



Summer 2021

# Down Syndrome Association of Central Kentucky

Support • Educate • Celebrate



*Sam Elbert*

**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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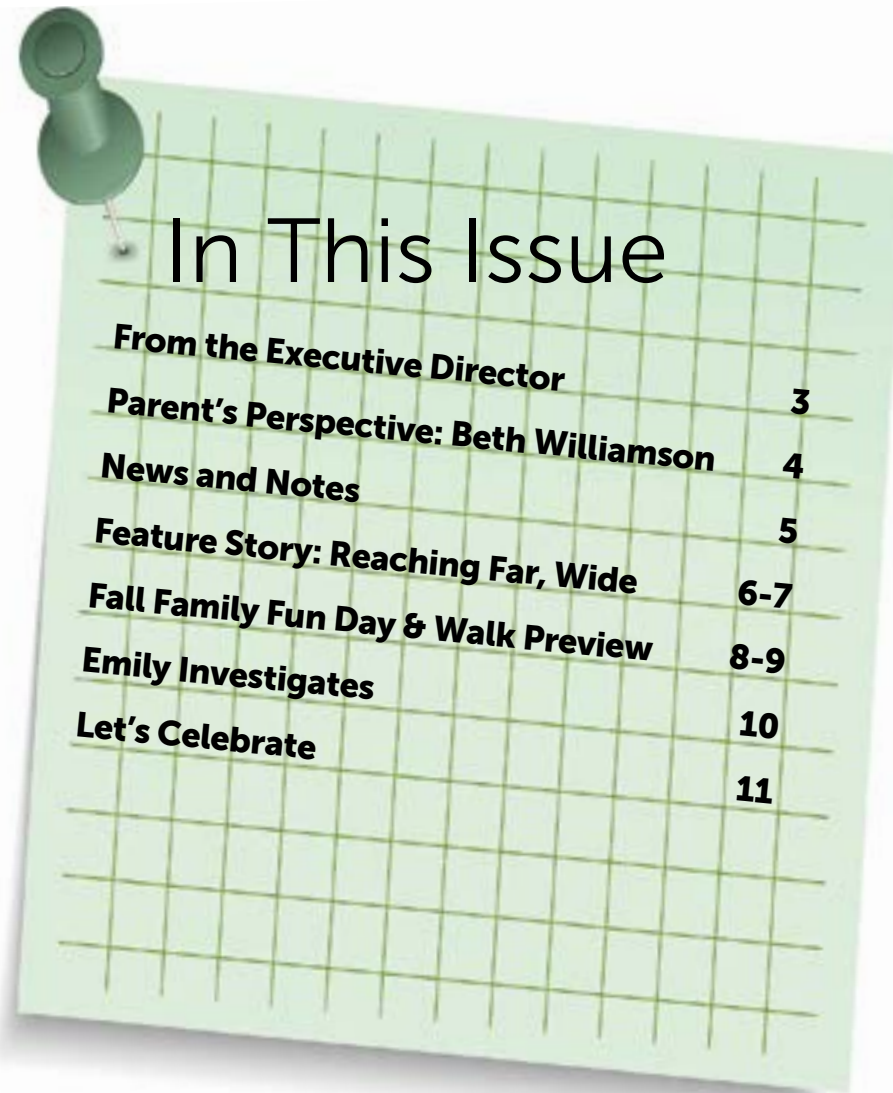
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DSACK Bylaws and financials are open for review, and the Board of Director Meetings are open to our community. Agenda items are determined well in advance.

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## Stay Connected



You can now RSVP for events right from our website calendar at [www.dsack.org](http://www.dsack.org)



To receive our weekly email blitz, email Terri at: [dsack.org@gmail.com](mailto: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](mailto:dsack.org@gmail.com)



Follow DSACK @DSAofCentralkY on Twitter.

Visit our calendar on [www.dsack.org](http://www.dsack.org) to see current events, activities and educational opportunities!

## So good to see you - yes, SEE you - again!

By Traci Brewer

I can't tell you how happy my heart has been to start seeing our DSACK friends and families in person again. Our first in-person event was our gala, and it was truly a magical night! Thank you to everyone who attended, sponsored, and donated. Thanks to the wonderful supporters of DSACK, \$51,000 was raised in one evening. WOW!

