



Fall 2019

Down Syndrome Association of Central Kentucky

Support • Educate • Celebrate



Raylan Ball

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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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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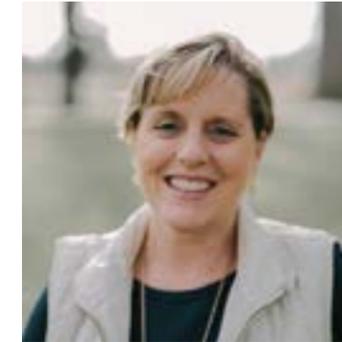


With start of new school year, being prepared is key to success

By Traci Brewer

It's hard to believe another summer has come to an end. As I type this, parents and children are shopping for new backpacks, new shoes, the perfect binder, and so on. There is nothing quite like the excitement of shopping for school supplies. It's as if the world can be conquered with blank paper, new markers, unopened glue sticks and brand new scissors.

Sending children to school is also a time of stress. It doesn't matter if your child has Down syndrome or not, every parent worries about how the new school year will unfold. Students also feel anxious or nervous about what lies ahead of them this year. (Even if they don't admit it!) The best chance of ensuring a successful school year is to be prepared. Let's go back to those new school supplies. As I see parents toting in humungous bags of school supplies to



prepare their child's school and classroom for success, it reminds me that we must also prepare our students and ourselves before the adventure begins.

Many families are choosing to home school, and a lot of our DSACK families no longer have children in school. Regardless of the individual circumstances, the key to success always lies in being prepared. We know for students with Down syndrome, this is even more important.

Overlearning, repetition and routine can play huge roles in achieving goals and positive outcomes. "Use it or lose it" takes on a whole new meaning when pertaining to individuals with Down syndrome. The skills that have been worked on for an entire year can be lost if they are not continually put into practice. More than ever, we should all be lifelong learners, but for people born with Down syndrome, it is critical to avoid regression, depression and even dementia.

With the many programs that DSACK offers, there is plenty of opportunity to learn new skills and keep honing the skills already learned. We offer educational programs for every age through our Learning Program, which teaches early math and literacy skills; Summer Enrichment Program; We Work! Career Planning Initiative, Bike Camp, Cooking Skills, Healthy Movement Class, and College Bound

Courses in partnership with Bluegrass Community and Technical College. Everything is absolutely free, thanks in a very large part to our annual Family Fun Day and Walk proceeds. So, while we enjoy the friendly competition of contests for billboards, magazines, names on t-shirts, etc., keep in mind that without a successful event, many of these programs will come to an end. The team that raises \$300 is just as important as the team that raises \$15,000. Together, we keep DSACK going!

You'll read more about some of these programs in this issue of our magazine. Be sure to have your tissues handy when you read our Be Inspired story about an amazing adoption, as well as powerful wisdom conveyed through our Parent's Perspective article. What an amazing tribe we have here at DSACK! I am so honored to be on this journey with each and every one of you.

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!

Fall Family Fun Day and Walk

Sept. 14, 9 a.m.-1 p.m.

Masterson Station Park Fairgrounds

Carnival-type games, inflatables, kids' activities, food trucks and so much more!



