



# Friends of NCBDDD

In Support of the National Center on Birth Defects and Developmental Disabilities

***Quarterly Check In***  
***Friday, September 9***  
***2pm ET-3:30pm ET***

***866-794-4983 for audio***

***<http://aucd.adobeconnect.com/friends/>***  
***for visual***

***“Improving Health”***

# Friends of NCBDDD

In Support of the National Center on Birth Defects and Developmental Disabilities



***Welcome***

***Shannon Haworth, AUCD  
Communications Chair***



# Friends of NCBDDD

In Support of the National Center on Birth Defects and Developmental Disabilities



***Welcome***

***Sara Struwe, SBA  
Vice-Chair***



## Highlights from the National Center on Birth Defects and Developmental Disabilities

***Coleen Boyle  
NCBDDD***



The logo consists of three overlapping curved shapes in shades of blue and green, resembling a stylized wave or a protective shield.

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## ***Champions:***

***Sara Struwe, SBA***

***Roberta Carlin, AAHD***

***Jennifer Bolden-Pitre, Family Voices***

## ***Family Liaison:***

***Jeannette Meijas, Statewide Parent Advocacy Network  
of New Jersey***



**IMPROVING HEALTH**  
OF PEOPLE WITH DISABILITIES



**Friends of NCBDDD**

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# Improving Health of People with Disabilities Across the Lifespan

Roberta Carlin, AAHD

Sara Struwe, SBA



# Friends of NCBDDD

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## American Association on Health and Disability (AAHD) [www.aahd.us](http://www.aahd.us)

Mission: To promote health and wellness initiatives for children and adults with disabilities

- Reduce Health Disparities
- Advocate for Community Inclusion
- Promote Full Accessibility
- Integrate Disability into Public Health Agenda



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## Health Disparities and Disability

According to CDC, between 37-57 million of Americans report having some level of a disability; 12.5% of population has a disability which “seriously limits” them

- People with a disability are:
  - Over twice as likely to not see a doctor due to cost
  - Over 30% more likely to be obese
  - 60% more likely to smoke
  - Over 2.5 times more likely to develop diabetes
  - Women with disabilities less likely to have a current mammogram
  - Women with disabilities less likely to have a current pap test
  - Over 3.5 times more likely to have a cardiovascular disease (18-44 y.o)





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## What is AAHD doing to Improve Health of People with Disabilities?

- Research
- Public Policy
- Education and Dissemination
- Public Awareness



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## Three AAHD Initiatives for Today's Discussion- Improving Health of People with Disabilities

- National Disability Navigator Resource Collaborative (NDNRC)
- [www.nationaldisabilitynavigator.org](http://www.nationaldisabilitynavigator.org)
- Disability Research and Dissemination Center (DRDC)
- [www.disabilityresearchcenter.org](http://www.disabilityresearchcenter.org)
- National Breast Health Collaborative for Women with Disabilities (NBHCWD) (October 2016)



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## National Disability Navigator Resource Collaborative (NDNRC)

Mission: Cross – disability initiative to provide information and support to ACA navigators and enrollment specialists ensuring people with disabilities receive accurate information and select the most appropriate health insurance program when enrolling in the ACA marketplace

Two Tier Strategy: Educate People with Disabilities and Navigators

[www.nationaldisabilitynavigator.org](http://www.nationaldisabilitynavigator.org)

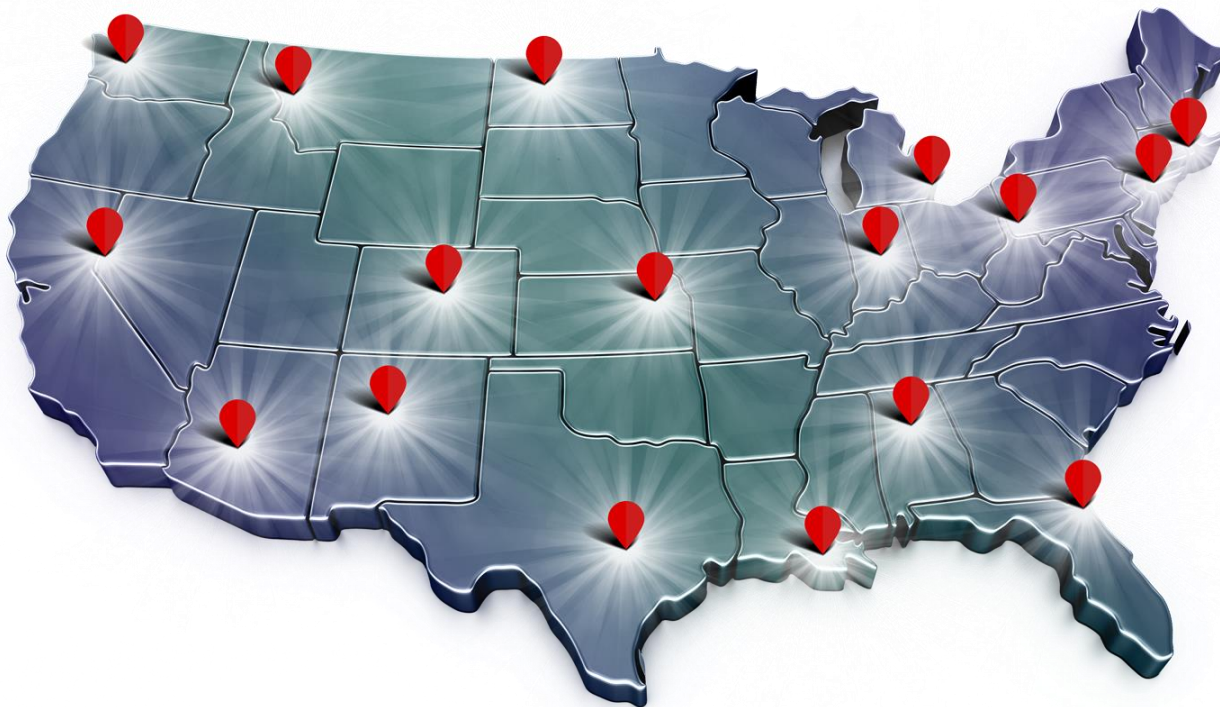
# NDNRC Partners



National Disability Navigator Resource  
Collaborative  
A project of the American Association on  
Health and Disability



