NATIONAL **FRAGILE X**
FOUNDATION

ADVOCACY DAY 2012

WASHINGTON, DC

March 6-7, 2012

NATIONAL **FRAGILE X**
FOUNDATION
forward

1615 Bonanza Suite 202-Walnut Creek, CA 94596

(800) 688-8765 or (925) 938-9300

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SECTION I: Advocacy Day Agenda

AGENDA
March 6-7, 2012

TRAINING DAY: Tuesday, March 6th, 2012

12:00 noon – 1:00 p.m.	Advocacy Day Registration (sign in and pick up materials)
1:00 p.m. – 1:15 pm.	Welcome to Advocacy Day 2012 Brad Whitus, President and Chair, Public Policy & Government Affairs Committee
1:15 p.m. – 2:00 p.m.	Preparing for Game Day: What to Expect Holly Roos, LINKS Program Assistant, National Fragile X Foundation
2:00 p.m. – 3:10 p.m.	2012 NFXF Public Policy Agenda: An Overview Jeffrey Cohen, Director of Government Relations, National Fragile X Foundation
3:10 p.m. – 3:30 p.m.	BREAK
3:30 p.m. - 4:45 p.m.	Framing your Message: Hook, Line & Sinker Christopher Kush, CEO & President, Soapbox Consulting
4:45 p.m. – 5:15 p.m.	Distribution of Meeting Schedules & State Delegation Meetings
5:15 p.m. – 5:30 p.m.	Questions

ADVOCACY DAY: Wednesday, March 7th, 2012

6:45 a.m. – 7:00 a.m.	Bus loading for 7 a.m. departure to Capitol Hill
7:45 a.m. –8:00 a.m.	Picture on Capitol Steps
8:00 a.m. – 9:00 a.m.	House Floor hosted by Congressman Harper U.S. Capitol (House Floor) and Mini Tour of Capitol (time permitting)
9:30 a.m. – 5:30 p.m.	Congressional Visits

Section II: Priorities, Rationale and Meetings

Federal Public Policy Agenda

PRIORITY ONE:

Sustain federal investments in translational research and drug development(**NIH and DOD**) and *dedicated* public health initiatives and data collection (**CDC NCBDDD**) *at not less than 2012 levels of funding* specifically aimed at improving the lives of individuals living with Fragile X-associated Disorders and their families. This includes an update and continued implementation of the NIH Research Plan for Fragile X and continued federal support for the Fragile X Clinical & Research Consortium.

PRIORITY TWO:

Secure passage of bills that will have an immediate effect on the quality of life of individuals living with Fragile X-associated Disorders and their families. This includes the Achieving a Better Life Experience **(ABLE) Act** to create tax-advantaged savings plans for individuals with disabilities, the **Keeping All Students Safe Act** to protect students from ineffective and dangerous seclusion and restraint practices in schools and the Transition toward Excellence, Achievement & Mobility **(TEAM)** Acts to promote successful transition into adulthood and increased opportunities for post-secondary education and economic advancement.

Federal Government Affairs: Priorities and Rationale

The National Fragile X Foundation is seeking continued support from Congress to improve the lives of individuals with Fragile X-associated Disorders and their families. ***Here's <u>why</u>:***

1. **WE'RE VERY CLOSE TO REAL BREAKTHROUGHS:** The neurological pathways responsible for fragile X syndrome (FXS) are known. Drugs capable of reversing the adverse effects of this genetic mutation in animal models are now in human trials. In addition to FXS, it is widely believed that the same pathways in the brain are involved in Autism and these same drugs may ameliorate aspects of Autism Spectrum Disorders (ASD) as well.

   Given this explosion of knowledge and dramatic progress towards breakthrough treatments, we are asking Congress to continue (and -- when possible -- to grow) federal investments in translational research, and addressing the public health impact at *the NIH, CDC and DOD* leading to continued breakthroughs that *will improve learning, quality of life and meaningful community participation of individuals with FXS and Autism Spectrum Disorders*.

2. **WHEN TREATMENTS BECOME AVAILABLE FAMILIES WILL NEED ACCESS TO CARE:** Dramatic breakthroughs will create an instant and potentially overwhelming demand for access to treatment and there will likely be a critical shortage of knowledgeable medical providers capable of explaining and delivering these anticipated therapies.

   For these reasons, we are asking Congress to continue (and when possible to grow) federal investments that ensure access to therapeutic services and supports through continued dedicated funding of the CDC's national Fragile X Public Health initiative.

   Congressional investments, which include funding of the ***Fragile X Clinical & Research Consortium (FXCRC),*** *continue to support the collection of critical data that will fully define the clinical aspects of Fragile X amenable to treatment, have led to improved access to comprehensive services and optimal care for individuals with Fragile X across a network of 25 clinics throughout the U.S. and promoted early diagnosis leading to improved intervention.*

3. **WE CAN AND MUST DO A BETTER JOB OF PROTECTING AND HELPING INDIVIDUALS WITH FXS, ASD AND OTHER I/DD ATTAIN MAXIMUM SELF-SUFFICIENCY:** Adults with FXS (and ASD and other intellectual disabilities) are capable and motivated to work alongside their typical peers. They are also capable of attaining a greater degree of self-sufficiency than current laws allow. Some primary and secondary school age children with fragile X syndrome and other intellectual disabilities are subject to ineffective and dangerous seclusion and restraint practices in schools. When these students graduate high school the protections of the IDEA end and the transition to adult life is often difficult resulting in a life of isolation and dependence.

   For these reasons, we are asking Congress to pass pending legislation which will allow this population and their families to save money without losing critically needed supports, to attain optimal economic self-sufficiency and to protect them from dangerous seclusion and restraint practices in schools.

   Congress can provide these protections, reduce the federal deficit, lower reliance on entitlement spending and improve opportunities to work, generate income, and save for future supports required to live as independently as possible by passage of the ***ABLE, Keeping All Students Safe,*** *and* ***TEAM Acts.***

Advocacy Day Congressional Meetings

The OPENING

Who I am, what is FX - How it has impacted my life - Why we need your help

- Introduce yourself and be sure to include the name of your city;
- Explain that you are in Washington for the 9th Annual NFXF Advocacy Day and that the NFXF is committed to accelerating the translation of promising research discoveries into breakthrough therapeutic interventions and sound practices;
- Explain your connection to FX including the name of your family member impacted (show picture) and which condition they have;
- Tell a short anecdote that makes a powerful point about how your life/family has been impacted by FX
- If you have visited an FXCRC Clinic and benefited from the experience be sure to talk about that
- Other short points that you can build into this part of the discussion:
- Fragile X-associated Disorders include FXS, FXTAS, FXPOI which together encompass a spectrum of conditions that impact individuals and families throughout the life-span.
- As many as one in 130 women are carriers of a mutation on their FX gene that puts them at a 50% risk on having a child with FXS.
- The FX mutation is the most common known genetic cause of Autism. More than 50% of individuals with FX are also on the Autism Spectrum. Unlocking the secret of FX will likely lead to better treatments for Autism. The targeted drug treatments for FXS that are in Clinical Trials are also in trials for the treatment of Autism.

> ***Note: Not everyone in your groups needs to touch on all of these points. When you meet with your group throughout the day on Tuesday talk about how you want to divide the presentation.***

The ASK (Generally):

Now you can use the Key Messaging above:

We Need Your Help Because…

1. **WE'RE VERY CLOSE TO REAL BREAKTHROUGHS, SO…**

   We must assure continued progress toward targeted treatments. Over the last eight years Congress has supported groundbreaking work in the field of Fragile X-associated Disorders through the NIH, CDC and DOD. We are close to crossing the finish line of targeted treatments in the form of drugs capable of lessening or even eliminating many of the core symptoms of Fragile X Syndrome, Autism and other Intellectual Disabilities. To turn back now would have a devastating effect on the ability to complete this work.

