



New York Parent Association for Deaf-Blind

NYPADB e-news

NYPADB is Seeking Board Members

Board members meet on the second Monday of each month (except December) at 8:00pm for an hour or so. We discuss the activities & events planned for the year to achieve our goals, fundraising and expenditures, and issues in Deaf-Blindness. Visit www.nypadb.org to review our Mission Statement and Goals. If you are interested, please contact Barbara loughran.barbara@gmail.com or Clara nfadb.clara@gmail.com

Still Time to Help NYPADB to co-sponsor the 2016 Deaf-Blind Family Learning Retreat

gofundme.com/2a7bpsj2

Monies raised through this fundraiser will be used by NYPADB to support this year's DB Family Learning Retreat along with Visions VCB and NYDBC. Please donate to this wonderful family experience where we learn, play, and share together. **Deadline 6/30/2016!** Thank you!

Deaf-Blind Family Learning Retreat July 22-24, 2016

At Visions VCB – See Flyer Attached

Learn more about deaf-blindness and issues affecting your child, meet and socialize with other families who share your concerns, the children experience camp activities, while families enjoy time together! All Free this year! Travel stipends are available.

REGISTER: nydbc@qc.cuny.edu or 718-997-4856

REGISTRATION DEADLINE: July 5, 2016

NYDBC Transition Institute

NYDBC is very happy to announce that we will be hosting our first-ever statewide transition institute focused on the needs of transition age young adults who are deaf-blind between the ages of 14-21!

DATES: July 7 - 9, 2016

Thursday, July 7th & Friday, July 8th - Professionals & Families

Saturday, July 9th - Families ONLY

ACCEPTED ATTENDEES:

- Professionals working directly with transition age young adults with dual sensory loss, including transition counselors, social workers, vocational rehabilitation counselors, etc.
- Family members with a child who is deaf-blind between the ages of 14-21.

LOCATION: Queens College 65-30 Kissena Blvd. Queens, NY 11367

RSVP DEADLINE FRIDAY, JUNE 17, 2016

nydbc@qc.cuny.edu

For more information please contact: susanne.morrow@qc.cuny.edu

Family-to-Family Communities Project webinar

June 8, 2016, 12:00pm PST

Join Carol Darrah and Toni Hollingsworth (MS) as we share results of the F2FC pilot project and plan for the next phase. Link to webinar information here- <https://nationaldb.org/events/detail/0/1004>

The Family-to-Family Communities (F2FC) project, a collaboration of the National Family Association for Deaf-Blind (NFADB), the National Center on Deaf-Blindness (NCDB), and State Deaf-Blind Projects, offers a unique way for families to connect with one another. Small groups of families come together monthly, via phone conference or distance technology, to get to know one another, share information and resources, celebrate successes, offer support during challenges, and simply to lend an understanding ear.

Spanish Webinars for Families

6/18/16: at 3:00pm COMMUNICATION

Escúchame, me estoy comunicando! *Listen, I'm talking to you!*

Estrategias y sugerencias de cómo promover comunicación. *Strategies and suggestions to promote communication.*

Aprendiendo a escuchar lo que nuestros niños tratan de comunicarnos. *Learning to listen to what our children are trying to tell us.*

For more information, contact Clara Berg at nfadb.clara@gmail.com.

Online Class: Accessible Literacy for Early Readers

Starts on **June 20 – July 24, 2016** and runs for 5 weeks. This course emphasizes the importance of accessible literacy for children who are blind, visually impaired or deafblind. Participants will become familiar with different strategies and tools that can be used to create and modify literacy materials for early readers that will support a love for literacy. Participants will also create accessible books for their student/child as part of their assignments. For

registration and more information, see <http://www.perkinselearning.org/earn-credits/online-class/accessible-literacy-for-early-readers>

Recommended Resources for Vision Professionals

<http://www.pathstoliteracy.org/blog/recommended-resources-vision-professionals>

Camp Abilities

June 26 – July 2, 2016

Camp Abilities Brockport is a one-week educational sports camp for children and teens who are blind, visually impaired, and deafblind. The camp is set up to provide a one-on-one instructional situation for each person, which is often on the contrary to other camps designed for people with visual impairments.

