



Spring 2021

Down Syndrome

Association of Central Kentucky

Support • Educate • Celebrate



Charlee Olmstead

MISSION STATEMENT | To celebrate and support people with Down syndrome and their families and to educate ourselves and others throughout Central and Eastern Kentucky.

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Stay Connected



You can now RSVP for events right from our website calendar at www.dsack.org



To receive our weekly email blitz, email Terri at: dsack.org@gmail.com



To join our private facebook group where you can communicate with other DSACK families, go to <https://www.facebook.com/groups/82674673490/> and request to be added to the group.



To "like" our official facebook page and receive updates from our association, go to <https://www.facebook.com/TheDownSyndromeAssociationofCentralKentucky>. dsack.org@gmail.com



Follow DSACK @DSAofCentralkY on Twitter.

Visit our calendar on www.dsack.org to see current events, activities and educational opportunities!

There's so much to learn; start here

By Traci Brewer

Did you get your certificate? You know, the one that new parents get certifying them in being an expert on all things Down syndrome the moment their baby is born. You didn't? My daughter, Emily, is 23 years old, and I'm still waiting to get my certificate. ****Sigh****

While you are waiting on that certificate to come in the mail, go ahead and dive into the pages of this magazine to educate yourself and others, be inspired, gain a new perspective, and see the great things we have planned for World Down Syndrome Day on March 21.

As with any child, there is so much to learn as we become the best parents, grandparents, aunts, uncles, or friends we can be to help that child grow into the best version of themselves. For children with Down syndrome early intervention services such as First Steps is an essential piece! For this edition, DSACK interviewed the First Steps staff. They explain the role of First Steps, how to get started, what they offer, and how to determine what goals are best for your child. Did you know First Steps coordinators assist families with

the transition to preschool, private therapy agencies, Medicaid Waiver programs and more? This program is definitely a positive life-changer for children ages 0-3 and their families.

Our Be Inspired section features Laiel Stansel, DSACK mom, as she shares a glimpse of her life growing up with an aunt who was born with Down syndrome and how that prepared her to be a mom to Eden and her other children. Laiel explains that having DSACK is "the difference between navigating the adventure blindly versus having a community of support." Her grandparents did not follow the advice of well-meaning medical professionals and friends when they were told not to bring their precious baby girl home. How thankful we are for these brave families who paved the way for a better future for people with Down syndrome and their families. In many ways, they are why DSACK exists today!

Another DSACK mom, Amber Horne, shares how her perspective has changed on what should be celebrated and recognized and in finding joy in everyday things. Along with setting high expectations



comes the great benefit of celebrating all the steps made toward meeting the goal. We should all celebrate the little things, right?!

You don't want to miss a new feature article that will be appearing in our DSACK magazines going forward. Emily Wright, self-advocate and DSACK's administrative assistant, will be sharing her discoveries through interviews with others in her "Emily Investigates" column. For this edition, Emily interviewed parent Lauren Wheatley about her connection to DSACK and what that has meant for her family. Emily has a list of topics to tackle for upcoming magazines, so don't be surprised if you hear from her about an interview!

Don't forget about World Down Syndrome Day coming up on March 21. It's a great time to raise awareness and reflect on the joy that extra 21st chromosome has brought to you, your family, and others. Typical of DSACK, we couldn't decide on just one way to celebrate, so read on to find out the many opportunities you can join in as we celebrate this year. We have everything from crazy mismatched socks, to an art class for the whole family, to sending postcards shouting to the world that 3/21 is a day to celebrate. Read on to learn how to register and join in the fun.

DSACK is many things to many people, but above all we are a community that accepts, supports, understands, and encourages one another. Our identity as an organization has been shaped and influenced by so many, many people, and for that we are eternally grateful. We are so glad you are part of our community whether you are a parent, family member, or friend. YOU make a difference in our DSACK community, and we are so very thankful!

I look forward to celebrating with you on 3/21. Do you have your socks picked out yet?