2. **WHEN TREATMENTS BECOME AVAILABLE FAMILIES WILL NEED ACCESS TO CARE, SO…**

   We <u>must</u> build upon important work already made possible by Congress and sustain federal Public Health investments and dedicated funding of the CDC's national Fragile X Public Health initiative. With support from the Fragile X Public Health Program at the CDC's National Center on Birth Defects and Developmental Disabilities the NFXF has invested significantly in the creation of the Fragile X Clinical & Research Consortium (FXCRC), a network of 25 clinics across the country that are collecting vital public health data, creating a database and registry which will identify treatment targets and support clinical trials of targeted drug therapies, and develop best practices for the treatment of Fragile X-associated Disorders. **Turning back is not an option.**

3. **WE CAN AND MUST DO A BETTER JOB OF PROTECTING AND HELPING INDIVIDUALS WITH FXS, ASD AND OTHER I/DD ATTAIN MAXIMUM SELF-SUFFICIENCY, SO…**

   We <u>must</u> address the unmet needs of K-12 students and adults living with FX and other significant disabilities. Individuals with FX are capable and motivated to work and earn comparable wages alongside their typical peers. They and their families want to save money in the same way that those without disabilities can to attain a greater degree of self-sufficiency than current laws allow. In primary and secondary school some experience dangerous and ineffective seclusion and restraint practices. When they graduate, the transition to adult life is often difficult resulting in a life of isolation and dependence. There are bills pending now in Congress that will address each of these issues. *We can do a better job* and with Congress' help we can help individuals attain a greater degree of self-sufficiency, maintain entitlement to needed benefits, keep them safe in school and assure they have the opportunity, encouragement, and support necessary to lead an independent, productive adult life

The ASK (Specifically):

What We Are Asking Our Members of Congress to Do

Remember: We are only asking for 2 things

1. **Directive Appropriations Language (DAL)**

   We hope the Congressman/Senator will do everything in their power to support continued growth of key federal programs focused on Fragile X-associated Disorders. Specifically, ***we respectfully request that you sign on to a letter to Appropriators that is being circulated by our champions which endorses the following***:

   - Sustained, dedicated and level funding of the CDC's Fragile X Public Health Initiative in FY2013 Appropriations with increased and broadened support for the Fragile X Clinical & Research Consortium.
   - Support for the current effort to update the NIH Research Plan on Fragile X Syndrome and Associated Disorders and thereafter for an intensified effort to accomplish the goals and objectives in the Plan, as well as, collaboration, coordination and NIH support for the CDC funded Fragile X Clinical & Research Consortium and data collection through a FX registry and database.
   - Support for the continued inclusion of Fragile X-associated Disorders among the list of eligible healthcare conditions for targeted biomedical research funding through the U.S. Department of Defense Peer Reviewed Medical Research Program.

If you say nothing else the short specific ask is………**Sign on to our Champion's Letter to Appropriators-all the details are in the leave behind folder.**

2. **Co-Sponsorship of Pending Legislation**

   We hope the Congressman/Senator will support pending Bills that will have an immediate impact on the life of my (son/daughter/family member/family) impacted by a Fragile X-associated Disorder. Specifically, ***we respectfully request that you co-sponsor the following Bills***:

   For all Representatives/Senators: **Cosponsor** the Achieving a Better Life Experience Act of 2011 (ABLE Act)

   - House Champions: Ander Crenshaw (R-FL); Jim McDermott (D-WA)
   - Senate Champions: Bob Casey (D-PA); Orrin Hatch (R-UT)

   For all Representatives: **Cosponsor** the TEAM Legislation

   - TEAM-Education Act (H.R. 602)
   - TEAM-Empowerment Act (H.R. 603)
   - TEAM-Employment Act (H.R. 604)

   For all Senators: **Cosponsor** the Keeping All Students Safe Act (S. 2020)

   If you say nothing else the short specific ask is… Please CO-SPONSOR the ABLE, KEEPING ALL STUDENTS SAFE AND TEAM ACTS- all the details are in the leave behind folder.

The CLOSE

Follow-up and Thank You

- Can we count on the Congressman's/Senator's support for the Fragile X community? May I follow up with you once you've had a chance to reflect on our requests and/or discuss our requests with the Congressman/Senator directly? If so, what is your preferred mode of communication? (Be sure to get the card of the individual you meet with so you have their contact information)

- **THANK YOU** for your time and consideration of our requests. It means a great deal to me to know that you care about my family and our priorities. For me, for my family and for all the families impacted by a FXD back home in our community and across our state…Thank You.

- **(If you met with a member of the staff)** I'd like to follow up directly with the Senator/Representative next time he/she is in the home state office. There are other families that couldn't make the trip to DC and many would like to meet at your local office. Who should I contact to set that up?

  Now would be a perfect time to take a minute to fill out the Meeting Evaluation Form. If you're rushed to get to your next meeting take the first opportunity you have to fill out the form to be sure you'll remember what was said during each meeting.

Section III: Frequently Asked Questions

1. **How many people are Fragile X carriers?**

   As many as one in 130 women are carriers of the Fragile X mutation. Estimates vary for the number of male carriers and studies are ongoing. There are many conflicting studies so data collected by the CDC funded FXCRC will finally make it possible to determine the true prevalence. The results will also help determine how many men are at risk for developing Fragile X-associated tremor/ataxia syndrome.

2. **How many people in the US have Fragile X?**
   - Over one-million Americans carry a Fragile X mutation and have, or are at risk for developing, a Fragile X-associated Disorder.
   - Over 100,000 Americans have Fragile X Syndrome.
   - Nationwide newborn screening will help us to further refine these numbers.

3. **What are the Fragile X-associated Disorders?**
   - ***Fragile X syndrome (FXS):*** The most common inherited form of intellectual disabilities. FXS occurs in both genders, though boys tend to have more severe symptoms. It causes behavioral, developmental and language disabilities.
   - ***Fragile X-associated tremor/ataxia syndrome (FXTAS):*** An adult onset (over 50) progressive neurological condition (like a combination of Parkinson's and Alzheimer's) causing tremors, balance and memory problems, primarily in male carriers, which can, in some instances be life ending.
   - ***Fragile X-associated primary ovarian insufficiency: (FXPOI):*** A cause of infertility, early menopause and ovarian problems in women who are carriers (20's and 30's)

4. **How do you test for Fragile X?**

   A simple DNA blood test can conclusively determine if an individual has fragile X syndrome, or is a Fragile X carrier.

5. **What is the relationship between Fragile X and Autism?**
   - The mutation that causes FXS is also the most common known genetic cause of autism. So FX provides a unique opportunity to find the cause of and treatments for autism.
   - Groundbreaking drugs to treat FXS (based on research funded by NIH) are also in clinical trials for individuals with Autism)
   - Up to two thirds of all children diagnosed with fragile X syndrome also have autism, an autism spectrum disorder or behaviors associated with autism.

6. **What is the relationship between Fragile X and other medical conditions?**

   Research into Fragile X will help shed light on other conditions such as Alzheimer's, Parkinson's, reproductive problems in women and other medical conditions that may have a genetic basis.

Likely Questions from Congressional Staff

1. **Who should I contact to express my support for Fragile X requests?**

   HOUSE OF REPRESENTATIVES
   - Congressman Gregg Harper (R – MS)
     - Staff contact: Scot Malvaney Scot.Malvaney@mail.house.gov
   - Congressman Eliot Engel (D-NY)
     - Staff contact: Cristina Batt Cristina.Batt@mail.house.gov

   UNITED STATES SENATE
   - Senator Debbie Stabenow (D – MI)
     - Staff contact: Alex Sheff alex_sheff@stabenow.senate.gov
   - Senator Johnny Isakson (R – GA)
     - Staff contact: Francie Pastor Francie_Pastor@isakson.senate.gov

2. **How much money is the federal government currently devoting to Fragile X at the NIH and CDC?**
   - CDC: ~$1.7 million in FY 2011
   - NIH: ~ $27 - $28 million a year across all institutes over the last several years
   - DOD: ~$3 million in 2010, 2011 awards pending

3. **How many people in my state are impacted by a FXD?**

   Take the population of your State and divide by 130. That will give you an estimate of the number of individuals who have or could develop a FXD.