# Community Outreach Collaboratives



<http://www.nationaldisabilitynavigator.org/about/community-outreach-collaboratives/>

National Disability Navigator Resource  
Collaborative

A project of the American Association on  
Health and Disability



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## Disability Research Dissemination Center (DRDC)

[www.disabilityresearchcenter.org](http://www.disabilityresearchcenter.org)

- AAHD, University of South Carolina School of Public Health, SUNY Upstate Medical University – Partnership among 3 PI-Institutions
- NCBDDD Cooperative Agreement
- Purpose: To expand the capacity of NCBDDD to identify and fund innovative research in the field of birth defects, disabilities, human development and blood disorders; foster training of health and public health professionals; advance disability science and evidenced based practice and use progressive mechanisms to disseminate knowledge
- Three Cores: Administration & Research; Training & Evaluation; Dissemination and Policy



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## National Breast Health Collaborative for Women with Disabilities

- Mission: To promote national awareness and promote universal accessibility and training at mammogram facilities throughout the United States in order to reduce the incidence of breast cancer in women with disabilities
- Launch Date: October 2017 – Breast Cancer Awareness Month
- Membership: Steering Committee



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## AAHD Multi – Tier Strategy to Improve Health For People with Disabilities

### **AAHD Ongoing Initiatives**

- Disability and Health Journal [www.disabilityandhealthjnl.com](http://www.disabilityandhealthjnl.com)
- Disability and Public Health News – weekly electronic newsletter – [www.aahd.us](http://www.aahd.us)
- NDNRC Weekly Update – weekly electronic newsletter
- AAHD National Dissemination Center - [www.aahd.us](http://www.aahd.us)
- AAHD Public Policy Center [www.aahd.us](http://www.aahd.us)
- AAHD Scholarship Program – [www.aahd.us/scholarship](http://www.aahd.us/scholarship)
- AAHD Liaisons
- AAHD List serves
- National Quality Forum





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## AAHD Multi – Tier Strategy to Improve Health For People with Disabilities

### AAHD Contracts/SubContracts/Teaming Agreement

- Disability Research Dissemination Center (DRDC) – CDC Funded
- National Center Health Physical Activity and Disability (NCHPAD) – CDC Funded
- Special Olympics – CDC Funded
- University of Washington – NIDILRR funded
- Washington State – CHRIL – NIDILRR funded
- Susan Komen Foundation
- National Council on Aging – ACL funded
- Lakeshore Foundation
- Deloitte Consulting LLP
- NDNRC – Robert Wood Johnson Foundation funded



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## AAHD Multi – Tier Strategy to Improve Health For People with Disabilities

### AAHD Coalitions (Not complete list)

- Consortium for Citizens with Disabilities (CCD)
- National Quality Forum (NQF)
- National Health Council (NHC)
- Disability Rehabilitation and Research Coalition (DRRC)
- Coalition for Health Funding (CHF)
- Maryland Health Benefits Exchange Standing Advisory Committee Member
- Coalition for Whole Health (CWH)
- Disability and Aging Collaborative (DAC)
- Mental Health Liaison Group (MHLG)
- Patient Centered Primary Care Collaborative (PCPCC)
- ITEM Coalition – Independence Through Enhancement of Medicare and Medicaid
- APHA Disability Section – Executive Committee



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## Contact Information

Roberta Carlin, MS, JD  
AAHD Executive Director  
110 N. Washington Street, Suite 328J  
Rockville, MD 20850

301-545-6140 ext. 206

[rcarlin@aahd.us](mailto:rcarlin@aahd.us)

[www.aahd.us](http://www.aahd.us)

[www.aahd.us/membership](http://www.aahd.us/membership)



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## The Spina Bifida Association

### MISSION

The mission of the Spina Bifida Association (SBA) is to promote the prevention of Spina Bifida and enhance the lives of all affected.

[www.spinabifidaassociation.org](http://www.spinabifidaassociation.org)



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## WHAT IS SBA DOING TO IMPROVE THE HEALTH OF PEOPLE WITH SPINA BIFIDA?

- Research
- Public Policy
- Education and Dissemination
- Public Awareness
- Focus on Adults



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## RESEARCH

- World Congress on the Research and Care for People with Spina Bifida

**MARCH 16-19, 2017**

**LOEWS CORONADO BAY – SAN DIEGO, CALIFORNIA**

<http://spinabifidaassociation.org/sbworldcongress/>

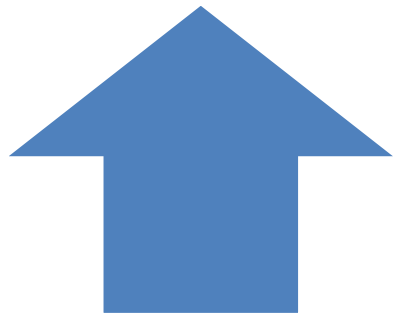
- Only multi-disciplinary meeting of its kind



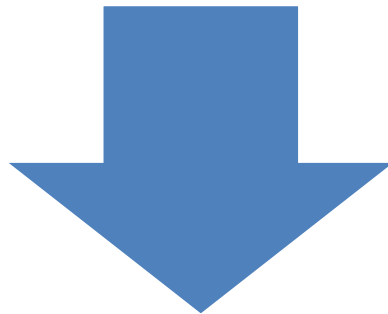
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## FOCUS ON ADULTS



Increase in people with SB  
aging



Little Access to care  
Lack of qualified healthcare  
providers and general  
knowledge about aging with SB



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## ADULTS WITH SB

- No accurate, general statistics on adults with Spina Bifida
- Over 60% of the questions the National Resource Center receives are from adults with Spina Bifida
- We believe that 40-60% of the overall people living with Spina Bifida in the US are adults





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## RESEARCH INITIATIVES

### **Adult with Spina Bifida Survey**

- Children's Hospital of Colorado
- University of Colorado
- State University of New York Upstate Medical University
- SBA



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## **ADULTS WITH SPINA BIFIDA SURVEY**

[https://www.research.net/r/sba\\_adult\\_survey](https://www.research.net/r/sba_adult_survey)



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## Adult Spina Bifida Survey

### No Regular Source of Care

The survey brought you to this page because you indicated that you DO NOT have a regular source of medical care. The questions below are meant to identify why you do not have a regular source of care.

