How to Increase Advocacy Efforts in Your State

Presented By
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fragile·x

Society of Connecticut

Advocacy, Education, Awareness & Support.

History of Connecticut Advocacy

- Action Alerts
- Advocacy Day in Washington
    - 2007 – one person
    - 2008 – two people
    - 2009 – six people
    - 2010 – nine people
    - 2011 – seven people
    - 2012 – eight people
- Fragile X Awareness Day in Connecticut

Connecticut Team – Lisa, Gene, Emma, Nancy, Joe and Andy with Representative Harper (2009)

Connecticut Team – Andy, David, Tammy, Luke, Roberta, Gene, Lisa, Joel and Kirk with Representative Harper (2012)

Connecticut Advocates
Training Day 2010

Action Alerts

- Forward action alerts to:
  - Family
  - Friends
  - Co-workers
  - Business Associates
  - Teachers
  - Therapists

Ways to Increase Your FX Contacts

- Plan a Fragile X meeting
  - Advocacy
  - LINKS Group
  - Fundraiser
  - Social
  - Educational Conference
- Ask NFXF to send and/or email notification of your event to their contacts in your state

Contact Information Needed

- Name
- Address
- Phone Number
- Email Address
- Connection to Fragile X (FX Family Member, Physician, Teacher, Therapist, Other)

Build Relationships with Your Contacts (They are all potential advocates.)

- Forward action alerts
- Provide updates
- Provide information
- Provide support
- Explain ways to get involved

Build Relationships with Your State Representatives and Senators

- Contact them (email and phone calls)
- Visit them
- Tell your story
- Sign up on their facebook pages
- Volunteer for their campaigns
- Invite them to special events
- Attend legislative breakfasts
- Attend rallies
- Make donations

In-State Activities

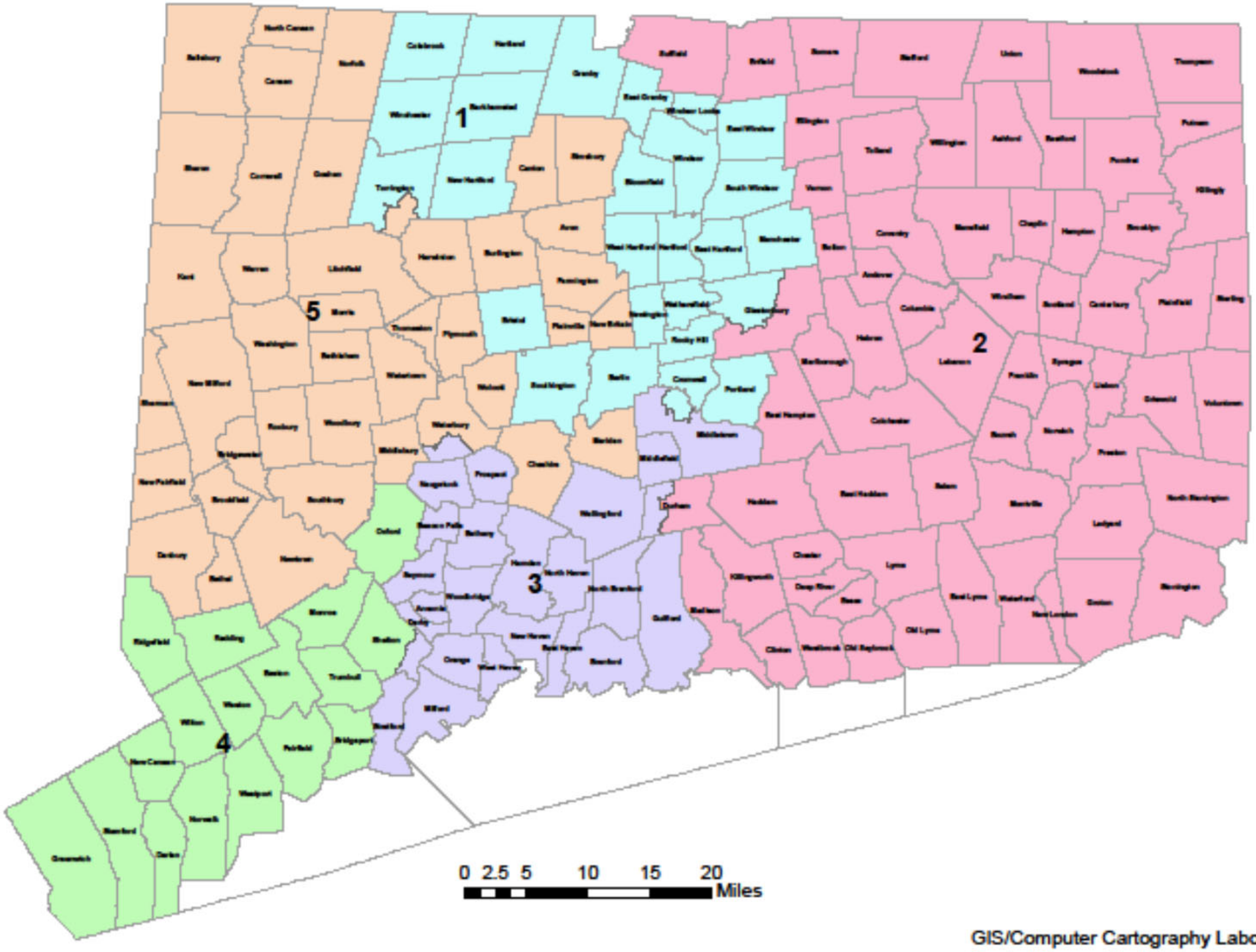
- Fragile X Awareness Day in Connecticut
  - Contact a State Representative or Senator to begin the process
  - Request support from your contacts
    - Testify in front of the Government Administration and Elections Committee of the State General Assembly
    - Write testimony for submission if unable to attend
- Host a Legislative Breakfast