COMING UP:

- March 1-21 - Penn Station's Round Up for Down Syndrome campaign
- March 13 - Coffee Chat - Medicaid Waivers
- March 20 - Art from the Heart
- March 25 - May 13 - College Bound Class
- April 6 - May 11 - Cooking Class
- April 17 - Coffee Chat (details coming soon)

Check out the DSACK calendar at www.dsack.org for details!



Everyday tasks a cause for celebration

By Amber Horne

I cried last night. Not heaving sobs or anything like that, but definitely had tears coming down my face. I cried because my 6-year-old son went to the fridge and pulled out a cup of milk. To some, it might seem like an ordinary task and certainly not one that would warrant tears, but Conor has absolutely changed my perspective on what deserves celebration and recognition.

To start, he walked to the fridge. As he was walking over, he clearly said "drink of milk, please." He then pulled open the door, reached for his cup, and walked away drinking it. He even listened when, through my tears, I told him to close the fridge.

The task was monumental for so many reasons – he walked to the fridge; he initiated a sentence, and expressed a want; he actually wanted to drink something; he had enough strength and balance to open the fridge door; he raised up onto his tiptoes to reach his cup; and he followed a direction to come back and close the door. Six reasons for celebration within the span of about 15 seconds. At least six therapy goals that he worked on for years all rolled into a single task. I looked across the room and caught my husband's eye – he had seen the whole thing too and we were both filled with pride.

We never expected to find so much joy and pride in the seemingly everyday things. Six years ago, we also didn't expect Conor to be born with Down syndrome. Even more so, we didn't expect the multiple medical problems that accompanied his Down syndrome diagnosis.

We didn't expect a prolonged NICU stay, multiple surgeries and hospitalizations, and a



Paul and Amber Horne with, from left, Grayson, Davis, and Conor.

living room filled with medical equipment. From the start, Conor's story has had so many twists and turns that we didn't see coming. Conor came home from the NICU with a feeding tube, oxygen, and a heart/oxygen monitor. He wore oxygen continuously for the first year of his life and intermittently since. He had his feeding tube in until just before his third birthday. No matter how many books we read, statistics we heard, or predictions we were told, Conor's outcomes were often different than expected (sometimes better and sometimes not).

Conor is living a life that we never expected, which in turn means that we are too. And though there have been challenges, what has been more unexpected are the rewards.

Our lives are so much better because of Conor and because of his diagnosis. The experiences we have had have given us whole new perspectives and had such a positive impact on our family. We have been blessed with a front-row seat to something extraordinary. We've seen prayers answered and miracles granted.

Expectations will likely always be a part of Conor's life, whether they are set by medical professionals, educators, or society in general. There have been times in Conor's life we were told to expect the worst or when we have been disappointed because he didn't meet the best expectation. These experiences are teaching us that maybe sometimes we need to ignore the expectations and,

instead, focus on the goals; and that there can be a distinct difference between the two.

A lot of the expectations set for him will be out of our control and they may even be low, but we can ensure that our goals never will be. The goals that we set and that he one day sets for himself can always be positive and will hopefully always be high. We may not be able to predict when or how Conor will learn new things or accomplish his goals, but we can absolutely be there to work alongside him and to celebrate every step of the way.

Amber Horne is an occupational therapist with University of Kentucky HealthCare. She and her husband, Paul, have 3 boys – Davis, 7, Conor, 6, and Grayson, 4.

Crazy Socks and more for World Down Syndrome Day

DSACK will once again join the global chorus to raise awareness and advocate for the rights, inclusion, and well-being of those with Down syndrome on March 21, World Down Syndrome Day.

Among the things planned this year – a "Wear Your Crazy Socks" campaign. Everyone is encouraged to wear their mismatched socks on March 21. This year, we've ordered these special socks through Pals Socks. Wearing these fun socks offers the opportunity to tell the people you see that day about the true joys of Down syndrome.

DSACK is also offering a painting class with Father Norman Fischer on March 20 at 10 a.m. "Father Norm," an avid artist, is a friend of several DSACK family members and staff. He will lead us through a step-



by-step process of creating your own collage-type painting. No experience needed. And no extra chromosome is required to participate. Visit the DSACK calendar at www.dsack.org for more information.