If you believe you came to this page in error, click the "Previous Page" button at the bottom of this page, and return to Question 17.

**19. If you do not regularly see a medical provider who handles your care, why not? (check all that apply)**

- ☐ I do not currently have insurance
- ☐ I couldn't find a Primary Care Provider to take my insurance
- ☐ I could not find a Primary Care Provider to treat my Spina Bifida
- ☐ I could not find a Primary Care Provider who understands my needs
- ☐ I had a negative experience with a healthcare provider, and have avoided going back
- ☐ I can't find the transportation I need to get to a medical office
- ☐ The medical office does not have the right access (i.e. ramps, elevators) for me to get into the building
- ☐ Unknown/Unsure
- ☐ Other (please describe)

Prev

Next



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## HEALTHCARE PROVIDER OUTREACH

- Finding ways to encourage Healthcare Providers to include people with Spina Bifida in their practice
- Outreach to:
  - American Urological Association
  - Association of Academic Physiatry
  - Association of Spinal Cord Injury Professionals



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## FOR MORE INFORMATION

Contact:

Sara Struwe, MPA

President & CEO

Spina Bifida Association

[sstruwe@sbaa.org](mailto:sstruwe@sbaa.org)

(202) 618-4747



## Improving Health

### Our Mission:

**connecting families through peer support**

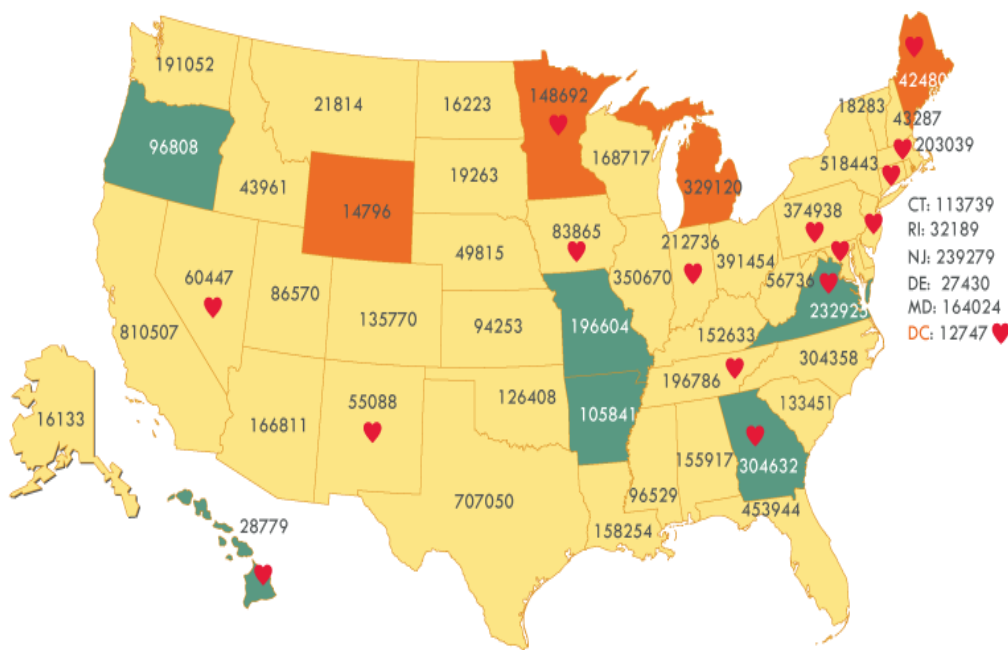
**To develop effective voices for improving  
quality at all levels of health care**



# A Network of Family Organizations A Diaspora of Programs



Family Voices State Affiliate Organizations and Family-to-Family Health Information Centers Helping Families of Children with Special Health Care Needs and Assisting Professionals



nn # of Families with CSHCN in state<sup>1</sup>

- States where SAO and F2F is within the same organization
- States where SAO is within a different organization from the F2F
- States with F2F only; SAO in progress
- States with National Family Voices staff/consultant/national board member

- **F2F Network (51)**
- **National Center for Professional Partnerships**
- **CAHMI- Well Visit-Planner Tool Kit**
- **AUCD/CDC**
- **AAP/Bright Futures**
- **PCORI**
- **Emergency Preparedness**
- **Zika 1 Page Resource**
- **KASA**
- **AIM**
- **NDNRC**

<sup>1</sup>National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved [03/08/15] from [www.childhealthdata.org](http://www.childhealthdata.org).

# Special Initiatives:



**National Disability Resource Collaborative (NDNRC) initiative:** 9 Family Voices state affiliate organizations (SAO's) in ND, CO, IN, RI, WA, LA, TX, AZ, and NV have been very successful in assisting navigators within their states so that families of children and youth with special needs receive adequate information about the ACA.

**MCHB Alliance for Innovation (AIM) Initiatives:** This MCHB initiative is focused on improving systems for CYSHCN; health care access for children, care and access for pregnant women, Bright Futures/health and wellness for children. Family Voices has several small subcontracts under this grant. Our work includes providing the family perspective.



