



#### **Objectives**

- 1. Discuss effective ways to advocate for children with childhood apraxia of speech in various settings such as in the school, medical and private practice communities as well as when dealing with insurance reimbursement.
- 2. Identify how to build a team of collaborative professionals (e.g., speech-language pathologist, psychologist, developmental pediatrician, occupational therapist etc.) to best support children with CAS.
- Identify important questions to ask speech-language pathologists about knowledge, training, and expertise in evaluating and treating children with apraxia.

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#### Disclosures:

Anne is the owner of Strive to Thrive Therapy, LLC. There are no other relevant financial or non-financial disclosures.

Jennifer owns Pediatric Communication Center, a private speech-language pathologist practice in Connecticut. There are no other relevant financial or non-financial disclosures.



#### What is Advocacy?

Per Bartleby's American Heritage Dictionary (2008)

Advocacy is "the act of pleading or arguing in favor of something, such as a cause, idea or policy; active support"

Having your voice heard on issues that are important to you

Having your views and wishes considered when making decisions about your life or your child's life

Parents and caregivers of children with childhood apraxia of speech may encounter situations where they need to advocate for their child's best interests

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# What is Childhood Apraxia of Speech (CAS)?

Per ASHA (2007):

"Childhood apraxia of speech (CAS) is a neurological childhood (pediatric) speech sound disorder in which the precision and consistency of movements underlying speech are impaired in the absence of neuromuscular deficits (e.g., abnormal reflexes, abnormal tone). CAS may occur as a result of known neurological impairment, in association with complex neurobehavioral disorders of known or unknown origin, or as an idiopathic neurogenic speech sound disorder. The core impairment in planning and/or programming spatiotemporal parameters of movement sequences results in errors in speech sound production and prosody."



## Advocating for Your Child with Childhood Apraxia of Speech

- Why advocate for your child with CAS?
  You know your child best and serve as their voice
  You and your child are a vital part of your community, family, school team, and medical team
  To to build awareness and provides education to others of your child's needs, concerns, hopes and goals
  To ensure your child's needs are being met appropriately
  To set your child up for success
  To provide yourself a sense of comfort as you gain a better understanding of CAS, your child's needs and how to help
  Facilitate trust with your team of professionals

How...???



## **Advocacy Topics**

- Advocacy in the Medical World
- Advocacy with your Speech and Language Pathologist
- Advocacy- Insurance, Grants, and Healthcare Funding
- Advocacy in the Community
- Advocacy- Educational Setting
- Advocacy- Augmentative and Alternative Communication Supports
  Advocacy- Your Team
  Advocacy Within the Family

- Self- Advocacy
- Advocacy- Apraxia Awareness Day
- Advocacy- Resource Guide
- Advocacy- Organizations



### Advocacy- Medical World

Obtain a referral for a speech and language assessment for your child when you have concerns about your child's speech

Make the call sooner than later! Many therapists and clinicians have wait lists

Express your concerns with your pediatrician, developmental pediatrician, and obtain a referral

Find a speech and language pathologist that has advanced knowledge and expertise in childhood apraxia of speech

expertise in childhood apraxia of speech
Gentle reminder: childhood apraxia of speech *is* a speech and language
diagnosis that has been given by other professionals

• SLPs are able to complete a dynamic motor speech assessment to decide if childhood
apraxia of speech is the most appropriate diagnosis at a given time
Refer to other providers if you notice other concerns (we know there usually is
another area of concern with childhood apraxia of speech)

• Fine motor- Occupational Therapy (OT)

• Gross motor- Physical Therapy (PT)

• Cognitive and academic concerns- Neuropsychologist

• Social/ Emotional- Mental Health Care Providers- Psychologist, Social Workers,
Counselors

Apraxia / Kids Counselors

## Advocacy in the Medical World

- Obtain a second opinion about your child's diagnosis with a therapist who has advanced training and expertise in childhood
- apraxia of speech
   Apraxia Kids Directory
   Always o.k. to get a second opinion
   Connect the apraxia specialist with your ongoing therapist

