))
  - o This bill would reform step therapy protocols in Colorado's Medicaid program by requiring an exemption process by which qualifying patients can request and be granted an exemption from taking another medication before accessing the medication their provider prescribes.
  - o HB 23-1183 has passed the House and crossed over to the Senate. There was a hearing on 3/30 in the Senate Health & Human Services Committee during which the bill was passed unanimously out of committee and rereferred to the Senate Committee on Appropriations.
- Hawaii Interstate Medical Licensure Compact ([SB 674/HB 666](#))
  - o SB 674 has passed through the Senate and passed through its third of three committees on the House side on Thursday! It will next head to the House floor for a full vote – TBD when that will be, but I will keep everyone posted. NORD has put together [an action alert](#) for advocates in Hawaii to contact their Representatives in support of the IMLC bill.
  - o I also want to give a shoutout to our very own Region A Taskforce member Judy who has testified in support of the IMLC legislation several times throughout this legislative session!
- New Mexico Interstate Medical Licensure Compact ([SB 67](#))
  - o SB 67 would adopt the Interstate Medical Licensure Compact in New Mexico. The IMLC is an agreement between states that helps to streamline the medical licensure process for out-of-state physicians who are already licensed in another state. This makes it easier for out-of-state physicians to get licensed in additional states, which expands access to telehealth services.
  - o SB 67 has been referred to the Senate Health and Public Affairs Committee.
- New Mexico Biomarker ([HB 73](#))
  - o HB 73 would require state-regulated insurance plans to cover biomarker testing. Biomarkers can be very helpful in determining what treatment may be the most effective for a given condition.

- HB 73 is awaiting the Governor's signature!
- Oregon Rare Disease Advisory Council (RDAC) ([HB 2047](#))
  - RDACs seek to give the rare disease community a voice in state government by bringing together stakeholders across the rare disease community to make recommendations to policymakers on what policies will best service the state's rare community.
  - An informational hearing on the bill will likely take place when it comes closer to the end of the session.
  - If you live in Oregon and would like to be connected with the OR RDAC coalition, reach out to Annissa Reed at [areed@rarediseases.org](mailto:areed@rarediseases.org) after this meeting.
- Washington RDAC ([SB 5097](#))
  - NORD will be working alongside other patient organizations and legislative partners to pursue a budget provision for the legislation as an alternate way to establish the council, as the legislation did not move forward.
  - If you live in Washington and would like to be connected with the WA RDAC coalition, reach out to Annissa Reed at [areed@rarediseases.org](mailto:areed@rarediseases.org) after this meeting.
- Washington Biomarker ([SB 5074/ H 1450](#))
  - HB 73 would require state-regulated insurance plans to cover biomarker testing. Biomarkers can be very helpful in determining what treatment may be the most effective for a given condition.
  - This legislation has been assigned to the House Appropriations Committee
- California RDAC
  - Unfortunately, we were unable to submit budget requests, as the lawmakers that we identified as our strongest potential champions expressed that due to the limitations imposed by current budget shortfall, they had other priorities they are focused on this year and were unable to champion the efforts. We are hoping to host an in-person RDAC advocacy day in Sacramento with our coalition leaders in the future. The coalition will regroup within the next few months to begin discussing 2024 strategy.
  - If you live in California and would like to be connected with the CA RDAC coalition, reach out to Annissa Reed at [areed@rarediseases.org](mailto:areed@rarediseases.org) after this meeting.

### **Legislation Flagged by Taskforce Members\***

- California Treatment for PANDAS and PANS ([AB 907](#))
  - Region A Taskforce member Reggie Barnes flagged California's AB 907, a bill that would provide coverage for the prophylaxis, diagnosis, and treatment of Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-onset Neuropsychiatric Syndrome (PANS). If you're interested in learning more about this bill you can contact Reggie Barnes at [reggie@autoimmuneregistry.org](mailto:reggie@autoimmuneregistry.org).