We will also participate in Penn Station East Coast Subs' Round Up for Down Syndrome campaign again this year. We encourage everyone to frequent your local Penn Station March 1-21. Last year, the campaign raised more than \$8,000 for DSACK!

Lastly, DSACK encourages you to reach out to teachers, physicians, pastors – anyone who has had an impact on your loved one with Down syndrome's life – and thank them for their support. We will provide the preprinted, stamped postcards; all you have to do is address and sign them.

"World Down Syndrome Day is all about creating awareness and advocating for our loved ones. We believe these opportunities are a surefire way to do both," said DSACK Executive Director Traci Brewer.

DID YOU KNOW? The date for World Down Syndrome Day is always the 21st day of the third month to signify the uniqueness of the triplication (trisomy) of the 21st chromosome, which causes Down syndrome.

Drama class a hit

DSACK was so excited to offer its first-ever Drama Class for individuals with Down syndrome ages 16 and up. Sixteen people signed up for the virtual class, which was led by Trent Stephens, co-founder of Central Kentucky Improv.

For six weeks in January and February, participants laughed a lot while learning improvisation techniques and developing skills such as: teamwork, listening, self-confidence, quick thinking, eye contact, problem solving, voice projection, and adapting to change.

Stephens has taught improv classes at various Fayette County schools, the Lexington Senior Center, and Eastern Kentucky Correctional Complex. He has also directed theater productions at Sts. Peter and Paul School in Lexington, where he worked directly with an individual with Down syndrome.

The class was so popular that future classes are under consideration. Stay tuned for more information.



Holiday Party - pandemic style!

Because the Holiday Party could not go on as usual, DSACK got creative and offered Cruisin' Through the Holidays - a drive-thru event where children could greet Santa from a distance, drop off letters to him, and get a whole slew of treats. Everyone was all smiles.

Para ayudar a traducir esta revista al español, llame a la oficina de DSACK en 859-494-7809

Q&A with First Steps, Kentucky's Early Intervention System

First Steps – the Kentucky Early Intervention System (KEIS) – provides services for children birth to age 3 who have developmental delays or a medical condition such as Down syndrome, which puts them at risk of delays. First Steps is part of New Vista, the Community Mental Health Center for Central Kentucky that provides mental health, substance abuse, and intellectual and developmental disability services to more than 25,000 Kentuckians each year.

First Steps falls under the Individual with Disabilities Education Act (IDEA), so the program is funded by state and federal dollars. Early intervention systems can be found in all 50 states, although they may look a little different from state to state. Kentucky has one of the leading early intervention programs in the nation.

Following is a Q&A with the New Vista First Steps staff:

Q. What are the key principles of early intervention?

A. The key principles of early intervention are:

- Infants and toddlers learn best through everyday experiences and interactions with familiar people in familiar contexts.
- All families, with the necessary supports and resources, can enhance their children's learning and development.
- The primary role of a service provider in early intervention is to work with and support family members and caregivers in children's lives.
- Interventions with young children and family members must be based on explicit principles, validated practices, best available research, and relevant laws and regulations.

Q. What geographic area do you serve?

A. First Steps is a statewide program and has 15 Points of Entry across the state. New Vista is the local lead agency serving as the Point of Entry for the Bluegrass and Lincoln Trail districts. New Vista is responsible for receiving referrals and determining eligibility for children in 25 counties including Fayette, Hardin, and 23 other surrounding counties.



newvista

Q. When should a parent of a child with Down syndrome contact First Steps?

A. Children who have Down syndrome are eligible for First Steps due to having an established risk condition. These children are automatically eligible for assessment, help with developing an Individualized Family Service Plan (IFSP), and ongoing service coordination. If a child is referred soon after birth, developmental delays may not be present. This means they would likely receive service coordination only. The child's development will be monitored closely and as soon as a delay appears, we can add early intervention services. By having the IFSP already in place, we can get early intervention services started as soon as the delay is noticed because all the enrollment and assessment requirements have been completed previously.