4. **Who Should I Contact to Learn More about the ABLE Act?**
   - Barbara Riley, Communications Director, Congressman Ander Crenshaw – (202) 225-2501
   - Todd Winer, Communications Director, Congresswoman Cathy McMorris Rodgers – (202) 225-006
   - April Mellody, Communications Director, Senator Robert Casey, Jr. – (202) 224-6324
   - Caitlin Dunn, Press Secretary, Senator Richard Burr – (202) 228-1616

5. **Who Should I Contact to Learn More about the KEEPING ALL STUDENTS SAFE Act?**

   Michael Gamel-McCormick, Senate HELP Com Michael_Gamel_McCormick@help.senate.gov

6. **Who Should I Contact to Learn More about the TEAM Acts?**

   Scot Malvaney-Representative Harper Scot.Malvaney@mail.house.gov

7. **If I have further questions regarding these requests or the National Fragile X Foundation's priorities who should I contact?**

   Jeffrey Cohen
   Director of Government Affairs, NFXF
   Phone: (734) 407 2413 Cell: (313) 806 1190 Email: j.cohen@fragilex.org

Section IV: Draft Report Language and Fact Sheets

NFXF Appropriations Requests and Draft Report Language

Centers for Disease Control and Prevention (CDC)

National Center on Birth Defects, Developmental Disabilities, Disability and Health (NCBDDD)

> *Fragile X – Fragile X-Associated Disorders [FXD].— Within the amount provided the Committee has included level funding to support NCBDDD's continuation of dedicated public health activities concerning FXD. The Committee encourages the CDC to continue to focus its efforts on data collection to identify and define the population impacted by FXD and the public health impact of these conditions and to continue to build a database and registry to support further epidemiological research, surveillance, screening and the promotion of early interventions and supports. The Committee commends CDC for its renewed support of the Fragile X Clinical & Research Consortium (FXCRC). The Committee encourages the CDC to build upon and expand this effort to bring about positive outcomes for families through a dedicated outreach to all populations impacted by a FXD, including those historically underserved groups such as ethnic and language minorities, which includes dissemination of information about and access to clinical services, best practices and ongoing clinical trials. The Committee encourages CDC to work with the NICHD and to support, consolidate and coordinate Federal investments in data collection efforts related to Fragile X.*
>
> *The Committee expresses concern that despite a clear directive rejecting the consolidation for disability initiatives at the NCBDDD proposed in FY2012 without an assessment of the needs of people with disabilities that included the categories of disabilities currently served, validated the value of such a consolidation, considered the input of stakeholders, and established the basis for any proposed efficiencies and commonalities, that no such assessment was undertaken and no such validation demonstrated. Consolidation is once again rejected and this requirement is continued for FY 2013*

National Institutes of Health (NIH) Office of the Director

> *Fragile x-associated Disorders (FXD) - The Committee commends the NIH, through the NICHD, for its effort to update the NIH Research Plan on Fragile X Syndrome and Associated Disorders in light of the significant progress made toward targeted drug treatments since the Plan was published. The committee requests a report on the updated goals and objectives before the end of calendar year 2012 and urges NIH, working with NICHD, the Fragile X Clinical and Research Consortium and the private research sector, to fully implement and prioritize these updated goals and objectives. NIH is*

encouraged to support translational research that shows significant promise of safer and more effective treatments for FXD. The Committee encourages NIH to develop and support collaborative efforts amongst all NIH institutes and other governmental entities and encourages NICHD to work with the CDC, to support, consolidate and coordinate Federal investments in data collection efforts related to FXD.

Therapeutics for Rare and Neglected Diseases Program (TRND); National Center for Advancing Translational Sciences (NCATS) - In light of the well-established network of academic, government, biopharmaceutical and patient advocacy groups already focusing on FXD, the committee encourages TRND to support new partnerships in FX to accelerate potential new treatments that benefit patients with this rare and neglected disease. In light of the fact that translational research on FXD involves targets that may be relevant to multiple diseases and may lead to a better understanding of and possible treatments for Autism, other intellectual and developmental disorders, premature menopause, Parkinson's and Alzheimer's, the Committee encourages NCATS to consider Fragile X as a model for future efforts.

Department of Defense (DOD) Congressionally Directed Medical Research Program

Peer Reviewed Medical Research Program (PRMRP) – The DOD is strongly encouraged to continue Fragile X-associated Disorders in the PRMRP eligible research topics for FY 2013 portfolio. These funds will advance translational research into Fragile X Syndrome and Fragile X-associated Disorders, including research examining the relationship among fragile X syndrome, autism, and autism spectrum disorders (ASD).

Fact Sheets

Fact Sheet: Sustaining NIH Research on Fragile X-associated Disorders

> *"Fragile X syndrome is an excellent model for autism. Today, just a relatively short period of time after the gene for Fragile X was isolated, clinical trials are proceeding for drugs that seek to correct the central neurochemical defect underlying the condition. I've seen some early results from these trials, and they look quite encouraging to me."* - Francis S. Collins, M.D., Ph.D., Director, NIH

FY2013 Appropriations Request: National Institutes of Health

The NFXF urges Congress to sustain existing federal investment in biomedical research managed by the National Institutes of Health (NIH) and to direct NIH to maintain its investment in Fragile X research at not less than current levels to support a) the update and renewed commitment to full implementation of the NIH Fragile X Syndrome and Associated Disorders Research Plan b) the utilization of TRND and NCATS to support the development of targeted drug therapies c) NIH support for the Fragile X Clinical & Research Consortium (FXCRC) and d) the development of a unified database and registry of FX patients.

Previous NIH Support for Fragile X

The Fragile X Research Breakthrough Act of 2000, a provision of the Children's Health Act (Title II), authorized funding for the establishment of at least three Fragile X Research Centers. In response, the National Institute of Child Health and Human Development (NICHD) funded three Centers in March 2003 in the amount of $3.75 million "... to conduct research to improve the diagnosis and treatment of, and to find a cure for Fragile X-associated disorders." These Centers have proven critically important to the development of effective therapeutic interventions as well as our epidemiological understanding of the condition. As a result of various public and private research efforts, effective treatment for Fragile X-associated Disorders is close to becoming a reality-the condition has been reversed in multiple animal models and new drugs are currently in human trials. However, even as the potential for treatments and a cure increase, federal funding for Fragile X-associated Disorders (FXD) research has not always kept up. For many years, federal funding remained stagnant and even dropped from FY 2005 ($22 million) to FY 2006 ($20 million). In FY 2007, though, thanks to continued pressure from Congress, the NIH devoted $27 million to Fragile X research and projects, which steadily increased to $32 million in FY2009. In FY 2010 and 2011 this amount retreated to 29 million. Now, the NFXF wants to ensure that NIH is focusing on translational research that shows the greatest promise to discover and bring to market viable treatments and interventions for FXD. The NFXF also wants to make sure that NIH is partnering with the CDC, the Fragile X Clinical & Research Consortium and the private sector to maximize efficiencies and optimize our resources by working together collaboratively on research questions and priorities of mutual interest and a unified database and registry of patients.

Rationale/Justification for Request

In 2011 fourteen of the NIH's individual Institutes and other research entities supported 92 diverse grants to find a treatment and cure for FXD. Given this array of NIH-based Fragile X efforts, the current effort underway to update the NIH Fragile X Syndrome and Associated Disorders Research Plan (The Research Plan), the availability of the Therapeutics for Rare and Neglected Diseases (TRND) and National Center for Advancing Translational Sciences (NCATS) programs, and the undeniable reality that targeted drugs capable of treating the underlying neuro-biological mechanism in FX (and likely Autism) are moving toward FDA approval, a renewed effort to achieve the goals set out in the updated Research Plan, as well as, increased NIH support for the Fragile X Clinical & Research Consortium must be undertaken to focus and coordinate strategy for maximizing resources dedicated to FXD. An additional benefit of identifying viable treatments for FXD is the potential application of these therapeutic interventions to related disorders including autism, schizophrenia, pervasive developmental disorders, and other forms of X-chromosome-linked intellectual disabilities.

Action Requested

Congressional leaders are asked to support the NFXF's FY 2013 appropriations request and suggested appropriations report language by co-signing a group letter to the Appropriations Committee leadership. Appropriations Committee members are respectfully encouraged to include this appropriations request among their FY 2013 funding priorities.