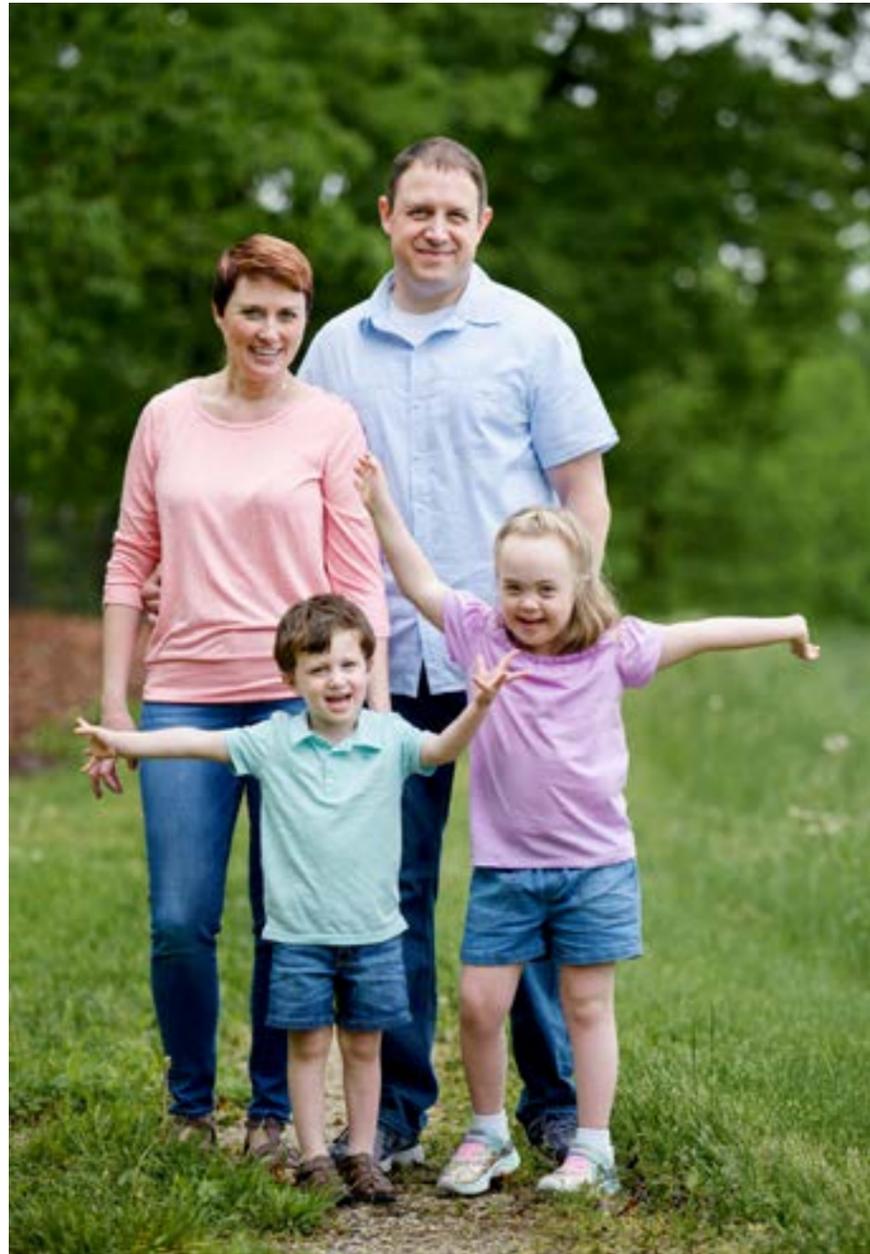
Children teach us who they are; our job is to listen

By Angie Madden

Oh, the fear and worry. It washed over me in waves and waves and waves when I found out Olivia had Down Syndrome when I was 16 weeks pregnant. Would she be healthy? Would she be happy? Would she be able to live on her own? Would she make friends? What would her life be like? What would my life be like? Would I be able to be everything she needed?

I started to read and Google everything. And then my fear swelled and grew to include a million other things that weren't already on my list. So, I stopped Googling, but one good thing that came out of that process was the realization that a large part of what I was going through was grief. Grief for the child I thought I would have. That child was replaced with someone completely unknown and unfamiliar to me. Before my girl was born, I had already decided what she would look like, what she would grow up to do and be, and I was ready for that, but I was not ready for this.

I wallowed it in for a while, but then, when I was ready, I started talking about it with friends and family, and finally, I reached out to DSACK. Through that, the most wonderful thing happened. I realized that what I was feeling was normal and something a lot of parents felt. I also learned that my vision and expectations for the life that Olivia would live were absolutely silly to put upon her or any child. Why would I plan her life before she even arrived, before I even got to hold her squishy little hand in mine and see her eyes open and say hello to the world for the first



Angie Madden, Matt Shorr, Lee and Olivia

time? Our children teach us who they are and it is our job to listen and learn and guide.

Everyday, I listen to what Olivia tells me about who she is and who she wants to be, and, oh, what I have learned. I have learned, first of all, that all of my fears were without warrant. Olivia is healthy and happy (except when she isn't, of course) and she has tons of

friends. Her life is a joy to her and us and so many people in our friend circles, families and community.

"Everyday I listen to what Olivia tells me about who she is and who she wants to be, and, oh, what I have learned."

My life is a million times better with her in it. She makes me belly laugh almost every day as I experience all the joys she finds and the merriment she makes. I cannot be everything that she needs, but that is why we have our village of family, friends, teachers and therapists. She is fiercely independent and resilient and will give everything her all before she will ask for help, so, although I haven't learned if she will live independently yet or not (she is only 6), I know that she has the desire to give it one heck of a go...if that is what she wants for her life.

Listening to my child about who and what she wants to be is only one of a million lessons I have learned and will learn as we go along. But it is the most important lesson that Olivia has taught me so far about being the parent of a child with Down Syndrome and of a child without. Cheers to you Olivia for making me a better parent and better person.

Angie Madden is the mother of Olivia, 6, and Lee, 3. She is a teacher in the Gifted and Talented Program at Cassidy Elementary School in Lexington.