Q. What is the referral process? Can a parent refer his or her own child?

A. Anyone who has a concern about a child's development can make a referral to First Steps if the child's parents are aware the referral is being made. Parents can make the referral themselves; a doctor referral is not necessary. There are specific events that must occur before an IFSP can be developed. It is a federal requirement the IFSP is placed for all eligible children within 45 calendar days of when the referral is received unless the family needs to delay the timeline.

Here is a general timeline of what happens after a referral is received in a Point of Entry office.

- The family will receive a phone call from their assigned service coordinator within five days of the referral.
- The service coordinator will schedule an intake visit with the family. During the intake visit, the service coordinator will gather a lot of information from parents as well as provide information about First Steps and completing all necessary paperwork.
- Once medical records are received from the child's pediatrician and any needed hearing assessments are completed, the child will be scheduled with one of our child evaluation specialists who will complete an assessment of all five areas of development (motor, communication, self-help, cognitive, and social emotional). This assessment is to assist in program planning and determining if the child is showing any developmental delays. The child evaluation specialist will formally determine the child's eligibility for First Steps.
- The service coordinator completes a routines-based interview with the family, which will help determine the family's priorities and concerns which are used to develop outcomes for the IFSP.
- An IFSP meeting will be conducted to formally write out the child and family's plan for early intervention services.
- If the IFSP team determines early intervention services are needed, they will begin no sooner than five working days and no

later than 30 calendar days from the IFSP meeting.

Q. What service professionals do you provide for families?

A. New Vista provides all duties at the Point of Entry Offices in the Bluegrass and Lincoln Trail districts. Our New Vista Point of Entry Offices house a variety of professionals:

- Intake coordinators receive and process all referrals received in our districts.
- Service coordinators facilitate the intake, family assessment, evaluation/assessment referrals, and IFSP development for the children we serve. Service coordinators ensure the families' rights are honored and the law is followed when creating IFSPs as well as monitoring parent satisfaction of the early intervention services they are receiving. Service coordinators can assist the family with referrals to other services outside of First Steps to address any medical needs. These outside services will not be paid for using First Steps funding and must be paid by the family's private insurance or Medicaid.
- District child evaluation specialists at New Vista complete evaluations and determine eligibility for all children in our districts. District child evaluation specialists' disciplines could be different at each Point of Entry but usually are an occupational therapist, speech pathologist, early childhood educator, social worker, or physical therapist.
- Point of Entry managers and service coordinator supervisors monitor and supervise Point of Entry staff in addition to monitoring services provided by state early intervention contractors to ensure the districts are meeting state and federal requirements.

Kentucky's Early Intervention System service professionals not under the Point of Entry are referred to early interventionists/early intervention providers. The First Steps Early Intervention Providers are either independent contractors or subcontractors of agencies who hold a First Steps contract with the state lead Agency:

- Developmental interventionists.
- Speech pathologists.
- Occupational therapists.
- Physical therapists.
- Assistive technology specialists.

The IFSP team, comprised of the parents, service coordinator, evaluator, and potential service providers, determines what services

the child and family need to achieve the outcomes written on the plan. Each IFSP is individualized, and no two plans will look the same. Early intervention services can be provided by a wide variety of professionals. Early intervention services address a child's developmental delay and cannot address medical conditions or medical concerns.

Many children with Down syndrome could benefit from both First Steps Early Intervention services as well as private medical therapy such as feeding therapy, which would be accessed outside of First Steps.

Q. How do therapists and parents decide on what goals are best for the child?

A. Service coordinators will complete a family assessment using a routines-based interview with the family. This interview highlights areas of priority for the family. In early intervention, the family is the driver of services and goals they would like worked on. The early intervention providers support the family in these goal areas. The providers on the IFSP team can assist the family and service coordinator with realistic expectations for reaching each outcome, but they do not write outcomes for the family.

Each family is completely different, which

means each IFSP is different. One family may have several priorities they want addressed while other families may want to focus on just a couple priorities at a time. Either way is completely fine.