### **Living Rare Living Stronger 2023**

- NORD's annual patient and family forum, Living Rare Living Stronger, will be taking place in Washington, DC on May 6. Folks have the option to attend in person or virtually and attendance is free for patients and caregivers!

- To learn more about Living Rare Living Stronger and to register for the event, please visit [livingrare.org](https://livingrare.org).

### **Inflation Reduction Act Action Alert and Webinar**

- For the first time, the Centers for Medicare & Medicaid Services (CMS) will be negotiating the price of certain prescription drugs, thanks to the Inflation Reduction Act passed last year. This could have significant impacts - some positive, some potentially problematic - for the more than 25 million people living with a rare disease.
- CMS wants to hear from you and seeks public comment as it finalizes the program's requirements and parameters. Let CMS know how the law will impact you including:
  - o What it means for patients to afford the life-changing medicines they need to manage their rare disease.
  - o That it's unacceptable for 90% of the 7,000+ rare diseases to not yet have an FDA-approved treatment, so CMS must be careful not to stifle rare disease drug development.
  - o Ensuring that the impacted drugs have an acceptable price and patients are not forced to wait before taking these medicines due to burdensome step therapy and prior authorization practices.
  - o The fact that rare disease patients and caregivers have key insights to share on their complex health challenges, including the value of a particular therapy compared to alternative treatment options.
- NORD has put together [an action alert](#) for you to contact CMS. There is a template letter with space for you to add your own story as well if you'd like to. Feedback is due April 14, 2023.
- Additionally, please join us on Tuesday, April 11 from 2:00 PM - 2:45 PM EST for a fireside chat with Kristi Martin, Chief of Staff and Senior Advisor for the Center for Medicare at CMS and Heidi Ross, Vice President of Policy and Regulatory Affairs at NORD to learn more about this important law. [Register for the April 11 webinar with CMS here.](#)

### **Our next national meeting will take place on May 23!**

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*\*Unfortunately, NORD does not have the capacity to engage on every issue that may impact members of the rare disease community or disease-specific legislation, however, the following bills have been flagged by members of NORD's Policy & Advocacy Taskforce. If you'd like to flag a bill for inclusion on the meeting minutes, please email Supraja Sowmiyanarayanan at [ssowmiyanarayanan@rarediseases.org](mailto:ssowmiyanarayanan@rarediseases.org)!*

## NORD Region B Policy & Advocacy Taskforce Meeting Minutes

### Introductions

- Please join me in welcoming our two new Region B Co-Chairs, Breana Bagley and Nicole Ivelic!
  - o Breana is a caregiver to her mother who was diagnosed with a rare pancreatic disease eight years ago. She is also an attorney with a specialization in health law and has engaged in advocacy efforts with NORD and the National Pancreas Foundation for many years. Breana is located in the Chicago, IL area.
  - o Nicole is a mother to her son, Noah, who was diagnosed with Malan Syndrome in 2021. She had to fight for answers and testing to receive her son's diagnosis and hopes to help others push for change. Nicole is also located in the Chicago area.
- Supraja Sowmiyanarayanan has joined NORD's Policy team as Program Assistant. Supraja will be helping with Taskforce communications, so you can expect to see her name in your email inbox in the future!

### NORD Policy Updates

- Missouri Interstate Medical Licensure ([HB 348](#)/[HB 285](#)/[SB 393](#))
  - o These bills would adopt the Interstate Medical Licensure Compact in Missouri. The IMLC is an agreement between states that helps to streamline the medical licensure process for out-of-state physicians who are already licensed in another state. This makes it easier for out-of-state physicians to get licensed in additional states, which expands access to telehealth services.
  - o HB 348 seems to be the bill that is moving. It has passed out of the HCS Committee and been placed on the House informal perfection calendar to be considered by the House.
- Arkansas Rare Disease Advisory Council ([HB 1357](#))
  - o HB 1357 unfortunately did not move forward before the legislature adjourned this year. NORD will continue working alongside a coalition of advocates in Arkansas to prepare for 2024.
- Iowa Rare Disease Advisory Council ([HF 287](#))
  - o The legislation was assigned to the House Health and Human Services Committee; however, it was not heard by the Committee's deadline. NORD will continue working alongside a coalition of advocates in Iowa to prepare for the 2024 legislative session.
- Texas Rare Disease Advisory Council ([HB 4619](#)/[SB 1408](#))
  - o SB 1408 has been assigned to the Senate Health & Human Services Committee, and HB 4619 has been assigned to the House Public Health Committee.
- Oklahoma Biomarker ([SB 513](#))
  - o SB 513 would require state-regulated insurance plans to cover biomarker testing. Biomarkers can be very helpful in determining what treatment may be the most effective for a given condition.
  - o The bill has passed through the Senate and has been referred to the House Public Health Committee where a hearing was held on April 5 during our Region B Taskforce meeting.

