## 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>, <u>accurate information</u>. 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."

## 2002

-Priscila Tamplain, PhD

First Research
Symposium focused
on childhood
apraxia of speech by
Apraxia Kids

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

## 2007

The American Speech and Hearing Association published papers on childhood apraxia of speech (CAS) written by a committee of specialists many of whom were and still are involved with Apraxia Kids. It called for research around CAS.

2013 Second Research

Second Research
Symposium hosted
by Apraxia Kids

2022

Third Research
Symposium hosted by
Apraxia Kids

2023

Special edition of ASHA Journal dedicated to articles from the third Research Symposium



Childhood Apraxia of Speech Association of North America (Apraxia Kids) began as an online network of parents. 2004

Apraxia Kids hosted its first National Conference

2009

Apraxia Kids launched a Research Grant program

2013 - 2022

Explosion of published research articles on CAS

2023

Awarded \$500,000 in research grants since