Fact Sheet: Supporting CDC's National Fragile X Public Health Initiative

FY2013 Appropriations Request: Centers for Disease Control and Prevention

The National Fragile X Foundation (NFXF) is seeking level funding at the FY 2012 level to support the dedicated National Fragile X Public Health Initiative within National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC). This funding is requested to support existing and new activities, including the further expansion of the epidemiological and public health data collection activities of the Fragile X Clinical and Research Consortium (FXCRC), the further development and coordination of the consortium’s database and registry with other overlapping efforts, a targeted outreach to typically underserved populations, and further epidemiological research, surveillance, screening and the promotion of early interventions and supports to address the significant public health impact of Fragile X associated Disorders (FXD).

Previous Federal Support for Fragile X

Since 2003, Congress has urged the CDC to create and grow a Fragile X public health program to conduct surveillance and epidemiological research on FXD as well as provide education to health care professionals and the public on FXD and other developmental disabilities. Over the last five fiscal years, Congress has provided nearly 10 million dollars in total funding to address gaps in FXD research, screening, treatment, and awareness. As a result, the CDC has funded multiple grants in the areas of Fragile X Epidemiology and Screening, Fragile X Cascade Testing and Genetic Counseling, the creation of a Single Gene Disorders Resource Network and in partnership with the NFXF, a Fragile X Clinical and Research Consortium (FXCRC). The FXCRC has now grown to 25 clinics across the country collecting critically needed data and providing specialty services and referrals to individuals with FXD. A greater effort is needed to make these services available to typically underserved populations and the NFXF can continue to partner with the CDC to accomplish this and believes CDC should invest its dedicated Fragile X resources to improving access to services for the underserved. The community is pleased with the CDC's progress thus far in implementing a public health program on FXD, but wants to assure that these funds are used for the purposes that Congress intended. In FY 2012 a proposal to consolidate CDC NCBDDD funding accounts (including FX) was rejected. The NFXF urges Congress to once again reject any such proposal and to continue the dedicated funding to address the unique and far reaching public health impact of FXD.

Rationale/Justification for Request

Although it is the leading known cause of inherited cognitive impairment and the most common known genetic cause of autism, and although more than half of all individuals with FX are on the autism spectrum, FX is not always included in current federal developmental screening or surveillance activities. In order to increase our understanding of Fragile X, the CDC national Fragile X public health initiative should focus its efforts on increasing epidemiological research, surveillance, and screening efforts, with particular attention towards collecting epidemiological data on the incidence and prevalence of FXD. The NFXF is pleased that upon expiration of an initial three year grant to support the FXCRC that a second grant was awarded in 2011 to assist the 25 FX U.S. clinics collect epidemiological data to better define and address the far reaching public health impacts of FXD and provide a database and registry through which ongoing clinical trials of targeted new drug therapies can be advanced. The NFXF welcomes new activities by the Agency to address this disorder through initiatives such as the early identification of individuals with a FXD; genetic counseling and a database of best practices. Each of these activities will have a profound impact on the Fragile X community, and could serve as a model for a more expanded focus on the appropriate screening, diagnosis, counseling and treatment of an array of developmental disabilities.

Action Requested

Congressional leaders are asked to support the NFXF's FY 2013 appropriations request for level funding (and continued dedication of this funding to FXD through the CDC NCBDDD) and suggested appropriations report language by co-signing a group letter to the Appropriations Committee leadership. Appropriations Committee members are respectfully encouraged to include this appropriations request among their FY 2013 funding priorities.

Fact Sheet: The Dept. of Defense and the Peer Reviewed Medical Research Program

FY 2013 Appropriations Request: Department of Defense

> *The National Fragile X Foundation (NFXF) supports the continuation of FXD in the Peer Reviewed Medical Research Program (PRMRP) at the US Department of Defense (DOD) among the list of health care conditions eligible for inclusion among the Congressionally Directed Topic Areas and the broadening of eligible conditions to include all Fragile X associated Disorders.*

Previous Federal Support for Fragile X

Since 2010, Congress has included fragile X syndrome on the list of health care conditions with direct relevance to military health and funded select medical research projects of clear scientific merit. Because the impact on military families includes not only fragile X syndrome, but also, Fragile X associated Tremor Ataxia Syndrome and Fragile X associated Premature Ovarian Insufficiency Congress is urged to include all three FXD as eligible for funding.

Rationale/Justification for Request

The PRMRP at the DOD was established in 1999 and continues to fulfill Congressional intent by funding research of scientific merit with direct relevance to the health of the warfighter and the military family, and the American public. PRMRP appropriations, which totaled $50 million in FY2010, 2011 and 2012 have provided funding for projects in more than 60 topic areas. Many projects funded by the PRMRP have begun to yield military combat health support technologies and products in the areas of Combat Casualty Care, Military Infectious Diseases, Military Operational Medicine, Chronic Disease Management, and Medical Chemical and Biological Defense, thus complementing the current USAMRMC Core priorities.

The follow topic areas were included in the FY2012 PRMRP Congressionally Directed Topic Areas: arthritis, composite tissue transplantation, drug abuse, dystonia, epilepsy, food allergies, **fragile X syndrome**, hereditary angioedema, inflammatory bowel disease, interstitial cystitis, lupus, malaria, nanomedicine for drug delivery science, neuroblastoma, osteoporosis and related bone disease, Paget’s disease, polycystic kidney disease, post-traumatic osteoarthritis, scleroderma, tinnitus, and tuberculosis. As a result of this investment, since FY2010, the following projects specific to Fragile X were funded: Clinical Trial Award, University of CA, Davis, Randi Hagerman; Investigator-Initiated Research Award, Stanford University, Marius Wernig; Investigator-Initiated Research Award, University of CA, Berkeley, Lu Chen. 2011 awards are currently in review.

Given the significant increase in intellectual and developmental disabilities among military personnel, their families and the general population, the list of eligible topic areas should be expanded to include all three Fragile X-associated Disorders among the list of eligible healthcare conditions for targeted biomedical research funding through the U.S. Department of Defense.

Action Requested

Congressional leaders are asked to support the NFXF's FY2013 appropriations request and suggested appropriations report language by sending a letter to the Appropriations Committee leadership. Appropriations Committee members are respectfully encouraged to include this appropriations request among their FY 2013 funding priorities.

Fact Sheet: Achieving a Better Life Experience Act of 2011 (ABLE) (H.R. 3423)

Support the Achieving a Better Life Experience Act

The ABLE Act provides for the establishment of Accounts to fund the care of family members with disabilities. The ABLE Act was reintroduced in the 112th Congress on November 15th by U.S. Senator Robert Casey and U.S. Representative Ander Crenshaw. S. 1872 and H.R. 3423

General Purpose

To encourage and assist individuals and families in saving for supporting individuals with disabilities and to maintain health, independence, and quality of life. To provide funding for disability-related expenses on behalf of designated beneficiaries with disabilities that will supplement, but not replace, benefits provided through private insurances, Medicaid, SSI, the beneficiary's employment, and other sources.

Created under Existing 529 Codes for Qualified Tuition Programs:

- Creates a new subsection (f) ABLE Account within Section 529 of the Internal Revenue Code;
- Easy to open and available in any state; Same annual contributions apply (After $13K gift tax)
- Same tax-free treatment applies (Income earned grows tax-free, withdrawals for qualified disability expenses are tax-free; Same reporting requirements as traditional 529
- A beneficiary may have either an ABLE account or a traditional 529 qualified tuition program. (Multiple ABLE accounts or multiple 529 plans still allowed); Rollovers allowed from an ABLE account to traditional 529 if beneficiary is no longer deemed disabled. (All other 529 rollovers apply to ABLE accounts)

Qualified Disability Expenses:

- Education-including tuition preschool-post-secondary, books, supplies, tutors, and special education services.
- Housing- For a primary residence, rent, mortgage, home improvements-modifications-maintenance-repairs, real property taxes, and utilities.
- Transportation- Mass transit, the purchase or modification of vehicles, and moving expenses.
- Employment Support-Expenses related to obtaining and maintaining employment, job-related training, assistive technology, and personal assistance supports.
- Health Prevention and Wellness: Including premiums for health insurance, mental health, medical, vision, and dental, rehabilitation services, durable med equip, therapy, respite, long term services and supports, nutritional management, communication services and devices, adaptive equipment, assistive technology, and personal assistance AND Any other expenses which are approved by the Secretary under regulations and consistent with the purposes of this section including financial management and administrative services, legal fees, expenses for oversight, monitoring, or funeral and burial expenses.