# For More Information:



Jennifer Bolden Pitre, MA, JD  
[Jboldenpitre@familyvoices.org](mailto:Jboldenpitre@familyvoices.org)  
[www.familyvoices.org](http://www.familyvoices.org)  
[www.fv-ncfpp.org](http://www.fv-ncfpp.org)  
[www.fvkasa.org](http://www.fvkasa.org)



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## Improving Health – Jeannette Mejas

- ***Children with Special Healthcare Needs:*** For a range of health-related resources and tools concerning access to care for children with special healthcare needs, visit our Family to Family Health Information Center/Family Voice webpage at:
  - [www.spanadvocacy.org/content/family-family-health-information-center-family-voices-nj](http://www.spanadvocacy.org/content/family-family-health-information-center-family-voices-nj).
- Special resources of interest include our Healthcare Financing Fact Sheet Series:
  - [www.spanadvocacy.org/content/health-care-financing-factsheets-english](http://www.spanadvocacy.org/content/health-care-financing-factsheets-english)
- Maximizing Reimbursement Under NJ's Autism and Other DD Health Insurance Mandate:
  - [www.spannj.org/cyshcn/core\\_outcome\\_3/Maximizing%20Coverage%20ASD%20&%20Other%20DD.pdf](http://www.spannj.org/cyshcn/core_outcome_3/Maximizing%20Coverage%20ASD%20&%20Other%20DD.pdf)
- Health Advocacy Toolkit webpage at:
  - [www.spanadvocacy.org/content/health-advocacy-toolkit](http://www.spanadvocacy.org/content/health-advocacy-toolkit)
  - (with our Health Advocacy Guide at [www.spanadvocacy.org/content/gps-families-and-individuals-disabilities-health-advocacy-guide](http://www.spanadvocacy.org/content/gps-families-and-individuals-disabilities-health-advocacy-guide)).



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## Improving Health

- ***Children's Mental Health:*** You can access SPAN's Children's Mental Health Family Guide at [www.spanadvocacy.org/content/childrens-mental-health-family-guide](http://www.spanadvocacy.org/content/childrens-mental-health-family-guide).
  - Our Health Advocacy Toolkit also has related resources at [www.spanadvocacy.org/content/health-advocacy-toolkit](http://www.spanadvocacy.org/content/health-advocacy-toolkit).
  - Download the NJ Department of Children and Families' Youth and Family Guide to the Children's System of Care, including child behavioral health, at [www.performcarenj.org/families/youth-family-guide.aspx](http://www.performcarenj.org/families/youth-family-guide.aspx) (English and Spanish).
- ***Transition to Adult Life:*** Listen to a SPAN presentation on Transition to Adult Life and access resources at [www.spanadvocacy.org/content/look-future-transition-adult-life-workshop](http://www.spanadvocacy.org/content/look-future-transition-adult-life-workshop).
  - SPAN's brief fact sheet on transition is at [www.spanadvocacy.org/sites/g/files/g524681/f/files/SPAN-TRANSITION-Fact-Sheet-FINAL.pdf](http://www.spanadvocacy.org/sites/g/files/g524681/f/files/SPAN-TRANSITION-Fact-Sheet-FINAL.pdf).
  - Check out other Transition resources at [www.spanadvocacy.org/content/transition-school-adult-life](http://www.spanadvocacy.org/content/transition-school-adult-life) and [www.spanadvocacy.org/content/youth-resources-empowerment](http://www.spanadvocacy.org/content/youth-resources-empowerment).
  - For a guide on transition to adult healthcare, go to [www.spanadvocacy.org/content/being-healthy-adult-advocating-your-health-and-health-care](http://www.spanadvocacy.org/content/being-healthy-adult-advocating-your-health-and-health-care).

# Disability/Special Needs Resources



- Special Child Health Services Case management units 609-777-7778  
<http://www.state.nj.us/health/fhs/sch/sccase.shtml>
- NJ Department of Health Resources for Specific Conditions  
<http://www.state.nj.us/health/fhs/sch/services.shtml>
- NJ Division of Disability Services Resource Guide  
[http://accessdmv.net/humanservices/dds/RD\\_08.pdf](http://accessdmv.net/humanservices/dds/RD_08.pdf)
- Centers for Independent Living [www.njsilc.org](http://www.njsilc.org)  
609-581-4500

# Thank You

## for joining this discussion

For more information contact us at:  
Statewide Parent Advocacy Network  
35 Halsey Street, 4<sup>th</sup> Floor  
Newark, NJ 07102  
Phone: 973-642-8100 ext. 108  
Toll Free: 800-654-SPAN  
Fax: 973-642-8080  
Jmejias@spannj.org  
[www.spannj.org](http://www.spannj.org)



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In Support of the National Center on Birth Defects and Developmental Disabilities

## Disability as a Health Disparity

- As a group, people with disabilities fare far worse than their nondisabled counterparts across a broad range of health indicators and social determinants of health.
- Adults with disabilities are 2.5 times more likely to report skipping or delaying health care because of cost.
- Although they have higher rates of chronic diseases than the general population, adults with disabilities are significantly less likely to receive preventive care.



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## Changes Required to Improve the Health of People with Disabilities

- Improved access to health care and human services,
- Increased data for decision-making,
- Strengthened health and human services workforce capacity,
- Explicit inclusion in public health programs, and
- Increased preparation for emergencies.



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In Support of the National Center on Birth Defects and Developmental Disabilities

## Improving the Health of People with Disabilities Work Group Focus

- Improved access to health care and human services
- Strengthened health and human services workforce capacity
- Explicit inclusion in public health programs





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In Support of the National Center on Birth Defects and Developmental Disabilities

## EFFORTS THUS FAR

### **CMS - Office of Minority Health**

- Teleconference and Continued Communications -
- Teleconference with CMS staff and NORC contractors who are creating educational toolkits and modules for healthcare professionals that serve people with disabilities.
- Our workgroup offered to:
  1. send the NCBDDD Disability and Health State Grantee list
  2. disseminate to our large Friends of NCBDDD list serve CMS's desire to obtain case studies for modules
  3. help identify speakers with disabilities for CMS conferences and meetings
  4. review CMS modules for disability content



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## EFFORTS THUS FAR

### **US Access Board - Improving Health of People with Disabilities**

- Workgroup has been closely monitoring status of proposed accessibility standard for medical accessibility - Section 4203 of Affordable Care Act requires US Access Board to issue accessibility standards for medical diagnostic equipment to accommodate adults with disabilities.
- Includes exam tables, exam chairs, weight scales, mammography equipment and imaging equipment.
- Board is meeting September 14th to vote on final standards for medical diagnostic equipment. We will report back to Friends after Sept. 14th AccessBoard meeting.



