



NATIONAL
DOWN SYNDROME
CONGRESS

Different Ways to Advocate

Parent & Self-Advocate Panel

Jawanda Mast, Parent Advocate &
Founder 321Advocate, *Facilitator*

Panel:

LaTaasha Byrd, Parent Advocate, Florida

Dria Law, Parent Advocate, New Jersey

Erin Mullen, Global Consultant & Parent Advocate, Virginia

Jessie Smart, Self-Advocate, Mississippi



NATIONAL
DOWN SYNDROME
CONGRESS

What is Advocacy?

- Dictionary: *the act or process of supporting a cause or proposal*
- Grassroots advocacy: collective action at the local level by individuals (“ordinary citizens”) to effect change
- Telling your personal story to try to turn “what is” into “what should be”; putting a real face on the issues
- Providing education and information to elected officials and the broader community about issues, problems and concerns
- Is it the same as lobbying? NO.
 - But lobbying can be a part of advocacy efforts.
- Continuum of advocacy activities depending on comfort level, time, passion for the issue.

Who is an advocate? YOU ARE!



Different Ways to Advocate Panel

LaTaasha Byrd
Parent Advocate
Florida

WELCOME

La Taasha Byrd, BS, MS

- Mother to Cairo, 9, who has Down syndrome
- Member – Down Syndrome Association of Central FL, Down Syndrome Foundation of FL
- Multicultural Outreach Coordinator, Family Network on Disabilities
- Special Needs Advocate and Speaker
- Author – “Inclusion Is for the Included: A Collection of Stories from a Special Needs Mom”
- Blogger, CountdownToK.com



Cairo Byrd, 9

- 3rd Grade
- Member – Macedonia MBC Children's Choir
- Member – Macedonia MBC Children's Chapel
- Subject – Countdown To K blog
- Avid Hug Ambassador
- Dancer Extraordinaire

BREAK COMMON BARRIERS

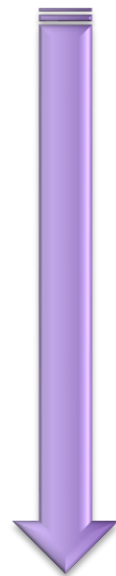
TELL YOUR STORY WITH PURPOSE AND ABILITY

- SOCIETAL PERCEPTIONS
- CULTURAL NORMS
- FAMILY DYNAMIC



START AT THE BEGINNING

*ADVOCACY BEGINS WITH
JUST ONE STEP*



ACCESS

APPROACH

ASSIST



NATIONAL
DOWN SYNDROME
CONGRESS



SELF-ADVOCACY

PREPARE TO PASS THE TORCH

- INDIVIDUAL STRENGTHS
- FAMILY TRADITIONS
- EDUCATION
- LEVEL OF INDEPENDENCE

**Special
education**

is **NOT** a

ROOM

Inclusion is a
RIGHT

and it
WORKS



- **PRESUME COMPETENCE**

- Have an open mind and high expectations

- **COMMUNICATE WELL AND OFTEN**

- Foster positive partnerships

- **BE CALM AND KIND**

- Be an ally, not an adversary

Different Ways to Advocate Panel

Dria Law
Parent Advocate
New Jersey

The Law Family

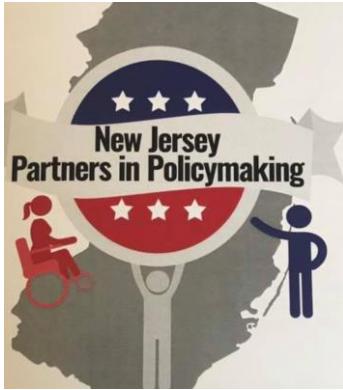


Why Advocacy?