The key principles of early intervention include:

- The early intervention process, from initial contacts through transition, must be dynamic and individualized to reflect the child's and family members' preferences, learning styles and cultural beliefs.
- IFSP outcomes must be functional and based on children's and families' needs and family-identified priorities.

Q. What are the developmental concerns you most often see in children with Down syndrome?

A. Children with Down syndrome meet developmental milestones at different rates just like children without Down syndrome.

In infants, the impact of lower muscle tone and gross motor delay on play routines and environmental exploration can affect holding head up, tummy time, rolling, sitting, standing, pulling to stand, and walking.

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Grandmother's example paved way for raising daughter with Down syndrome



As a child, Laiel Stansel remembers her Aunt Nadine as the “cool, fun” aunt. They were pen pals when Stansel was learning to write. They visited often, playing cards, going for late-night swims, and making midnight snacks.

Stansel didn't think differently because Aunt Nadine had Down syndrome. She was just part of the family who was loved and treated like everyone else.

“I knew growing up that she had Down syndrome, and it wasn't a big deal, just a fact,” she said.

What was also a fact is that, during the time when Nadine was born, most people with Down syndrome were still being institutionalized. Stansel's grandparents bucked the trend, however, and decided to keep Nadine at home with their other children.

“The oldest of my grandparents' children was 12 at the time Nadine was born. People would come up to my grandparents and tell them where they could drop Nadine off at the state institution and that keeping her would not be good for their other children,” she said.

No doubt, Stansel's experiences with her Aunt Nadine have had a profound impact on the approach she's taken to parenting her own daughter, Eden, who also has Down syndrome. She said she's thankful every day for her grandparents and others who paved the way for her.

“I learned that it is OK to go against the system and chart your own course,” she said.

For Stansel and her husband Dusty, that course looks much like the course her grandparents



Laiel and Dusty Stansel with, from left, Eden, Brandston, Jaxon, and Isla.

took. They treat Eden, 3, just like their three other children and set the same high expectations.

“I asked my Grandma for advice when Eden was born. She said, ‘You'll learn a lot from her and she'll learn a lot from you.’ My Grandma said to do with Eden the same as I do with my other children. She said to give her all the opportunities and let her try things,” Stansel said.

“Eden is going to learn what my other kids learn, it just going to take her a little longer and

ly busy, with doctors' appointments, that connecting with DSACK wasn't on the top of my to do list and then I just forgot about it.”

Finally, however, the Stansels made the connection and “it's the difference between navigating the adventure blindly versus having a community of support.”

“DSACK helps me because they are understanding, compassionate, and help to ease my nerves. I don't have to go through things alone. DSACK helps me to make educated decisions affecting Eden. They respect me and don't tell me how to do things. DSACK families make different choices for their children and that's OK, we all support each other in our choices. Not everyone's family or child is the same,” she said.

Further, Stansel said, “They helped us navigate the IEP process, offered support after Eden's open heart surgery, and provided us with some awesome learning resources through the Learning Program. Eden loves the books and all of her therapist rave about how good they are.”

Today, Eden loves “music, baby dolls, teasing others, Oreos, cookies, and being outside. She is very loving and motherly. She likes to have fun, try whatever her older brothers are doing, and laugh.” She has three siblings, Brandtson 9, Jaxon, 5, and Isla 1.

And Aunt Nadine? Since her mother (Stansel's grandmother) passed away in 2019, she has been living in Utah with one of her sisters. She and Stansel text and FaceTime often.

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In toddlers, the impact of lower muscle tone and gross and fine motor delay on play routines and environmental exploration can affect standing, pulling to stand, walking, climbing stairs, running, play, mealtimes, dressing, and bathing.

Communication and talking within daily routines, mealtime routines, and play and cognitive skills can also be delayed.

Q. Can you provide an example of how you might approach one of those concerns?

A. Recognizing the key principles of early intervention, First Steps follows a model for early intervention based on evidence-supported practices of parent-mediated interventions, routines-based interventions, natural environments, and strength-based coaching.

- Coaching is the interaction style used to shape visits that include joint planning to start, observation, action/practice, feedback, reflection, and joint planning to end.

