Friends of NCBDDD Quarterly Check-In

So You Think You Know NCBDDD?

A back-to-basics webinar on NCBDDD’s current work and how the Friends of NCBDDD supports those efforts

March 23, 2017
3:00 pm – 4:00 pm
Welcome

Becky Abbott
Chair, Friends of NCBDDDD
National Center on Birth Defects and Developmental Disabilities (NCBDDD) 101
Making a Difference Across a Lifespan

Stephanie Dulin, MBA
Deputy Director, NCBDDD

QUARTERLY FRIENDS CHECK-IN MEETING

March 23, 2017
Agenda

- Welcome
- History of NCBDDD
- Our Mission
- Our Organization
- FY17 & FY18 Budget
- NCBDDD Thematic Areas
  - Savings Babies
  - Helping Children
  - Protecting People
  - Improving Health
- Strategic Health Initiatives (SHIs)
History

The Children’s Health Act of 2000 established the CDC’s National Center on Birth Defects and Developmental Disabilities (NCBDDDD).

NCBDDDD was officially established in April 2001.
Mission

We work to save babies by studying and addressing the causes of birth defects; help children reach their potential by understanding developmental disabilities; reduce complications of blood disorders; and improve the health of people living with disabilities.
FY 2017 President’s Budget Request | $136 Million

FY16 Request: $68M
FY16 Enacted: $64M
FY17 Request: $136M

BA
PPHF

FY2017 Budget
Budget Status

- FY17 Status – Continuing Resolution until April 28th
- FY18 Status – White House released its FY18 Budget Blueprint
  - $54 billion increase for Dept. of Defense and other Defense spending
  - Large decreases to non-defense spending, including HHS
    - “Reforms key public health, emergency preparedness, and prevention programs. For example, the Budget restructures similar HHS preparedness grants to reduce overlap and administrative costs and directs resources to States with the greatest need. The Budget also creates a new Federal Emergency Response Fund to rapidly respond to public health outbreaks, such as Zika Virus Disease. The Budget also reforms the Centers for Disease Control and Prevention through a new $500 million block grant to increase State flexibility and focus on the leading public health challenges specific to each State.”
Thematic Areas

SAVING BABIES
HELPING CHILDREN
PROTECTING PEOPLE
IMPROVING HEALTH
MAKING A DIFFERENCE ACROSS LIFESPAN
NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES

SAVING BABIES
THROUGH BIRTH DEFECTS
PREVENTION AND RESEARCH
1 IN 33
IS BORN WITH A
BIRTH DEFECT

In the U.S. each year, the total costs for hospital care of children with birth defects exceed $2.6 BILLION. Universal screening for critical congenital heart defects in all states can REDUCE THE RISK OF DEATH AND DISABILITY for about 1200 babies each year.

HELPING CHILDREN
LIVE TO THE FULLEST BY UNDERSTANDING DEVELOPMENTAL DISABILITIES
1 IN 68
HAS AUTISM SPECTRUM DISORDER

Medical costs for children with autism are estimated to be SIX TIMES HIGHER than for children without autism.

PROTECTING PEOPLE
AND PREVENTING COMPLICATIONS OF BLOOD DISORDERS
1 IN 10
WITH A BLOOD CLOT WILL DIE IF IT MOVES TO THE LUNGS

Healthcare costs associated with blood clots in the U.S. are $10 BILLION or more each year. Preventing readmission due to a blood clot can save an average of $15,000 in hospital costs per patient.