<http://www.campabilities.org>

The 2016 Camp Abilities Long Island

July 7th – 10th at Adelphi University

<http://www.campabilitieslongisland.org>

Accessing the Dream: Preparing Deaf-Blind Youth for a Self-Determined Life

June 2016 - National Transition Initiative, NCDB

All young adults who are deaf-blind need *extensive* transition planning and services in order to experience success in adult life. Transition Institutes have historically sought to bring together young adults and their families to build skills and provide training in the pursuit of better personal transition outcomes. These institutes are a collaborative effort across 21 State Deaf-Blind Projects over a span of 10 years. The energy of the 2012 and 2015 Transition Institutes provided opportunities to capture interviews with youth, families, and service providers to share their perspectives on the experience of transition.

This video product is based on the *Taxonomy for Transition*

Programming developed by Paula D. Kohler, Ph.D. The video chapters offer insight and understanding based on foundational best practices in transition planning: Student-Focused Planning, Student Development, Interagency Collaboration, Program Structure, and Family Involvement.

<https://nationaldb.org/pages/show/accessing-the-dream-preparing-deaf-blind-youth-for-a-self-determined-life>

Calling All Family Leaders - NFADB Symposium

This summer, NFADB will be hosting their parent leadership conference in Austin, TX, **July 16 – 18**, at St. Edwards University. The day prior, on July 15, NCDB will be holding a family specialist training for individuals who serve in the role of Family Specialist for their state deaf-blind project. The agenda for the family specialist day includes:

- Taking a strategic approach to engaging and connecting families, and
- Mentoring and supporting families.

We hope that all family specialists working for state deaf-blind projects will be able to attend both events. Formal registration for the symposium will begin soon via the [NFADB website](#). As we all know, the cornerstone of a successful life for a learner who experiences deaf-blindness is a strong support system. This training will be a major step forward in advancing parent leadership skills and building family networks. Questions? Contact [Clara Berg](#) or [Megan Cote](#).

2016 Usher Syndrome Family Conference

Saturday, July 9, 2016 8:00 AM - 6:00 PM Pacific Time

This annual gathering, a place for individuals with Usher syndrome, family members, friends and professionals to learn about the latest advances in Usher syndrome research. The event's science sessions, family panel, research Q&A, lengthy breaks and evening social allow for the opportunity to connect with others impacted by Usher syndrome and engage with researchers who are working tirelessly towards a cure.

Washington Athletic Club

1325 Sixth Avenue, Seattle, Washington 98111, USA

<http://www.cvent.com/events/ush2016-usher-syndrome-family-conference/event-summary-62b3eda082ab4f73ac06e0663cb367ab.aspx>

CHARGE Accounts

Newsletter by the CHARGE Syndrome Foundation

http://chargesyndrome.org/documents/charge_accounts_newsletter_Spring_2016.pdf

Communication Considerations for Children With Hearing Loss

May 31, 2016 By [Kirsten Marconi](#)

ASHA Blog <http://blog.asha.org/2016/05/31/communication-considerations-for-children-with-hearing-loss/>

Refocusing on Choices

Amidst renewed debate about teaching signed versus spoken language to

children who are deaf, a cadre of professionals calls for emphasizing all forms of early language access.

Elizabeth Thompson Beckley

The ASHA Leader, May 2016, Vol. 21, 44-49.

doi:10.1044/leader.FTR1.21052016.44

<http://leader.pubs.asha.org/article.aspx?articleid=2520089&resultClick=3>

Epic! Books for Kids – Summer Reading Challenge

Reading on Epic! can help prevent summer slide and allow your kids to stretch their imaginations and learn this summer. Kids who read 5 or more books by 8/31 will earn a Summer Reading Certificate - showing how many books read - to print at home or show off to their teacher at school. Epic App for ios gives kids access to over 15,000 books for kids 12 and under for a monthly fee of \$4.99. Try a free month <https://www.getepic.com>

Literacy Skills Checklist

<http://literacy.nationaldb.org>

Resources on ABLE Accounts

<http://parenttoparentnys.org/education/library-detail/C168/>

Webinars Presented by Parent to Parent NYS

<http://parenttoparentnys.org/news/statewide-events/>

What is the National Coalition on Deafblindness doing?

