

# Friends of NCBDDD Newsletter

August 2014

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# Greetings from the Friends of NCBDDD Chair

Dear Friends,

August means the end of the summer and the beginning of fall – one last trip to the beach, getting children back to school and getting ready for all of the meetings that we seem to have each fall!

Here are some strategies to stay on top of things (and still be able to carve out a little time for fun!):

## **Stay connected with social media**

Follow NCBDDD on Twitter @CDC\_NCBDDD. NCBDDD has streamlined its Twitter strategy from five handles to [one](#). This will result in increases in followers and engagement. The more followers NCBDDD has, the more potential exposure there is to the topic areas that matter to all of us as Friends! You can also follow me @adrianegriffen for Friends news and public health updates.

## **Use your Champions to stay connected with all those meetings**

Are you going to be at DaSY? How about APHA? Oh, are you presenting at the regional consortium meeting? How can you be at all of these different meetings that all happen within a few weeks of each other and stay on top of everything in your day to day work?!?! Here's an idea – use your Champion to stay connected when life gets busy. A full list of Champions is available on the Friends home page at [www.friendsofncbddd.org](http://www.friendsofncbddd.org). Champions will be your conduit to the Friends Executive Committee and leadership of the Center, so please reach out to the Champion in your particular focus area to share any updates or ideas you may have.

## **Find a Friend on the listserv – you are not alone**

You are receiving this e-newsletter because you are a member of a dynamic coalition of like-minded, engaged professionals and families in the areas of blood disorders, birth defects and improving the health of people with a disability across the lifespan. If you are in need of a piece of information or a resource, chances are that one of your colleagues will be able to help. Why not solicit their feedback and advice with a quick post to our Friends of NCBDDD listserv at [friendsncbddd@lyrisvs.aucd.org](mailto:friendsncbddd@lyrisvs.aucd.org).

Many thanks for the communications committee's ongoing efforts to develop a streamlined approach that helps to keep you connected with each other! A subcommittee of this group is meeting later this month to make plans for an in person Friends meeting later this fall. Stay tuned for details!

Last but not least, I wanted to let you know that August is a special month as we note 30 years of CDC service from NCBDDD's Director, Dr. Coleen Boyle. Friends, let's celebrate by sharing our good wishes for continued success by tweeting an update that includes the Center's new handle (@CDC\_NCBDDD).

Here's to a happy end of summer and a productive start of the fall!

Adriane Griffen, MPH, MCHES

Friends of NCBDDD Chair

# Parent Corner

Roxanne Romanick is a parent with North Dakota Family Voices. Please find her inspiring story below.

Julie Beckett

Roxanne's Story:

Two years I had something phenomenal happen to me...I had reason to remove my bike from the rafters of our garage where it had hung for at least five years without any activity. I became a bike rider again. Why that happened is an even better story...My thirteen year old daughter with Down syndrome became an independent two-wheel bike rider. Suddenly we had a physical activity that we could share and I had a very motivating reason to ride my own bike.

Elizabeth had attended a Lose the Training Wheels Bike Camp in 2005 when she was 6 years old; however she never quite got the hang of trying to ride and we never could improve her confidence enough to get her motivated and enthusiastic about riding. So the years passed and when she hit her teenage years, we decided that if we were going to get this accomplished, we'd need some help, so we started to seek out Lose the Training Wheels camps across the country.

Lose the Training Wheels, (newly named iCan Shine in 2013), is a national, non-profit organization that was grew out of the vision of a mechanical engineer, Dr. Richard Klein. He continues to design and develop bikes and all of the hardware to teach the mechanics of bike riding. iCan Shine collaborates with local organizations and individuals to conduct over 100 five day camps in 32 states and 3 provinces in Canada serving nearly 3,000 people with disabilities each year. They state on their website: "The impact of learning to ride a bicycle independently, and our high level of success in helping people with disabilities accomplish this feat, continues to drive demand for our programs and fuel our growth." iCan Shine estimates that about 80% of all the people that participate end the camp riding a two-wheel bike independently. The additional 20% make progress toward the goal and have the experience of being in control of a bike.

Because of the distance and the cost to take Elizabeth to a camp out-of-state, we chose to turn to our local Down syndrome support network, Designer Genes of North Dakota to see if they would consider hosting a camp right in our home town. Through various partnerships and sponsors, we were able to raise the \$12,000 needed and 32 riders were on bikes at the beginning of August that year.