It is such an amazing experience to see the support from our community, many of whom do not have a family member born with Down syndrome, come together to make sure we can continue to offer our important programs and services at no cost. There were tears of joy, laughter, hugs, and best of all raised awareness about the amazing potential of people



with Down syndrome.

Speaking of seeing people in person and happy hearts, our Summer Adventure Camp was amazing! I hope you enjoyed the pictures of our students on social media, as they met together weekly to experience a new adventure, including an obstacle course, art class, cooking, music fun, swimming, shaved ice, and more! I definitely underestimated how

very much I have missed seeing our students and their families face-to-face. Not only did we have Adventure Camp together, but students also met weekly via Zoom with their assigned teacher to work on specific academic goals in reading, math, and life skills. Seeing the smiles, sharing hugs and high fives, and learning together was the best way I can think of to share a Tuesday evening for five weeks! Thanks to our volunteers, staff, teachers and families for making this happen. It was fabulous!

While it has been so refreshing to reconnect in person, the recent pandemic has taught us the value of virtual programming. Be sure to read the story by Beth Williamson about how her son Matthew participated in many of our virtual classes all the way from Taiwan. Yes, DSACK now has an international

reach! Because reaching families who are not within driving distance is so important, we are now planning to offer nearly all of our programs with a hybrid model of in person or virtual. How exciting!

Our beloved Family Fun Day and Walk will be live and in person on Sept. 11! This is a huge day of celebration and also our largest fundraiser of the year. Much of our budget for 2022 including programs, staffing, and services will be determined by the success of this fundraiser. If you haven't already set up your team, head on over to [fundraise.dsack.org/2021](http://fundraise.dsack.org/2021) to get it going. As always, we have several contests and friendly competitions to motivate your team. The day will be full of fun, games, music, and food, and of course our walk. You don't want to miss it!

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SEPTEMBER 11, 2021

FOOD TRUCKS CARNIVAL GAMES  
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## DSACK a great resource from thousands of miles away

By Beth Williamson

"I think your son may have Down syndrome." These words were spoken by an OBGYN in a delivery room in a hospital in Taiwan, just minutes after the birth of our son, 25 years ago. As the doctor examined our slightly blue son, he spoke those words in English to my husband Rod. Over the next few days, the subsequent conversations about Matthew's diagnoses and health needs were all in Mandarin Chinese. There were few resources about Down syndrome available at that time in Taiwan, none in English. The internet was very new, with limited access.

During the next few weeks, in consultation with both Taiwanese and American doctors, it was decided that to get the best care for Matthew we should move back to the U.S., which we did when he was 6 months old. Like many of you, we began learning all that we could, got all of the medical and therapy help available, and settled in to our new life back in America. However, by the time Matthew was 6 years old, other than the usual ear infections and therapy needs, he was growing and developing well so we agreed to return to Taiwan to continue our work here.

Matthew has done well. Because none of the international schools that teach in English provide special education, I home-schooled him, even continuing to do "lessons" with him today. After all of these years, there are few resources or programs for people with Down syndrome that are available in Taiwan in English. Medical care here has advanced, but culturally the needs and value of people with Down syndrome are still not at the level that they are in the U.S.

We open up our home regularly to host a fellowship of Taiwanese families with children with special needs, however, language continues to be a barrier for Matthew in both communicating and developing friendships.

There are days that I feel very lonely, having to meet all of his needs myself, and knowing that he struggles to make friends and have activities with peers because of these barriers. I also miss having other par-



Beth, Rod, and Matthew Williamson

ents to talk with in English about the journey we are on with Matthew, and to learn about available resources and treatments specifically designed for people with Down syndrome for some medical concerns that have recently been discovered.

