

Working the Room: Advocacy You Can Use



Sharron Close, PhD, MS, CPNP-PC, FAAN

Dorothy Boothe, PhD

Awareness

- Number One issue cited by X & Y patients and families as barriers to
 - Health care access
 - Educational Support
 - Legal and disability concerns
- The MOST Protected (withheld/hidden) information creates barriers



Can you hear me now?

Who? What? Why Should Anyone Care?



Communication is Bi-directional

Patients
And
Families



Doctors
Nurse Practitioners
Psychologists
Psychiatrists
Educators
Insurance
Policy
And More

Finding your Voice: Individually and Collectively

Is anybody else dealing
with this?.....

Who can I talk to?.....

Is there any help at all?..

Who Knows.....

Why is this so hard?.....

Am I alone?.....



WHY IS IT LIKE THIS?

The X & Y Chromosome Community Must Be Heard



- Common Language
- Normalization
- Widespread Knowledge
- Accessible Education
- Advocacy in all forms

Advocacy in Its Many Forms

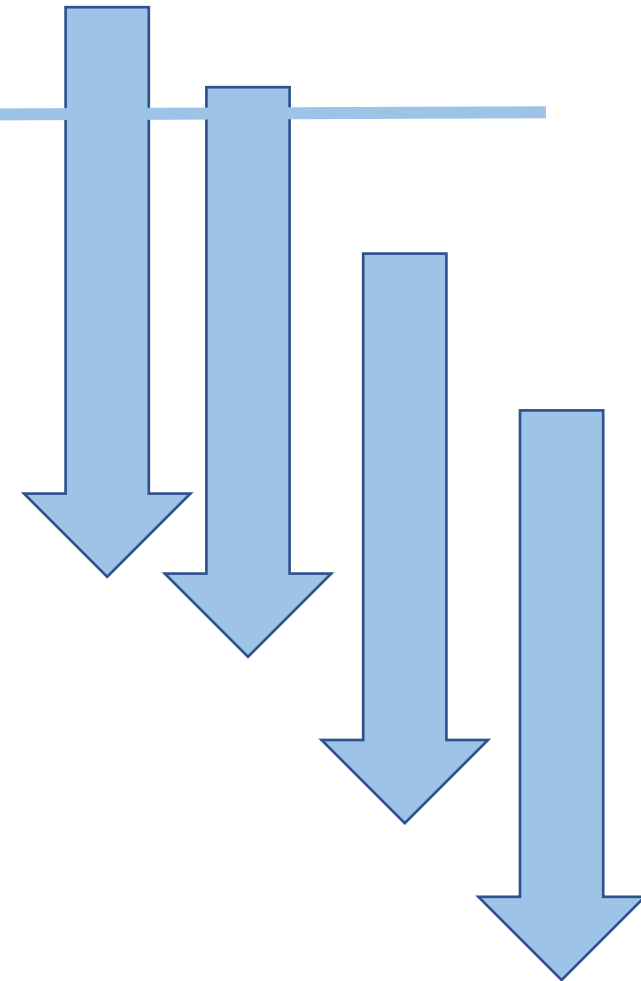
- Person to Person/People to People
 - Social Media Groups
 - In-Person Support Groups
 - National Advocacy group (AXYS)
- Person to Institution/People to Institution
 - School Districts/Schools
 - Vocational and Employment Settings
 - Legal and Law Enforcement
 - Judicial System
- Person to Systems/People to Systems
 - Insurance
 - Adjuvant Service Needs
 - Representation



It is LITERALLY, In our Hands

Impact of Advocacy

- Knowledge
- Actions based on Knowledge
- Network Knowledge Development
- Development of Familiar Language
- Awareness and Normalization
- Contagion of Awareness
- Patient-Centered Direction
- Patient-Centered Agency to affect Change



CHANGE!

From Invisible..... To Visible



Working the “Room”: Find someone who is involved already

- Attend another senate resolution and make a friend
- How to pull a senator to the ropes
- “I am one of your constituents”
- Specific to ask them: support funding for SPECIFIC
- Get used to being in the environment
- Get involved with other people in disability community
- Medicaid waivers; sometimes asking for the same thing



Organize Your Thoughts: Write out your story

- Support in school district
- Health insurance not covering medications or services
- Own personal story is powerful in a face-to-face
- Serendipitous introductions
- Kids might be able to page with legislators
- Kids can talk to their legislators
- Contagion of contact
- Find out what committees do your reps sit on?
- Who is important in making decisions in health care?



