



NATIONAL FRAGILE X FOUNDATION

Your Visit with Your Members of Congress August 2019

The Opening

- Explain that you are representing Fragile X families
- Explain Fragile X and share your personal story in 2-3 minutes. You can take longer if other advocates are not at the meeting.

The Asks

Continue Funding for Fragile X Research and Programs: Currently the NIH, CDC, and DOD fund Fragile X research and programming. Each budget year, members of Congress (MOC), the President, and the agencies work together to set funding levels and priorities. As part of that process, an MOC can express directions and preferences to the Appropriations Committees responsible for the final say on these matters.

One way your MOC expresses these preferences is to cosign a letter to the Appropriators to continue funding for Fragile X and to direct how some of the funds are used by the agencies. The letter comes from our Champions and it is circulated among all MOCs requesting that they add their names to the letter. After all of the signatures are collected, our Champions deliver the letter with all the signatures to the Appropriations Committees. **Before your meeting, check the list I provided to see if they signed the letter this Spring. If so, thank them for their support.**

ASK: At this point in the year, there isn't a direct ask UNLESS your Senator sits on the Defense Appropriations Subcommittee (Rs: Shelby, McConnell, Alexander, Collins, Murkowski, Graham, Blunt, Moran, Hoeven, and Boozman; Ds: Durbin, Leahy, Feinstein, Murray, Reed, Tester, Udall, Schatz, and Baldwin). If you are meeting with any of these offices, share the Senate letter and ask that they make sure Fragile X is included as an authorized research area for the DOD's Peer Reviewed Medical Research Program.

The bill has not been released or considered yet by the Senate Subcommittee because they were awaiting a final budget deal, which will be enacted before they leave for the August recess. They will consider this in September. DO NOT let them get away with "requests were due this Spring." Ask them to support it in the report language for the bill.

SENATE: Support the Autism CARES Act (H.R. 1058; S. 427). Note that this legislation covers all developmental disabilities in most of its programs, despite the focus on autism in the name. The legislation will:

- Authorize programs – awareness, training, and research – for developmental disabilities, including autism. They cover all developmental disabilities. The training programs fund



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distance and in-person training for professionals who treat developmental disabilities, fellowships for developmental pediatricians, and autism-related research.

- Reauthorizes the programs for five-years.

H.R. 1058 passed the House under suspension on 7/24/2019. Suspension means no one objected to its passage. This needs to pass in September before the programs expire (they are authorized for five years at a time). Ask your Senator to support its passage. They are likely to act on the House bill rather than the Senate bill to expedite the process.

HOUSE: Cosponsor the HEADS Up Act (H.R. 2417). The legislation defines individuals with intellectual and developmental disabilities (IDD) as a “medically underserved population” to help increase the services available to them. It provides for:

- Loan repayment and training programs to medical professionals providing care to people with IDD in HSRA’s Workforce Development and Training Programs including the National Health Service Corps Scholarships.
- Financial incentives for medical providers to treat people with IDD in the form of higher Medicare and Medicaid reimbursement rates.
- Incentivize new research.
- Federal funding for health centers and public health infrastructure such as Federally Qualified Health centers (FQHC).

Rep. Moulton (D-MA-6) and Rep. Fitzpatrick (R-PA-1) are the lead sponsors. Contact Chrissy Raymond with Rep. Moulton or Joe Knowles with Rep. Fitzpatrick. There is no Senate bill.

HOUSE: Join the Fragile X Caucus. There is no financial cost to joining the Caucus nor are they signing on to any policy positions.

The Close

- Can we count on your support? How should I follow up with you?
- Thank you for your time and consideration of our requests.
- Be sure to leave your business card/contact information.
- Send a personal thank you note – preferably via mail, but email is great too.

If asked for more information, please let them know that Dan Whiting will follow-up with them or they can reach Dan at dan@fragilex.org or (202) 531-9091.