The Public Health Committee unanimously reported the bill out of Committee with a recommendation to pass the legislation.

### **Legislation Flagged by Taskforce Members\***

- Missouri and North Dakota Copay Accumulator (MO [HB 442](#) & ND [HB 1413](#))
  - o Region B Taskforce Member Darlene Shelton flagged Missouri and North Dakota copay accumulator legislation. These bills would require state-regulated insurance providers to apply funds paid by a copay card toward a beneficiary's annual deductible.
  - o HB 442 has been passed by the Missouri House of Representatives and crossed over to the Senate where it is awaiting a referral to a committee.
  - o HB 1413 has been passed by the North Dakota House and Senate and is currently in conference committee where House and Senate representatives are hashing out the difference between the versions passed in each chamber.
  - o For more information on these copay accumulator bills, please contact Darlene Shelton at [darlene@dannysdose.com](mailto:darlene@dannysdose.com).

### **Living Rare Living Stronger 2023**

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- To learn more about Living Rare Living Stronger and to register for the event, please visit [livingrare.org](https://livingrare.org).

### **Inflation Reduction Act Action Alert and Webinar**

- For the first time, the Centers for Medicare & Medicaid Services (CMS) will be negotiating the price of certain prescription drugs, thanks to the Inflation Reduction Act passed last year. This could have significant impacts - some positive, some potentially problematic - for the more than 25 million people living with a rare disease.
- CMS wants to hear from you and seeks public comment as it finalizes the program's requirements and parameters. Let CMS know how the law will impact you including:
  - o What it means for patients to afford the life-changing medicines they need to manage their rare disease.
  - o That it's unacceptable for 90% of the 7,000+ rare diseases to not yet have an FDA-approved treatment, so CMS must be careful not to stifle rare disease drug development.
  - o Ensuring that the impacted drugs have an acceptable price and patients are not forced to wait before taking these medicines due to burdensome step therapy and prior authorization practices.
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## NORD Region C Policy & Advocacy Taskforce Meeting Minutes

### Introductions

- Please join me in welcoming our new Region C Co-Chair, Jeron Hill!
  - o Jeron is a rare disease patient and advocate living with the rare bleeding disorder Hemophilia B. Jeron has extensive speaking and advocacy experience in the bleeding disorder community and is excited to bring his knowledge and expertise to NORD's Policy & Advocacy Taskforce. Jeron is located in North Carolina.
- Supraja Sowmiyanarayanan has joined NORD's Policy team as Program Assistant. Supraja will be helping with Taskforce communications, so you can expect to see her name in your email inbox in the future!