Former CT Senator Jonathan Harris proclaiming Fragile X Awareness Day in CT

Becoming an Advocacy Champion

- Take an active role to develop and work with other advocates in your community
- Be aware of all congressional districts
- Educate yourself on committee assignments (i.e. Appropriations)

Connecticut - Congressional Districts 2002



GIS/Computer Cartography Laboratory
Central Connecticut State University
April 2002

Build Your State Advocacy Team

- Locate a list of the towns/cities that are represented by each district in your state
- Organize your contacts by district
- Email your contacts about Advocacy Day
- Request that this email be sent to the NFXF contacts in your state

Connecticut Congressional District #1
John B. Larson (D)

Barkhamsted
Berlin
Bloomfield
Bristol
Colebrook
Cromwell
East Granby
East Hartford
East Windsor
Glastonbury
Granby
Hartford
Hartland
Manchester
Middletown
New Hartford
Newington
Portland
Rocky Hill
Southington
South Windsor
Torrington
West Hartford
Wethersfield
Winchester
Windsor
Windsor Locks

http://www.ct-n.com/civics/maps/Connecticut%20Congressional%20Districts_text.htm

- ***Call your contacts*** about the state and federal advocacy efforts
  - ➢Share your personal experience as an advocate
    - ➢Meeting other advocates from around the country
    - ➢Social opportunities
  - ➢Ask them to come to Washington
    - ➢Meet with their legislators
    - ➢Tell their story
    - ➢Be empowered
  - ➢Support them through the process
    - ➢Travel arrangements
    - ➢Accommodations

- Follow up
    - Emails
    - Phone calls
    - Facebook
- If they can not attend in Washington
    - Ask them to write letters to their legislators which will be hand delivered
    - In 2010, a successful effort began where letters were an acceptable method of requesting face to face meetings

Sample Email Sent to Contacts

To our Fragile X Friends,

Even if you can not make it to Washington DC for Advocacy Day this year, **please write a letter!**

We will hand deliver your letter to your representative. If someone is in Washington DC from your district, presenting your letter during their meeting will strengthen their message. If nobody is there for your district, your letter will enable us to get a face to face meeting with your representative.

Here is a description of what the letter should include:

1. Describe in **250 words or less** what a day in the life of a person with Fragile X is like or how Fragile X has impacted your life or the life of someone you know.
2. Please address your letter(s) to Senator (insert name), Senator (insert name) and your representative. If you are not sure who your representative is, please check http://www.house.gov/ (top left, by zip code).
3. Letters should not request or comment on issues, programs, politics, etc.
4. Make sure to include your name, address, phone number, and email address (very important!).

Please email this letter(s) to us at (put in your email address) with a topic of "Advocacy Letter" no later than (insert date).

Thank you.