Not too late to meet Walk goal

DSACK's Fall Family Fun Day and Walk – the most important fundraiser of the year – is just around the corner, Sept. 14! But it's not too late to plan on joining the fun, including as part of a Walk team. Just go to fundraise.dsack.org to sign up.

We are getting closer to our \$160,000 goal each day. It's more important than ever to join a team or make a donation. This event goes a long way in funding all DSACK's programs and keeps them free for everyone. We can do it!

A special shoutout to our sponsors (as of presstime): Wesbanco, Bank of Lexington, Associates in Pediatric Therapy, Wilson Pediatric Therapy and Learning, Stewart Home and School, Kentucky Marble and Granite, Marshall Pediatric Therapy, Applied Behavioral Advancements, Newtech Systems, Orbis Corp.,



American Sound and Electronics, Life Plan of Kentucky and IPM Pest and Termite. In-kind sponsors include Air Time Inflatables, Lamar Advertising, Wildcat Moving, Baby Boo Photography and Teasley Rolling Video Games.

Grants approved

DSACK is once again the recipient of a WHAS Crusade for Children Grant. This year, we received \$3,000 to fund the salaries of the education coordinator and supplemental staff who are responsible for coordinating and implementing DSACK's educational programming (read more about this programming on pages 6-8). These programs include the Learning Program, Summer Enrichment Program and Strider Bike Camp.

In addition, DSACK was awarded a \$3,200 grant from the Children's Charity Fund of the Bluegrass. Those funds will be used for the Learning Program, DSACK's early math and literacy program.

Inaugural Down with Dares a success

DSACK's first ever Down with Dares was a huge success, not only in funds raised - \$2,200 - but in awareness raised. About 100 people participated in the photo scavenger hunt in downtown Lexington. Here are just a few snapshots of the fun evening.



DSACK's educational programming helps students with Down syndrome reach the

Head of the class

Not a day goes by that Hana Toupin doesn't leave work smiling.

"It's true," said Toupin, DSACK's education coordinator. "I just feel so happy to be a part of all the wonderful things we are doing educationally for our students with Down syndrome."

Toupin, a special education teacher by training, coordinates and implements three of DSACK's educational programs – the Learning Program, the Summer Enrichment Program and the Strider Bike Camps. (Other programs include the We Work! Career Planning Initiative and the College Bound Program.)

"It never ceases to amaze me to see what our small organization is able to do and the impact that it has," she said.

Executive Director Traci Brewer, likewise, smiles when talking about the educational programming offered by DSACK. (Actually, she's happy to talk about all the programs and services DSACK provides.) But she turns serious when talking about the necessity for such programs.

"Too many of our students fall through the cracks when they go to school," she said.

"There's a definite learning profile for people with Down syndrome, and so often teachers are not trained to teach to that very specific profile. So we feel it's important to step in."

First, Brewer said, it's critical to immerse



Hana Toupin leads DSACK's educational efforts.

children with Down syndrome in education before they start regular school. The Learning Program – which is available for children as young as 5 – does just that. The program is a 10-month program that focuses on math and literacy, as well as social skills, music and art.

In addition to working with children, the Learning Program also educates parents.

"The really great thing about the Learning Program – like all our programs – is that it teaches the parents, too. Parents can't advocate for their children if they don't know what to expect," Toupin said.

Brewer agreed. "We think it's just as important to educate families as much as students," she said.

With the Learning Program, children might be learning math and reading skills downstairs in the DSACK Learning Center while

the parents are learning teaching strategies for their children upstairs in the DSACK main office. Additionally, parents are encouraged to share the curriculum materials with their children's teachers.

Toupin teaches the Learning Program, which meets once a month, with help from Jill Myers, a reading and math intervention teacher with Fayette County Public Schools.

"I think it's great that DSACK is giving the kids and the families this opportunity," Myers said.

Beyond the Learning Program is the Summer Enrichment Program – a program aimed at stopping regression during the summer when school is not in session. The program is currently for ages 7 to 11, but plans to include similar sessions for middle and high schoolers are under consideration.

"We know that children with Down syn-



Music time was a favorite part of Summer Enrichment program.



Cooking classes were also a big hit.

drome regress rapidly if they are not learning something," Brewer said. "We want to be able to offer that small classroom and individualized instruction so gains they've made in school will not be lost during the summer."

Math, reading, independent living skills, social interaction, music, art and cooking are all incorporated into the camp-like experience of Summer Enrichment, Toupin said.

"We realize it's summer, so we're trying to bring in things that will be fun and exciting as well as educational," she said.