The primary activity of the Coalition's Leadership Team is its continued support for the Alice Cogswell and Anne Sullivan Macy Act, also known as House Resolution 3535 (i.e., H.R. 3535). Here is a little background. Rep. Matt Cartwright, Democrat from Pennsylvania, introduced H.R. 3535 into the House of Representatives on September 17, 2015. After being initially referred to the House Committee on Education and the Workforce, the bill was then referred to the House Subcommittee on Early Education, Elementary, and Secondary Education in March 2016.

Of particular importance to the Coalition is Title III of H.R. 3535, which addresses issues related to deaf-blindness. Specifically, Title III amends IDEA to add interveners as a related service and corrects the current federal definition of deafblindness by proposing a new definition that is clearer and is consistent with other federal definitions. Title III also requires states to report on how they will ensure the availability of qualified interveners and teachers of children who are

deafblind.

Supporters of the bill recently organized two days of events on behalf of H.R. 3535. In March, supporters of the bill organized a national day of advocacy in Washington D.C., during which supporters met with Senate and House staff members to share stories, answer questions, and gain support. In April, supporters organized a very successful national call-in day, calling Senate and House offices to communicate support for the bill.

What's happening right now with H.R. 3535?

As of May 14, 2016, H.R. 3535 had 28 co-sponsors from the House of Representatives. These co-sponsors, from ten U.S. states, are listed here in order of the date of their co-sponsorship—from oldest to most recent—with their respective party affiliation, U.S. state, and Congressional district number.

Rep. McKinley, David B. [R-WV-1]*	09/17/2015
Rep. Takano, Mark [D-CA-41]*	09/17/2015
Rep. Cardenas, Tony [D-CA-29]*	09/17/2015
Rep. Castor, Kathy [D-FL-14]*	09/17/2015
Rep. Grayson, Alan [D-FL-9]*	09/17/2015
Rep. Honda, Michael M. [D-CA-17]*	09/17/2015
Rep. Huffman, Jared [D-CA-2]*	09/17/2015
Rep. Ryan, Tim [D-OH-13]*	09/17/2015
Rep. Kaptur, Marcy [D-OH-9]	09/28/2015
Rep. Jolly, David W. [R-FL-13]	10/02/2015
Rep. Eshoo, Anna G. [D-CA-18]	10/20/2015
Rep. Crowley, Joseph [D-NY-14]	10/28/2015
Rep. Israel, Steve [D-NY-3]	11/16/2015
Rep. Swalwell, Eric [D-CA-15]	11/18/2015
Rep. Welch, Peter [D-VT-At Large]	12/10/2015
Rep. Napolitano, Grace F. [D-CA-32]	01/07/2016
Rep. Brady, Robert A. [D-PA-1]	02/03/2016
Rep. Delaney, John K. [D-MD-6]	02/09/2016
Rep. Sanchez, Loretta [D-CA-46]	03/07/2016
Rep. Murphy, Tim [R-PA-18]	03/07/2016
Rep. Larson, John B. [D-CT-1]	03/07/2016
Rep. Schiff, Adam B. [D-CA-28]	03/07/2016
Rep. Doyle, Michael F. [D-PA-14]	03/14/2016
Rep. DelBene, Suzan K. [D-WA-1]	04/29/2016
Rep. Donovan, Daniel M., Jr. [R-NY-11]	04/29/2016

Rep. Thompson, Mike [D-CA-5]	04/29/2016
Rep. Edwards, Donna F. [D-MD-4]	04/29/2016
Rep. Hastings, Alcee L. [D-FL-20]	04/29/2016
Rep. Thompson, Glen [R-PA-5]	05/16/2016

What's needed right now for H.R. 3535?

Additional sponsors for H.R. 3535 are needed in the House of Representatives and eventually the Senate as well. There is a special focus on identifying Republican Representatives and Senators in order to demonstrate strong, bipartisan support for the bill.

For the full text of H.R. 3535, go to:

<https://www.congress.gov/bill/114th-congress/house-bill/3535/text>

To track the progress of H.R. 3535, go to:

<https://www.congress.gov/bill/114th-congress/house-bill/3535>

For information about what you can do to support H.R. 3535, check out the American Foundation for the Blind at:

<http://www.afb.org/info/get-connected/take-action/take-action-macy-act/125>

To find out more about the National Coalition on Deafblindness or to contact the Coalition, go to:

<http://www.thedbcoalition.org>

Members of the Coalition Leadership Team

Linda Alsop

Maurice Belote

Tracy Luiselli

John Mascia

Sally Prouty

Stephanie Smith