

25 Years of ATP: Ellen Bernstein-Ellis

“Just remember, you will learn more from the students and ATP members, than they’ll learn from you.” These are the words that Dr. Jan Avent, ATP’s pioneering founder and leader from 1996-2008, offered to me as I stepped into the director’s position in the Fall of 2009. I found her insight to be inspiring and true. I thank Dr. Avent for that sage advice and for being a remarkable and treasured mentor.

As I reflect on over a decade of service as ATP director, I stand in admiration and appreciation of the amazing lessons I’ve learned from the clinicians, the ATP members and their families, and my colleagues. All of my proudest moments and accomplishments have been collaborative endeavors.

First, hats off to the ATP clinicians. In fact, in our 25 year history, ATP has trained about 450 clinicians and even more student volunteers. Year after year, our ATP graduate clinicians have developed creative materials, established a positive, supportive, and safe therapeutic environment, and worked incredibly hard to provide effective and innovative services for our ATP members and families, whether in-person or online. They have supported a team approach and I credit my accomplishments as Director to our joint efforts. It has been one of my greatest sources of pride to see their growth in clinical skills and confidence.

I’m also proud of the sense of community that ATP offers to its members. Despite there being over 2.5 million people with aphasia in the U.S., most ATP members tell us that they are meeting other people with aphasia for the first time when they come to our program. Few family members have received any skilled communication partner training. The ATP members, their families and friends, continue to be a source of inspiration and motivation. They come to ATP determined to improve their communication skills and work tirelessly towards that goal. They form a community of support, sharing their stories and offering each other insight, encouragement, humor, and honesty. They learn from each other and provide hope and optimism to their peers. They also take great pride in their role of providing training and experience for the clinicians.

My accomplishments as ATP Director also reflect the support, talents, and commitment of a wonderful team of SLHS colleagues: Dr. Jan Avent, who has provided invaluable mentorship and support, Dr. Janet Patterson, who first invited me to help supervise ATP groups; Dr. Nidhi Mahendra, who co-directed the program with me 2010-2011 and continued with unwavering support as department chair; Bonnie Groth, Dr. Ramanathan, and Karen Jang who skilfully

co-supervised Cooperative therapy and/or Community Groups; Shelley Simrin and Jenny Rosenquist, Clinic Co-Directors who always make sure we have well-trained clinicians; Dr. Gravier who joined our faculty in 2019 and serves expertly as both a supervisor and ATP Research Director; Sophia Kanenwisher who joined us with her remarkable skill set during my leave 2018-2019, stayed on to co-direct with me, and now serves as ATP's current Director, Dr. Kashinath who provided exceptional support and leadership as chair for 7 years; and Marianna Wolff, our extraordinary ASD who has been a valued partner in both managing the daily operations and envisioning our dreams for ATP.

Some changes in ATP structure and programming

In order to address the SLHS department's need to provide training to more clinicians in the program, to balance the workload of ATP clinicians compared to those in the regular clinic, and to address the growing numbers in the ATP program, we made some adjustments to the ATP programming, including incorporating the large community group that met on Wednesday afternoons into the ATP umbrella of services. In addition we:

- Doubled the number of clinicians involved in ATP each quarter/semester from 4 to 8 or more, depending on the program needs
- Added additional student orientation training to help strengthen the foundation of LPAA-focused group facilitation skills.
- Assigned clinicians to either morning or afternoon groups:
 - A.M.: ATP Activity Groups: Reading & Writing Group (30 minutes) followed by theme-based Conversation Groups (60 minutes)
 - P.M.: Cooperative Therapy (60 minutes for 8 clients); Community groups--Book Club, News Group, or Choir (90 minutes)
- Established a Graduate Student Volunteer Coordinator position to provide support and skilled communication partner training for the approximately 12-20 student volunteers who interacted with ATP members during the self-directed practice time during the lunch break or during one of the ATP groups.
- Added a collaboration with Kinesiology, originally under the leadership of SLHS graduate student Sandy Cleary, to offer an interprofessional exercise class. Dr. Gravier and her NRRL lab expanded the exercise class to a research project..