Legislators WANT to Hear From You

Footage with Senator Unterman

Making Contact

- Telephone appointment
- Get to know the legislative assistant
- Make specific requests:
- Document/Photograph/Create News & Press Releases
 - To create a Proclamation
 - To request senator or representation to attend an event
 - Post to social media

Legislators are PEOPLE (just like us)

- Demonstrate kindness and respect
- Politely disagree, if required and then use this opportunity to MAKE THE CASE
- You can influence the way they think about things
- Thank them for their time and attention
- Leave an GOOD impression

“What do I want someone to **remember** about me?”

“How do I want to be **perceived?**”

“How can I **create** the right **impression?**”

Memorable BRANDING



Tools to Begin: Finding Your Legislators

- <https://www.senate.gov/senators/contact/>
- <https://openstates.org>

Partners in Policy Making

- Partners in Policy Making : course (in every state) developmental disabilities

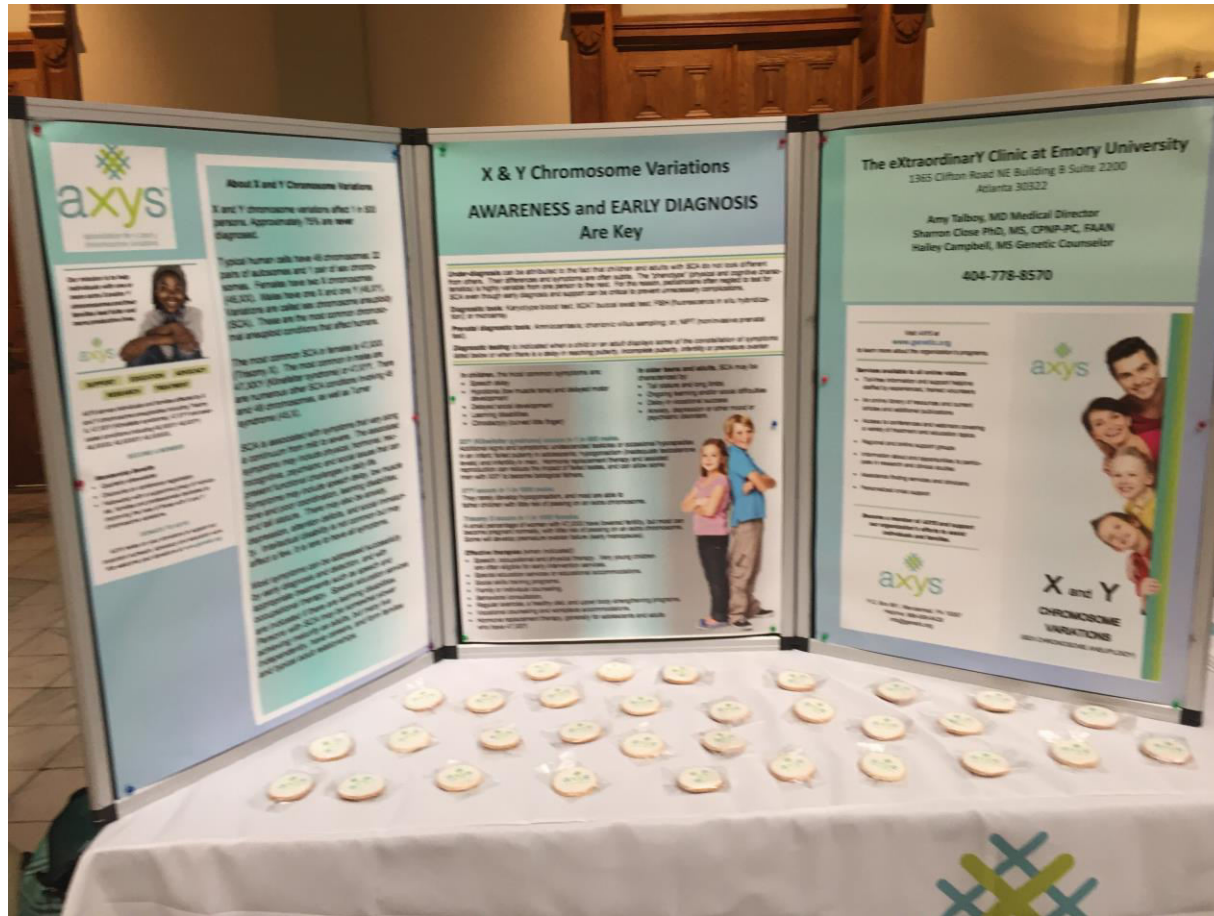


- <http://partnersonlinecourses.com>

SHOW UP!