IMPROVING HEALTH
OF PEOPLE WITH DISABILITIES
1 IN 5
AMERICANS HAS SOME KIND OF DISABILITY

Annual healthcare costs associated with disability are nearly $400 BILLION. Early hearing screening and intervention of children with hearing loss saves approximately $200 MILLION in additional education costs each year.
SAVING BABIES
Through Birth Defects Prevention and Research

1 in 33
Babies are born with a birth defect
SAVING BABIES
Through Birth Defects Prevention and Research

Major Programs

• Birth Defects
• Congenital Heart Defects
• Fetal Alcohol Spectrum Disorders (FASDs)
• Neural Tube Defects/Folic Acid
SAVING BABIES
Zika and Pregnancy Surveillance

- Staffing: 119 staff currently deployed to Zika with 68 full-time at EOC
- FY17 Supplemental funding: Using $27 million built the strongest and most innovative birth defects surveillance system (in 50 jurisdictions) to date to protect babies from Zika.
- FY18 no proposed funding
- Zika Vital Signs: MMWR on US Zika Pregnancy Registry (UZPR) update and infant follow up – April 4th
HELPING CHILDREN
Live to the Fullest by Understanding Developmental Disabilities

1 in 68
Children are identified as having Autism Spectrum Disorder
HELPING CHILDREN

Live to the Fullest by Understanding Developmental Disabilities

Major Programs

• Autism and Other Developmental Disabilities
• Attention-Deficit/Hyperactivity Disorder (ADHD)
• Early Hearing Detection and Intervention
• Fragile X Syndrome
• Promoting Child Development - Positive Parenting Programs
• Tourette Syndrome and Tic Disorders
PROTECTING PEOPLE
Preventing Complications of Blood Disorders

1 in 5 people with hemophilia will develop an inhibitor in their lifetime.
PROTECTING PEOPLE

Preventing Complications of Blood Disorders

Major Programs

• Hemophilia
• Sickle Cell Disease
• Thalassemia
• Venous Thromboembolism
IMPROVING HEALTH
Improving the Health of People with Disabilities

1 in 5 Americans has a disability
IMPROVING HEALTH

Improving the Health of People with Disabilities

Major Programs

- Disability and Health
- Fragile X Syndrome
- Muscular Dystrophy
- Spina Bifida
Strategic Health Initiatives (SHIs)
Strategic Health Initiatives (SHIs)

NCBDDDD has three SHIs in order to accelerate the Center’s public health impacts around these action areas:

- **Attention-Deficit/Hyperactivity Disorder**
- **Hospital-Acquired Venous Thromboembolism (HA-VTE)**
- **Treating for Two: Safer Medication Use in Pregnancy**
Attention-Deficit/Hyperactivity Disorder (ADHD) Supporting behavior therapy for children under 6 with ADHD

- Parents learn skills and strategies to help their child.

- Children are given positive reinforcement and a structured environment.

- Young children avoid possible side effects from ADHD medications.
Prevention of Healthcare-Associated Venous Thromboembolism (VTE)

The Problem

Preventing serious blood clots after hospitalization or surgery

Blood clots affect as many as 900,000 Americans each year leading to approximately 100,000 premature deaths.

Accomplishments

Large Healthcare Network or Multi-Hospital System
- Mayo Clinic, Rochester, Minnesota
- University of California Health, Center for Health Quality and Innovation, Oakland, California

Medium Healthcare Network or Multi-Hospital System
- University of Wisconsin Health, Madison, Wisconsin
- Intermountain Healthcare, Murray, Utah

Large Single Hospital
- Northwestern Memorial Hospital, Chicago, Illinois
- The Johns Hopkins Hospital, Baltimore, Maryland

Small to Medium Single Hospital
- Harborview Medical Center, Seattle, Washington
- Hutchinson Regional Medical Center, Hutchinson, Kansas
Treating for Two Initiative

**Treating for Two: Safer Medication Use in Pregnancy** initiative focuses on improving the health of women and babies and preventing birth defects and other adverse pregnancy outcomes. We’re working to:

- Expand and accelerate research to fill knowledge gaps
- Deliver up-to-date information to support decision making among prescribers, pharmacists, and consumers
- Evaluate evidence to facilitate reliable guidance
Discussion

For more information, contact CDC
1-800-CDC-INFO (232-4636)

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.
## 2017 Executive Committee