How to Qualify for an ABLE Account

Any individual who is receiving, deemed to be, or treated as receiving SSI benefits or disability benefits under Title II of the Social Security Act OR Any individual who has a medically determined physical or mental impairment, which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 month or is blind, and provides a copy of their diagnosis signed by a physician. No one who qualifies for an ABLE account is able to use that eligibility to secure supplemental security income benefits or Medicaid.

Treatment of ABLE Account under SSI and Medicaid

When the assets in an ABLE account reach $100,000, if the beneficiary is receiving SSI, any monthly SSI benefits will be placed in suspension. If the assets in the ABLE account drop back below $100,000, the SSI benefit suspension ceases and the benefit resumes. The beneficiary will not have to reapply for SSI benefits. No one with an ABLE account who is currently receiving Medicaid will lose their benefits or their eligibility– even if their SSI benefits are suspended.

Medicaid Payback Provision:

If the qualified beneficiary dies (or ceases to have a disability) with assets in an ABLE account: The assets are first distributed to any State Medicaid plan that provided medical assistance to the beneficiary. The Medicaid payback is calculated based on amount paid by Medicaid after opening the ABLE Account.

WHY PASS THE ABLE ACT?

Individuals with disabilities and families need savings tools for the future without being penalized.

The ABLE Act addresses the lack of viable savings options for individuals with disabilities by creating a new vehicle to save for the future without fear of tax obligations or of losing publicly-financed benefits for health insurance and other supports. Individuals with disabilities and their families must have the opportunity and tools to save and plan for their future and long-term support. Most savings vehicles today are not viable options for citizens with disabilities and their families.

- A typical tax-deferred 529 plan can't help a family with a child who may not go to college or become financially independent. The need for savings is even greater for a child with a disability because he or she will likely require additional spending on medical treatment and assistive technology. Without a clear vision of the future, individuals with disabilities and their families must choose between saving or risking a penalty if their child cannot use the funds according to the account restrictions.
- Several savings tools available today count against an individual's eligibility for Medicaid, SSI or SSDI thus adding further burden on citizens with disabilities and their families.

Until a major overhaul of the SSI/SSDI and Medicaid programs, citizens with disabilities and their families continue to be relegated to a life of poverty, facing barriers to economic advancement and self-sufficiency.

- The Americans with Disabilities Act (ADA) set a framework for policymaking that defined the nation's goals regarding individuals with disabilities to "assure equality of opportunity, full community participation, independent living, and economic self-sufficiency." Policies in conflict with this goal, poorly-coordinated programs, and escalating demand create enormous barriers for citizens with disabilities to reach attain the goals of the ADA.

- Citizens with disabilities who rely on publicly-financed supports for health insurance (SSI/SSDI and Medicaid) are relegated to a lifetime of poverty, as they are limited in the amount they can work, earn and save without jeopardizing their eligibility for benefits. As a result, citizens with disabilities are three times more likely to live at or below the poverty line than their nondisabled peers.

The rising demand and costs of federal disability entitlement programs is unsustainable and puts citizens with disabilities at risk.

Program enrollment and costs for the largest federal disability programs are growing rapidly. From 1996 to 2006, the number of individuals with disabilities receiving SSA's Disability Insurance increased by 42%. As of March 2010, over 1.1 million children were receiving SSI. Two-thirds will remain on benefits for life, costing in excess of $200 billion.

Publicly-financed supports must be modernized to promote work, savings and self-sufficiency among citizens with disabilities -- the ABLE Act is the first step toward reform by allowing individuals with disabilities to save for their future

The system cannot continue to sustain itself with these growing demands. The ABLE Act allows individuals and families to plan and save for the future, relieving some of the dependency that would otherwise be placed on federal programs.

ACTION REQUESTED

Members of Congress are encouraged to co-sponsor The ABLE Act. Contact:
Barbara Riley, Rep Ander Crenshaw – (202) 225-2501;
Todd Winer, Rep Cathy McMorris Rodgers (202) 225-2006;
April Mellody, Senator Robert Casey, Jr. – (202) 224-6324;
Caitlin Dunn, Senator Richard Burr – (202) 228-1616

Fact Sheet: Keeping All Students Safe Act (H.R 1381) (S. 2020)

In the 111th Congress, Reps George Miller (D-CA) and Cathy McMorris-Rodgers (R-WA) introduced the Preventing Harmful Restraint and Seclusion in Schools Act (H.R. 4247). This legislation was later renamed the Keeping All Students Safe Act and passed the House on March 3rd 2010 by a vote of 228-184. The bill established federal minimum safety standards to limit the use of restraint and seclusion in schools by:

- Banning the use of mechanical and chemical restraints, physical restraints that restrict breathing and aversive interventions that compromise health and safety
- Prohibiting physical restraint and seclusion being used as planned interventions only used as a last resort in emergency circumstances where a student's behavior poses an imminent danger of physical injury and less restrictive interventions would be ineffective
- Requiring school personnel to be trained and certified, and require that they continuously monitor students during interventions; Requiring schools to establish procedures to be followed after R/S are used, including parental notification
- Requiring states to report the yearly number of R/S incidents
- Creating a discretionary grant program to assist states, districts and schools to establish, implement and enforce the minimum standards; support data collection and analysis; support training; and improve school climate and culture through the implementation of school-wide positive behavior supports.

Former Senator Christopher Dodd (D-CT) and Senator Richard Burr (R-NC) introduced legislation in 2010 (S.3895) to establish Federal minimum standards related to the use of seclusion and restraint in schools. While the legislation did attempt to restrict the use of seclusion and restraint it permitted S/R to be written into the IEP. S. 3895 was not considered by the Senate before the end of the 111th Congress.

The 112th Congress: On April 5, 2011, Reps George Miller (D-CA) and Gregg Harper (R-MS) reintroduced the Keeping All Students Safe in Schools Act (H.R. 1381). The Act now has 31 cosponsors. The National Fragile X Foundation is working to add cosponsors in the 112th Congress. On December 16, 2011, Senate HELP Chairman Tom Harkin (D-IA) introduced S. 2020, the Keeping all Students Safe Act. This legislation calls for the protections provided in H.R. 1381, and offers further safeguards, including:

- Prohibition of the use of seclusion
- Prohibition of the use of restraint when contraindicated by a student's medical condition
- A required debriefing following an emergency restraint; emphasis on evidence based prevention measures, and a limitation on the force used during a restraint.

This legislative proposal would prohibit the use of seclusion in locked and unattended rooms or enclosures, prohibit the use of mechanical and chemical restraints and physical restraints that restrict breathing, and prohibit aversive behavioral interventions that compromise health and safety. These prohibitions are needed because there is great variability from state to state regarding prohibition of these dangerous activities. In addition the legislation would:

- Only allow for physical restraints to be used in emergency situations
- Only impose physical restraints that did not inhibit a student's primary means of communication
- Prohibit including the use of S/R in a student's IEP or behavioral plan
- Establish policies to promote preventative programming to reduce the use of restraints
- Collect data on the occurrence of seclusions and restraints

- Conduct a debriefing with parents and staff after a restraint is used and plan for positive behavioral interventions to prevent the future use of restraints
- Establish a state grant program to enhance the State's ability to promote preventative programming and training for personnel.

ACTION REQUESTED

Congressional leaders are encouraged to co-sponsor The Keeping All Students Safe Act.

