



ALDAgram – January 2015

ALDA Boston began 2015 with a fantastic New Year's Brunch at the Westford Regency on January 11th. Commissioner Heidi Reed, MCDHH, welcomed everyone and talked about what the Commission has been doing and the work that needs to be done for more connectivity. Valarie Roe Burrows, former Access Coordinator at the MFA, spoke with excitement and stimulated us to do more to support those with hearing loss who may not have access to groups like ALDA and HLAA. Valarie emphasized that all cultural venues need to consider hearing loss when they think about programming and technology. Karen Moss, our wonderful guide for our ALD tours, also attended the brunch, and she knew by name everyone of us who had attended tours. As always, a hearty thanks to Nancy Eaton for providing CART.



Everyone seemed to have had a good time; no one could possibly have left hungry. We were sorry that we could not accommodate everyone who wanted to attend, and we'll try to fix the situation for next year.

January is Membership Renewal Time. Many thanks to those who have renewed their 2015 membership: Barbara Abineri, Carol Agate, Merlyn Cajolet, Anne Canfield, Alice Costa, Jim Dalis, Nancy Eaton, Peggy Ellertsen, Matt Ferrara, Moira Hennessey, Patricia Holland, Barbara Johnson, Alice Miller, Jim O'Donnell (with a donation), Ellen Perkins, Heidi Reed (with a donation), Lou Sakin, Linda Sakin (with a donation), Terri Stewart, Ann Tanona, Tina Thompson, Beth Wilson.

If you haven't yet renewed, please take a moment to do so now. Our address is at the top of the ALDAgram. You are the voice of ALDA, and we are only as strong as our members.

Welcome New Member Rosemarie Trevani from Hopedale, MA. Alice Costa introduced Rosemarie to ALDA, and Rosemarie looked like she enjoyed the brunch.

Members in the News

Best wishes to Peggy Ellertsen, who has been appointed to the HLAA Board of Trustees. Nancy Sonnabend is another HLAA/ALDA member on the Board.

Congratulations to Nancy Kingsley, Editor-in-Chief of *ALDA News*, Ellen Perkins, and Nini Silver for graduating from the 2014 Peer Mentoring Program at Gallaudet University.



Upcoming ALDA Events



By now you should have received the flyer announcing our Valentine's Day Chocolate Madness and Panel Discussion, which will take place in the looped Lexington Library Large Meeting Room. CART will also be provided. Don't forget your favorite chocolate treat; we'll provide the drinks. We'll have a panel discussion with four members of ALDA who have hearing aids, implants, or a combination of both. Hear why they've chosen the devices they're using, what's working, what's not, and what's next on the horizon for them.

The Annual Business meeting and Election of Officers will take place on April 12th at the home of Ann Tanona in Natick. Program to be announced.

Other Events of Interest

Saturday, January 24th, Geoff Plant, President of the Hearing Rehabilitation Foundation, will give participants an opportunity to observe individuals with hearing loss as they work with Geoff in “real-time auditory training sessions.” Mass. Eye & Ear Infirmary. 1:30 p.m.

Sunday, March 8th is the next BEA gathering at the West Suburban YMCA in Newton from 1 – 3 p.m. There will be a panel of spouses “sharing their thoughts about the challenges encountered during their spouses’ hearing journey and some of the communication strategies that work best.”

April 14th is Deaf and Hard of Hearing Constituents’ Day at the State House, so mark your calendars now.

Museum of Fine Arts Accessible Guided Tours, 2015 There will be no ALD tours in January or February. The March 21 tour will be “The Ancient World.” Look for the 2015 schedule of tours on the ALDA website under “Happenings In & Out of Town.”

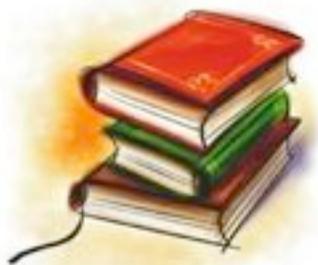
News of Note

In December, the U.S. Senate overwhelmingly passed the Achieving a Better Life Experience (ABLE) Act of 2014. First introduced in 2006, and subsequent sessions of Congress, the ABLE Act will allow people with disabilities (with an age of onset up to 26 years old) and their families the opportunity to create a tax-exempt savings account that can be used for maintaining health, independence and quality of life. To read more, go to <http://www.realeconomicimpact.org>

The Today show recently had a news clip about a boy with severe hearing loss who can’t hear the music but “feels” the beat of the music. Vako Gvelesiani performs with the Brooklyn Nets Kids. Watch the video at http://www.today.com/news/brooklyn-nets-kids-dancer-defies-odds-performs-despite-severe-hearing-1D80393097?_source=xfinity|mod&par=xfinity

“A new agreement announced January 7 between researchers at the National Institutes of Health (NIH) and a biotechnology company provides funding to continue an important clinical treatment study for Niemann-Pick disease type C (NPC), a debilitating and often fatal genetic disease. Audiologists and other research staff from the NIH’s National Institute on Deafness and Other Communication Disorders (NIDCD) will continue to play a key role in the ongoing research being conducted at the NIH’s Clinical Center.” To read more, go to <http://www.nih.gov/news/health/jan2015/ncats-07.htm>

“From Vertigo to Tinnitus, Ear Ailments are New Focus for Drugs” is the title of a January 9th article in *The New York Times*. “A drug to treat or prevent [age-related hearing loss](#) will be something that people take every day for the rest of their life,” said Edwin W. Rubel, a professor of hearing science at the University of Washington and co-founder of a start-up called Oricula Therapeutics. “Even if it could just delay age-related hearing loss by five or 10 years, that would be wonderful.” Read the full article at <http://www.nytimes.com/2015/01/10/business/ear-disorders-long-neglected-attract-drug-makers-attention-.html?smid=nytcore-ipad-share&smprod=nytcore-ipad>



I don’t remember who recommended *Burn Down the Ground* by Kambri Crews. It’s a memoir of a young girl growing up in rural Texas with deaf parents. I’ve just taken out the book from the library and haven’t started it yet, so I’ll quote from the book jacket: “As a child, Kambri Crews wished that she’d been born deaf so that she, too, could fully belong to the tight-knit Deaf community that embraced her parents.”