

August 1, 2022 – July 31, 2023





Dear Friends,

On behalf of our Board of Directors, Professional Advisory Council, and dedicated staff, I am pleased to share our 2023 Annual Report, highlighting the successes of this past year. Included you will find an insert highlighting our commitment to research as the leading organization focused on childhood apraxia of speech (CAS).

This past year was full of new initiatives and opportunities for Apraxia Kids. In addition to our new Parent Portal, Apraxia Kids launched an IEP Roadmap to aid families as they advocate for their child. We remain committed to providing the most up to date resources and evidence-based information to our community each and every day.

On October 19th, members of our staff, Board, and Professional Advisory Council joined the Royal College of Speech Language Therapists and Mikey Akers from Mikey's Wish at Parliament in London to educate Parliamentarians and change the terminology used in England from verbal dyspraxia to childhood apraxia of speech. What an amazing opportunity to bring further awareness to CAS on the global stage.

As the leading nonprofit focused on childhood apraxia of speech, our commitment to spreading awareness, building a strong support community, sharing evidence-based resources, and empowering families to better advocate for their children remains strong.

Looking ahead, we remain committed to increasing our impact, upholding our core values of support, education, awareness, advocacy, and research. Together, we can achieve our vision of a world where every child with apraxia of speech reaches their highest communication potential.

We are excited for the future and look forward to sharing new resources, information, and learning opportunities.

Thank you for your continued commitment and for allowing us to give hope!

Angela Grimm **Executive Director**





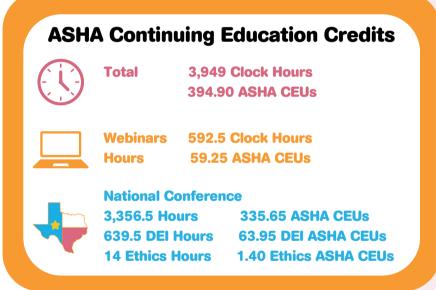
Echeration

National Conference

As a core pillar of our mission, education remains critical as our professionals and families seek evidence-based information. This past July, **300** caregivers, professionals, and researchers gathered in Plano, Texas July 6-8 for the Apraxia Kids National Conference. In addition, **328** attendees joined us virtually from across the globe. With an emphasis on cultural and linguistic diversity, attendees were able to learn about assessment and treatment for children whose first language is not English, as well as various other topics such as AAC, evidenced-based research results, social challenges, treating literacy and coarticulation issues, and advocacy. A reoccurring highlight of our in-person conference is all of the opportunities for attendees to network and make valuable connections.

<u>Boot Camp</u>

Apraxia Kids Intensive Training was held August 2-5 for 25 speechlanguage pathologists (SLPs) from the United States, Canada, Brazil and Puerto Rico. They completed a total of 37.5 hours of training and are now working on their case studies with their mentor to complete the final requirement to graduate.



Kristin Johnson Scholarship

The Kristin Johnson Scholarship was established to honor Kristin's extraordinary life as an SLP whose life was taken too soon by a motor vehicle accident. Thanks to the generosity of her family and the support of the community, a fund has been established with Apraxia Kids offering scholarships to graduate students specializing in pediatric speech sound disorders. This past year, Apraxia Kids awarded 4 scholarships recognizing the following students.

- Alexandra Garabedian, Eastern New Mexico University, Alexandra found her *'why' when she was diagnosed with CAS when she was younger*.
- **Madeline Cheyne**, Montclair State University, Madeline has worked with Dr. Elaine Hitchcock and is passionate about a research focus.
- Lucero Varela Zavala, Saint Mary's College Notre Dame, Lucero's goal is to be a bilingual SLP to bridge gap in Latinx/Hispanic communities.
- **Amber McIvor**, University of Northern Colorado, *Amber is passionate about CAS research*.