The training bikes are designed with a special, detachable roller that replaces the back tire. As the rider grows in confidence and speed, they are called in for a "pit stop" and the roller is replaced with another that has more "wobble" or angle. The rider then takes off and again adjusts to the "wobble" and again gains confidence to provide more balance. The camp requires that each rider has two volunteers that will support them (emotionally and physically) as they ride. These volunteers typically are with the rider all week and a huge bond is formed between them. By Wednesday of the week of camp, the riders are moving onto two-wheels and are riding in an outdoor area.

Elizabeth had immediate success and was an independent bike rider by Wednesday. She had the entire arena in cheers and tears when she took off on her own. Later that summer, she took a 9 mile ride with her dad and me. The next summer, we tackled a 21 mile ride through Minnesota. What is so good to know is that she will always have the option of riding her bike to get where she wants to go as she gets older. Next on her list -- her driver's permit!

Roxanne Romanick

# News from NCBDDD

## **Dr. Georgina Peacock Named Acting Director, NCBDDD's Division of Human Disabilities and Development**

Please join NCBDDD in welcoming Dr. Georgina Peacock as the acting director of the Division of Human Development and Disability. Dr. Peacock will be joining the division August 24 serving in a 120 day detail while we continue our efforts to recruit and hire a permanent director.

Dr. Peacock is a developmental-behavioral pediatrician and a Medical Officer with the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC). She currently leads the Children's Preparedness Team, working with CDC's Office of Public Health Preparedness and Response (OPHPR). The Children's Preparedness Team is an initiative to enhance CDC's public health disaster preparedness and response for children. She also represents CDC on a number of federal and national committees including the HHS Pediatric/Obstetric Integrated Program Team, the HHS CHILD Working Group, and the American Academy of Pediatrics Disaster Preparedness Advisory Council.

During the 2009-2010 influenza pandemic, Dr. Peacock co-led CDC's H1N1 Children's Health team. In this capacity, she worked with key pediatric partners to ensure children issues were considered. She has continued to work and publish on influenza, particularly with regards to children with neurologic conditions and other special health care needs.

Her first years at CDC were spent working on the "Learn the Signs. Act Early." This program focuses on increasing early identification of children with autism and other disabilities. She served as the CDC lead on the development of the Autism Case Training (ACT) curriculum which teaches doctors about identification, diagnosis and treatment of autism.

Dr. Peacock continues to see patients in a developmental clinic at the Good Samaritan Health Center and is an adjunct professor with the Georgia State Center for Leadership in Disability and Georgia State LEND program.

Dr. Peacock completed her Bachelors of Science in Cell and Molecular Biology and German at the University of Michigan. Dr. Peacock received her Doctor of Medicine and Masters in Public Health from University of Kansas. She completed her Pediatrics Residency and Developmental-Behavioral Pediatrics Fellowship at Developmental Disabilities Center at the University of Kansas Medical Center.

## **Dr. Shannon Griffin-Blake Named New Branch Chief for the Disability and Health Branch**

Dr. Shannon Griffin-Blake was recently named the new Branch Chief for the Disability and Health Branch, Division of Human Development and Disability (DHDD) at CDC's National Center on Birth Defects and Developmental Disabilities. She will provide leadership, strategic management and operational experience to CDC's disability and health portfolio, which includes, but is not limited, to 18 funded state programs, five national public health practice and resource centers, and disability research and epidemiology expertise.

Dr. Griffin-Blake brings to DHDD a rich experience in community engagement and mobilization, community assessment and evaluation, data collection and management, physical activity surveillance, intervention effectiveness and model development, chronic disease prevention, mental health promotion, and health equity.

In her latest CDC role, Dr. Griffin-Blake was Branch Chief for Program Development and Implementation within the Division of Community Health (DCH), National Center for Chronic Disease Prevention and Health Promotion at CDC. She provided scientific direction and programmatic oversight for multiple DCH programs, including the Strategic Alliance for Health, Communities Putting Prevention to Work, Community Transformation Grants, and Racial and Ethnic Approaches to Community Health (REACH). Dr. Griffin-Blake assisted with the development of the Chronic Disease Management Information System (CDMIS) – a system led by a workgroup that received the 2013 CDC/ATSDR Honor Award for Excellence in Information Technology.