Two years ago, I came across the Down Syndrome Association of Central Kentucky on Facebook and began following them. Then last fall I learned that because of COVID-19 they were offering classes via Zoom. Traci Brewer graciously allowed Matthew to "Zoom in" from Taiwan. Gradually, he has begun getting to know the names and faces of other young adults like him. The teachers have been wonderful in the way that they include him and make him feel a part of the class even from half a world away. He has enjoyed the Healthy Movement classes and the Drama Class, and he has had his first opportunity to be taught by a college professor in the nutrition course. Given the 12-hour time zone difference, it isn't easy for him to get up at 6 a.m. to attend class. Recent sleep issues have impacted his attendance, but we are hoping

that he will be back online soon.

I've had the opportunity to join in a Coffee Chat on Medicaid, something that has allowed me to begin networking with other parents and service providers. Traci has been a wonderful resource as we are needing to connect with medical professionals in the U.S. to address his recent medical needs. I read all of the Facebook posts from parents and am beginning to feel a part of a "community" of people who understand the joy and challenges of parenting our precious children.

While there is nothing good about COVID-19, DSACK has made the best of it by using the internet, and specifically Zoom, to keep us all connected, informed, and cared for. I send my deep appreciation to Traci and the team there. We are looking forward to someday seeing Matthew's classmates, and all of you, face to face .... maybe even without masks!

Beth Williamson and her husband Rod, along with their son Matthew, are missionaries in the country of Taiwan. When not in Taiwan, they reside in Wilmore, Kentucky.

## Summer program a real adventure

DSACK's Summer Enrichment Program – renamed Summer Adventure Camp – offered 10 children with Down syndrome a new, exciting learning adventure this year. Working off the successful virtual model used last year, the program provided both an at-home and in-person component, said Education Coordinator Hana Toupin.

For at-home learning, each child in the program received a box with reading, math, and living skills activities. Terri Rue, Jean Bryant, and Traci Brewer provided one-on-one weekly tutoring sessions. As with past summer enrichment programs, they were designed to combat the problem of regression during the summer months when school is not in session,

Toupin said.

"Summer regression is a persistent problem for students with Down syndrome. That means the first few months of a new school year must be spent relearning previously introduced concepts. DSACK hopes to combat the problem with Summer Adventure Camp," she said.

Then each Tuesday during the six-week program, students and their families met at Shillito Park for such activities as yoga, music, and art. Several community partners, including Sarah Smitha of Candy Mountain Music, educator Jill Isenhour, and Horn and Associates, led a variety of activities. Volunteer Natalie Sauer also helped. A swim party concluded the program.



## Grants awarded

A big thank you to Children's Charity of the Bluegrass for a grant for the DSACK Learning Program. This fundraising organization's primary goal is bettering the lives of children throughout the state. We couldn't do what we do without partners such as this.

DSACK also received a \$1,000 Employee Vibrant Community Grant from Corning Incorporated Foundation! DSACK was submitted for the one-time grant by Corning employee and DSACK parent Vinay Patel. We were among the first 50 eligible applications! Thank you, Corning Incorporated Foundation and Vinay.

## Gala a huge success

After a year off due to COVID, the DSACK Nothing Down About It Gala returned in May 2021. This hybrid event – both in-person and virtual – proved to be a big success, with more than \$50,000 raised. The gala featured live and silent auctions, a cocktail hour, dinner, and fun and games. More than 100 people "attended."



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



# COVID prompts DSACK to reach farther, wider

It might be difficult to look on the bright side of a global pandemic, but consider this: Since the COVID-19 virus hit more than a year ago, DSACK has reached more people in more places than ever before.

"It's really been amazing to see how far and wide we can reach during this time," said Traci Brewer, DSACK executive director. "When the pandemic forced us to shut down our in-person programs and events, we immediately pivoted and brought everyone together using video technology. It was a big success."

If you don't want to take Brewer's word for it, just ask Rod and Beth Williamson of Wilmore, who are serving as missionaries in Taiwan and whose son Matthew has Down syndrome. During the pandemic, Matthew was able to participate in several classes despite a 12-hour time difference.

"Matthew has enjoyed the classes very much, especially the Healthy Movement Class and the virtual Cooking Class," his mom said.



Matthew Williamson

It wasn't always easy for Matthew to join in. He had to get up at 6 a.m. just to participate in the evening classes. But he did so enthusiastically and benefitted greatly, she added.