  Bring your private/outside team together WITH your educational
  - Ask to have a meeting with everyone (it can be an IEP meeting) to discuss strengths, challenges, and goals
     Connect your pediatrician/specialists with your ongoing therapists
- to discuss progress

  - Continuity of care is key to the overall picture
    Have your SLP connect with pediatrician, developmental pediatrician
    regarding progress and concerns Apraxia/Kids

M.D. Developmental and Behavioral Pediatrician and Division Director for Developmental Pediatrics for Advocate Children's Hospital in the Chicago Suburbs

How does a family get a developmental pediatrician evaluation? What does it consist of?

- Getting an evaluation with a Developmental and Behavioral Pediatrician can be a bit tricky as long waiting lists are common.
- There are only 20 of us in this specialty in Illinois and about 800 nationwide.
- Developmental Pediatricians often see patients on their own or within a team of providers for a multidisciplinary assessment, depending on the clinic and the need. One of these multidisciplinary team clinics is the Medical Diagnostic Clinic through the State of Illinois Early Intervention program for children under 3 years old.
- On that clinic team we have a Developmental and Behavioral Pediatrician lead, Speech and Language Pathologist, Occupational Therapist, Developmental Therapist or Child Psychologist, and sometimes a Physical Therapist.



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#### Advocacy in the Medical World- Dr. James Weedon,

M.D. Developmental and Behavioral Pediatrician and Division Director for Developmental Pediatrics for Advocate Children's Hospital in the Chicago Suburbs

What is your role in the community?

- My role as a subspecialist is to be a referral resource to General Pediatricians to evaluate, diagnose, and manage children with a variety of developmental problems from Autism Spectrum to ADHD, learning problems, behavior issues, and communication disorders.
- I help to set practice guidelines for our medical system for treatment and support of children with special needs in the community, therapy, and hospital setting.
- I also help to promote and integrate community programs into my practice for the benefit of my families.
- As part of our outreach, I give lectures in the community, schools, businesses, and Early Intervention.
- Illinois specific- As a founding board member, I have helped to create a family and therapy nonprofit support organization called the CITY of Support that is open to all families of children in therapy regardless of their diagnosis.

M.D. Developmental and Behavioral Pediatrician and Division Director for Developmental Pediatrics for Advocate Children's Hospital in the Chicago Suburbs

What is your role for assessment and treatment of children with childhood apraxia of speech?

- I participate in the medical and developmental evaluation of a child with suspected Childhood Apraxia of Speech by taking a thorough and holistic developmental and medical history, structured observation of communication and behavior, and performing a neurological exam to look for differences in tone, reflexes, and coordination including motor planning.
- I will often work in conjunction with an SLP either in my clinic or from the community to collaborate to make a diagnosis of CAS together. I will often have children with suspected CAS do an oral motor imitation exam and practice a variety of sounds and combination of sounds from different motoric areas of the mouth to test for errors and consistency. If I suspect a neurological or underlying brain condition that may explain the difficulties, I may refer to a neurologist for brain imaging or EEG.

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#### Advocacy in the Medical World- Dr. James Weedon,

M.D. Developmental and Behavioral Pediatrician and Division Director for Developmental Pediatrics for Advocate Children's Hospital in the Chicago Suburbs

What information do you look for from a family and outside providers when considering the diagnosis of childhood apraxia of speech?

- Part of my developmental history includes a prenatal and perinatal history, full medical history, developmental history, and review of records.
- I am looking for the history of onset of babbling, regression, feeding history, and intelligibility understanding of close family and those who do not know the child as well.
- I want to know from an evaluating or treating SLP about oral motor movements, inconsistent
  errors in words or differing placements of sounds in words, secondary groping behaviors,
  and how the child has responded to treatment.



M.D. Developmental and Behavioral Pediatrician and Division Director for Developmental Pediatrics for Advocate Children's Hospital in the Chicago Suburbs

How do you support families who come to you with a diagnosis of childhood apraxia of speech?