For 9 years, Dr. Griffin-Blake has served public health and targeted populations at CDC. She came to the Agency in 2005, and as a Northrop Grumman contractor, provided ongoing evaluation technical assistance and support to Racial and Ethnic Approaches to Community Health (REACH) awardees and partners. Dr. Griffin-Blake later joined the ranks of CDC employees as a behavioral scientist and was identified to lead the National Partnership with the YMCA of the USA. In 2008, she joined the CDC's Healthy Communities Program as a Supervisory Health Scientist and Team Lead to coordinate and direct local, state, tribal and territorial efforts focused on creating healthy communities through sustainable, innovative and evidence-based community health promotion and chronic disease prevention programs. Dr. Griffin-Blake's has also served as the architect of the CDC's **C**ommunity **H**ealth **A**ssessment a**Nd** **G**roup **E**valuation (CHANGE) Tool and Action Guide that has been used by hundreds of communities across the country and can be found on the CDC website in both English and Spanish.

Dr. Griffin-Blake holds a Bachelor of Science in Public Health from the University of North Carolina at Chapel Hill, a Master of Arts in Health Education and Promotion from East Carolina University and a Doctor of Philosophy in Health Behavior and Promotion from the University of Georgia.

## **Now Live! Disability and Health Data System (DHDS) Tutorial Videos**

CDC Division of Human Development and Disability (DHDD) in collaboration with the National Association of County & City Health Officials (NACCHO) have created four Disability and Health Data System (DHDS) tutorial videos. The tutorial videos teach users how to use the web tool to access data from the Behavioral Risk Factor Surveillance System (BRFSS) about the health of adults with disabilities. These videos also teach users about the data tool and how to use three of its features: interactive maps, customizable data tables and state profiles. DHDS is an online interactive tool that provides instant access to state-level, disability-specific health data. Users can customize the disability and health data they view, making it easy to identify health disparities between adults with and without disabilities.

The videos are available on the Disability and Health Website:

<http://www.cdc.gov/ncbddd/disabilityandhealth/dhds-materials.html>

## **Stop the Clot Forum**

On August 28, 2014, the [National Blood Clot Alliance](#) will host its next “Stop The Clot” forum in Rochester, New York. This educational forum is an interactive program that provides basic information about blood clots, signs and symptoms, risk factors, prevention and treatment. The “Stop the Clot” forums provide a venue to share up-to-date information to people whose lives are affected by blood clots and clotting disorders with experts in the field. Attendees will be better equipped to make decisions about their health, communicate with their health care providers, and cope with living with blood clots and clotting disorders.

The guest speaker for this event will be Peter Kouides, MD. Dr. Kouides is the Medical & Research Director at the Mary M. Gooley Hemophilia Center, based in Rochester, New York. For more information about this event, please contact Judi Elkin at [jelkin@stoptheclot.org](mailto:jelkin@stoptheclot.org).

## **CDC and NCBDDD Honor the 24th Anniversary of the Americans with Disabilities Act**

July 26<sup>th</sup> marked the 24<sup>th</sup> Anniversary of the Americans with Disabilities Act of 1990 (ADA). The National Center on Birth Defects and Developmental Disabilities (NCBDDD) joined in recognizing ADA as a platform for the inclusion of people with disabilities in federal efforts related to health and health care. Inclusion of people with disabilities into mainstream health programs and services can improve the health of Americans living with disabilities across their lifespan, allowing them to reach their full potential, experience independence and contribute to their communities.

In honor of the ADA anniversary, NCBDDD’s Division of Human Development and Disability released a CDC Public Health Matters Blog, “[ADA Anniversary: Including People With Disabilities in Public Health](#),” as well as an internal agency-wide informational posting for CDC staff titled, “The Americans with Disabilities Act: A Platform for Healthy Living.”

## **New 2014 Disability and Health Data System (DHDS) Updates**

CDC, NCBDDD's Division of Human Development and Disability announces new features and updates to [Disability and Health Data System \(DHDS\)](#), an online interactive tool that provides instant access to state-level health data about adults with disabilities.