### NORD Policy Updates

- Ohio Biomarker ([HB 24](#))
  - o HB 24 would require state-regulated health plans to cover biomarker testing.
  - o HB 24 has been assigned to the House Insurance Committee and a hearing on the bill took place on March 29, but a vote to move the bill out of the committee hasn't happened yet.
- Indiana Rare Disease Advisory Council ([HB 1201](#))
  - o Passed the House and has crossed over to the Senate where it has been referred to the Senate Committee on Health & Provider Services. A hearing on the bill is scheduled for April 12 at 9:00 AM EST.
- Michigan Rare Disease Advisory Council ([HB 4167](#))
  - o HB 4167 has passed the House and crossed over to the Senate where it has been referred to the Senate Committee on Health Policy.
- Georgia Biomarker ([HB 85](#))
  - o HB 85 would require state-regulated insurance plans to cover biomarker testing. Biomarkers can be very helpful in determining what treatment may be the most effective for a given condition.
  - o The bill has passed through both chambers and the legislation is awaiting the Governor's signature.
- Florida Biomarker ([HB 805](#) / [SB 1218](#))
  - o Similarly to HB 85 in Georgia, HB 805 & SB 1218 would require state-regulated insurance plans to cover biomarker testing.
  - o SB 1218 has been assigned to the Senate Health Policy Committee, the Appropriations Committee on Health and Human Services, and the Fiscal Policy Committee. HB 805 has been assigned to the House Healthcare Regulation Subcommittee. Both bills are awaiting hearings and we will provide further updates when we have that information!
- Kentucky Biomarker ([HB 180](#))
  - o Another biomarker bill, HB 180 will require state-regulated health plans to cover biomarker testing.

- HB 180 has been passed by the Kentucky legislature and was signed by the Governor at the end of March!
- North Carolina Medicaid Expansion ([HB 76](#))
  - HB 76 will expand eligibility for Medicaid to low-income childless adults with an annual income at or below 138% of the federal poverty level.
  - The North Carolina legislature has passed HB 76 and Governor Roy Cooper has signed the bill into law. Medicaid expansion will take effect upon the signing into law of the Fiscal Year 2023-2025 Appropriations Act.
- North Carolina Interstate Medical Licensure ([SB 324](#))
  - SB 324 would adopt the Interstate Medical Licensure Compact in North Carolina. The IMLC is an agreement between states that helps to streamline the medical licensure process for out-of-state physicians who are already licensed in another state. This makes it easier for out-of-state physicians to get licensed in additional states, which expands access to telehealth services.
  - SB 234 has been referred to the Committee on Rules & Operations of the Senate. No hearing has been scheduled yet.

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  - That it's unacceptable for 90% of the 7,000+ rare diseases to not yet have an FDA-approved treatment, so CMS must be careful not to stifle rare disease drug development.
  - Ensuring that the impacted drugs have an acceptable price and patients are not forced to wait before taking these medicines due to burdensome step therapy and prior authorization practices.
  - The fact that rare disease patients and caregivers have key insights to share on their complex health challenges, including the value of a particular therapy compared to alternative treatment options.
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## NORD Region D Policy & Advocacy Taskforce Meeting Minutes

### Introductions

- Please join me in welcoming our new Region D Co-Chair, Barbie Ann Stephen!
  - o Barbie is a rare disease patient and caregiver to her son who has a rare disease, as well as a PhD candidate in the Translational Health Sciences program at the George Washington University. Barbie is located in Maryland.
- Supraja Sowmiyanarayanan has joined NORD's Policy team as Program Assistant. Supraja will be helping with Taskforce communications, so you can expect to see her name in your email inbox in the future!

### NORD Policy Updates

- New York Interstate Medical Licensure Compact ([S 2216](#))
  - o S 2216 would adopt the Interstate Medical Licensure Compact in New York. The IMLC is an agreement between states that helps to streamline the medical licensure process for out-of-state physicians who are already licensed in another state. This makes it easier for out-of-state physicians to get licensed in additional states, which expands access to telehealth services.
  - o S 2216 has been introduced and referred to the Higher Education Committee
- Massachusetts Interstate Medical Licensure Compact ([HD 1221](#))
  - o HD 1221 would adopt the IMLC in Massachusetts.
  - o This bill has been referred to the Joint Committee on Public Health, waiting on a hearing date.
- Maryland Prior Authorization ([SB 308](#))
  - o Unfortunately, SB 308 did not move this year.
- Delaware Rare Disease Advisory Council ([SB 55](#))
  - o SB 55 has passed out of the Senate Health and Social Services Committee and is awaiting a vote in the full Senate.
- Maryland Rare Disease Advisory Council ([SB 188](#)/[HB 302](#))
  - o SB 188 and HB 302 have been passed by the Maryland legislature and are awaiting the Governor's signature!
- Maryland Step Therapy Reform ([SB 515](#)/[HB 785](#))
  - o SB 515 and HB 785 would reform step therapy protocols in Maryland's state-regulated insurance plans by requiring an exemption process by which qualifying patients can request and be granted an exemption from taking another medication before accessing the medication their provider prescribes.
  - o SB 515 and HB 785 have been passed by the Maryland legislature and are awaiting the Governor's signature!
- Maryland Telehealth ([SB 534](#))
  - o This bill extends flexibilities allowing the definition of "telehealth" to include certain audio-only mediums for the purpose of reimbursement by certain state-regulated insurance plans to June 30, 2025, and requires the Maryland Medical Health Care

