

# Phelan-McDermid Syndrome Foundation Advocacy Priorities

The following document has been created to help educate our community about the advocacy priorities of the Phelan-McDermid Syndrome Foundation. We thank the National Fragile X Foundation for the original document from which this was modified.



## MONITOR

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PMSF is closely monitoring a range of federal policies, initiatives, and legislation that may directly impact the Phelan-McDermid syndrome community. However, final decisions about each of these have not yet been made so it is important for us to keep our eye on it. Since it's challenging to keep up with everything, we recommend focusing on the two or three most important priorities for you and your family from the list and treating those as your primary action items to monitor. Once we know more, we will share this with our community and help provide key information so that you can contact your US Representatives/Senators, if needed.

- Disability Services and Support Program Policies
  - Medicaid, SSI, Education/IDEA/504, Vocational training and employment support
- Federal research funding opportunities
- NIH cuts to facilities and administrative costs, “indirects”
- Telehealth policies
- Drug prices and access policies
- Achieving a Better Life Experience (ABLE) Policies
- Caregiver support policies
- Rare disease inter-agency coordination
- FDA Rare Hub initiatives
- Rare pediatric disease designation and priority review voucher programs



## STAY INFORMED and TAKE ACTION

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We know your lives are extremely busy, and keeping up with what is happening in the federal government is often not at the top of your mind. However, more than ever, the Phelan-McDermid syndrome community needs as much support from as many people as we can get to make sure clinical care and special education services are maintained, research and scientific discoveries continue uninterrupted, and funding for care and research is maximized. To stay informed and learn about Action Items, the following links and organizations are great resources. You do not need to follow them all, just pick one or two to have bookmarked or sign-up for emails!

- [Phelan-McDermid Syndrome Advocacy Facebook page](#)
- [EveryLife Foundation](#)
- [National Organization for Rare Disorders \(NORD\)](#)
- [National Down Syndrome Congress](#)
- [The Arc](#)

