

## 2015 Strategy DRAFT

Main Target Audience: Policy Makers

Secondary Target Audience: Families and people with a disability

Primary Goal: Increase awareness and value of NCBDDD at CDC and public health agencies

Secondary Goal: Increase communication with others beyond members of Friends

Long Term Goal: Finding state and congressional champions

Secondary Long Term Goal: Increase funding

Short term goals:

- Create shared calendar of events
- Integrate Advocacy Coalition talking points into existing member policy efforts and “asks”
- Develop more personal stories from families and people with a disability
- Develop visual collaterals
- Host twitter chat and Google Hangout and invite other partners
- Facilitate 5-10 Hill and state visits

Thematic areas	Champions
<b>Saving babies through birth defects prevention and research</b>	Diane Wilkinson, March of Dimes <a href="mailto:DWilkinson@marchofdimes.org">DWilkinson@marchofdimes.org</a> Kerri Wade, Association of Women's Health, Obstetric and Neonatal Nurses <a href="mailto:kwade@awhonn.org">kwade@awhonn.org</a>
<b>Helping children live to the fullest by understanding autism and other developmental disabilities</b>	Pat Johnson, American Academy of Pediatrics <a href="mailto:PJohnson@aap.org">PJohnson@aap.org</a> Adriane Griffen, Association of University Centers on Disabilities <a href="mailto:agriffen@aucd.org">agriffen@aucd.org</a>
<b>Protecting people and preventing complications of blood disorders</b>	Katie Verb, Hemophilia Federation of America <a href="mailto:k.verb@hemophiliafed.org">k.verb@hemophiliafed.org</a> Randy Fenninger, National Blood Clot Alliance <a href="mailto:rfenninger@stopthecлот.org">rfenninger@stopthecлот.org</a>
<b>Improving the health of people with disabilities</b>	Roberta Carlin, American Association on Health and Disability <a href="mailto:rcarlin@aahd.us">rcarlin@aahd.us</a> Sara Struwe, Spina Bifida Association <a href="mailto:SStruwe@sbaa.org">SStruwe@sbaa.org</a>

*The Whole is Greater than the Sum of its Parts: Friends Together*  
*November, 12 2014 Meeting Notes*

**Thematic Focus Area: Improving the health of people with disabilities**

- Target audience: Policy Makers
- Tools: Influence: 1. media/general public 2. Buy-in families 3. public/private partners – let them know NCBDDD exists
- Long term goal: Increase funding
- Goals within the CDC (partner with these models/campaigns):
- Pediatric Preparedness Model
- Million Hearts Campaign
- Physical Activity Model
  - Federal collaborators: 1. The CDC Washington 2. White House 3. CDC\_Frieden (tweet) and other social media 4. CDC internal newsletters and website
- Goal: Increase communication with others beyond members of Friends
  - Develop visual collaterals
  - Campaign to build macro awareness of NCBDDD
    - Identify campaign theme
      - ADA 25<sup>th</sup> Anniversary
      - Commit To Inclusion
      - Congressional Briefing
      - 6by'15
      - Public Health Data/Health Care/ACA
      - Showcasing Health Disparities
    - Notes: potential access issues and need to maintain funding
- Short term Goal: Identification of Strategic Health Initiative for NCBDDD in the area of improving health of people with disabilities
- Short term wins:
  - New/old Friends
  - HELP Disability
  - People with a disability and their family members
  - ADA Families
  - JAMA
  - OWH Minority Health, Disability Caucus
    - Include in our asks: To share calendars and event visits
  - Common themes:
    - Friends Activities: schematic, Disability Awareness Month, outside networking, CHF-NHC, Google Docs sharing, Grass Roots Act, ICTA in April

**Thematic Focus Area: Saving babies through birth defects prevention and research**

- Target Audience: Policy Makers

- Restore funding to the center
- Generate public awareness
- Short term wins/objectives:
  - 5-10 Hill visits
  - Conference call on January 20: parent focused in conjunction with ground rounds
  - Twitter Mom super stars and mommy bloggers
  - March 3<sup>rd</sup> Virtual Hill Day (World Birth Defects Day)
  - “#1 in 33, This is Me”
  - Tomorrow’s Chat
  - Moms Rising
  - March of Dimes active everyday action campaign (adapted)
  - Google Hangout

**Thematic Focus Area: Helping children live to the fullest by understanding Autism and other developmental disabilities**

- Target Audience: Policy Makers
- Goal: Increase awareness and value of NCBDDD at CDC and public health agencies
- Long Term Goal: Finding congressional champions
- Short term goals:
  - 1. Improving communications among organizations and partners
  - 2. Getting on the ‘short list’ of asks
  - 3. Building in more personal stories from families/individuals with developmental disabilities
  - 4. Friends (partner organizations) make hill visits together to educate staff members on NCBDDD
  - 5. Continual touch points: phone, in-person visits with congressional champions throughout the year

**Thematic Focus Area: Protecting people and preventing complications of blood disorders**

- AMCHP – January 25-27
- March is Hemophilia month
- Fragile X – March 4
- AUCD – Disability seminar – April 1
- AAP – April (Leg Con)
- ACAP – April/May
  - Putting science into practice
  - Using what centers have done for Hemophilia messaging
  - Combined messaging during Women’s Health Week
  - January shared action plans



# Friends of NCBDDD

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