- **In the Senate contact** Michael Gamel-McCormick, Senate HELP michael_Gamel_McCormick@help.senate.gov
- **In the House contact** Scot Malvaney-Representative Harper Scot.Malvaney@mail.house.gov

Fact Sheet: Transition toward Excellence, Achievement & Mobility Legislation (TEAM) (H.R. 602)

Youth with Significant Disabilities Want Equal Opportunity to Become Productive, Responsible, Contributing Citizens in Adulthood

Early intervention is critical to the future success of all youth in preparation for adulthood, including individuals with significant disabilities. Thus, **the discussion of transition and employment** should begin as early in an individual's life as possible. Evidence-based research has conclusively documented that youth with disabilities who were educated in inclusive settings, exposed to work experience and career exploration and participated in a paid work experience while in school had better post-secondary and employment outcomes.[1]

Despite the public funding going into the provision of employment services for individuals with disabilities requiring significant supports, the participation rate of persons with disabilities in employment remains low. The employment rate drops significantly for persons with more severe conditions. Four out of five persons with significant disabilities are not considered part of the labor force.[2] Only one in ten individuals with mental disabilities receiving Social Security Supplemental Security Income (SSI) payments are considered to be in the workforce.[3]

When state education, vocational rehabilitation, workforce development, Medicaid, and other public agencies work closely together early to support and promote the growth and development of youth with significant disabilities, individuals benefit from the synergistic coordination of supports and are able to achieve better outcomes. To ensure effective coordination among these entities, it is critical that systemic changes allow for flexible braiding of resources, coupled with a collective presumption that publicly-financed supports should focus on and prioritize the attainment of outcomes associated with post-secondary education, integrated employment, and economic advancement of individuals with significant disabilities.

To address several of these systemic barriers and better promote the advancement of Americans with significant disabilities transitioning from youth to adulthood, a trio of bills called the Transitioning towards Excellence in Achievement and Mobility (TEAM) legislation was introduced in February of 2011.

- The **TEAM-Education Act** (H.R. 602) would amend the Individuals with Disabilities Education Act by requiring transition components to be included in Individual Education Plans (IEPs) for all IDEA-eligible students at the age of 14.
- The **TEAM-Empowerment Act** (H.R. 603) would amend the Developmental Disabilities Act to establish Transition Planning and Service Divisions within the State Developmental Disability Authorities, as well as Individual Transition Plans to advance best outcomes and self-determination.
- The **TEAM-Employment Act** (H.R. 604) would amend the Rehabilitation Act to realign preferred outcomes for individuals with significant disabilities, and streamlines public funding by requiring the VR systems to actively engage with other state entities.

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[1] Cimera, R. *Journal of Vocational Rehabilitation*, 2008.
[2] American Community Survey, 2008.
[3] National Disability Institute, 2009. www.reitour.org.

Fact Sheet: TEAM-Education Act (H.R. 602)

Cosponsor Transitioning towards Excellence, Achievement & Mobility through Education Act

POLICY OVERVIEW

Despite significant public expenditures, students with intellectual and developmental disabilities frequently transition out of high school lacking the proper skills required to find and maintain employment or pursue post-secondary education. This is due to a lack of hands-on work experience and training to youth with significant disabilities that is typically offered to non-disabled students. Low expectations dominate individualized education plans (IEPs) for students with special needs despite the potential and desire of many to pursue opportunities to better prepare them for the workforce and adulthood. Although the Individuals with Disabilities in Education Act (IDEA) requires schools to provide transition services to support students with disabilities during their high school years, there currently is no enforcement, monitoring or evaluation to ensure that there is strong compliance with this important provision.

PURPOSE OF LEGISLATION

The legislation provides three separate legislative responses to better align existing federal programs providing publicly-funded supports to focus on one goal – ensuring that every youth with a significant disability has the opportunity, encouragement and support to become gainfully employed in an integrated setting, pursue a post-secondary education, and meaningfully engage in typical community settings upon leaving high school.

TEAM-EDUCATION ACT OF 2011: BILL SUMMARY

H.R. 602 amends IDEA to encourage and empower schools districts, states educational authorities, students with significant disabilities, their families and transition teams to plan for and achieve employment in an integrated setting at minimum wage or higher after high school.

- **Adds requirements to ensure IEPs holistically address the transition needs of students:** Lowers the age when transition planning must be included in an IEP to 14 and allows the State Intellectual/Developmental Disability (I/DD) Agency to participate on the team to provide the experience to successfully obtain integrated employment, economic self-sufficiency, independent living and community involvement.
- **Allows for IDEA Part B discretionary dollars to be used by school districts to hire or contract with professionals with transition expertise:** Clarifies that school districts are allowed and encouraged to use IDEA discretionary funds for hiring transition experts or contracting out transition services as needed.
- **Modifies the Definition of *Transition Services*:** Ensures that the definition of transition services includes customized employment services and training in advocacy and self-determination to better prepare youth for jobs and self-advocacy. Clarifies that transition services do not include facility-based or other segregated programs.
- **Establishes Support for Local Transition Coordinators:** Provides $50 million to Local Educational Agencies (LEAs) to pilot the hiring of internal transition services coordinators who would be responsible for facilitating relationships with public and private entities on behalf of the student.

POLICY RATIONALE

The goal of publically-funded transition services for youth with disabilities should be helping them acquire the skills, knowledge and experience required to successfully obtain a job in an integrated setting at minimum wage or higher, achieve full community participation and optimal self-sufficiency. Congress must establish a coordinated, comprehensive approach to the investment of public resources that expands and improves the choices of those transitioning into adulthood. H.R. 602 would streamline the transition process and require coordination between the state education and State I/DD authority to maximize the use of resources through systems alignment. Clarifying that facility based or other segregated experiences are not acceptable transition services will focus IEP teams on high expectations for all students and identifying opportunities that lead to integrated employment, post-secondary education, independent living and optimal self-sufficiency.

ACTION REQUESTED

Congressional leaders are encouraged to co-sponsor all three of the following legislative proposals: TEAM-Education Act; Team-Empowerment Act; and TEAM-Employment Act. **To cosponsor one or more of these innovative legislative bills, please contact Scot Malvaney in the Office of U.S. Representative Gregg Harper (R-MS) at scot.malvaney@mail.house.gov or (202) 225-5031.**

Members of the Senate are encouraged introduce a companion bill in the Senate

Fact Sheet: TEAM-Empowerment Act (H.R. 603)

Promote the Advancement of Youth with Significant Disabilities to Become Productive, Contributing Citizens of Society in Adulthood

Cosponsor the Transitioning toward Excellence, Achievement & Mobility through Empowerment (TEAM-Empowerment) Act of 2011

POLICY OVERVIEW

73% of the $33.5 billion in annual Home & Community Based Waiver funds provided to state Medicaid programs yearly are aimed at supporting individuals with complex intellectual and developmental disabilities. Despite this significant investment thousands continue to be placed in segregated settings making subminimum wages. These outcomes are in direct conflict with the intent of the Home & Community Based Services waiver initiative. State I/DD agencies are responsible for managing the waiver funding to state Medicaid agencies yet they lack the direction, guidance, support and infrastructure required to utilize these funds as intended – to get citizens with significant disabilities into the community through integrated employment, civic engagement, and independent living.

PURPOSE OF THE LEGISLATION

The legislation provides three separate legislative responses to better align existing federal programs providing publically-funded supports to focus on one goal – ensuring that every youth with a significant disability has the opportunity, encouragement and support to become gainfully employed in an integrated setting, pursue a post-secondary education, and meaningfully engage in typical community settings upon leaving high school.

OVERVIEW OF THE TEAM-EMPOWERMENT ACT (H.R. 603)

The TEAM-Empowerment Act of 2011 (H.R. 603) amends the DD Bill of Rights Act of 2000 to establish greater accountability of the DD System through the enhancement of existing infrastructure to support youth transitioning into adulthood and ensure that publicly-financed supports are aimed at integrated employment, post-secondary education, economic advancement, independent living, and meaningful community & civic engagement.

