



The National **Fragile X** Foundation

National Fragile X Awareness Day House Resolution

Action Alert

Representatives Bilbray (CA-50), Delahunt (MA-10), Hare (IL-17), and Harper (MS-3) have authored a resolution acknowledging July 22nd, 2009 as National Fragile X Awareness Day. This House Resolution (H.RES.611) urges physicians and health providers to utilize available diagnostic, developmental screening and surveillance modalities to better diagnose Fragile X-associated Disorders, private and public health insurance entities to provide full coverage for these diagnostic tools, and the National Institutes of Health (NIH) and related member institutes to fully implement the NIH Research Plan on Fragile X Syndrome and Associated Disorders.

How you can help: Please take a few minutes to call or write your Representatives today to ask them to cosponsor our Resolution! You can reach your Representatives by calling the Capitol Switchboard at 202-224-3121. If you don't know who your Representatives are, go to www.congress.org and enter your zip code in the upper right corner.

We have included both a script and email/letter template (below) to help you reach out to these offices. Please do not hesitate to contact me or Sara Weir (sara.weir@bakerd.com/202-312-7475) with any questions.

Regards,

Jeffrey Cohen
Chair, Public Policy Committee
National Fragile X Foundation

Script/Talking Points to Call Your Senators and Representative:

ADVOCATE:

Hi, my name is _____. I'm a constituent from ____ (home town) _____. Could I please speak to the Congressman's Legislative Assistant who handles disability and/or healthcare issues?

CONGRESSIONAL OFFICE:

Let me see if XXXX is available. May I ask what you are calling about?

ADVOCATE:

Sure, I'm an individual/parent of a child/adult with Fragile X. I would like to discuss a House Resolution that is very important to our family.

CONGRESSIONAL OFFICE DISABILITY/HEALTHCARE LEGISLATIVE ASSISTANT:

Hi, this is XXXX, how can I help you?

ADVOCATE:

Hi, this is ___ (your name) ___ from ___ (home town) _____. I'm an individual/parent of a child/adult with Fragile X. I would like to discuss a Resolution, H.RES.611, that is very important to our family. I am calling to ask my Representative to cosponsor the H.RES.611 led by:

- Representatives Bilbray (CA-50), Delahunt (MA-10), Hare (IL-17), and Harper (MS-3)

This Resolution urges:

- Physicians and health providers to utilize available diagnostic, developmental screening and surveillance modalities to better diagnose Fragile X-associated Disorders;
- Private and public health insurance entities to provide full coverage for these diagnostic tools; and
- The National Institutes of Health (NIH) and related member institutes to fully implement the NIH Research Plan on Fragile X Syndrome and Associated Disorders.

CONGRESSIONAL OFFICE DISABILITY LEGISLATIVE ASSISTANT:

I will let my boss know that we talked and make sure that he/she takes a look at the Resolution. (Note: When you talk to the legislative staff, you are likely to get the response.)

ADVOCATE:

If your boss is interested in signing on as a cosponsor, you may contact:

- Kemi Jemilohun (Kemi.Jemilohun@mail.house.gov or 202-225-5905) in Representative Phil Hare's office.

Thank you for your time. I hope your boss will consider cosponsoring this important Resolution. Can I get your email so that I can follow up with you on this issue? Thanks very much!

Email Template to Send to Your Senators and Representative:

Dear Representative XX:

On behalf of the individuals and families impacted by Fragile X, I am writing to ask you to cosponsor the ***House Resolution 611*** led by Representatives Bilbray (CA-50), Delahunt (M-10), Hare (IL-17), and Harper (MS-3). This House Resolution urges physicians and health providers to utilize available diagnostic, developmental screening and surveillance modalities to better diagnose Fragile X-associated Disorders, private and public health insurance entities to provide full coverage for these diagnostic tools, and the National Institutes of Health (NIH) and related member institutes to fully implement the NIH Research Plan on Fragile X Syndrome and Associated Disorders.

If you would like to cosponsor H.RES.611, please contact Kemi Jemilohun (Kemi.Jemilohun@mail.house.gov or 202-225-5905) in Representative Phil Hare's office.

Thank you for your consideration of this very important piece of Resolution.

Thank you,

[INSERT Advocate Name/Contact Information]