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## EFFORTS THUS FAR

Workgroup monitors emerging issues as they arise - EX. starting to look at full implementation of Section 4302 of the Affordable Care Act (ACA) which strengthens federal data collection efforts by requiring all national efforts collect information on race, ethnicity, sex, primarily language and disability status.

The logo consists of three overlapping curved shapes in blue, grey, and orange, resembling a stylized 'F' or a wave.

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*Update from NCBDDD/CDC*



**IMPROVING HEALTH**  
OF PEOPLE WITH DISABILITIES

# Friends of NCBDDD

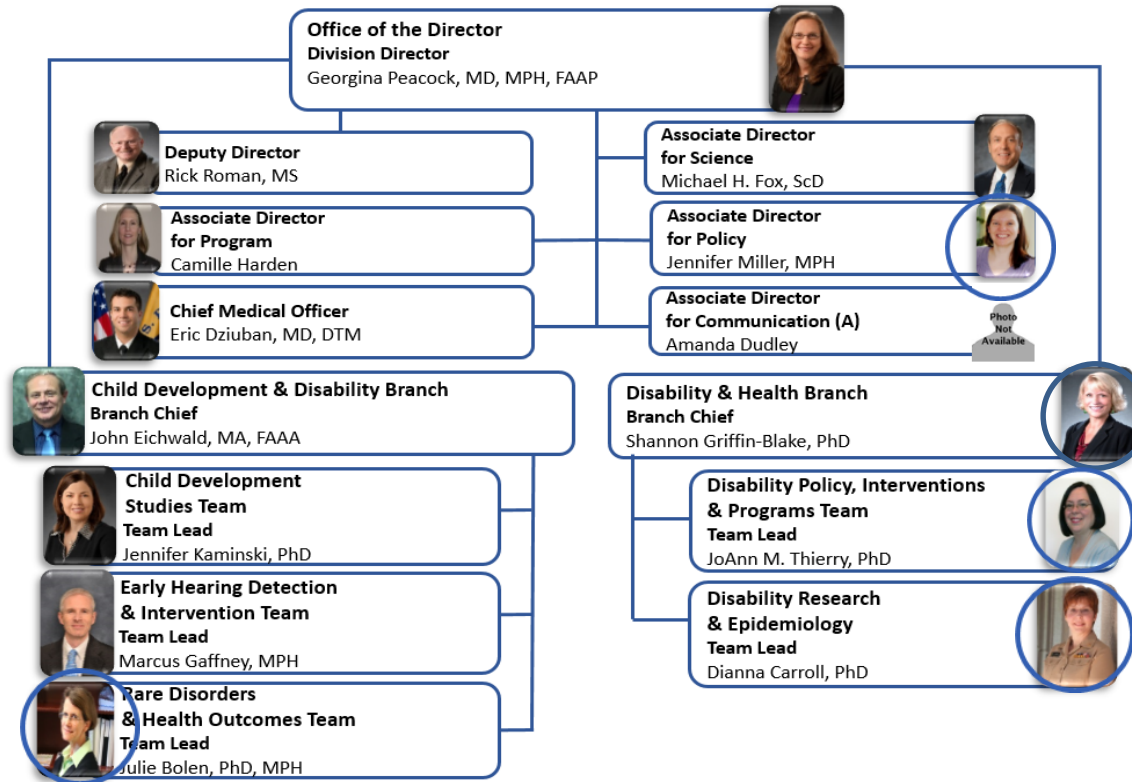
In Support of the National Center on Birth Defects and Developmental Disabilities

## IMPROVING THE HEALTH OF PEOPLE WITH DISABILITIES

### Organizational Chart

#### Division of Human Development and Disability

National Center on Birth Defects and Developmental Disabilities



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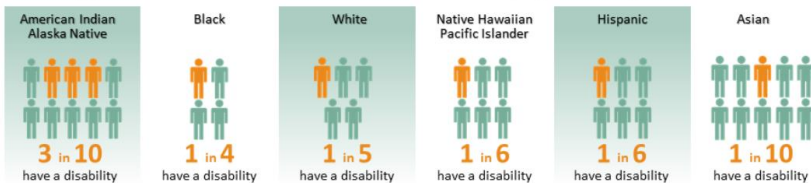
## IMPROVING THE HEALTH OF PEOPLE WITH DISABILITIES



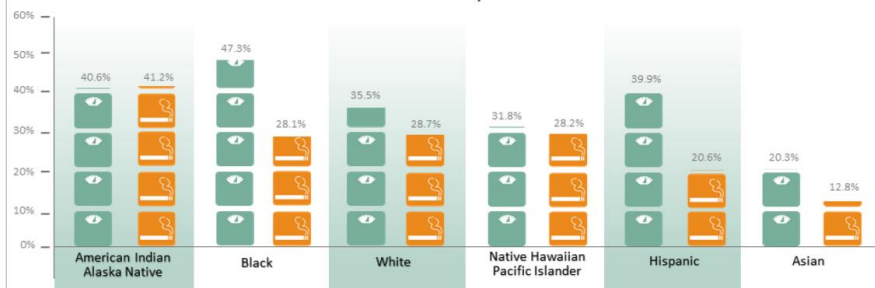
### Adults with Disabilities: Ethnicity and Race

When it comes to the health of people with disabilities, it's important to know the health differences among racial and ethnic groups

Approximate number of adults with a disability by ethnicity and race



Percent of adults with a disability who are obese or smoke



- **Disability Employment Awareness Event**
- **Cooperative agreement updates**
  - [State Disability and Health programs \(DD16-1603\)](#)
  - [National Centers on Disability \(DD16-1602\)](#)
- **Recent publications**
  - [Socioeconomic Factors at the Intersection of Race and Ethnicity Influencing Health Risks for People with Disabilities](#)
  - [Prevalence and Causes of Paralysis—United States, 2013](#)
  - [Comparison of 2 Disability Measures, BRFSS, 2013](#)
- **National Health Interview Survey**
  - [Redesign](#) & public comment period