As a DBP, I am concerned with making sure each child has an appropriate treatment plan
that is individualized to their needs. This includes making sure they have appropriate
school supports in the form of an IEP or 504 plan, access to speech therapy as an
outpatient with an appropriate provider to meet the child's needs, connection to a supportive
community, education about the condition, and identification and treatment of any comorbid
disorders or difficulties.



#### Advocacy in the Medical World- Dr. James Weedon,

M.D. Developmental and Behavioral Pediatrician and Division Director for Developmental Pediatrics for Advocate Children's Hospital in the Chicago Suburbs

How do you support families who are needing assistance with insurance coverage?

• I often advocate for families for coverage of speech therapy by writing letters of medical necessity or help with applications for grants. Often insurance companies need to be educated that CAS is a disorder with a neurological basis and is a medical condition, not just a developmental speech delay. The treatment requires treatment sessions that are more frequent bursts than typically what is covered for speech delay.



M.D. Developmental and Behavioral Pediatrician and Division Director for Developmental Pediatrics for Advocate Children's Hospital in the Chicago Suburbs

What do you discuss with families in regards to advocacy in the education setting?

- Childhood Apraxia of Speech has many other implications in the classroom other than affecting speech. For the preschool children, we emphasize early literacy activities and early identification of reading or learning difficulties as well as appropriate management of potential learning problems at school. We look for motor apraxia with other motor activities that may affect fine motor, handwriting, gross motor, and physical education activities. There are higher incidences of sensory modulation and sensory processing difficulties which may affect a child's regulation or attention in the classroom. Always we want to advocate for social and emotional supports. What this looks like in an IEP is different for every child, but in addition to speech therapy may include occupational therapy, social work, physical therapy, a behavioral intervention plan, classroom accommodations, academic pull out or push in supports, or even alternative classroom placement.
- A significant area of contention at times seems to be figuring out what the appropriate level of speech therapy services or minutes may be for children with CAS. We know that our children with CAS require an individualized and specialized treatment approach. This may not always be available in every school or district, but I advocate for individualized speech therapy and formalized training for the speech therapist in treatment for CAS.

#### Advocacy in the Medical World- Dr. James Weedon,

M.D. Developmental and Behavioral Pediatrician and Division Director for Developmental Pediatrics for Advocate Children's Hospital in the Chicago Suburbs

What do you discuss with families in regards to advocacy in the education setting? (continued)

• Always we want to advocate for social and emotional supports. What this looks like in an IEP is different for every child, but in addition to speech therapy may include occupational therapy, social work, physical therapy, a behavioral intervention plan, classroom accommodations, academic pull out or push in supports, or even alternative classroom placement. A significant area of contention at times seems to be figuring out what the appropriate level of speech therapy services or minutes may be for children with CAS. We know that our children with CAS require an individualized and specialized treatment approach. This may not always be available in every school or district, but I advocate for individualized speech therapy and formalized training for the speech therapist in treatment for CAS.



M.D. Developmental and Behavioral Pediatrician and Division Director for Developmental Pediatrics for Advocate Children's Hospital in the Chicago Suburbs

What do you discuss with families in regards to advocacy in the medical field/ for their medical team?

Many physicians may not be familiar with Childhood Apraxia of Speech and educational materials may be helpful. I try to give good resources and information in my medical visit reports with information that can be accessed not only by the family, but their referring physicians as well. If a family does not feel supported or wishes to change pediatricians, I help them to find a pediatrician who practices in a Medical Home model of care and participates actively in managing their care. I will help to coordinate referrals to other medical subspecialist providers if they are needed.



#### Advocacy in the Medical World- Dr. James Weedon,

M.D. Developmental and Behavioral Pediatrician and Division Director for Developmental Pediatrics for Advocate Children's Hospital in the Chicago Suburbs

What do you discuss with families in regards to advocacy in the family?

