

# Friends of NCBDDD Newsletter

July 2014

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# Greetings from the Friends of NCBDDD Chair

Dear Friends,

I want to be sure that you take note of the recent launch of [NCBDDD's Fiscal Year 2013 Annual Report](#). In this report you will find information about the Center's budget, state funding, accomplishments, and scientific publications. In addition, the Executive Committee of the Friends has collaborated with the Center to launch a new strategy centered around four thematic areas covered in the report including:

- Focus Area 1: Saving babies through birth defects prevention and research
- Focus Area 2: Helping children live to the fullest by understanding developmental disabilities like autism
- Focus Area 3: Protecting people and preventing complications of blood disorders
- Focus Area 4: Improving the health of people with disabilities

## Champions - Making a difference across the lifespan

We are excited to launch a new strategy of engaging Champions for each of these areas. It is my hope that this strategy will engage Friends who have interest in the particular focus areas in a more proactive way. Champions will have the opportunity to provide content area expertise and to join the newly formed Friends Communications Committee to coordinate messaging for key target audiences.

We are happy to announce the following members of the Friends as Champions:

- **Focus Area 1:** [Emile Wigode](#), March of Dimes
- **Focus Area 2:** [Pat Johnson](#), American Academy of Pediatrics; [Adriane Griffen](#), Association of University Centers on Disabilities
- **Focus Area 3:** [Katie Verb](#), Hemophilia Federation of America
- **Focus Area 4:** [Roberta Carlin](#), American Association on Health and Disability; [Sarah Yates](#), National Association of County and City Health Officials

These 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. These Champions will also be in touch with you in the weeks and months to come.

Finally, we can always use a few more Champions! An outline of Champions responsibilities is available on the Friends home page at [www.friendsofncbddd.org](http://www.friendsofncbddd.org). If you are interested in serving as a Champion, please contact me at [agriffen@aucd.org](mailto:agriffen@aucd.org).

Together we can do more than we can do separately, so let's use this opportunity to collaborate!

Thank you for all you do to make a difference!

Adriane Griffen, MPH, MCHES

Friends of NCBDDD Chair

# Parent Corner

In an attempt to help provide information to the Disability and Health (D&H) state programs about Family-to-Family (F2F) Health Information Centers (HIC) in their states, a memo was sent out after the May F2F training conference in Washington, DC, to ask how connected they have been with the state programs. The response from the F2F's varied — some knew the contact provided, some worked very closely serving on advisory board, while others had little to no contact with them.

This knowledge is helpful to the Center as they know how important contacts with families can really supply operational directions for the grants provided by NCBDDD. Recognizing that the F2F's communicate with many families and professionals who serve children with disabilities and special health care needs on a daily basis, these F2F's can serve as a point of information and direction. The F2F's can provide identification of areas that families recognize are lacking improvement in the overall service system. In addition, the D&H programs can reach out to the F2F's to seek areas where improvement and access is needed. The task of the F2F HIC's is to reach out to these programs that are providing information to state systems to better support persons with disabilities.

For more information about these interactions, please email me at [waivermom@earthlink.net](mailto:waivermom@earthlink.net).

Julie Beckett

# News from NCBDDD

## **NCBDDD's Congenital Heart Defects Webpages Updated**

NCBDDD has updated its congenital heart defect webpages. These new pages highlight updated information on care for individuals with congenital heart defects across the lifespan and critical congenital heart defect screening. You can see the new webpages [here](#).

## **New CDC Materials Available on Preventing Alcohol Use during Pregnancy & FASDs**

New, [free materials](#) are available to help you promote alcohol-free pregnancies to women in your communities! CDC has developed resources for women of childbearing age on preventing alcohol use during pregnancy and fetal alcohol spectrum disorders (FASDs) based on [formative research findings](#). The materials target women who are pregnant and women who are trying to get pregnant. The set of materials include print products (a brochure and three posters) that are available to [order](#) and are downloadable. Several social media tools, such as banners, badges, and e-cards are also available. Visit our website to learn more about all of the [new tools](#) that are available to you. Please help us spread the word – Pregnancy and alcohol don't mix. Why take the risk?