- Education
- Employment
- Housing

What Advocacy Looks Like for Us



Senator Troy Singleton

April 22, 2018 · 🌐

Senate President Steve Sweeney and I were honored to join the local NJ Down Syndrome affiliate organization (KIIDS), which provides services and education to families in Burlington, Camden and Gloucester counties, at their annual Fashion Show fundraiser this afternoon. This organization and the exceptional children and young adults that they support are an example of what's right in our state. A special thank you to my friend and co-chair, Dria Law, for inviting us to participate.



- Interacting with legislators & staff (federal & state)
- Establishing ourselves as a local Ds/disability resource
- Gathering knowledge
- Involved with school district
- Being the bridge for our local families



From Mom to Advocate to...Candidate

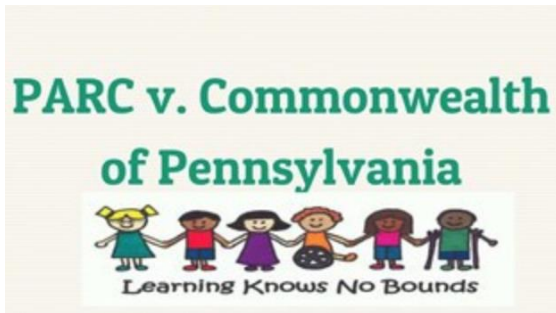


Where to Begin?



- Advocacy can take many forms
- Follow your interests
- Don't be afraid to push yourself
- Do your homework
- Build your credibility
- Keep in touch

The Road Behind & The Road Ahead



- 1972
- 2006
- 2019
- 20??



Different Ways to Advocate Panel

Erin Mullen

Global Down Syndrome
Foundation Consultant

and

Parent Advocate
Virginia





GLOBAL
DOWN SYNDROME FOUNDATION®

Making an Impact in Washington DC

Erin Book Mullen

Parent Advocate

Global Down Syndrome Foundation Consultant

Partner, Williams & Jensen, PLLC

NDSC Advocacy Training Day

Thursday • June 27, 2019

NDSC Annual Convention • Pittsburgh, PA

MOM and ADVOCATE

- ❖ Mother to Amelia (4) and CC (2)
- ❖ Partner at Williams & Jensen, a top 10 lobbying Firm in Washington, DC
 - Represent Global Down Syndrome Foundation
- ❖ Worked on behalf of clients in Washington for over 17 years
- ❖ CC was born in 2016 and everything changed



WHY SHOULD YOU GET INVOLVED?

Because engaging policymakers is one of the most effective ways to influence public policy;

Because everyone can and should lobby decision-makers on proposals and policies that impact their lives;

Because Members of Congress and their staff want to hear from YOU!!



GLOBAL'S GOALS

- ❖ Dramatically increase NIH research funding to benefit people with Down syndrome
- ❖ Educate Congress and the Administration about importance of medical care and research in the Down syndrome community;
- ❖ Elevate these issues at all levels of government and create new opportunities.
- ❖ Raise Money for Down syndrome research!

OUR ACCOMPLISHMENTS

- ❖ With Global, led the effort secure and garner support for the first-ever congressional hearing on Down syndrome research
- ❖ Successfully lobbied for a significant 71% increase of Down syndrome research funding at the National Institutes of Health (NIH) from \$35 million in FY2017 to \$60 million in FY2018



OUR ACCOMPLISHMENTS

- ❖ Creation of INCLUDE Project Research Plan (*IN*vestigation of *C*o-occurring conditions across the *L*ifespan to *U*nderstand *D*own syndrom*E*)
- ❖ Worked with Global to establish the Annual AcceptAbility Gala in Washington, DC which honors Congressional leaders and self-advocates in the Down syndrome community and raises money for life-changing research and life-saving medical care
- ❖ Current efforts include finalizing FY2019 funding level (\$77 million) and ensuring FY2020 is a \$22 million increase above expected FY2019 amount

HOW TO BE EFFECTIVE



- ❖ Be Prepared
- ❖ Tell Your Story
- ❖ Educate and Listen
- ❖ Make the Ask
- ❖ Build Relationships
- ❖ Find Other Ways to Advocate



BEING PREPARED

❖ Who are you meeting with?