Often having a good way to explain Childhood Apraxia of Speech in easy to understand terms is the best way for families to talk to their own family members. Our children with CAS do not struggle because they are lazy or that they are choosing to not speak or speak clearly. Often times progress may be slow and take a lot of time and practice. This may sometimes be difficult to understand. Having everyone on the same page and in agreement in the family helps keep the focus on the path moving forward.



M.D. Developmental and Behavioral Pediatrician and Division Director for Developmental Pediatrics for Advocate Children's Hospital in the Chicago Suburbs

What do you discuss with families in regards to advocacy in the community?

I encourage families to become active in the community with organizations such as Apraxia
Kids. Being connected with other families and building a support network is such an
important piece of treatment. We know from research that a family who is active in a
support network and is engaged in understanding and treating their child's CAS makes a
huge positive difference on the health outcomes of their condition. It is also a great way for
families to give back and support those who may be just beginning their journey with CAS.



#### Advocacy in the Medical World- Dr. James Weedon,

M.D. Developmental and Behavioral Pediatrician and Division Director for Developmental Pediatrics for Advocate Children's Hospital in the Chicago Suburbs

Any general resources or things for families to consider?

I want to emphasize something I am seeing more and more in my own clinics and is not written about much in the literature. What concerns me is the comorbidity of Childhood Apraxia of Speech with Autism Spectrum. One study from the Journal of Developmental and Behavioral Pediatrics in 2015 stated that almost 2/3rds of children with autism spectrum in their study also had CAS. This is often overlooked especially when many young children with autism spectrum are also pre-verbal or low verbal. While the focus on functional communication with visuals and AAC is an important piece of a treatment plan for children with autism spectrum, I never want families, schools, or therapists to lose sight of developing verbal speech for them. I often find myself advocating for treatments for CAS as a component of their treatment. If the focus is solely on use of AAC, verbal speech becomes an afterthought or sometimes is not ever addressed or given up in accomplishing. I think it is our duty to advocate for all children for this as part of their treatment plan.

## Advocacy with your child's speech and language pathologist(s)

#### Questions to ask an SLP

- Experience, education/training, comfort level in working with children diagnosed with sCAS/CAS
- Number of children worked with diagnosed with CAS
- Treatment approaches
- Parent involvement

#### Remember...

- PARENTS are the experts on their children
- SLPs are the experts in communication
- Go with your gut instinct



### Advocacy- Insurance

- Read your policy/ know your plan BEFORE you start treatment Find out if you need pre-authorization for all services Obtain a referral for speech and language therapy services, if needed Questions to ask your insurance
- - Talk to your speech and language pathologist and/or pediatrician who wrote the referral about the
- following:
   diagnosis code
   CPT code
   Is there a visit limit? You and your therapy team should all know at a given time the visit count!
   Is the limit a hard or soft maximum?
   Is the visit limit dedicated to speech or is it split between OT, PT, Chiro and ST?
   Are there any exclusions to your plan?

  Be prepared to be on the phone for an extended time when talking to an insurance
- company

  Try calling first thing in the morning

  Ask for the name of the representative and the reference number

  Who, what what discussed, date, time

  Know that SLP services can't be rendered more than once on the same day
- ASHA Consumer Checklist

https://www.asha.org/public/coverage/consumerchecklist/



#### Advocacy-Insurance

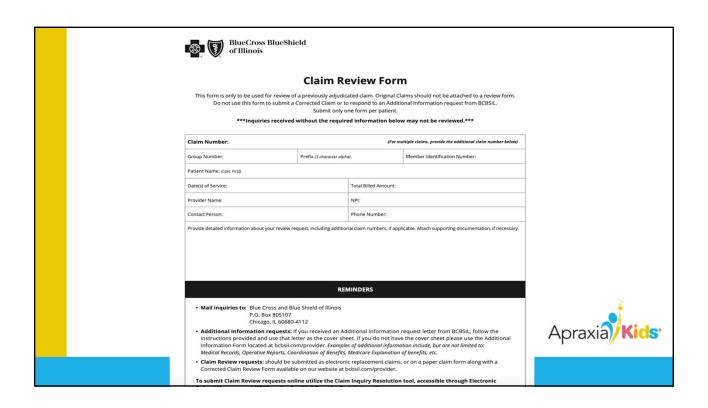
- Soft max limits may require submission of therapy documentation
  - Soft flax liftlis flay require submission of therapy documentation to support further therapy
    Discuss with your insurance company timelines for when to turn in notes and documents to ensure there isn't a gap in therapy
    Be prepared for a stop in therapy when visits run out
    Have knowledge of your out of pocket expenses in case request for additional visits is denied