Commission to study and make recommendations on the use of telehealth services in the state.

- New York Biomarker ([A1673 / S1196](#))
  - o A1673 and S1196 would require state-regulated insurance plans to cover biomarker testing. Biomarkers can be very helpful in determining what treatment may be the most effective for a given condition.
  - o Both bills have been assigned to the chambers' Insurance Committees and are awaiting hearings.
- New Hampshire Medical Nutrition ([SB 178](#))
  - o SB 178 would prohibit out-of-pocket spending on and allow coverage of special medical formula for Medicaid beneficiaries in New Hampshire.
  - o The Senate Finance Committee voted on 3/16 to rerefer SB 178, but no committee has been clarified as of yet.
- Connecticut Biomarker ([HB 6628](#))
  - o HB 6628 would require Connecticut's Medicaid program to cover biomarker testing. Biomarkers can be very helpful in determining what treatment may be the most effective for a given condition.
  - o HB 6628 was referred to the CGA-Appropriations Committee on March 7 and appeared to die in Committee, as all bills were supposed to be reported out of committee by March 31. However, the Governor's office and advocates from the American Cancer Society helped keep the bill alive. The Appropriations Committee will review the Governor's budget on April 13 and hopefully look to see if coverage of biomarker testing can be managed by the Medicaid budget.

#### **Legislation Flagged by Taskforce Members\***

- Connecticut Blood Plasma Collection ([HB 6836](#))
  - o Region D Taskforce Member Lesley Bennett flagged Connecticut's HB 6836, a bill that would require the Commissioner of Public Health to grant a waiver to clinical laboratories to conduct blood plasma collection prior to licensure.
  - o HB 6836 had a hearing in the Joint Committee on Public Health on March 6 and was reported out of the Committee at the end of March. The bill has now been referred to the Office of Legislative Research and Office of Fiscal Analysis.
  - o If you would like more information about HB 6836, please contact Lesley Bennett at [lesley.bennett@rareaction.org](mailto:lesley.bennett@rareaction.org).
- Connecticut Windshield Placards ([SB 995](#))
  - o Connecticut advocate Mary Caruso flagged CT [Senate Bill 995](#), a bill that would create a Windshield Placard Advisory Council within the Department of Motor Vehicles to:
    - Review laws concerning the issuance and use of removable windshield placards for people who are blind and people with disabilities,
    - Recommend best practices to the Commissioner of Motor Vehicles, and
    - Make educational materials available to providers, law enforcement officers, and the general public regarding the proper issuance and use of such removable windshield placards.

- Mary has been kind enough to put together a template letter for Connecticut residents to contact their elected officials, which can be found [here](#). You can contact Mary Caruso at [meirbode@aol.com](mailto:meirbode@aol.com) with any questions about SB 995.
- New Jersey Blood Glucose Monitoring ([A4875](#))
  - Region D Co-Chair Julie Raskin flagged New Jersey's A4875, a bill that expands the definition of basic life support to include blood glucose monitoring. The bill has been introduced and referred to the Assembly Health Committee.
  - If you would like more information about A4875, please contact Julie Raskin at [jraskin@congenitalhi.org](mailto:jraskin@congenitalhi.org).

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