Be in Strategic Pathways



In Session: Nerves and Hopefulness



- Singularity of Purpose
- Strength of Community
- Power of Combined Voices

Witnessing the Moment



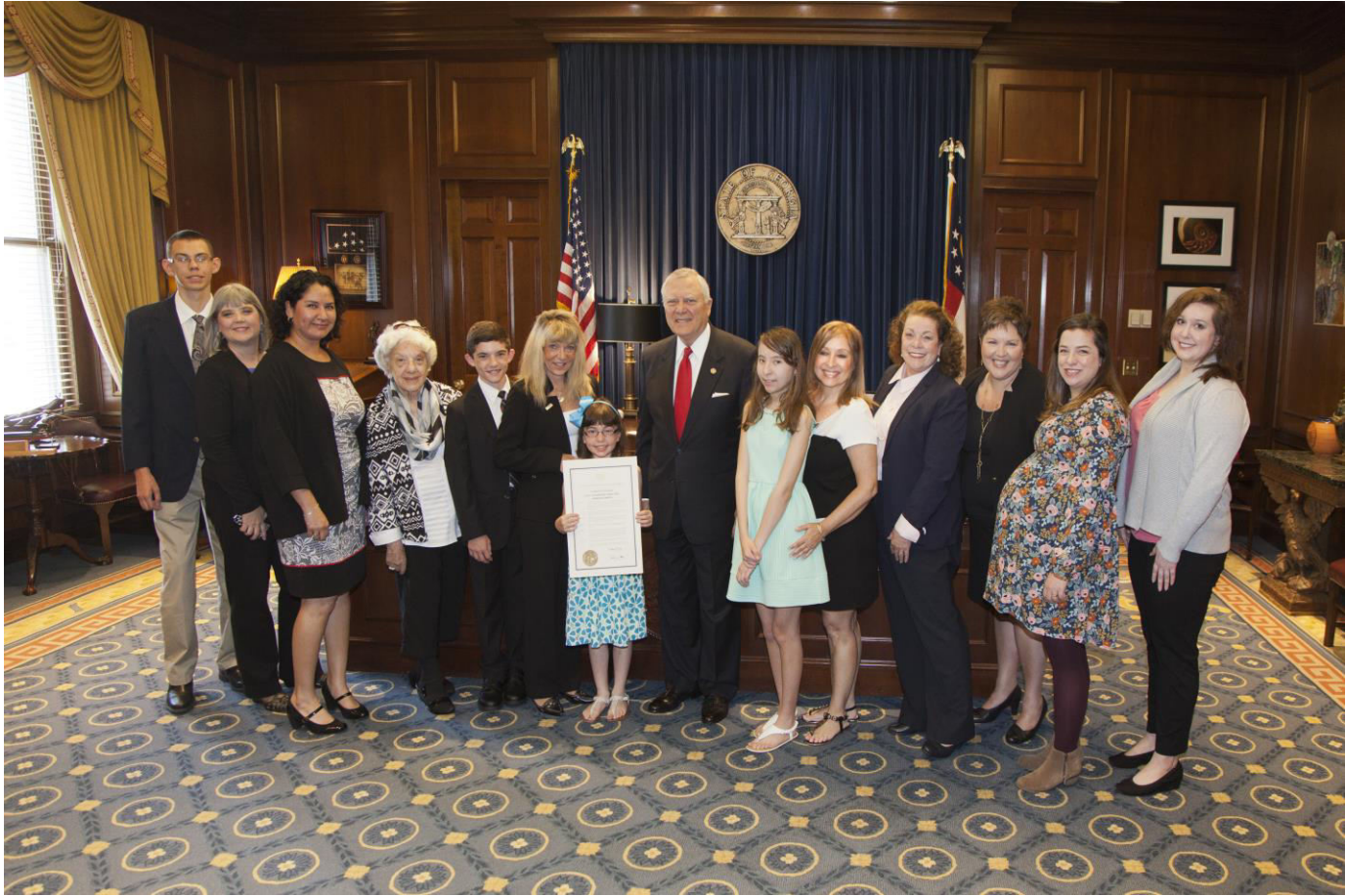
There THEY are: Up Front and Center



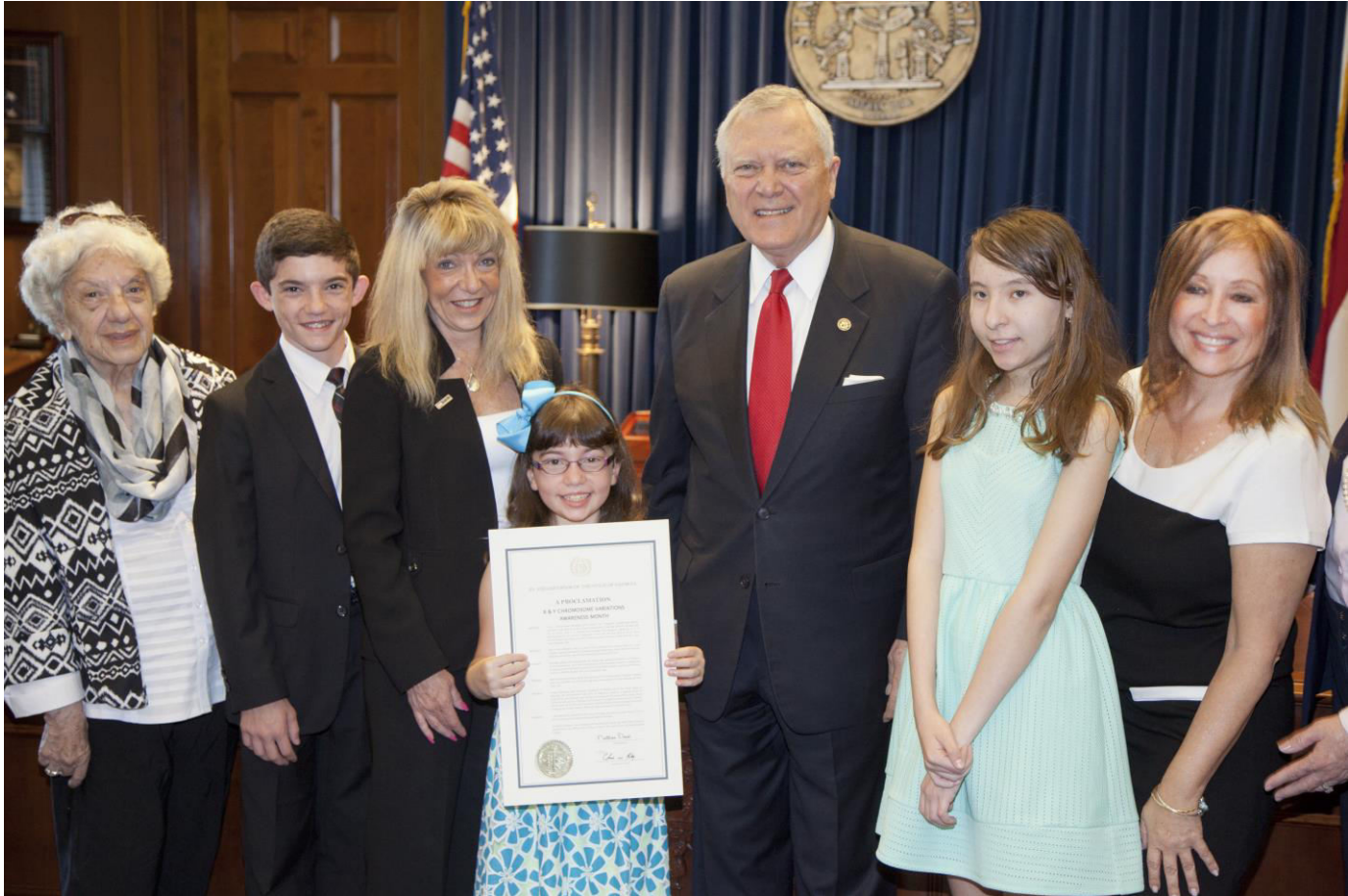
Singular Mission Accomplished



All the Way to the TOP: 2016



All the Way to the Top: 2017



Advocacy Has to Come From the Inside

- How important is it to you?
- Avoid "relying others"
- Nobody can tell your story better than you
- Be persistent, relentless and kind
- Keep showing up
- Reflect on your commitment: Value to the X & Y Chromosome community is based on each singular commitment



Step up and be Present

Questions