Appeals and Denials

- Obtain a copy of the reason for denial in writing
  Connect with your pediatrician or developmental pediatrician for a letter of
  medical necessity and additional medical documentation
   Reference ASHA's position statement on childhood apraxia of speech
  May have to appeal decisions- contact the insurance company about the

appeal process
Talk to your benefits coordinator at your place of employment regarding the Apraxia/Kids®

Be prepared for a lengthy process in appeals



### Advocacy-Insurance

- Out of Network Providers
  - · Some insurance companies will reimburse you for speech therapy when you are seeing an out of network provider
  - If you want to see a SLP who specializes in CAS and is out of network, check your out of network benefits to determine if you have coverage at this level
    - ask your insurance company the same questions about benefits as if your provider was in network to determine if a you may be able to see a specialist and be reimbursed
    - Your SLP should be able to help you with this process
  - Submit a superbill from your SLP to your insurance:
  - Superbill Templates for Audiologists and Speech-Language Pathologists (asha.org)



### **Advocacy- Grants**

- Unitedhealthcare Children's Foundation
  - https://www.uhccf.org/
- Small Steps in Speech
  - http://www.smallstepsinspeech.org/
- Orange Effect Foundation
  - https://theorangeeffect.org
- Apraxia Kids- Speech Tablets https://www.apraxia-kids.org/speech-tablets-for-apraxia/
- Some private practices offer scholarships to families
   Local Universities/Clinics may offer ST at a low cost/sliding scale Apraxia

### Advocacy- Healthcare funding

- Discuss concerns with local government officials such as state senators, governors, and other elected officials
- Appeal denials from health insurances; keep notes/reference numbers
- Contact your state's insurance commission
- Obtain letters of medical necessity from pediatricians, developmental pediatricians, speech-language pathologists
- Apply for social security disability in your state
- Be the squeaky wheel!
- Check out a sample appeal letter on the Apraxia Kids website;
  - https://www.apraxia-kids.org/apraxia\_kids\_library/sample-humanresource-letters/
     Apraxia Kids

### Advocacy in the Community

- Find your tribe!
  - Educate local professionals, neighbors, etc. in the community
  - Join your local Apraxia Kids Facebook Group
  - Join the volunteer walk committee for Walk for Apraxia
- Ask your school to host a "Dress Down" day in support of children with CAS
- Host fundraisers at local restaurants, breweries, ice cream shops
- Request that your city/town make May 14th Apraxia Awareness Day
- Participate in Apraxia Awareness Month (May)
- Join your local special education parent/teacher organization



### Advocacy in the Community

- Distribute pamphlets on childhood apraxia of speech!

  you can request pamphlets from Apraxia Kids at OR print off from www.apraxia-
  - Contact your local Apraxia Kids Volunteer Coordinator- check out local facebook
- group Libraries

- Doctor's offices
  Physical therapy offices
  Occupational therapy offices
- Social workers/ psychologists
- Reading specialists
- BCBAs'
- Art therapy Equine therapy
- Adjuatic therapy
- Play groups