New 2014 features of the data tool include:

- **2012 Behavioral Risk Factor Surveillance System (BRFSS) Data** - 2012 BRFSS data were recently analyzed and added to DHDS. Three new indicators were added to DHDS, which include:
  - Fallen in Past 12 Months
  - Injury Due to a Fall in Past 12 Months
  - Up-to-date Colorectal Cancer Screening
- **Interactive Map for Mobile Devices** - This feature allows you now to view an interactive map on a mobile device. You can view these maps on a smartphone, tablet, and all web browsers except Internet Explorer 8 or earlier.
- **Dual Area Profiles** - This feature allows you to view, side-by-side, multiple indicators for two geographic areas. You can view these profiles by clicking 'Dual Area Profiles' in the left navigation. There are three new dual area profiles available:
  - Health Overview
  - Disability Status Overview
  - Demographic Overview
- **Single Year Indicators Stratified by Demographic Groups** - Single year health data analyzed by demographic groups were added beginning with the 2011 data. With the addition of 2012 data, almost all health indicators are now analyzed by age, sex, and race/ethnicity.
- **P-values on Disability Disparity Estimates** - All health indicators now contain p-values for disparity estimates. P-values were added for each disparity estimate beginning with the 2011 data.
- **Changed indicator analysis to match current recommendations** - Two indicators were updated to be consistent with the current U.S. Preventive Services Task Force (USPSTF) recommendations. Their data prior to 2012 were removed from DHDS. Updated indicators are:
  - Mammogram in Past 2 Years
  - Pap Test in Past 3 Years

Users can:

- Determine the percentage of adults with disabilities in their state
- Find health data for adults with disabilities in their state, and compare these data to adults without disabilities
- Compare their state health data to other states, and to the United States & Territories average
- View data on a range of health topics for a single state

- Create and download customizable data tables

Visit DHDS at <http://dhds.cdc.gov> to view the recent 2012 data, updated [DHDS Fact Sheet](#), updated [2014 Update Notes](#), and updated [Health Indicator List](#) on the health of adults with disabilities in your health program area or your state. Please send questions to [dhds@cdc.gov](mailto:dhds@cdc.gov).

For more information on Disability and Health, visit <http://www.cdc.gov/ncbddd/disabilityandhealth>.

# News from our Partners

## **New Resources for Including People with Disabilities**

[The National Association of County and City Health Officials](#) (NACCHO's) [Health and Disability Program](#) has developed two new resources to help health departments think through the best strategies for including people with disabilities in public health programs, policies, and services. People with disabilities are more likely to experience inequities in their health status when compared to people without disabilities and they are less likely to be included in emergency preparedness planning. Log in to NACCHO's Bookstore to download our free guides: "[Strategies for Successfully Including People with Disabilities in Health Department Programs, Plans, and Services](#)" and "[Directory of Community-Based Organizations Serving People with Disabilities](#)." Contact [disability@naccho.org](mailto:disability@naccho.org) with any questions.

## **Dr. Robert L. Brent Receives 2014 Distinguished Public Service Award**

Dr. Robert L. Brent received the 2014 Distinguished Public Service Award from the [Health Physics Society](#) (HPS) at the annual meeting held on July 15, 2014 in Baltimore, Maryland. This award and associated memorizations are intended to acknowledge outstanding contributions to the profession of health physics while in public service or service to the general public that significantly contributes to the relationship between the public and the health physics profession. This is one of the meaningful awards given by the HPS and so far only four persons have received it.

## **PEHDIC Hosting New Webinar Series on Early Identification of Motor Delay**

The [Program to Enhance the Health and Development of Infants and Children](#) (PEHDIC), within the [American Academy of Pediatrics](#), is hosting a new webinar series titled, "Early Identification of Motor Delay." The webinar series will provide detailed guidance and resources to clinicians caring for children with Neuromotor delays. The next webinar cover the care coordination and co-management of children who have or may have a Neuromotor diagnosis. It will occur on August 26 at 3:00pm ET. [Register here!](#) [Click here](#) to read more about the webinar series.

## **Maternal and Child Health Library History Collection Update**

The [Maternal and Child Health \(MCH\) Library](#) at Georgetown University has updated its History Collection with new items to increase access to important historical resources. Please share this information among memberships, staff and library patrons.

These resources include:

- An index to the William McConway Hiscock Collection on Medicaid's Early and Periodic Screening, Diagnostic and Treatment (EPSDT) Program, a unique collection of reports and studies about the early years of this important federal program. EPSDT provides free physical screenings, immunizations, laboratory

testing, and health education, improving the odds that children from low-income communities will grow up to be healthy adults by receiving access to regular care. Medicaid and EPSDT, along with Medicare, were established July 30, 1965, providing essential health insurance to millions of children, pregnant women, and adults.