"Because he was having to wake up and come out of his room fairly early, he especially enjoyed those classes that had some movement and interaction. He has shown more responsibility in getting ready earlier, being at the computer on time, and helping to set up for the cooking class the night before," Williamson said.

Or ask the Keller family in Eastern Kentucky town of Barbourville. Their son, Steven, 3, has Down syndrome.

"Since we live two hours from Lexington, I would not have been as involved in DSACK if all the events were in person," said Steven's mom, Lisa. "The virtual events were a great way for us to participate without spending four additional hours on the road. I was happy that my family felt included."

The Kellers, who have eight children ranging in age from 3 to 18, participated in two of the virtual bingo nights and the virtual Coffee Chats.

You could also check in with Ethan Elbert, whose brother, Sam, has Down syndrome and who had been accustomed in participating in DSACK events prior to attending Hanover College last fall. He participated in a 21 Days to Do Something Extra from his dorm, sitting in on College Hang-out and even giving the other participants a virtual tour of his room.

"I like to do events with people as much as I can because I feel like we have become a sort of family over time," Elbert added.

In addition to 21 Days, Elbert also got a group of his friends together to participate in a virtual version of the Down With Dares photo scavenger hunt.

"We had a fun time and enjoyed doing the dares. I still have some of the videos from our dares saved on my phone. I would



Trent Stephens

definitely do something like this again," he said.

DSACK Drama Class instructor, Trent Stephens, who led the class from his home in Staunton, Virginia, likewise had a positive take on the virtual experience, despite a few "hiccups."

"I was very pleased with how our Zoom improv class went," he said. "Video conferencing has its limits and, at times, frustrations. That said, our class was so patient and encouraging with one another. I was blown away with how forbearing and loving the group was."

Stephens added, "The hiccups in our digital class were things that we have all been navigating over the past year. Varying comfort levels with the Zoom medium and homes with strained internet bandwidth made for some cumbersome moments."

Yet, the class overall was "well-suited" to improv, which "condition us to listen to understand, rather than listening to answer."

DSACK Education Coordinator Hana



The Keller Family

Toupin was also pleased with the use of video technology for the Learning Program, Book Club, and other educational classes.

"I couldn't have been happier with the way these classes went. It allowed students to participate who might not ordinarily be able to come to in-person classes. Plus, it was a great format for prompting student interaction because they were doing so from the comfort of their homes," she said.

Toupin received great feedback not only from parents, but from the students themselves.

"Everyone was so pleased with how it all worked out," she said. "I even noticed improvement in the way many of the students related to each other. There was easy communication between them."

Just as most college students had to adjust to taking classes online, so too did DSACK's College Bound class move to virtual.

"These college classes have become so valuable to our DSACK students, and we just weren't willing to forego these classes during the pandemic," Brewer said.

"BCTC and professor Dr. Ranjan, were so helpful in moving the group to online classes, and we completed two levels of



Sam and Ethan Elbert

Human Nutrition and Wellness online. We also continued with our weekly study group online, so our students continued to learn and build relationships with one another," she added.

While the technology enabled many of DSACK's programs and events to go on, one area of its work proved to be a little more challenging: medical outreach. Coordinator Courtney Elbert had to figure out new ways to maintain valuable contact with medical professionals and, most importantly, with new and expectant parents.

**"It's been a fun introduction to the group. I appreciate getting to meet other families and learning about how others with Down syndrome have grown up. I am encouraged as we share our experiences and ways we have overcome challenges."**  
- Lisa Keller

"All of this required creative effort in regards to communication and delivery such as coordinating delivering to doctors' and families' doorsteps, meeting in parking garages and lots socially distanced, talking through new families' windows at home, and mailing items since there were no in-person visits allowed," Elbert said.

So successful were Elbert's efforts that she exceeded the total number of information packets distributed when compared to each of the three previous years she's been in the role.

"To me, this creativity and willingness is proof of the resiliency of our new DSACK families, and of the commitment of our health care providers and DSACK's long-term relationships being more solid," she said.

Looking ahead, Brewer said DSACK may continue to do some programs virtually or at least offer a virtual component to in-person classes.