### Advocacy in the Educational Setting

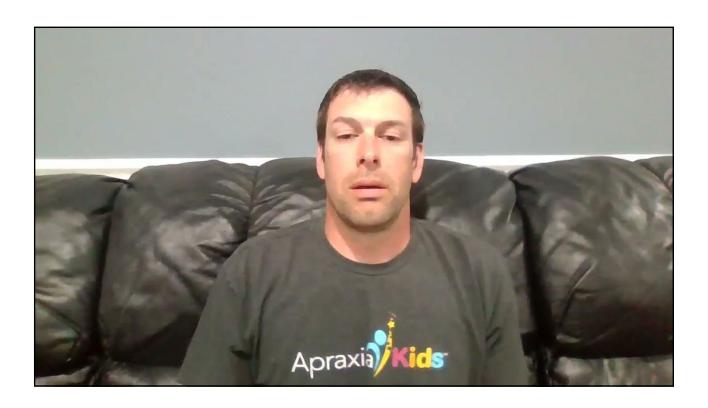
- Be proactive in advocating for supports and services in your child's education
- Educate your child's teacher(s) and classmates at the beginning of the school year on childhood apraxia of speech
- Send a letter to your classroom teacher
   Ask your teacher and team periodically about:
   Your child's communication in the classroom (with the teacher and students)

  - Any standardized testing completed Reading and writing skills, including levels and comparison to same aged
- Express your concerns to the teacher and team no matter the
- degree; request for further assessment early
  Discuss with the team any modifications and accommodations that need to be utilized based on your child's speech skills
  Hire a child advocate if you need assistance in getting the
- appropriate services for your child Apraxia/Kids®

# Advocacy-Individual Education Program (IEP)

- Know your rights and special education law
- Check to see if there are local special education groups in your community who help parents navigate the PPT/IEP process
- Learn special education law online: Wright's Law
   https://www.wrightslaw.com/
- Talk to other parents who have gone through the process
- Hire an advocate or attorney





#### Advocacy- Consider outside assessments

If you don't agree with the school-based teams decisions, interpretations, evaluations and/or recommendations, it is your right as a parent to request an Individual Education Evaluation (IEE).

You can always decide to use your insurance or pay privately for other outside therapies.



#### Advocacy- Access to Augmentative and Alternative Communication (AAC) Methods

- Discuss augmentative and alternative communication methods <u>early</u> with your child's speech and language therapist in order to give a mode for your child to communicate
  - Ask for an AAC assessment with a speech and language pathologist and/or team who has extensive knowledge and experience
- Have communication boards posted throughout your home and the community for your child to use
  - Many of the known AAC companies have communication boards available on their websites
     Saltillo
     Tobi Dynavox
- Advocate to have augmentative and alternative communication devices readily available in the home, classroom, and community

  Have an AAC assessment completed to determine the best system for your child Have low tech communication boards available throughout the community

  Look for funding for augmentative and alternative communication boards in child friendly environments, including playgrounds, museums, therapy centers

  Remember: It's never too early to advocate for AAC methods for your child!

## Advocacy- AAC

- Remember that your AAC device serves as your child's voice and you can request that it comes from school to home and vice versa
- Advocate for your child's team of professionals and your family to be trained on how to use the device
- Reach out to the local reps of the devices recommended
  Have a rep come to the follow up appointments
- Certain states, like Connecticut, have regional education centers which provide AAC assessments to local school districts

## Advocacy- Connect your Child's Team Members

- Consistent collaboration across all members of your child's team (school-based and outside professionals) is recommended for the best outcomes
- Have daily logs, google docs, etc. (with permission) to have providers share therapy targets
- Again, loop in the primary care physician (PCP) and/or the physician who wrote the initial script for speech therapy



#### Advocacy Within your Child's Family

- Educate family members on childhood apraxia of speech as well as your child's strengths AND challenges based on your comfort level
  - Reach out to close family and friends to have them listen and learn
- Encourage siblings to be active in helping with therapy homework
- Tell extended family to ask and learn from you or your speech and language pathologist on how to communicate with your child!
  - Offer brochures and reading materials on childhood apraxia of speech Apraxia Kids
- Knowledge is power!

## Advocacy- Self- advocacy

- Empower yourself with knowledge on CAS
- Find reliable sources when seeking information
- Ask your child about their thoughts, feelings and ideas on important topics
- Include your child in PPTs when appropriate
- Remember, self-care is extremely important for parents and caretakers. Advocate for your own needs, take care of yourself as often as you can, and lean on your trusted supports when needed.