"Some of my greatest accomplishments have been completing my bachelor's degree from Northern Arizona University. I have a bachelor's degree in communication sciences and disorders. I felt inspired to pursue the speech pathology field from my personal experiences in speech therapy. My speech therapists were kind and supportive people which allowed me to enjoy speech therapy a lot. I desire to help others who were just like me when I was younger." - Ambros

Support

IEP Roadmap

This past June, Apraxia Kids launched our new and free IEP Roadmap. Our initial goal was to develop a simple one-page resource or checklist to help families prepare for an IEP meeting. But our team quickly realized – we can do more – and we did! This project was developed by a small group of Apraxia Kids staff members and some incredibly dedicated volunteers, including parents and professionals with different perspectives across the country. Our goal was to consolidate and explain the IEP process in a more digestible and manageable way for families to navigate. This new resource is available on our website to empower our families to be the best advocate for their apraxia star!

Free Resources

This past year, Apraxia Kids updated many of our brochures, flyers, and resources along with creating new materials for our families and SLPs. We are pleased to share new resources for medical healthcare providers, school-based professionals, and librarians along with expanding our printable resources in French and Spanish. Apraxia Kids remains committed to furthering our outreach efforts to reach more families and educate more professionals.

Find Hope, Give Hope

Over the years, we have heard thousands of stories of those diagnosed with apraxia of speech. Each tale is unique, but offers a familiar journey. These stories have not only brought smiles and tears, but also a connection among our community members. Most importantly, one person's story can provide an abundance of hope to another family. In May 2023, we introduced our new platform called Find Hope, Give Hope and shared the stories of nine individuals. Since then, others have continued to share their stories! If you have a story of hope, we encourage you to share yours.



"I think our disability makes us who we are, and it helps us understand others, and strengthens us. Looking back, it amazes me all we have done in our family. For all families who are dealing with apraxia, don't give up, you are stronger than you think." -Brandon ♣



Apraxia/Kids

IEP Roadmap



Be the Voice

Often individuals want to raise awareness about childhood apraxia of speech or funds for Apraxia Kids, and utilize our Be the Voice program to help them succeed. Be the Voice continues to offer ideas, suggestions, and resources so awareness planning is easy for families and professionals. It also offers kits to enhance their experience. These kits include an SLP Kit, a Classroom Kit, an Event Kit, and a DIY Fundraising Kit. In 2023, over **786** kits were shared across the globe to help creative ideas be put into action.

Apraxia Awareness Month

Every year, Apraxia Kids is thrilled to be able to celebrate Apraxia Awareness Month! We invite our apraxia community to raise awareness and celebrate their Apraxia Stars. This year our theme was Find Hope, Give Hope where we asked families to share their stories so that other families could find hope in their own apraxia journey. Many members of our apraxia community also asked local landmarks to "turn blue" on May 14th, from Niagara Falls to Melbourne, Australia!



<u>Walk for Apraxia</u>

In 2023, Apraxia Kids hosted 62 in-person Walks across North America in addition to our Virtual Walk for Apraxia event. More than **900** Apraxia Stars were celebrated this year bringing together over 8,000 family members, friends, community members, and SLPs.

The Walk for Apraxia remains our largest community initiative raising funds and awareness that are essential to sustaining the FREE programs and services of Apraxia Kids.



"I want to say, that with tons of speech therapy and social interaction, **it does get better**. My confidence is much better now and I'm not afraid to enter a conversation or start a conversation. I've really come a long way with the help and support of what my mom calls a village." - Brody Slotnick



Apraxia Kids is so grateful for the continued support of Taco Cabana since our partnership began in May, 2022. With the commitment of the entire Taco Cabana team and all of their generous patrons, over **\$225,000** has been contributed to Apraxia Kids supporting our programs and services. With their support, Apraxia Kids was able to accomplish so much more than we ever envisioned.