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<tr>
<th>Member</th>
<th>Position</th>
<th>Affiliation</th>
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<tr>
<td>Becky Abbott</td>
<td>Chair</td>
<td>March of Dimes</td>
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<td>Sara Struwe</td>
<td>Vice Chair</td>
<td>Spina Bifida Association</td>
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<td>Jennifer Li</td>
<td>Membership Co-Chair</td>
<td>National Association of County and City Health Officials</td>
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<td>Sara Lyons</td>
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<td>Tanisha Clarke</td>
<td>Communications Chair</td>
<td>Association of University Centers on Disabilities</td>
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<td>Jennifer Bolden Pitre</td>
<td>Secretary</td>
<td>Family Voices</td>
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<tr>
<td>Jane Correia</td>
<td>Member-at-Large</td>
<td>National Birth Defects Prevention Network</td>
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<td>Daniel Crimmins</td>
<td>Member-at-Large</td>
<td>Georgia State University</td>
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<td>Patrick Johnson</td>
<td>Member-at-Large</td>
<td>American Academy of Pediatrics</td>
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<td>Barbara Kornblau</td>
<td>Member-at-Large</td>
<td>Coalition for Disability Health Equity</td>
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<td>Kate Taft</td>
<td>Member-at-Large</td>
<td>Association of Maternal &amp; Child Health Programs</td>
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<td>Adriane Griffen</td>
<td>Immediate Past Chair</td>
<td>Association of University Centers on Disabilities</td>
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Friends of NCBDDDD 2017 Priorities: Back to Basics

• Coalition management

• Intensifying education efforts: policymakers, partners, and stakeholders

• Further engage the full membership of the Friends

  — To help guide our efforts, we’re asking members of the Friends to complete a survey on your experiences with the Coalition

  — link: https://goo.gl/TQ8KaC
Updates from Membership and Communications Chairs

• Sara Lyons, Membership Co-chair
  – Updating membership list and directory

• Tanisha Clarke, Communications Chair
  – Updates to Friends of NCBDDDD website
  – REMINDER: Keep the Friends updated on the work of your organization!
    ▪ Monthly newsletter: content due the 10th of each month to acostalas@aucd.org
    ▪ Listserv: anyone can post to the listserv (friendsncbddd@lyrisvs.aucd.org)
Advocacy Coalition Co-Chairs

• Annie Acosta, Director of Fiscal and Family Support Policy, Public Policy, The Arc
• Pat Johnson, Assistant Director, Department of Federal Affairs, American Academy of Pediatrics
• Katie Verb, Director, Policy & Government Relations, Hemophilia Federation of America
• Becky Abbott, Deputy Director, Federal Affairs, March of Dimes
Coalition Members?

- Current membership list being updated
- If you would like to join, update contact information, or update contact person for your organization, please complete form at https://goo.gl/6A2ug3
FY17 & FY18 Budget Outlook

• FY 2017 President’s Budget Request - $136 Million
  • Status – Continuing Resolution until April 28th
• FY18 Administration Budget Blueprint
  • Significant decreases to Health & Human Services funding
  • $500 million block grant to CDC
• FY18 Advocacy Coalition Ask
  • $152.61 million for NCBDDD
Coalition Activities

• Appropriations letter containing FY18 ask from Friends
  • Letter will be circulated in recap email with information on how to sign
• Meetings with Appropriations Committee members
  • Advocacy coalition members will receive email about upcoming meetings; space limited
Thank You!

- A big thank you to Stephanie Dulin, Sara Lyons, Tanisha Clarke, Katie Verb, Sascha Chaney, Marian Wiley, and Anna Costalas
- Next Quarterly Call: June 22nd at 3:00 pm
- Send feedback to Becky Abbott (rabbott@marchofdimes.org)
Next Steps and Action Items

• Friends of NCBDDD
  – Complete survey
    – link: https://goo.gl/TQ8KaC

• Advocacy Coalition
  – Sign Advocacy Coalition funding letter supporting NCBDDD funding for FY 2018 (organizations only)
  – Encourage your organization’s government affairs representative to sign-up for the Advocacy Coalition
    – link: https://goo.gl/6A2ug3