- Reports from the U.S. Children's Bureau statistical series on child welfare, maternal and child health and crippled children's programs, juvenile courts, infant and childhood mortality, dated 1947-1971.
- Historical MCH posters from events and public education campaigns.
- New titles on newborn screening, getting to know Title V (for families), and caring for infants from 1935 to the present.

Please visit <http://www.mchlibrary.info/history/> to read these and other resources. Contributions to the library are also welcome.

This resource is funded by the Health Resources and Services Administration's Maternal and Child Health Bureau.

### **ACHA Webinar on Eisenmenger Syndrome**

Join this webinar from the [Adult Congenital Heart Association](#) (ACHA) to hear Dr. Naser Ammash, noted ACHD cardiologist and professor of medicine at the Mayo Clinic, talk about living well with Eisenmenger syndrome. Audience members will learn more about ways to help improve quality of life and outcomes. [Click here](#) to register!

# Conferences

[Improving Data, Improving Outcomes Conference](#)

September 8-10  
New Orleans, LA

[2014 Southwest Conference on Disability](#)

October 7-10  
Albuquerque, NM

[AUCD 2014 Conference](#)

November 9-12  
Washington, DC

[APHA 142nd Annual Meeting and Exposition](#)

November 15-19  
New Orleans, LA

# Webinars

[CDC Public Health  
Grand Rounds: Infertility](#)

August 19, 1 pm ET

[Living Well with  
Eisenmenger Syndrome](#)

August 25, 7pm ET

[Patient Care if Motor Delay  
is Identified - Do You Know  
the "Red Flags" to Look For?](#)

August 26, 3pm ET

[FASDs: Communication,  
Care Coordination and  
Co-Management](#)

August, 27 3pm ET

# Funding Opportunities

[Friends of NCBDDD](#)

[Family Liaison Opportunity](#)

Deadline: August 25

[CDC-RFA-DD15-1501:](#)

[CDC's ADDM Network](#)

Deadline: October 10

# Calling for News from NCBDDD Partners

Send in updates on conferences, meetings, special awards and journal or research announcements for the next edition of the Friends of NCBDDD E-Newsletter! Submit program highlights with a short summary of 150-200 words to [Melody Imoh](#) by **9/1**. Photos and web links are encouraged!

# Friends of NCBDDD Executive Committee

[Adriane Griffen](#)

Chair ([twitter.com/adrianegriffen](https://twitter.com/adrianegriffen))

[Craig Mason](#)

Vice Chair

[Sarah Yates](#)

Membership/Communications

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[Annie Acosta,](#)

Advocacy Coalition

Co-Chair

[Joe Isaacs](#)

Advocacy Coalition Co-Chair

[Roberta Carlin,](#)

Past Chair

[\\*Read the minutes of the monthly Executive Committee Calls here!](#)

# NCBDDD's Social Media Corner

## What's New for August?

In addition to breaking news, new publications and more, our social media will cover content from our three divisions with the following themes throughout the month of August:

### **August 2014**

Positive Parenting/Back to School

### **Week of August 4**

Back to School/ADHD

### **Week of August 11**

"Learn the Signs. Act Early."

### **Week of August 18**

Child Development

### **Week of August 25**

Children's Mental Health

## Follow NCBDDD on Twitter:

As you many know by now NCBDDD has streamlined its Twitter strategy from five handles to [one](#). At this time we would like to encourage all of you to include our new NCBDDD Connect badge to your signature block. It is a great way to increase the visibility of NCBDDD social media presence among our audiences—and hopefully it will result in continued increases in followers and engagement. The more followers NCBDDD has, the more potential exposure to the topic areas.

## **How to Add NCBDDD Connect Badge to E-mail Signature:**

To add the "Connect with NCBDDD" button to an e-mail signature follow the steps below:

1. Open Microsoft Outlook
2. Go to File > Options > Mail > Signatures
3. Right click the graphic below and select "copy"
4. Paste the graphic into your desired signature in the "Edit signature" field
5. Click on the graphic and then click the hyperlink icon  in the top right of the "Edit signature" field
6. Be sure <http://www.cdc.gov/ncbddd/connect/index.html> is listed in the URL box and hit OK



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 promoting child development; preventing birth defects and developmental disorders/disabilities; and enhancing the quality of life and preventing secondary conditions among people who are living with mental or physical disabilities, or a combination thereof. For any questions regarding this edition or previous editions please contact [\*\*\*Melody Imoh\*\*\*](#).