"I think before the pandemic we didn't think there'd be a lot of value in offering things virtually," she said. "But we see it now. Going forward we should be able to offer a hybrid for those who can't travel to Lexington for everything. It really makes sense."



## Ideas to help your team raise money

We have many suggestions for ways to raise money (keep your eyes out for some new ideas), but many may be contingent on restrictions that may still be in place to combat COVID-19. Here they are:

- Of course, encourage people to join your team. This is the most important thing you can do to help us raise funds. Then, once they've joined, encourage team members to become fundraisers themselves. Our software makes it incredibly easy to share on social media as a fundraiser.
- Hold a Facebook fundraiser for your team. Several families have already done this with great success.
- One of the easiest and best ways to raise money for DSACK is to sponsor a school or work change drive. Students and employees bring in their loose change over a set period of time. Ask if you can have a visible spot at the entrance for people to drop their change. One elementary school consistently raises a lot of money this way!
- Of course, you can also ask your employers, local businesses, doctor's offices, etc., to join us as a community partner. There are several different partnership levels; a form can be found on the Family Fun Day and Walk homepage at [fundraise.dsack.org/2021](https://fundraise.dsack.org/2021). Be sure to let us know if you get a community partner so we can make sure they get the benefits of their partnership package. Email us at [dsack.org@gmail.com](mailto:dsack.org@gmail.com) to let us know.
- Have a dress-down day or jeans day at your school or place of work. Everyone who wants to participate can pay \$1 – or whatever amount you determine.
- Have a bake sale or, better yet, offer your homemade specialty via social media and offer to deliver to those who purchase. One family sells homemade fudge every year, raising nearly \$300.
- Ask your employer to match funds raised by their employees for your team.
- Put your personal story on social media with a link to register for the Family Fun Day and Walk and/or donate. List your child's accomplishments. How has your family grown through your experience with Down syndrome? How have you grown? How has DSACK supported you? Mention what the funds will be used for as DSACK finds new ways to celebrate, educate, and support our families. This is also a great way to educate others about the amazing potential and advancements of people with Down syndrome.
- Ask your employer to allow extra time for lunch for those who join your team.



# Family Fun Day and Walk a go this year; set Sept. 11

After more than a year of COVID restrictions that kept us apart, DSACK is ready to bring everyone together again with its Family Fun Day and Walk. This all-important event is planned for Saturday, Sept. 11, at the Masterson Station Park Fairgrounds in Lexington.

As usual, it will be a day filled with the things we all need most – fun, fellowship, and memory-making moments. There will be carnival games, inflatables, a 1-mile fun walk, and so much more. The day gets started with registration and tailgating at 10 a.m. The walk follows at 11 a.m. The cost of participating on a walk team is \$21 and gets people “in the door” at the event.

“We’re so ready to see everyone again. It’s been way too long,” said Traci Brewer, DSACK executive director.

It will also be your chance to raise funds for DSACK. The Family Fun Day and Walk is the year’s most important fundraiser, enabling DSACK to offer all its programs

**Register your walk team at [fundraise.dsack.org/2021](https://fundraise.dsack.org/2021)**

and services free of charge to the families it serves.

“There’s no denying the importance of our Family Fun Day and Walk,” Brewer said. “It literally makes a huge difference in what we are able to do – and not do.”

So besides marking your calendars for Sept. 11, what can you be doing now to make this event a huge success? Plenty.

First and foremost, go ahead and set up your walk team. If you participated last year, you already have a team page. Just update it as necessary and let the fundraising begin.

Then, get creative with your fundraising

ideas.

“Everything you do now to raise funds will go toward your walk team. This includes starting now to get people signed up for your walk team but also things like Facebook fundraisers and other creative fundraisers. The sky’s the limit on what you can do to raise funds through this event,” Brewer said.

And remember, most people are ready and willing to help.

“Once you share your personal story and how DSACK has impacted your life, friends and family will be honored to help,” Brewer added.