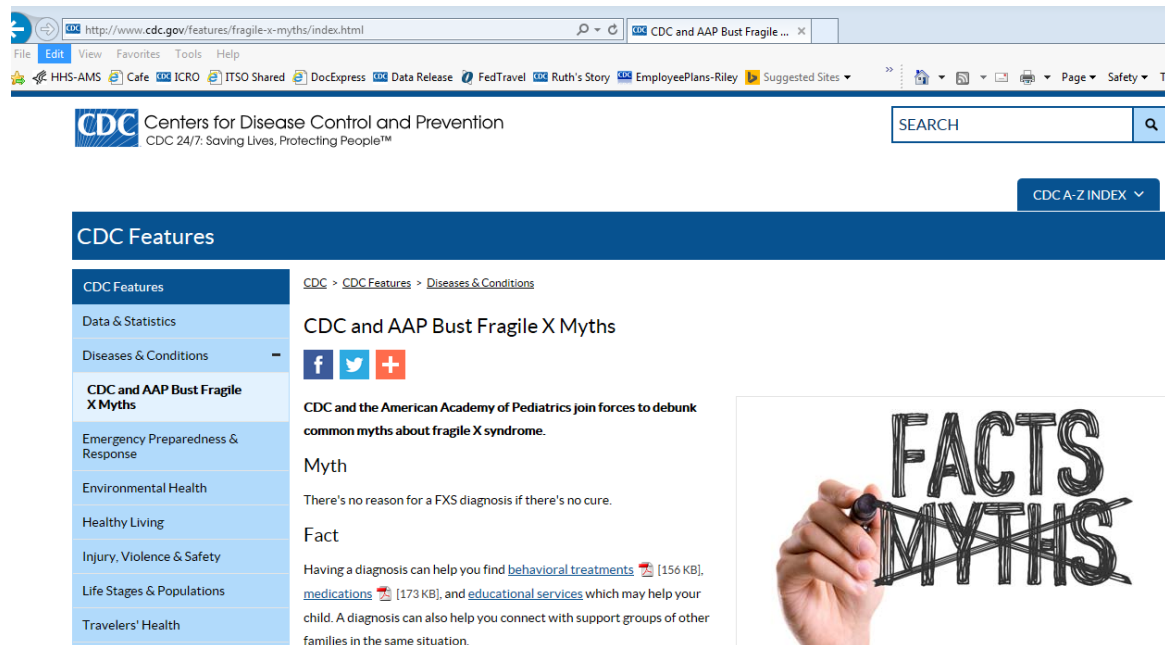
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## IMPROVING THE HEALTH OF PEOPLE WITH DISABILITIES

### Fragile X Myth Busters

- AAP News – July 1, 2016
- Reached more than 67,000 pediatricians
- Available at:
  - AAP.org
  - HealthyChildren.org
  - [cdc.gov/ncbddd/fxs/mythbusters](http://cdc.gov/ncbddd/fxs/mythbusters)



http://www.cdc.gov/features/fragile-x-myths/index.html

Centers for Disease Control and Prevention  
CDC 24/7: Saving Lives, Protecting People™

SEARCH

CDC A-Z INDEX

CDC Features

CDC Features

Data & Statistics

Diseases & Conditions

CDC and AAP Bust Fragile X Myths

Emergency Preparedness & Response

Environmental Health

Healthy Living

Injury, Violence & Safety

Life Stages & Populations

Travelers' Health

CDC > CDC Features > Diseases & Conditions

CDC and AAP Bust Fragile X Myths

CDC and the American Academy of Pediatrics join forces to debunk common myths about fragile X syndrome.

Myth

There's no reason for a FXS diagnosis if there's no cure.

Fact

Having a diagnosis can help you find [behavioral treatments](#) [156 KB], [medications](#) [173 KB], and [educational services](#) which may help your child. A diagnosis can also help you connect with support groups of other families in the same situation.

FACTS  
~~MYTHS~~

<https://www.cdc.gov/ncbddd/fxs/mythbusters>



***Improving Health: Including People with  
Disabilities in Public Health***

***Shannon Haworth, AUCD***



**INCLUDING PEOPLE WITH DISABILITIES: PUBLIC HEALTH WORKFORCE COMPETENCIES**



## About the Project

- The *Including People with Disabilities – Public Health Workforce Competencies* was a multiyear Project funded by
  - Centers for Disease Control & Prevention (CDC)
  - National Center for Birth Defects and Developmental Disabilities (NCBDDD)
  - Office for State, Tribal, Local, And Territorial Support (OT))
- Developed by a national committee comprised of disability and public health experts
- Provide foundational knowledge about the relationship between public health programs and health outcomes among people with disabilities
- Primarily designed for professionals already working in the public health field but can also be used for public health workforce training

## About the Competencies

- Compared to people without disabilities, people with disabilities are at a higher risk for poor health outcomes such as hypertension, obesity, falls-related injuries, and depression.
- Knowledge about the health status and public health needs of people with disabilities is essential for addressing health disparities.
- Most public health training programs do not include curriculum on people with disabilities and methods for including them in core public health efforts.
- Improve the health of people with disabilities by building a stronger public health workforce skilled in ways to include people with disabilities in all public health efforts.

[www.DisabilityinPublicHealth.org](http://www.DisabilityinPublicHealth.org)



## Four Competencies

**Competency 1:** Discuss disability models across the lifespan

**Competency 2:** Discuss methods used to assess health issues for people with disabilities

**Competency 3:** Identify how public health programs impact health outcomes for people with disabilities

**Competency 4:** Implement and evaluate strategies to include people with disabilities in public health programs that promote health, prevent disease, and manage chronic and other health conditions

[www.DisabilityinPublicHealth.org](http://www.DisabilityinPublicHealth.org)





## Call to Action:

# **Include people with disabilities in public health program planning and design**

## How:

- Identify a program, health promotion event, or community need
- Creative partnerships
- Talking with people with disabilities and caregivers
- Competencies resource for examples





## More Information

- **Contacts:**

**Shannon M. Haworth, MA** ([shaworth@aucd.org](mailto:shaworth@aucd.org))

Senior Program Manager, Disability and Public Health,  
AUCD

**Adriane K. Griffen, DrPH, MPH, MCHES** ([agriffen@aucd.org](mailto:agriffen@aucd.org))

Director, Public Health and Leadership, AUCD

- **Website:** <https://www.DisabilityinPublicHealth.org>

- **Learning Modules:**

<https://disabilityinpublichealth.org/learning-modules/>

- **Email:** [DisabilityinPH@aucd.org](mailto:DisabilityinPH@aucd.org)



### **Social Media:**

**Twitter:** @PHis4Everyone #DisabilityinPH

**LinkedIn:** Including People with Disabilities: Public Health Workforce Competencies

The logo consists of three overlapping curved shapes in blue, teal, and orange, resembling a stylized 'F' or a protective shield.

