

# Rare Disease Issues State by State

## Creating a State Rare Disease Caucus



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# Forming a Rare Disease Caucus

February 28, 2017

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# Forming a Rare Disease Caucus

## **Initial Steps**

- Research legislator co-sponsorship memos
- Invite legislators to a coordination & planning meeting
- Approach leadership in the House & Senate about creating the caucus

## **Launch of Caucus**

- Draft recruitment letter for Caucus Co-coordinators to sign and circulate
- Be sure to have a deadline for signing up
- Arrange for a Rare Disease Caucus announcement

# PA Joint Rare Disease Caucus



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## **Next Steps**

- Schedule initial meeting of the caucus
- Select or elect Caucus Co-Chairs (usually the coordinators)
  - Stress the bi-partisan and bi-cameral nature of the caucus
  - Seek diversity – geographic/gender
  - Provide background information – NORD's State Report Card

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## Results

- 26 members of the initial Rare Disease Caucus
  - 12 Senators
  - 14 Representatives
- Set Goals for the caucus
- Introduce legislation
  - House Bill 239 to establish a Rare Disease Task Force

# Questions / Open Discussion

Thank you!

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