Apraxia/Kids®

## **Advocacy- Organizations**

- Use social media to network and advocate
- Access the Apraxia Kids Website
  - Articles
  - Webinars
  - Access to SLPs with advanced training in CAS
- Attend an Apraxia Kids National Conference
  - Network with other parents
  - Attend courses
  - Participate in the "SLP is in" booths
  - Parent panels



## Advocacy- Resource Guide

- Apraxia Kids

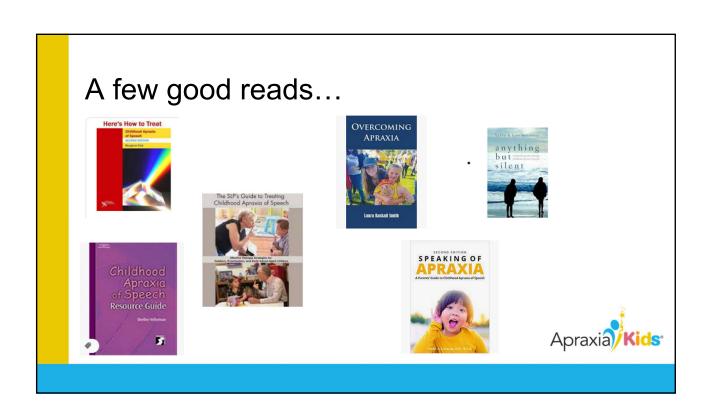
- - Dr. Jakielski
  - Sue Caspari Amy Clark
- Check out the professional advisory board for Apraxia Kids

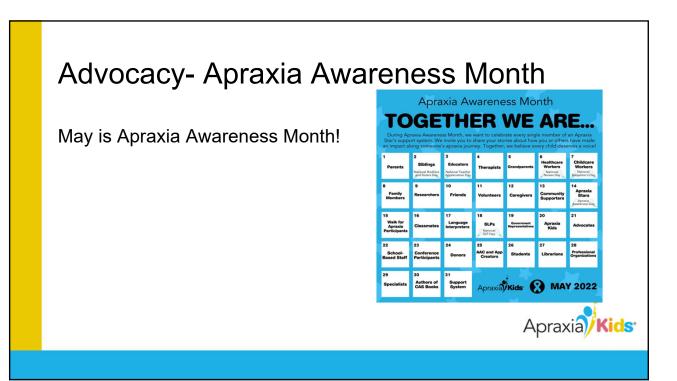


## Advocacy Resource Guide (Continued)

- Resource Guides
- Margaret Fish
  Dr. Shelley Velleman
  Cari Ebert and Dave Hammer
  Social Media (from reputable sources)
  Cari Ebert
  Jenny Bjorem
  Amy Graham
  Connect with Adults diagnosed with CAS
  Tessa McEvoy
  Mikey Akers







## Advocacy- Apraxia Awareness Day

May 14th is Apraxia Awareness Day



## Advocacy- Apraxia Kids

- info@apraxia-kids.org
- Laura Moorer, Vice President of Programs lauram@apraxia-kids.org
- Lou LaVecchia, Board Chair loul@apraxia-kids.org

Check out the Apraxia Kids website for more contact information



### Advocacy- Apraxia Kids Parent Portal

- Resource for families to access information on childhood apraxia of speech
  - Provides information to understand the diagnosis
  - Helps to answer initial questions
  - Provides explanations in print, videos, longer articles, webinars
  - Parents can continue to find more information and resources
    - Starting school

    - Attending IEP meetings
      Effects of CAS on reading and academic skills
    - Promoting social skills
    - Dealing with burnout
    - High School



## Thank you for your participation!

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#### **Discussion Questions**

- What did you learn about advocacy that you were unaware of prior to attending this webinar?
- What has been successful for your child in your advocacy journey thus far?
- What roadblocks have you experienced advocating for your child?