As in years past, everyone who joins your team automatically becomes a fundraiser, allowing them to reach out to their circle of friends and family members. Just imagine: If every person who joined a team shared it through social media and raised an additional \$100 apiece! What an easy way to make the 2021 fundraiser a

# 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 Board Member Shelley Sellwood-Davis. Shelley and her husband Cody have two sons, Patrick, 4, and Emmanuel, 18 months.



**QUESTION:**  
**HOW HAS SERVING ON DSACK'S BOARD IMPACTED YOU PERSONALLY?**

**ANSWER**

So much has changed in my life while I have been on the DSACK board! It has been beautiful to experience it with DSACK and the board members. Most notably, I have had my two children in my years on the board-- and they've both been at board meetings with me from time to time (nothing like starting them earlier, right?!). Learning to be a mother while serving on the board has been significant, as I have learned from my fellow board members who were also beginning their parenting journeys. I believe, and certainly hope, that being a mother has helped me be a better board member and think a bit differently, imagining my own children with each decision.

Overall, given the size of the community and areas that DSACK serves, I have been most impacted personally by how DSACK continues to really feel like a family. We have seen that most of all during the COVID-19 pandemic, with the level of engagement and incredible support, financial and otherwise.

**QUESTION:**  
**WHAT DO YOU SEE AS THE BOARD'S ROLE?**

**ANSWER**

It is an absolute privilege to serve as a board member on the Down Syndrome Association of Central Kentucky. While I can't speak on behalf of the entire board, I do believe they would agree with me that we see our role as ensuring that DSACK is able to be successfully fulfill its mission of serving individuals with Down syndrome and their families in an ever-growing number of ways. During my time on the board, we have tried to ensure that we reach families at all ages and stages, whether that be parents with a newborn or high school graduate ready for college classes and beyond.

I believe that we, as a board, exist to serve individuals with Down syndrome to ensure that all opportunities are an option, just as they would be for individuals without Down syndrome. Much of this work involves education of not those whom we serve, but

the community of Lexington and beyond. For example, we have recently tried to ensure that our fundraisers reach all audiences, as each of those events provides another opportunity for us to educate our community.

The board's role has shifted during the course of the pandemic and we have all worn different hats through the past year, but just as you are all committed to ensuring DSACK's success, so are we!

**QUESTION:**  
**WHAT ARE YOUR IMPRESSIONS OF HOW THE ORGANIZATION HAS ADAPTED DURING THE PANDEMIC?**

**ANSWER**

In short, humbled! When the pandemic began, we as a board were meeting weekly to discuss the necessary changes and impacts, both financially and logistically. We strategized and planned for the worst, but were in awe by the support of the community that enabled us to continue our mission, albeit a bit differently!

The creativity and resiliency of the DSACK staff is staggering. Whether planning car parades, virtual cooking classes (Who else learned to decorate cookies with fondant? I could use a refresher course, but at least they taste good!), movie nights, virtual hangouts, and so much more, our staff have climbed the many mountains the past year presented with success. The board never heard the word "no," but was given alternative plans. They have had to replan each and every single day of the past year to do so in a safe way. Their commitment is unlike anything I have ever seen. So, Traci, Courtney, Hana, Emily, and Terri, thank you!

## Let's Celebrate



Happy birthday Clay, who celebrated his 7th birthday in January!



Happy 2nd birthday to sweet Emersyn Grace! We couldn't imagine life without her and her sweet smile. She sure makes the world a better place.



Look who's sassy and 6! Happy 6th birthday Juno - we love you! Love, Mom, Dad and Evie



Happy 5th birthday Sky! We are so proud of you! Thank you for making our lives richer and fuller. Love, Mom, Dad, Isaac, Amelia, and Violet



These two beauties - Joella Mullis and Anna Juett - danced to Mamma Mia in the Parks and Recreation spring recital. They are stars!



Wishing our Tori the Tornado a happy 14th birthday! Love - Mom, Dad, and Karl

**Join Club 21**  
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The advertisement features a young girl with Down syndrome smiling and pointing upwards. The background is a soft-focus outdoor scene with green foliage. The text is overlaid on the image in white and yellow.

**Down Syndrome**  
Association of Central Kentucky  
Support • Educate • Celebrate

## MISSION STATEMENT

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