OUR STAFF

Angela Grimm, Executive Director

Laura Moorer, M.A., CCC-SLP, VP of Programs Earnie Sotirokos, VP of Digital Strategy Jaimie Barca, Development Manager April Black, Walk Manager

BOARD OF DIRECTORS

Lou LaVecchia, Chair Claudio Capone, Vice Chair Amber Pinskey, Treasurer Aly Taylor, Secretary Stephanie Fera, Esq. Gary Fernando, MD, FAAP Neil Kilby George Lin Edwin Mass, Ph.D. Jeff Mills Jonathan Spiegel Matthew Stevens Mary Sturm, Board Member Emerita Amber Vecchio Sarah White **Brennan Woods**

Courtney Powell, Office Manager Amanda Stein, Program Manager Amy Salera, Community Engagement Manager Audrey Swanderski, Marketing Coordinator

PROFESSIONAL ADVISORY COUNCIL

Edwin Maas, Ph.D., Chair Susan Caspari, M.A., CCC-SLP Amy Clark, M.S., CCC-SLP Elaine Dolgin-Lieberman, M.A., CCC-SLP Christina Gildersleeve-Neumann, Ph.D., CCC-SLP Maria Grigos, Ph.D., CCC-SLP Jenya luzzini-Seigel, Ph.D., CCC-SLP Patricia McCabe, Ph.D., (BAppISP), FSPAA, CPSP Amy Meredith, Ph.D., CCC-SLP Angela Morgan, Ph.D. Megan Overby, Ph.D., CCC-SLP Nancy Potter, Ph.D., CCC-SLP Jonathan Preston, Ph.D., CCC-SLP Brooke Rea, M.Cl.Sc, SLP (C) Ruth Stoeckel, Ph.D., CCC-SLP Edy Strand, Ph.D., CCC-SLP Nancy Tarshis, M.A., M.S., CCC-SLP Shelley Velleman, Ph.D., CCC-SLP

OUR VISION

A world where every child with apraxia of speech reaches their highest communication potential. Every child deserves a voice.

OUR MISSION

Apraxia Kids is the leading nonprofit that strengthens the support systems in the lives of children with apraxia of speech by educating professionals and families; facilitating community engagement and outreach; and investing in the future through advocacy and research.

Our Commitment to Research

Supporting research has been an important part of the mission of Apraxia Kids since its inception in 2000. As a core pillar of our mission, funding research projects around childhood apraxia of speech (CAS) remains a priority for Apraxia Kids, our Board of Directors and Professional Advisory Council. Since our first funded research project in 2009, Apraxia Kids has played a major role in the research community by funding research on various CAS topics including assessment, treatment, and social-emotional factors across the lifespan and with diverse populations. We are pleased to share the results of all of the grants we have funded on our Research Grants webpage.

Why is research so important? Research is necessary for clinicians to have guidance about best practices for assessment, diagnosis, and treatment in order to make the best decisions for each child with CAS. Apraxia Kids is committed to providing <u>quality</u>, accurate information. Evidence-based practice is information that is supported by research showing its effectiveness. Apraxia Kids hosts a multitude of current research studies on our Research Participation webpage. In order for these studies to be successful, families willing to have their child participate are critical.

The ultimate goal is to have studies that incorporate a large number of children with CAS and that include long term follow-up. That requires huge investments from larger foundations and federal governmental agencies like the National Institues of Health (NIH). However, those larger agencies will not fund research studies that have not already shown positive results from smaller, pilot studies. That is where Apraxia Kids fits into the picture – we can provide funding so that researchers can show preliminary data and apply for and receive additional, larger grants.

We also assist clinicians and families to stay up to date on important research as it becomes published by sharing articles and their summaries. All of the investigators of Apraxia Kids funded research have published articles about their results in peer-reviewed journals. These summaries and article links can also be found on our website.

Another way Apraxia Kids supports research is to give researchers who specialize in CAS a platform to come together and have meaningful discussions about the current state of research. As the leading organization focused on childhood apraxia of speech, Apraxia Kids has facilitated three Research Symposiums, bringing together researchers from across the globe to share their current research along with making recommendations for what future research is needed in the field.