(Insert your name)
(Insert your group name)
(Insert your phone number)

Connecticut Team – Lori, Gene, Andy, Tammy, Lisa, Stephen, Joel and Kirk (2010)

Lisa, Tammy and Andy with
CT Congressman John Larson (2011)

Lisa, Roberta, Tammy, Andy and David with CT Senator Richard Blumenthal (2012)

Connecticut Advocate Experiences

Often people are very driven towards causes and other times causes pick them, the latter was the case when our daughter Charlye was diagnosed with Fragile X. However it wasn't until I received the personal call from Andy and Tammy Selinger asking me if I was willing to join them in DC for Fragile X Advocacy Day did it occur to me that it was time for me to be proactive. Until then our family, like most, were dealing with the day to day challenges of Fragile X, reacting to the needs of our children.

Going to DC meant an opportunity to join with people who understood what we were going through, people who could teach my family more about what we might be up against. The opportunity to learn about the wonderful advances and see how quickly these have come about due to others who had taken this very same journey. But most importantly, it became an opportunity for me to learn how to vocalize the need for Fragile X awareness.

Meeting with Senators, Congressmen, and their staff is an interesting and thrilling experience for any citizen. But it is awe inspiring when you sit down as a part of a Fragile X Advocacy group meeting and their first comments are, "Yes we remember you and your cause." It validates the time, energy and expense. It shows how powerful the message is and it is a testament to the collective cause and its leadership. It proved to me that the experience will not be my last.

Stephen Sutton

From the time my daughter was first diagnosed with Fragile X in 2008, I knew that I wanted to volunteer in some way. When I saw the call for advocates on the listserv, I knew this was perfect chance for me to contribute without making a long term commitment to a committee. Being in Washington was an amazing experience! Not only did I get to meet people from the FX community, but I really felt like I was able to make a difference. Talking to legislators face to face and telling your story is incredibly empowering. On my last trip to DC, we literally got to see the fruits of our lobbying efforts. I sat in the House gallery and watched the representatives pass the House restraint bill and I realized, “Hey, they actually heard what we said about this bill.” It was an unforgettable feeling.

Lisa

For many years it was frustrating to find that nearly everyone I spoke with knew nothing about Fragile X, even people who worked with my son in school or in community programs. So it was with delight that I encountered Andy and Tammy Selinger who were so determined to educate whomever they could - teachers, doctors, caregivers, and the public in general - about Fragile X and how it affects our children. They give hope to other families with Fragile X that our voices can be heard. It has been gratifying when I have been able to participate in advocacy day in DC, to think that in some small way I am making a contribution to making the world a bit more open and receptive to people with Fragile X.

Nancy Habetz

Fairfield, CT

Joel and I were so excited about the trip to Washington for Advocacy day. Before went, neither of us knew quite what to expect but it turned out to be a tremendous experience for the both of us. The training session on day 1 was good and we met some great people. I was surprised to hear some of the stories which parents and their children have experienced. Some good, some bad. The one constant remained between us in that we all want the most for our children or any other individual who can be supported through the Fragile X Foundation. At dinner that night we couldn’t stop talking about our lives and how much we adore our kids and take great pride in their accomplishments. The tour of the House and State Capital we will never forget and Congressmen Harper from Mississippi was an excellent Host. We couldn’t have asked to be treated with more dignity and respect and I got this same feeling from each congressional meeting we attended. The opportunity to see the House vote positively on the “No Restraints and Seclusion Act” put the icing on the cake. Quite an experience for me and especially for my son. We actually felt as if the lobbying we did throughout the day came to fruition with immediate results. Amazing.

A few nights ago I asked Joel what he thought of the trip. He said “It was nice and we helped other children at the same time”.

When I asked him what he thought of the congressional meetings he said “Not so much”. When I asked him if he would go again he said. “That would be fine”, and for Joel to say that, I know he still remembers everything and feels good about himself for going.

We both look forward to attending another conference and contributing in any way possible to assist with the efforts of the fragile x foundation. I feel confident that each Advocacy day brings more awareness to the efforts and hopes of families all around the world. You and Tammy do an excellent job coordinating things and Joel and I look forward to our next trip to Washington.

Kirk Quintin

In Conclusion…

- All you need is:
    - Your story
    - Persistence
    - To know that you can make a difference
- This will not happen by itself.
- We need grassroots advocacy in each state.
- Keep the NFXF advocacy momentum going.