## **July: National Cleft and Craniofacial Awareness and Prevention Month**

Each year in the United States, more than 7,000 babies are born with a cleft lip with or without a cleft palate, or cleft palate alone. These conditions, along with other birth defects of the head and face, are called craniofacial birth defects. As you may know, July is [National Cleft and Craniofacial Awareness and Prevention Month](#), a great opportunity for people to learn more about these conditions. CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) featured a number of activities throughout the month of July to raise awareness about craniofacial birth defects:

- An announcement in the July 4th issue of the Morbidity and Mortality Weekly Report (MMWR):  
[http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6326a4.htm?s\\_cid=mm6326a4\\_w](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6326a4.htm?s_cid=mm6326a4_w)
- A recent publication estimating the number of babies that could be born without a cleft lip or cleft palate each year in the United States if women did not smoke during early pregnancy:  
<http://onlinelibrary.wiley.com/doi/10.1002/bdra.23274/abstract>
- A special July CDC Feature – Smoking Can Cause Clefts:  
<http://www.cdc.gov/features/cleft-lip-prevention/>
- Weekly Twitter messages. We have a new Twitter handle! We are tweeting at [https://twitter.com/CDC\\_NCBDDD](https://twitter.com/CDC_NCBDDD). We invite you to comment, re-post, re-tweet and follow @CDC\_NCBDDD!

We encourage you to share these links with your colleagues and friends. Feel free to post them on your own home page as well. Thank you for your continued support and dedication to improving the lives of families and children affected by craniofacial conditions!

### **New Web Resource on Alcohol Screening and Brief Intervention**

An online video on alcohol screening and brief intervention (SBI) is now available on [QuantiaMD](#) which offers free continuing education opportunities to physicians. This [presentation](#) by Dr. Lela McKnight-Eily, from CDC's Fetal Alcohol Syndrome Prevention Team, highlights findings from the CDC 2014 [Vital Signs report](#), Communication Between Health Professionals and Their Patients About Alcohol Use — 44 States and the District of Columbia, 2011, and key aspects of alcohol screening and brief intervention.

### **Congenital Heart Public Health Consortium Webinar Series**

The last session of the Congenital Heart Public Health Consortium (CHPHC) webinar series is right around the corner! Have you registered yet? If not, [register now](#), as space is limited! The fourth webinar, "Public Health Framework for Congenital Heart Defects" will occur on August 12, from 1:00-2:00pm ET. The webinar will introduce the Consortium's Public Health Framework that addresses the public health systems that monitor at all ages, solutions that address prevention disparities, as well as the assurances that are in place to reduce risk and improve outcomes for children and adults.

### **State Indicator Report on Physical Activity Released**

The Division of Nutrition, Physical Activity, and Obesity released the [State Indicator Report on Physical Activity, 2014](#), which presents data on physical activity behaviors and environmental supports that encourage increased physical activity in each state. You can use this report to learn what states across the nation are doing to encourage and support physical activity. Individual [Action Guides](#) summarize each state's data and provide suggested actions that state health departments can take to encourage and increase physical activity in their states.

The State Indicator Report on Physical Activity, 2014 reveals that more safe and convenient places are needed for Americans to be physically active in their communities and schools. According to the report, less than 38% of the U.S. population lives within a half mile of a park. And just over half (54%) of youth have parks or playground areas; recreation centers, community centers, boys' or girls' clubs; and sidewalks or walking paths available in their neighborhoods. Youth with access to neighborhood infrastructures that support physical activity are more active.

Please share these materials with your colleagues, partners, grantees, or others who are working to promote our nation's health.

# News from our Partners

## **NHF Initiates Practice Guidelines on Hemophilia Care**

The [National Hemophilia Foundation](#) (NHF), with the guidance of its [Medical and Scientific Advisory Council](#) (MASAC), recently announced that it is initiating a multi-year project to develop evidence-based clinical practice guidelines (CPGs) to ensure that patients with [hemophilia](#) in the United States and elsewhere receive high quality care. With ongoing changes in the healthcare environment, an NHF and MASAC working group determined that the first guideline would focus on evaluating care models for hemophilia management, including the comprehensive care model of the [hemophilia treatment centers](#) (HTCs). The goal of this guideline will be to support patient-centered clinical decision-making and optimize hemophilia care for each patient.