- Constituent Members and other key Leaders
 - House.gov; Senate.gov
- Know their committees, caucuses, and other biographical information
- Know if and how they have been involved with the Down syndrome and greater disability community
- Look at disability policy-related websites, policy statements, and issue briefs to stay informed
- Remember that you may meet with staff, and that is BETTER than OK!
 - **Chief of Staff:** Chiefs are in constant communication with a Member; the tight bond means that chiefs are often delegated to speak for the Member to constituents
 - **Legislative Director:** LDs tend to be specialists in the policies of the committees on which the Member serves; they may focus less on other areas
 - **Legislative Assistant:** LAs support the LD and Chief of Staff

WHAT ARE THE KEY COMMITTEES?

- ❖ Appropriations Committee
 - Draft Annual Federal Spending Bills
- ❖ Health, Education, Labor and Pensions (HELP) Committee (Senate)
- ❖ Energy & Commerce (House)

WHO ARE OUR CHAMPIONS?



Representative Tom Cole
Senior Member - House
Appropriations Committee

**Representative Cheri Bustos and
Chairwoman Rosa DeLauro**
Chairwoman and Senior Member -
House Appropriations Labor HHS
Subcommittee



Representative Cathy McMorris Rodgers
Son with Down syndrome,
Co-Founder of congressional caucus



Senator Roy Blunt
Chairman – Senate Appropriations
Labor-HHS Subcommittee



Representative Pete Stauber
Son with Down syndrome

WHAT SHOULD YOU BRING?

❖ Very little!

❖ Bring a one-page summary (a “leave behind”) for the office

- This document is a reminder to the person you met with of your main points and contact information
- It should include: information about YOU; the purpose of your meeting; and what your “ask” is...

❖ Relevant Legislative Materials

- Copies of bills or letters you are asking them to support

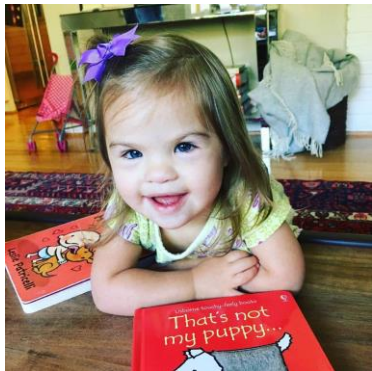
❖ Supporting Materials

- Such as a resource document from a disability group website, research information, news articles about the issue

Example of One Pager

DID YOU KNOW...

- ❖ About 50% of all infants born with Down syndrome are also born with a congenital heart defect
- ❖ Children with Down syndrome develop leukemia at much higher rates than the general population
- ❖ Alzheimer's disease and Down syndrome share a genetic connection, leading to the increased risk of dementia at an earlier age. Current studies suggest that **nearly 100% will have brain pathology of Alzheimer's by the age of 40.**
- ❖ It is rare for a person with Down syndrome to have a solid tumor cancer or cardiovascular disease, including heart attack and stroke.



ABOUT ME: My name is CC Mullen and I am a smart, happy, determined, unique 2-year-old who has Down syndrome. I love to sing read books, and run after my sister. I was born with a heart defect and had open heart surgery when I was 5 months old, and right now I am fighting hard against leukemia.



WHY I'M HERE: Medical and clinical research can improve the health and lifespan of people with Down syndrome, **and Down syndrome is one of the least funded genetic conditions by the NIH.**

- ❖ The additional copy of chromosome 21 leads to a radically different disease spectrum for people with Down Syndrome
- ❖ Individuals with Down syndrome are predisposed to or protected from major diseases that are the cause of death for over 50% of Americans
- ❖ Studying Down syndrome and these co-occurring conditions can improve the health and lifespan of people with Down syndrome and those without, potentially leading to breakthrough treatments.

WHAT WE NEED: MORE FUNDING FOR NIH THAT IS DEDICATED TO DOWN SYNDROME RESEARCH

HOW TO HAVE A GOOD MEETING?