- Caregivers and providers use these meaningful conversations to form a partnership to promote a child's learning and development. Both have key roles and use their knowledge to focus on what is important to caregivers within everyday activities and routines. The providers are typically with families less than 2 percent of the time the child is awake during a week. Therefore, the goal is to support families to help their child learn and grow. In each session, the caregiver and provider:

- Begin and end visits with a shared plan.
- Observe each other and try new ideas.
- Think, problem solve, and learn.

Q. Explain how you work with other agencies to meet the needs of children you serve.

A. With parent permission, First Steps service coordinators will work with other agencies to provide a good continuity of care for children. The parent can invite anyone to participate and share information at IFSP meetings, including representative from other programs they work with.

When a child is around 2 ½ years old, First Steps will hold a transition meeting with the family and representatives of other programs the child may be eligible for once they turn 3. The public preschool programs are covered in Part B of Individual with Disabilities Education Act and are the next natural transition for the child if the family is interested in preschool services.

Service coordinators also assist the family in finding other community resources they may be eligible for, such as:

- New Vista's Michelle P. Waiver Program
- New Vista's State General Funds Program
- New Vista's Early Childhood Mental Health Specialist
- Private therapy agencies
- Early Head Start
- Private child care facilities
- Feeding clinics

For more information on New Vista's First Steps Program, visit www.newvista.org, call the 24-Hour Helpline at 800-928-8000, or contact Angie Casey, program coordinator, at angela.casey@newvista.org.

Emily INVESTIGATES!

In each issue of DSACK's magazine, Administrative Assistant Emily Wright "investigates" our connection to families, friends, and the community. In this issue, she talked to parent Lauren Wheatley. Lauren and her husband Jeremy have a child with Down syndrome, Abel, and two other sons, Razor and Wells. The question posed to Lauren was:

HOW HAS DSACK IMPACTED YOUR FAMILY'S LIFE?

HERE IS HER ANSWER:

DSACK has greatly impacted my family's life in three major ways that happen to be their mission: Support, Educate, Celebrate.

SUPPORT:

When I received Abel's prenatal diagnosis, I heard about DSACK and just the thought of knowing an organization like this existed encouraged my heart so much. I joined the private DSACK Facebook group during pregnancy and was invited to the Christmas party, and even though we couldn't attend, it felt wonderful to be included from the very beginning. Now I know well the thrill of welcom-



ing new parents into our community.

After Abel's birth, DSACK provided a welcome bag to our family in the hospital. This bag included several items that brought joy and hope to us in the emotional days postpartum.

The new parent dinners we attended the first three years of Abel's life gave us an opportunity to connect with DSACK staff and other parents who were right there with us. We walked away from those dinners feeling refreshed and encouraged. The No. 1 impact DSACK has had on our family has been the community. We love being connected to other

families and have truly met our best friends through this organization. That includes meeting adults with Down syndrome just like you, Emily, and how grateful I am to call you my pal. Before Covid, we also enjoyed the monthly play group for kids 5 and under as often as possible.

EDUCATE:

DSACK has also provided education to our family. We have been to multiple coffee chats to learn about special needs trusts and financial planning, IEPs, behavior strategies, and more.

CELEBRATE:

DSACK has helped us celebrate Down syndrome with the annual gala and the Fall Family Fun Day and Walk! They help us get family and friends involved with these events as well, spreading celebration across our social circles. I love that DSACK is all about celebrating.

Ultimately, knowing that we have someone we can call in any situation is so priceless to us. I have called Traci over the most random questions floating around in my head to calling her in a panic in the middle of the night. Every time she answers and she helps me. DSACK lives out its mission every day by being available to its families to support, educate and celebrate!

Let's Celebrate



Our sweet Olivia is 17 years old on March 16. Happy birthday Olivia. We love you!
-Mommy, Daddy, and Charlee



Happy 2nd birthday to our sweet Charlee girl!

Join Club 21

Join DSACK's monthly giving program with as little as \$5 a month and help DSACK's mission to support, educate, and celebrate!

www.dsack.org/club21

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