A significant change in ATP format occurred in March of 2019 when Covid disrupted ATP's full in-person program. Within two weeks, thanks to the strong collaborative efforts of Sophia Kanenwisher and Michelle Graver, we figured out a way to get our students trained and services to our ATP members by setting up communication groups on Zoom. Approximately 80% of our ATP members, most of whom had never been on a Zoom call, joined our on-line groups. Although

Cooperative therapy was not continued in the programming, we were able to transition the Aphasia Tones choir to an online format. In addition:

- We developed an online orientation training for students highlighting telepractice best practices and principles within the context of facilitating LPAA-focused groups.
- Under the direction of Dr. Gravier's NRRL lab, we added tech groups where ATP members were provided with training on ipads or smart phones.
- Dr. Gravier and her kinesiology colleagues reconfigured their exercise research grant to twice weekly online classes.
- We collaborated with Boston University to offer a Book Club exploring the construction of a positive post-stroke identity by reading Debra Meyerson's *Identity Theft: Rediscovering Ourselves After Stroke* and was able to share the student training and clinical outcomes at several national and international conferences. We contributed to the development of book materials and a training manual for the nonprofit Stroke Onward which is being used by aphasia book clubs across the country.
- In partnership with graduate student Jennifer Truong, we developed an online student volunteer experience where undergraduates were trained as skilled communication partners and then offered weekly support to Book Club members who wanted a practice partner.

Selected Programming Highlights

ATP has a long history of promoting student scholarship in the context of communicative access and aphasia advocacy as part of the clinical training program. A sample of these projects include:

In 2015, the student team of Mark Ramelb, Brianna Brown, Pha Pha Hamilton, and Tammy Moon sponsored by the Project R2M2 mentoring grant led by Dr. Mahendra and Dr. Kashinath, developed a University-wide aphasia awareness event that presented the campus premier of *Aphasia, The Movie*, bringing in lead actor Carl McIntyre as guest speaker. Event outcomes were presented at the CSHA conference.

In 2016-2017, we partnered with the CSUEB Chief of Police Boykins to develop an aphasia-friendly personal safety training presentation. Graduate students Lyssa Rome and Carla Gottschalk-Jacobson presented posters at the ASHA and CSHA conferences and the Aphasia Access Leadership Summit in 2017.

In 2017-2018, graduate student Theresa Yao, as Cal State East Bay's first Albert Schweitzer scholar, led a summer community volunteer program for ATP members. Collaborating with Hayward City Library and Cal State East Bay

Education Department, Yao trained ATP members to be puppeteers to accompany story time or to take other roles assisting the program. She presented her project outcomes at several conferences.

In 2021-2022, Dr. Gravier and I became a member of Project BRIDGE Western Region Team associated with the Patient-Centered Outcomes Research Institute (PCORI). This project supported member engaged research and two ATP members became stakeholder participants on the Aphasia Tones Choir Interview CSR project.

Aphasia Tones Choir

Fall quarter 2009, as I started as the new ATP Director, I learned that our students possess remarkable talents and are brave enough to work at the “intersection of communication and participation” (Glista & Pollens, 2007). When Michelle Lussier shared she had training as a singer, I asked this new clinician if she would like to help launch the ATP choir. Despite this being her first clinical experience, she boldly walked right into that intersection.

The aphasia choir has always been a team effort. It’s been led for the past 12 plus years by extraordinarily talented, inventive, and dedicated SLHS graduate clinicians. That first year, Michelle, along with Shiri Oren, Jennifer Driscoll (a music major), and Ava Scofield, brainstormed with me about how to integrate LPPA principles into the choir to maximize participation at every choir rehearsal and performance. While our choir strategies continue to evolve, that has been our guiding touchstone. Every Aphasia Tones director and their support team strives to find creative ways to build communicative confidence, musicality, and social bonds, showing the members and the community that they can shine in the spotlight. We were proud to present those initial lessons at CSHA and ASHA conferences, with poster presentations that laid out our approach, roles, and evaluation process.

We’ve been delighted to assist in mentoring the start of other aphasia choirs across the U.S. and around the world. We are also proud to present annual Aphasia Awareness concerts each Spring--13 so far, including three online Sing-alongs during Covid. We’ve had many memorable experiences, concerts, and awards, including:

- The first aphasia choir to ever perform at CSHA in 2012.
- The first aphasia choir to perform in Yosemite in 2013 to honor the launch of the first aphasia-friendly brochure in the NPS.
- First international aphasia concert, performing to a crowd of about 200 in South Africa via Skype with the Siyathemba Singers, the Stroke-TBI choir

from the University of Pretoria, led by Tanya Brown MTh & Dr. Glenn Goldblum SLP in 2013 ·