- ❖ Be on Time
- ❖ Be Flexible (your meeting time may change! your meeting may happen in the hallway!)
- ❖ Say Thank You!
- ❖ Stay on Topic
- ❖ Do Not Discuss Politics or Make Assumptions
- ❖ Ask Questions and Let Them Talk
 - “How can we help?”
- ❖ It is ok to say “I don’t know”
- ❖ Make the Ask!



BE A RESOURCE

❖ Send a thank you message

- Send a follow-up e-mail several days after meeting
- Keep the message brief, thank the office for their time, and remind the office of the issue at hand
- Leave a link to a reliable source of information on the issue for the office to reference

❖ Attend events in the district

- Attend town halls or other public events in the district to build a stronger relationship with your representative

❖ Stay in touch

- Send staff any follow-up information they asked for or you offered to share during your meeting
- Do not over-communicate, but do pass along new information about your issue as it is released

OTHER WAYS TO ENGAGE

❖ Say Thank You on Social Media

- Tag the member / office that you met with, post a picture if you took one

OPINION > EDITORIALS

Congress should give it up for Down syndrome research

❖ Use local media sources

- Submit op-eds on why NIH needs more funding for Down syndrome research
- Send letter to the Editor thanking your member for supporting our cause

People with Down syndrome are a gift to bioscience

BY MICHELLE SIE WHITTEN, CONTRIBUTOR - 10/24/16 03:33 PM EDT

2 CO

❖ Engage in-district office

LETTER

The 'Down syndrome disconnect': An open letter to medical professionals and expectant parents

FORMULA FOR SUCCESS

❖ YOU!

➤ **NOTHING** happens without YOU!

❖ Know what you want and ASK FOR IT!

❖ Be Respectful

❖ Be Grateful

❖ Be Consistent

❖ Follow-up



Different Ways to Advocate Panel

Jessie Smart
Self-Advocate
Mississippi

Jessie Smart

- 30 years old
- Lives in Olive Branch, MS
- Graduated from Lewisburg HS with an occupational diploma
- Attended 2 semesters NW MS Jr college
- Communications Asst at DSAM
- DSAM Board of Directors 2010-2016
- NDSC Board of Directors 2015-2018

Political Advocacy



Met with MS Senator Roger Wicker in Washington, DC to advocate for the ABLE Act

Political Advocacy



Mississippi LT Governor Tate Reeves has been a supporter of the ABLÉ Act



Mississippi Governor Phil Bryant signs the ABLÉ Act
April, 2017

Educational Advocacy



As part of my occupational degree requirement, I served as a teacher's assistant at Lewisburg Primary School

Educational Advocacy



I spoke at the teacher training seminars on inclusion in the classroom

Speaking at the new parent brunch



Advocating for Community Opportunities

Making a presentation at a Civitan Meeting



Interview by local tv station at our annual Step Up Walk



“Yes I Can”



In 2009 I received an international award from the Council of Exceptional children. This award was named the “Yes I Can” award

Personal Advocacy

I served on our local Down Syndrome Association of Memphis and the Midsouth(DSAM) Board of Directors for six terms.

- The DSAM board has two self advocates .
- Importance of the self advocates on local boards:
- Go out into the community to meet business owners,
- Speak at educational seminars
- Represent our organization
- Meet with our local and state representatives.

We, as self advocates, need to speak about issues that are important to us. Serving on the Board of Directors in your organization is the best place to begin. This allows us to have our voices heard.



Personal Advocacy



My motto has always been
“YES I CAN”
and
“ YOU CAN” TOO!!!

Thank & You and Contact Us

LaTaasha Byrd, Parent
Advocate, Florida
admin@countdowntok.com

Dria Law, Parent Advocate,
New Jersey
jerdria@hotmail.com

Erin Mullen, Global Consultant
& Parent Advocate, Virginia
ebook78@gmail.com

Jessie Smart, Self-Advocate,
Mississippi
jessierebs@aol.com