# Friends of NCBDDD

In Support of the National Center on Birth Defects and Developmental Disabilities

*Updates from other  
Thematic Areas*

*Katie Verb, HFA*



**PROTECTING PEOPLE**  
AND PREVENTING COMPLICATIONS  
OF BLOOD DISORDERS



# PROTECTING PEOPLE



## Phase 2 of the Stop the Clot, Spread the Word Campaign launched - August 9<sup>th</sup>

- Targets recently hospitalized/surgery and trauma patients
- Campaign assets include: web content, video, infographic, radio news release, mat release, digital multimedia press release, and an HHS blog

## World Thrombosis Day - October 13<sup>th</sup>

- Dr. Frieden is providing opening remarks (video) to the webinar
- Webinar is actually taking place on October 12<sup>th</sup> from 11-12pm
- Other activities we are doing for include an MMWR announcement, “Did you Know?” feature, and a Twitter chat on October 13<sup>th</sup> from 12-1pm



# PROTECTING PEOPLE



## September is Sickle Cell Awareness Month

- Promotional activities include a CDC.gov feature, unveiling of a new 5 facts about SCD infographic, Facebook post, a month-long Twitter campaign, sharing of Instagram graphics, and an OSTLS “Did You Know?” email blast

## First quarter of 2017 (TBD) Public Health Webinar Series on Blood Disorders

- Featuring the [NHF McMaster Guideline on Care Models for Hemophilia](#) which has been published and accepted to the National Guideline Clearinghouse

## September 22<sup>nd</sup> Webinar

- Voices of 5,000+ Patients: The First National Survey on Experience of Care at U.S. Hemophilia Treatment Centers. Judith Baker, Brenda Riske, Rick Shearer





# Friends of NCBDDD

In Support of the National Center on Birth Defects and Developmental Disabilities

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*Updates from other  
Thematic Areas*

*Patrick Johnson, AAP*



**HELPING CHILDREN**

LIVE TO THE FULLEST  
BY UNDERSTANDING  
DEVELOPMENTAL DISABILITIES



# HELPING CHILDREN



- Learn the Signs. Act Early. – helping parents in Zika-impacted areas
- ADHD – [Vital Signs™](#), webinars for providers and parents, and state outreach



## What parents learn when trained in behavior therapy





# Friends of NCBDDD

In Support of the National Center on Birth Defects and Developmental Disabilities

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*Updates from other  
Thematic Areas*

*Becky Abbot, MoD*



**SAVING BABIES**  
THROUGH BIRTH DEFECTS  
PREVENTION AND RESEARCH



# SAVING BABIES



- Congenital Heart Disease (CHD) Updates
- Longitudinal data linkages for birth defects research and prevention
- Treating for Two – virtual focus groups completed
- Fetal Alcohol Spectrum Disorder (FASD) Prevention



**Congenital Heart**  
PUBLIC HEALTH CONSORTIUM



*Safer Medication Use in Pregnancy*

September 18  
**FASD**  
FETAL ALCOHOL SPECTRUM DISORDERS  
**Awareness Month**



# Friends of NCBDDD

In Support of the National Center on Birth Defects and Developmental Disabilities

## *Communications Update*



*Shannon Haworth*  
*Communications Chair*



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# 2016 Communication Plan

| Goals  | Objectives   | Audiences   | Timelines   |
|--|--|---|---|
| <p>1. Increase awareness of NCBDDD at CDC and public health agencies.</p> <p>2. Increase communication with others beyond members of the Friends.</p> <p>3. Increase awareness of how your organization plays a role in public health.</p> | <p style="text-align: center;"><b><u>Awareness Campaign</u></b></p> <ul style="list-style-type: none"><li>• <b>Communications kit</b><ul style="list-style-type: none"><li>• One pager on the Friends of NCBDDD</li><li>• Template for sharing stories (can be highlighted on website quarterly)</li><li>• Template for presentations on the Friends coalition</li><li>• Dear colleague email template for recruitment</li></ul></li><li>• <b>Communications Calendar</b><ul style="list-style-type: none"><li>• Google Calendar - linked or embedded</li><li>• All members can view</li><li>• Call for calendar items (with call the monthly call for newsletter items)</li><li>• Populated monthly</li><li>• Colored coded by thematic area</li></ul></li><li>• <b>Social Media</b><ul style="list-style-type: none"><li>• Twitter - @FriendsofNCBDDD</li><li>• LinkedIn group</li></ul></li></ul> | <p>Policymakers, Families, NGOs, self advocates</p> <p>Possible target audiences: physicians, health promotion, maternal health in low income/rural areas</p> | <p>By April 2016, offer members of the Friends coalition an editable package of materials that they can integrate into their social media and ongoing communications plans</p> <p>By April 2016 communications calendar, LinkedIn group, Twitter</p> <p>Committee meets quarterly – Next meeting - September 2016</p> |



# Friends of NCBDDD

In Support of the National Center on Birth Defects and Developmental Disabilities

## How to Use the Communications Kit

- Share handouts with local elected representatives or during hill visits
- Share handouts at conferences
- Use the PowerPoint presentation to share information
- Share materials with local organizations
- Invite colleagues, and others to join – Dear Colleague Letter
- Refer others to the to [calendar](#)
- Start a discussion on [LinkedIn](#)
- Retweet interesting or important news to [@FriendsOfNCBDDD](#), or schedule a Twitter chat



# Friends of NCBDDD

2 members

Manage



Start a conversation with your group

Enter a conversation title...