For this project, NHF is partnering with [McMaster University](#), which has an international reputation for its work in CPG development, for the guideline on care models. Drs. Holger Schünemann and Alfonso Iorio of the Department of Clinical Epidemiology and Biostatistics at McMaster University will be serving as co-principal investigators for the project.

The first guideline panel meeting was held on June 21<sup>st</sup>, during the 60<sup>th</sup> annual meeting of the [International Society on Thrombosis and Haemostasis \(ISTH\)](#) Scientific and Standardization Committee in Milwaukee, WI. At this meeting, the panel members reviewed the scope of the guidelines and the questions that will be addressed by the guidelines. The guideline project on models of hemophilia care should be completed by the end of 2015.

## **AAHD Project Accessibility USA Launches Interactive Learning Modules**

The [American Association on Health and Disability](#) (AAHD), in collaboration with the Susan G. Komen Foundation, has launched 5 interactive Learning Modules about the importance of breast cancer awareness and accessibility of mammography facilities for women with disabilities. These modules are geared towards healthcare staff at mammography and healthcare facilities. Certificates of Completion are available for those that complete the Learning Modules. The URL for the Learning Modules is <http://project-accessibility-usa.org/Home.htm>. The Learning Modules are available for all healthcare professionals to utilize and share with colleagues.

The Learning Awareness Modules are part of a larger AAHD project, Project Accessibility USA, which offered the following services to Komen affiliates and grantees:

- 1) On - site facility assessment and on - site and virtual technical assistance to improve facility accessibility
- 2) Innovative and engaging interactive on - line training and professional development modules to increase staff awareness regarding mammography accessibility for women with disabilities
- 3) Access to materials

on the Breast Health Accessibility Resource Portal. Later this year, AAHD plans to launch the National Breast Health Collaborative for Women with Disabilities that will initially focus on national dissemination of breast health materials focusing on accessibility for women with disabilities. For more information, please email [contact@aahd.us](mailto:contact@aahd.us) and place in subject line "Breast Health Collaborative."

### **Vitamin Grants for Undernourished Children and Mothers!**

Proper nutrition during the period from conception through a child's fifth birthday is critical to building the foundation for a healthy and productive life. Vitamin Angels is a non-profit organization distributing vitamins and minerals to children and mothers that are experiencing hidden hunger as the result of gaps in the consumption of a variety of healthy foods. We are actively seeking new NGO partners, especially those who target underserved populations and those without access to national health services, to add vitamin supplementation to their existing projects.

Vitamin Angels donates the following products to qualifying non-profit organizations in the U.S. and abroad:

- High dose vitamin A for children 6 to 59 months of age (in eligible countries).
  - Albendazole (\*only when paired with vitamin A.)
- Children's Multivitamins – for children 6 to 59 months of age.
  
- Women's Prenatal-Postnatal Multivitamins

Technical assistance and operational support to implement vitamin supplementation programs is provided.

If you or an organization you know is interested in becoming a Vitamin Angels program partner, visit [vitaminangels.org/vitamingrant](http://vitaminangels.org/vitamingrant) for eligibility requirements and our micronutrient grant application, or contact [programs@vitaminangels.org](mailto:programs@vitaminangels.org).

### **July is Fragile X Awareness Month and the NFXF Invites You to Help Spread the Word about Fragile X!**

Fragile X Awareness Day, which occurred on July 22, is officially recognized by Congress. Together we can build recognition for this rare condition. By participating in the National Fragile X Awareness Month campaign, you show the world you care, deeply, about Fragile X, and about getting us one step closer to a cure. [Click here](#) to make a donation and learn how to help raise awareness.

### **Ohio Graduate of the PHF supported 2014 E-Learning Institute**

Dr. Norma J. Ryan, RN, MCHES, Coordinator for Ohio Connections for Children with Special Needs (OCCSN) at the Ohio Department of Health, recently completed the 2014 E-Learning Institute, a collaborative effort between the Public Health Foundation

(PHF) and the Centers for Disease Control and Prevention's (CDC) Division of Scientific Education and Professional Development (DSEPD).

Dr. Ryan's Quick-Learn Lesson is an e-learning module for the 5As Healthy Weight Program, based on a brief intervention model, for health professionals working in women's health centers. The 5As approach was developed to address obesity and overweight in women of childbearing age since both are potential risk factors for certain birth defects.