- Recording a *Happy Birthday* music video to celebrate Dr Oliver Sacks' 80th birthday, at request of National Aphasia Association in 2013
- The first aphasia choir to perform at a SRO Hayward city sponsored event in 2015 featuring Dr. [Nidhi Mahendra](#) as keynote speaker at City Hall.
- The initiation of a Harmonica group in 2015 led by graduate student Kasondra Vanpykeren-Gerth.
- Receives RAISE "Most Creative" award, 2015, from the National Stroke Association; Records *This Land is Your Land* for NSA website under direction of Cynthia Byward and Ruchi Kapila.
- Receives Bay Area Proud award from KNTV in 2016.
- The first joint aphasia choir performance at CSHA in 2018 with Sac State aphasia choir.
- Collaborative songwriting project with ATP members led by Choir Directors Madison Cano Fox and Marian Alonso, creating the original song, "*I'm Here*" premiered at ATP 20th Gala in 2017.
- CSR project 2016-2018 led by Madison Cano Fox and by Christy Thies in 2021-2022 evaluating the impact of long-term participation in the Aphasia Tones Choir by completing qualitative interviews. Results have been presented at multiple national and international conferences.
- Invited performers at the 2019 Pacific Stroke Association Conference to over 200 doctors, nurses, allied health practitioners and researchers
- Awarded best student poster presentation at 2021 Aphasia Access Leadership Summit for *We Won't Back Down: Keeping the Aphasia Tones Singing During Covid* led by [Raveena Birdee](#), Weiyan Zheng, Megan Godoy

National Parks Collaboration

In 2012, National Park Service (NPS) Ranger Mary Kline received a grant from Yosemite Conservancy to develop the first aphasia friendly brochure in the NPS system. ATP became the citizen experts on the project and provided input on important features of the design and reviewed the brochure prototypes. It was a year-long partnership and in Spring of 2013, ATP traveled to Yosemite to participate in the official launch of the final product. For some ATP members, it was their first ever visit to Yosemite, for the rest of ATP, it was their first time back to the park since their stroke. To see that brochure:

<https://www.nps.gov/yose/planyourvisit/upload/aphasia-guide.pdf>

This advocacy project was presented at ASHA and CSHA conferences, the 2017 Aphasia Access Leadership conference, and has just been featured as a model advocacy project in the aphasia textbook by Dr. Brooke Hallowell, *Aphasia and other acquired neurogenic language disorders: A Guide to Clinical Excellence, 2nd edition, (2022)* San Diego: Plural Publishing. This project has received numerous awards, including the ASHA 2015 Distinguished Service Award and the CSHA 2014 Public Service Award. (<https://www.youtube.com/watch?v=EY2gInefCp4>)

In Spring of 2016, ATP began a collaboration with Golden Gate National Recreation Area (GGNRA) Ranger, Richard De La O. Similar to the Yosemite project, ATP members served as the citizen experts and consulted on the development of an aphasia-friendly guide for Alcatraz. Another guide for Muir Woods is under development. To see a sample of the collaboration process, see this brief video by Dr. Jan Avent: <https://drive.google.com/a/csueastbay.edu/file/d/0B867L8IXM0BddUpjbERfUIE4UkE/view?ts=572c2192>

In Fall of 2017, I was proud to be asked to present on aphasia and skilled communication partner strategies to the annual disability training workshop sponsored by the GGNRA and attended by approximately 40 plus park rangers.

ATP's evolving impact

In 2017, ATP was honored to be selected as Program of the Year by CSHA, recognizing its ongoing excellence in training students, providing community services, and raising aphasia awareness and advocacy. It was an award shared by the ATP graduate clinicians, my ATP colleagues, past and present, and most importantly, by all of the ATP members and their families who have been part of the program the past 25 years. That same year, the Miner family generously set up an endowment fund for ATP to honor Jan Avent's contributions to ATP and to support the Aphasia Tones Choir. It's been a humbling career honor to be able to support ATP clinicians with this fund.

While reflecting on ATP's many past accomplishments and achievements, perhaps the most significant is my confidence in what lays ahead for ATP. I am proud to be handing off ATP's leadership to the capable, creative, and compassionate hands of [Sophia Kanenwisher](#) and Dr. [Michelle Gravier](#). They have already started to implement new programs and opportunities for ATP. From creating a website to help students manage the ATP resources, to offering ATP's first summer intensive program, to expanding the clinical services offered by the exercise collaboration and launching another interprofessional research

project with social work, I see ATP's future as very bright and exciting and that's a very rewarding place to be.

Citations:

Glista, S. O., & Pollens, R. D. (2007). Educating clinicians for meaningful, relevant, and purposeful aphasia group therapy. *Topics in Language Disorders*, 27(4), 351-371