[Conversations](#) [Jobs](#)



**Shannon Marie Haworth, M.A.**

Public Health Program Manager, Association of University Centers on Di...

OWNER

... 5d

## Physical Activity for All Twitter Chat with ABC's Dr. Besser

When: Tuesday, May 24, 2016 1:00 – 2:00pm EST

Where: use #abcDrBchat to follow and be part to the conversation

With:

- Division of Human Development and Disability's Disability and Health Branch at the National Center on Birth Defects and Developmental ... [Show more](#)

[Like](#) [Comment](#)



Reply to this conversation...

### ABOUT THIS GROUP

The Friends of NCBDDD is a coalition of government and private sector participants who work together to enhance the mission and activities of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) in identifying the causes of bi... [Show more](#)

### MEMBERS

2 members



[Invite others](#)

<https://www.linkedin.com/groups/7051366>



Friends of NCBDDD Calendar of Events

|  |  |     |  |     |  |     |  |     |  |       |  |      |       |        |
|--|--|-----|--|-----|--|-----|--|-----|--|-------|--|------|-------|--------|
| Today ◀ ▶ April 2016 ▾                         |  |     |  |     |  |     |  |     |  | Print |  | Week | Month | Agenda |
| Sun  |  | Mon |  | Tue |  | Wed |  | Thu |  | Fri   |  | Sat  |       |        |
| 27   |  | 28  |  | 29  |  | 30  |  | 31  |  | Apr 1 |  | 2    |       |        |
| Autism Awareness/Acceptance Month              |  |     |  |     |  |     |  |     |  |       |  |      |       |        |
|  |  |     |  |     |  |     |  |     |  |       |  |      |       |        |
|  |  |     |  |     |  |     |  |     |  |       |  |      |       |        |
| 3  |  | 4   |  | 5   |  | 6   |  | 7   |  | 8     |  | 9    |       |        |
| Autism Awareness/Acceptance Month              |  |     |  |     |  |     |  |     |  |       |  |      |       |        |
| National Public Health Week - NPHW.org         |  |     |  |     |  |     |  |     |  |       |  |      |       |        |
| 1pm Creating the Healthiest Nation by 2030- NP |  |     |  |     |  |     |  |     |  |       |  |      |       |        |
|  |  |     |  |     |  |     |  |     |  |       |  |      |       |        |
| 10   |  | 11  |  | 12  |  | 13  |  | 14  |  | 15    |  | 16   |       |        |
| Autism Awareness/Acceptance Month              |  |     |  |     |  |     |  |     |  |       |  |      |       |        |
| National Public Health Week - NPHW.org         |  |     |  |     |  |     |  |     |  |       |  |      |       |        |
|  |  |     |  |     |  |     |  |     |  |       |  |      |       |        |
| 17   |  | 18  |  | 19  |  | 20  |  | 21  |  | 22    |  | 23   |       |        |
| Autism Awareness/Acceptance Month              |  |     |  |     |  |     |  |     |  |       |  |      |       |        |
| 2pm Webinar Series on Blood Disorders: Update  |  |     |  |     |  |     |  |     |  |       |  |      |       |        |
|  |  |     |  |     |  |     |  |     |  |       |  |      |       |        |
| 24   |  | 25  |  | 26  |  | 27  |  | 28  |  | 29    |  | 30   |       |        |
| Autism Awareness/Acceptance Month              |  |     |  |     |  |     |  |     |  |       |  |      |       |        |
|  |  |     |  |     |  |     |  |     |  |       |  |      |       |        |

**Friends of NCBDDD**

@FriendsofNCBDDD

TWEETS

18

FOLLOWING

32

FOLLOWERS

14

## Trends · Change

#FreddieGray

44.7K Tweets

#GameofThrones 🐉

604K Tweets

#ScaleBackABook

17.3K Tweets

#My2WordAddiction

33.5K Tweets

#NeroTrial

4,662 Tweets

#mondaymotivation

114K Tweets

#SeGanaMintiendo

3,320 Tweets

NOT GUILTY

32.1K Tweets

#FreePurvi

1,884 Tweets

Officer Nero

26.5K Tweets



What's happening?

**CDC** @CDCgov · 2h

T3: You can do your own inspection before getting into public or private pools, hot tubs/spas, etc. #HealthySwimChat



29



13



# Friends of NCBDDD

In Support of the National Center on Birth Defects and Developmental Disabilities



## *Discussion*

### *Improving Health Kitchen Cabinet*

*Moderated by Sara Struwe, Vice Chair*



**SAVING BABIES**  
THROUGH BIRTH DEFECTS  
PREVENTION AND RESEARCH



**HELPING CHILDREN**  
LIVE TO THE FULLEST  
BY UNDERSTANDING  
DEVELOPMENTAL DISABILITIES



**PROTECTING PEOPLE**  
AND PREVENTING COMPLICATIONS  
OF BLOOD DISORDERS



**IMPROVING HEALTH**  
OF PEOPLE WITH DISABILITIES



# Friends of NCBDDD

In Support of the National Center on Birth Defects and Developmental Disabilities

## *Open Discussion*

## *Q & A*

*Jennifer Li, Member Co-Chair*



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# Friends of NCBDDD

In Support of the National Center on Birth Defects and Developmental Disabilities



## *Wrap Up*

***Sara Struwe***  
***Vice Chair, Friends of NCBDDD***



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# Friends of NCBDDD

In Support of the National Center on Birth Defects and Developmental Disabilities

## ***2016 Schedule***

***Friends In-person  
Meeting  
December 7, 2016***

***Renaissance Hotel,  
Washington DC  
(after the AUCD Conference)***

***Registration link will be sent out  
soon!***



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***We need your feedback! Please  
take the survey!***

***Share your stories - Go to  
Friends Stories tab at***

***[www.friendsofncbddd.org](http://www.friendsofncbddd.org)***