The target audience for the quick-learn lesson are health professionals working in women's health centers.

This second E-Learning Institute focused on empowering a group of nine education and training staff who were selected from over 200 applicants, from state, tribal, local, and territorial (STLT) health departments, with the tools and resources needed to efficiently and effectively develop e-learning modules that could be added to the TRAIN network<sup>[1]</sup> Dr. Ryan was paired with mentor Darral Brown MSc., M.Ed., Instructional Designer, working with EDCELS in CDC/DSEPD.

[1] TRAIN is learning resource for professionals who protect the public's health – <http://www.train.org>.

### **New Resources about EPSDT Services in Medicaid**

The [Maternal and Child Health Library](#) (MCH Library) at Georgetown University released a new knowledge path, Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) Services in Medicaid. The knowledge path points to resources about providing and strengthening EPSDT and includes tools for state Medicaid programs, health care practices, training, and finding data and statistics, journal articles, reports, and other materials. The knowledge path is available at [http://www.mchlibrary.org/KnowledgePaths/kp\\_EPSDT.html](http://www.mchlibrary.org/KnowledgePaths/kp_EPSDT.html).

A separate brief presents resources to help families find care, services, and support for their children, learn more about EPSDT, and find tools to help them play a more active role in their children's EPSDT-related visits. The brief is available at [http://www.mchlibrary.org/families/frb\\_EPSDT.html](http://www.mchlibrary.org/families/frb_EPSDT.html).

We welcome your comments and would appreciate your help in sharing this information with your colleagues via your website, social media, or e-news services.

### **Public Health is for Everyone**

[Public Health is for Everyone](#) is new, one-stop resource to increase the capacity of public health professionals to create programs that benefit entire communities, including

people who have a disability. Users can search and browse disability and health related resources by their interests and professional needs. Resource topics include: Nutrition, Health care access, Physical activity, Emergency preparedness, Obesity, Accessibility, Tobacco, and general inclusion issues. Practical, hands-on resources such as field guides, factsheets, checklists, brochures and other tools are featured. To check out the new [Public Health is for Everyone](#) toolkit, please visit [www.phetoolkit.org](http://www.phetoolkit.org).

Do you have a practical free resource to share? [Submit a resource](#) to further develop [Public Health is for Everyone](#).

[Public Health is for Everyone](#) is maintained by the Association of University Centers on Disabilities (AUCD) with support from CDC's Office for State, Tribal, Local and Territorial Support and the National Center on Birth Defects and Developmental Disabilities.

### **News from Avery's Angels Gastroschisis Foundation**

To start off July and propel the 5th Anniversary of our awareness day (July 30th), Avery's Angel's Gastroschisis Foundation re-launched its [website](#), which is now fully comprehensive. It includes frequently asked questions for parents and families as well as updated research links, information about programs, links for resources and news. Avery's Angel's couldn't be happier to achieve this long held goal.

### **University of Montana Developing Health Related App for Persons with Disabilities**

The University of Montana is developing a health related app for persons with disabilities. They are currently looking for individuals with disabilities to review materials and various educational formats (e.g., video, audio, PowerPoint, animation, etc.) on their computer in order to gain information on which tools are the best received. The first 40 respondents will receive a \$10 stipend. [Click here](#) to learn more!

# Upcoming Conferences

[2014 Southwest  
Conference on Disability](#)

October 7-10  
Albuquerque, NM

[AUCD 2014 Conference](#)

November 9-12  
Washington, DC

# Upcoming Webinars

[Public Health Framework  
for Congenital Heart Defects](#)

August 12, 1pm ET

[FASDs: Roles, Referrals  
and Reimbursement](#)

August 13, 3pm ET

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

August 19, 1 pm ET

[Living Well with  
Eisenmenger Syndrome](#)

August 25, 7pm ET

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

August, 27 3pm ET

# 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 [Tory Christensen](#) by 8/1. Photos and web links are encouraged!

# Friends of NCBDDD Executive Committee

[Adriane Griffen](#)

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

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Vice Chair

[Sarah Yates](#)

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Advocacy Coalition Liaison

[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

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 [Tory Christensen](#).