Since the 2022 Research Symposium, many of the presenters have written research papers reporting the findings they presented at the Symposium and these have been published in a special issue of the Journal of Speech-Language and Hearing Research and summaries of these papers can be found on the Apraxia-Kids website. To summarize the symposium, Dr. Tricia McCabe and Dr. Molly Beiting led the development of a paper "Research priorities for Childhood Apraxia of Speech: A long view" which will be published shortly as the prologue to the special issue. This paper synthesizes the symposium round table discussions and shares the joint research recommendations of the symposium attendees.



"The Apraxia Kids Doctoral Grant played a pivotal role in my research. The grant provided the necessary resources, support, and network to successfully complete my project. My findings suggest there is still widespread misunderstanding among early intervention speech therapists when it comes to diagnosing apraxia. Understanding these misconceptions is a critical first step towards dismantling them and ensuring that kids with apraxia receive the early support they need. Additionally, as a doctoral student, this grant allowed me to build skills, experience, and expertise that I will need as I continue on my path towards becoming a researcher of apraxia. I am so grateful for this grant both for investing in important research projects and also future researchers like myself!" -Hannah Valentine, M.S. CCC-SLP Doctoral candidate at NYU



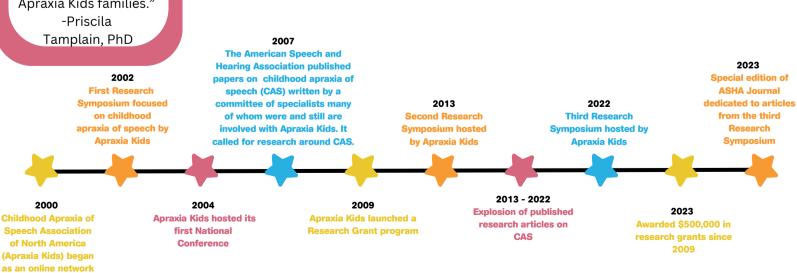
"Funding from Apraxia Kids enabled an interdisciplinary collaboration aimed at understanding the prevalence rates of Developmental Coordination Disorder in children diagnosed with CAS. The grant has allowed us to travel to several clinics across the country and collect data on motor difficulties of a large sample. Our findings will lead to essential changes in standard care for children with CAS and this has all been possible due to Apraxia Kids! Thank you for funding research that directly impacts the **community** and giving us the honor to work with the amazing Apraxia Kids families." -Priscila Tamplain, PhD

of parents.

In summary, the paper recommends CAS research priorities around four main questions:

- 1. "What questions should we ask?" which includes topics related to assessment, treatment, and outcomes with an emphasis on functional outcome measures (e.g., participation, intelligibility, social-emotional well-being etc). Recommendations here also include adopting "precision medicine" as a goal, so that the right treatment is delivered in the right dose at the right time.
- 2. "Who should be in the research?" which recommends a focus on the diversity of people with CAS including bilingual and multilingual people, those of different races and ethnicities, those with multiple diagnoses and people at all stages of the lifespan. This theme also includes the need for more diverse epidemiological and longitudinal studies that look at the incidence and distribution of CAS across diverse populations and over longer periods of time.
- 3. "How do we conduct the research?" which recommends adopting a "big science approach" using multiple sites, open access data repositories, and standardized data collection across research teams. Most importantly, this theme recommends that researchers ask people with lived experience of CAS to design, run and report on research with them.
- 4. "How do we change practice?" The final theme looks from research to practice and recommends that a new approach called "Implementation Science" be adopted in designing and completing research. This new approach asks researchers to design their studies from the beginning with the end user, clinician, or parent, in mind and is aimed at improving how soon research findings are translated into on the ground practice. Other recommendations in this theme include more use of infographics and video summaries, measurement of what happens in clinical practice, and the development of clinical guidelines.

Research is a much-needed collaboration between researchers, clinicians and families so that children receive the services needed to find their voice. Without the financial support of the apraxia community, Apraxia Kids would not be able to provide research grants, help researchers recruit participants, or provide digestible summaries of articles. If everyone plays a role, the opportunities are endless!



Research Timeline