- **Establishes of Transition Planning & Service Divisions within State I/DD Authorities…** to provide the capacity and expertise required to successfully transition youth with significant disabilities from high school into meaningful community engagement and integrated employment.
- **Creates of Individualized Transition Plans to Better Focus Resources …**to ensure a seamless transition from high school into the I/DD system and provides support aimed at promoting integrated employment, post-secondary education, economic advancement and community engagement through optimal self-sufficiency.
- **Advances Self-Determination & Optimal Self-Sufficiency among Citizens with Significant Disabilities…** through training in self-advocacy, self-determination, and peer mentoring.
- **Promotes Greater Coordination among All State Agencies Providing Publicly-Financed Supports to Citizens with Significant Disabilities…** and will facilitate a Memorandum of Understanding between key State agencies to foster effective collaboration.
- **Ensures Greater Accountability among State I/DD Authorities…** by providing the Secretary of DHHS through the Administration on Developmental Disabilities (ADD) the authority to disburse assistance to states which agree to participate.

POLICY RATIONALE

The TEAM-Empowerment Act (H.R. 603) establishes greater accountability of the I/DD service delivery system by developing a connection between state educational agencies and state I/DD authorities. Additionally, the legislation ensures that publicly-financed supports are focused on successful transition into adulthood and self-sufficiency resulting in integrated employment, post-secondary education, economic advancement, independent living, and meaningful community & civic engagement.

ACTION REQUIRED

Congressional leaders are encouraged to co-sponsor all three of the following legislative proposals: TEAM-Education Act of 2011; Team-Empowerment Act of 2011; and TEAM-Employment Act of 2011. **To cosponsor one or more of these innovative legislative bills, please contact Scot Malvaney in the Office of U.S. Representative Gregg Harper (R-MS) at scot.malvaney@mail.house.gov or (202) 225-5031.**

Members of the Senate are encouraged to consider introducing a companion bill in the Senate

Fact Sheet: TEAM-Employment Act (H.R. 604)

Promote the Advancement of Youth with Significant Disabilities to Become Productive, Contributing Citizens of Society in Adulthood

Cosponsor the Transitioning towards Excellence, Achievement & Mobility through Employment (TEAM-Employment) Act

POLICY OVERVIEW

Citizens with intellectual and developmental disabilities experience a 90% unemployment rate yet the systems designed to assist Americans in finding work often fail. The intrinsic value which accompanies integrated work and right to earn living wages should be available to all citizens. When provided the right supports and opportunities, these individuals are capable of success, have better long-term health and rely less on public entitlements.

PURPOSE OF THE TEAM LEGISLATION

The legislation provides three separate legislative responses to better align existing federal programs providing publicly-funded supports to focus on one goal – ensuring that every youth with a significant disability has the opportunity, encouragement and support to become gainfully employed in an integrated setting, pursue a post-secondary education, and meaningfully engage in typical community settings upon leaving high school.

THE TEAM-EMPLOYMENT ACT: BILL SUMMARY

The TEAM-Employment Act of 2011 (H.R. 604) amends the Rehabilitation Act of 1973 to establish accountability for systems charged with providing citizens with significant disabilities job training and support through state Vocational Rehabilitation (VR) agencies to ensure economic advancement through post-secondary education or integrated employment at minimum wage or higher. The legislation seeks to achieve these reforms by:

- **Realigning Desired Outcomes of Publicly-Financed VR Supports toward Post-Secondary Education & Integrated Employment:** VR programs are directed to strive toward employment in integrated settings at the greater of minimum or competitive wages with commensurate benefits, independent living and community participation. VR agencies will no longer be able to determine individuals ineligible to receive supported employment services.
- **Ensuring Flexibility for Individualizing and Targeting Supports…** through a presumption of employability for all individuals and provides more flexible means for individuals to utilize services.
- **Promoting Systems Change through State Innovation & Performance Accountability…** through demonstration grants for ten states annually to implement reform strategies through Employment First principles focused on improvement of post-secondary education and integrated employment outcomes. Grantees would be held accountable under strict evaluation plans and could not use funds to place participants in facility-based segregated settings.

POLICY RATIONALE

The TEAM-Employment Act (H.R. 604) requires VR systems to actively engage with other state entities under the presumption that all citizens can work in integrated settings at competitive wages. The legislation requires that public funds are utilized to assist individuals toward self-sufficiency and economic advancement. Increased flexibility of funding streams will amplify self-sufficiency, integrated employment, post-secondary education, economic advancement, independent living, and meaningful community & civic engagement.

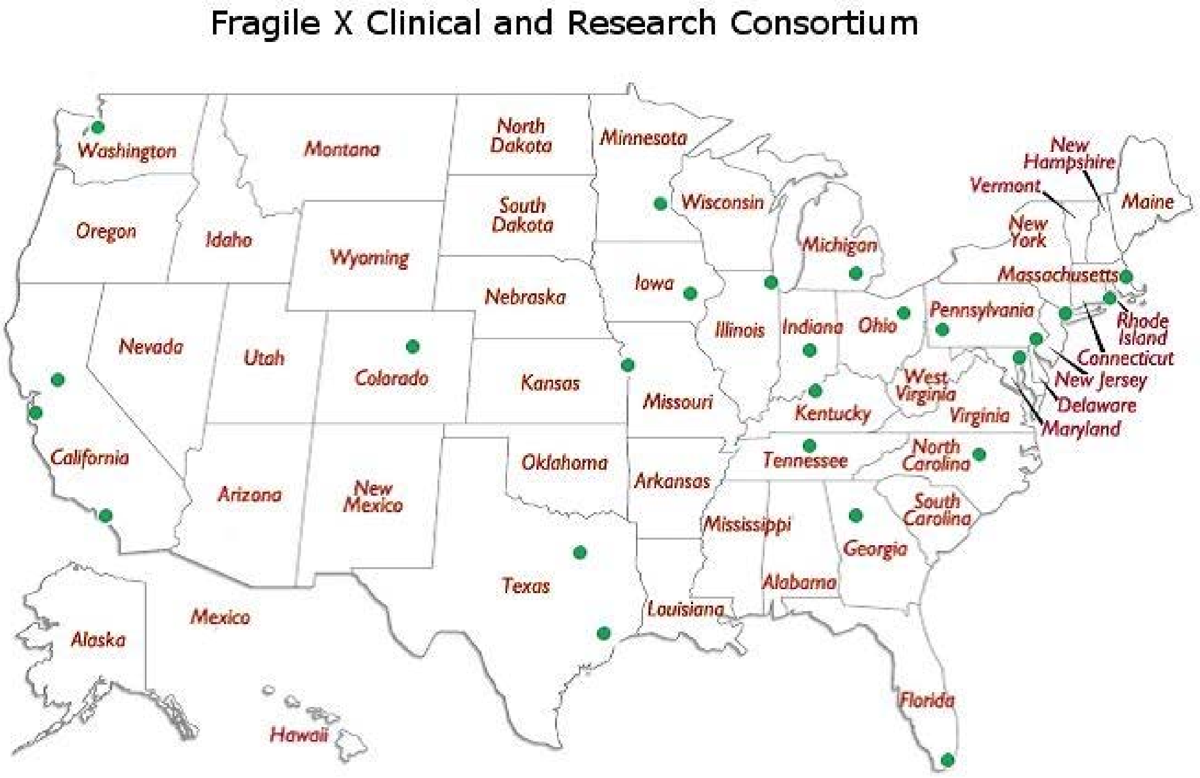
ACTION REQUIRED

Congressional leaders are encouraged to co-sponsor all three of the following legislative proposals: TEAM-Education Act of 2011; Team-Empowerment Act of 2011; and TEAM-Employment Act of 2011. **To cosponsor one or more of these innovative legislative bills, please contact Scot Malvaney in the Office of U.S. Representative Gregg Harper (R-MS) at scot.malvaney@mail.house.gov or (202) 225-5031.**

Members of the Senate are encouraged to introduce a companion bill in the Senate

Section V: Supplemental Materials, Follow-Up, and Contact Info

List of FXCRC Partners and Map of Clinic Sites



FXCRC Members:

1) Akron, OH: Akron Children's Hospital
2) Ann Arbor, MI: University of Michigan Hospitals and Clinics
3) Atlanta, GA: Emory University School of Medicine
4) Baltimore, MD: Kennedy Krieger Institute
5) Boston, MA: Children's Hospital Boston
6) Chicago, IL: Rush University Medical Center
7) Dallas, TX: University of Texas Southwestern School of Medicine
8) Denver, CO: Children's Hospital of Denver
9) Durham, NC: Duke University Medical Center
10) Houston, TX: Texas Children's Hospital
11) Indianapolis, IN: Riley Hospital for Children
12) Iowa City, IA: University of Iowa Hospitals and Clinics
13) Kansas City, KS: University of Kansas Medical Center
14) Long Beach, CA: Stramski Children's Developmental Center, Miller Children's Hospital
15) Louisville, KY: University of Louisville
16) Miami, FL: Mailman Center for Child Development
17) Minneapolis, MN: University of Minnesota
18) Nashville, TN: Vanderbilt Center for Child Development
19) Philadelphia, PA (area): Elwyn Fragile X Center
20) Pittsburgh: PA: Children's Hospital of Pittsburgh
21) Providence, RI: Brown University Medical Center
22) Sacramento, CA: U.C. Davis M.I.N.D. Institute
23) Seattle, WA: Children's Hospital and Regional Medical Center
24) Stanford, CA: Stanford University School of Medicine
25) Staten Island, NY: NY State Institute for Basic Research in Developmental Disabilities

Appropriations Committee Sign-on Letter of Support from Congressional Champions

Note: *This is the letter that our champions are sending to Appropriators. First they ask their colleagues to join them by signing this letter. You are asking your Member of Congress to "sign-on". Your "leave behind" packet includes a copy of this letter.*

Dear Chairman and Ranking Member:

As Members of Congress committed to improving health of children and adults in the United States, we respectfully request your support for federal funding for treatment and cure of Fragile X and its related conditions. Specifically, we seek your support for directives to:

- Implement the NIH Research Plan on Fragile X Syndrome and Associated Disorders; and continue funding for translational research that shows significant promise of a safe and effective treatment for Fragile X-associated Disorders (FXD).
- Continue Fragile X-associated Disorders as an eligible research topic for the FY 2013 Peer Reviewed Medical Research Program (PRMRP) at the Department of Defense.
- Maintain level and dedicated funding for CDC's national Fragile X public health program and continue to support the Fragile X Clinical & Research Consortium.

Fragile X Syndrome (FXS) is a genetic condition that causes behavioral, developmental and language disabilities throughout life. FXS is caused by a mutation of a gene on the X chromosome and is the most common inherited form of intellectual disabilities. The same mutation is also the most common known genetic cause of Autism. The same mutation is also linked to early menopause in females-as early as their 20's (called FXPOI-pronounced "fax-poy") and, a progressive tremor and dementia causing condition in older male carriers (called FXTAS-pronounced "fax-tas"). Over 100,000 Americans have fragile X syndrome and over 1,000,000 Americans carry the Fragile X mutation and either have, or are at risk for developing a Fragile X-associated Disorder.

New targeted drugs have successfully reversed core symptoms of FXS in multiple animal models and are currently in clinical trials in humans. These appropriations requests are critical to continue to build the public health infrastructure needed to meet a great and varied need and to assure continued progress toward targeted treatments which are realistically possible in the nearer term. These appropriations make it possible to build upon important work already initiated by the federal government at the Centers for Disease Control & Prevention (CDC), National Institutes of Health (NIH), and the Department of Defense (DOD). The CDC has recognized the significant public health impact of FX and has provided resources to ensure the continued growth and evolution of the Fragile X Clinical & Research Consortium.

The Committee's past support of the important work underway at the NIH and CDC will have a considerable impact on the important projects under consideration at these agencies. Yet there is even more that needs to be done. In order to ensure the rapid translation of ongoing research into high-impact, effective treatments and practices, continued resources must be focused on the goals and objectives of the NIH Research Plan on Fragile X Syndrome and Associated Disorders and the growth and development of the Fragile X Clinical & Research Consortium.

While we understand the challenges the Committee faces in prioritizing requests, we believe support for enhancing Fragile X research and public health activities is imperative given the significant impact Fragile X has on families and communities across the country and the great potential for effective treatments that is within reach. We thank you for your consideration

Suggested Thank-You Letter to Congressional Leaders

Note: *After Advocacy Day you will receive an E-Action Alert with a link to a prepared thank you letter that you can personalize and email. We recommend that you send your own personal note as soon as you get home. This can be typed or handwritten and can be mailed or emailed. Use the letter below or create your own but make it personal and stay on point. The letter below is to the Senator or Representative. If you met with staff you need to adjust the letter accordingly.*

Dear Representative/Senator _______________:

Thank you for meeting with me during my visit to Washington, DC. It was a pleasure to participate in the legislative process, and I appreciate your time and interest.

ADD IN YOUR PERSONAL STORY AND CONNECTION TO FRAGILE X-ASSOCIATED DISORDERS HERE

On March 7, 2012, I visited your office as part of the National Fragile X Foundation's Annual Advocacy Day. We sought your support for various public health and research priorities to help my family and others living with a Fragile X-associated Disorder. Specifically, we are asking you to sign a congressional letter to the House/Senate Subcommittee on Labor HHS Appropriations.

Our main requests are to:

- *Implement the NIH Research Plan on Fragile X Syndrome and Associated Disorders; and continue funding for translational research that shows significant promise of a safe and effective treatment for Fragile X-associated Disorders (FXD).*
- *Continue Fragile X-associated Disorders as an eligible research topic for the FY 2013 Peer Reviewed Medical Research Program (PRMRP) at the Department of Defense.*
- *Maintain level and dedicated funding for CDC’s national Fragile X public health program and continue support for the Fragile X Clinical & Research Consortium.*

Each of these requests will have a profound impact on the Fragile X community, and will play a vital role in supporting families living with fragile X syndrome, FXTAS, or FXPOI.

I also shared with your staff my interest in your support for legislative proposals that would greatly enrich the lives of individuals with Fragile X and their families. Specifically, I would like to respectfully ask that you consider co-sponsoring the following legislation:

- The Achieving a Better Life Experience Act (ABLE Act)
- The Keeping All Students Safe Act
- The Transition towards Excellence, Achievement &Mobility Acts (TEAM)
    - TEAM-Education Act of 2011 (H.R. 602)
    - TEAM-Empowerment Act of 2011 (H.R. 603)
    - TEAM-Employment Act of 2011 (H.R. 604)

If you have already co-sponsored any or all of these bills, I thank you for your support.

Again, thank you for taking time out of your busy schedule. On behalf of my family and the National Fragile X Foundation, I appreciate your listening to my concerns regarding Fragile X. I look forward to hearing from you soon on whether you were able to support my requests.

Sincerely,

Contact Information

NFXF Advocacy Day Reference Sheet

CATEGORY	KEY CONTACTS	CONTACT INFO
NFXF Washington Team	Jeffrey Cohen, Director Government Affairs	(313) 806-1190
NFXF Board Leadership	Brad Whitus, Board President	(832) 651-9026
Soapbox Help Desk	Soapbox Help Desk	(202) 362 5910
Rep Harper's Office	Ask for Emily Penn-she won't be able to help with specific scheduling but if you really need help with something call her	(202) 225 5031
NFXF Staff	Robert Miller, Executive Director	(925) 586-7100
	Linda Sorensen, Associate Director	(925) 283-1897
	David Salomon, Communications Coordinator	(925) 385-8431
Capitol Hill Operator	*If you need to contact any congressional office for any reason, dial this number and ask to be transferred to any Senate or House office.*	(202) 224-3121
Emergency Numbers for Capitol Hill	**Emergency**	**911**
	Capitol Hill Police – Non Emergency	(202) 225-5151
	Washington DC Police – Non Emergency	(202) 727-1010
Hotel Information	Doubletree Hotel 300 Army Navy Drive Arlington, Virginia	(703) -416-4100
Metro Information	Closest to Capitol Hill – House Side	Capitol South Metro (Orange/Blue Lines) House Side
	Closest to Capitol Hill – Senate Side	Union Station (Red Line)
	Closest to Hotel	PENTAGON CITY Station (Yellow and Blue lines)