As with the Learning Program, the Summer Enrichment program is parent-focused, too. Toupin – along with Myers, who also helps with that program – met initially with parents to coordinate more individualized instruction for each child. And parents receive weekly reports and photos of class activities. Data is kept on current math and reading levels to share with schools.

Because individuals with Down syndrome should be continual learners, like they're typical peers, DSACK offers the College Bound Program for young adults. The program, in partnership with Bluegrass Community and Technical College in Lexington, offers an adapted, non-credit college-level course each semester.

"For most adults with Down syndrome, the social floor falls out when they leave high school. And employment rates are terrible for people with disabilities in general. Plus, we found out that a lot of our adults just want to go to college – like many of their



One-on-one instruction is an important part of DSACK's programs.

peers. So, we partnered with BCTC to give them that opportunity."

So far, two public speaking courses have been offered. This fall, an art class is on the agenda.

"Since Emily graduated from high school in 2008, one of her greatest life goals has been to attend college," said Maribeth Wright about her daughter. "Thanks to DSACK and BCTC, she can now say that she has reached that goal."

When you add in the We Work! Career Planning Initiative and classes like DSACK's Teen Cuisine, it would appear that the slate of offerings is complete. But, Brewer said, that will never be the case.

"We will never be done with finding ways to educate ourselves and others. We are always looking for ways to open more doors of opportunity and set high expectations for our Down syndrome community," she said.

Continued from page 7

Learning Program – This is an early math and literacy program for children ages 5 to 10. It meets once a month for 10 months. DSACK provides a light supper for families before each session to encourage friendships and support community building. After dinner, students meet in the DSACK Learning Center to review math and reading materials, social skills, music and art. Parents meet in the office conference room to learn teaching strategies and receive a take-home curriculum of reading and math materials to work on until the next session.

Summer Enrichment Program – This is an eight-week program provided during summer break for students 7 to 11 years of age. Students meet three times a week to review academic goals as determined with parents in math and reading, independent living skills, social interactions with same-age peers, music, art and cooking. Parents are provided weekly progress reports and photos of class activities. Data is kept on retention of current reading and math levels to share with schools.

Strider Bike Camp – This camp incorporates parents and volunteers to help students ages 6 and up learn to ride and steer a Strider bike. (Strider bikes do not have pedals and focus the student's attention on balance.) By the end of the five-week camp, many students who have never ridden a bike



empower teens and young adults as they explore career fields in their interests. DSACK does this by teaching job readiness, exploring career possibilities via internships, job site visits, volunteer opportunities and more. Parents also attend sessions weekly for eight weeks to hear information on such topics as supported employment, postsecondary opportunities, how working affects government benefits and special needs planning.

Cooking Skills – This program, for ages 12 and up, teaches students about food safety, label reading, healthy eating, powering up with breakfast, and meal planning and budgeting. Led by a Nutrition Education Program Assistant with Fayette County Cooperative Extension, classes include cooking, games and a take-home recipe for all participants. Parents accompany their child to each class.

College Bound Program – This eight-week offering works with Bluegrass Community and Technical College to enable students with Down syndrome to attend adapted, non-credit college-level courses on topics such as public speaking, art, and family and consumer sciences. The classes are taught by college professors, and a weekly study group is provided to help students review what was learned in class and prepare for the next one.

are able to steer between parking cones and navigate a small ramp.

We Work! Career Planning Initiative – This 13-week program helps educate, train and

Coming up!

There are plenty of exciting events and activities coming up. Here are some to be on the lookout for:



Fall Family Fun Day & Walk	Sept. 14
BCTC 2D Art Class	Sept. 9-Oct. 28
Healthy Movement Dance Class	Sept. 23-Nov. 11
Learning Program	Sept. 24-May 26
Holiday Party	Dec. 14

Be sure to check the DSACK calendar at www.dsack.org for additional information and to register for events and activities.

Dental care and Down syndrome

Reprinted with permission from Dentably.com

When it comes to heading to the dentist, many have feelings of stress and anxiety. For patients with down syndrome, these feelings can be much more intense. The dental experts at Dentably Magazine – Dr. Greg Grillo and Dr. Andrew Jordan, have spent many years working with patients and caregivers to prepare for dental visits and providing them with tips and instruction for instilling good oral hygiene habits.

Patients with Down syndrome may have dental issues that are different from those without Down syndrome. For example, young patients with Down syndrome often will have both baby and permanent teeth later in life due to delays in eruption. Some dental problems that are seen in patients with Down syndrome are due to genetics, but other issues may be present as a result of hygiene habits, issues with the jaw or bite formation, complications with chewing or other factors.

Finding the right dentist

Although it is unusual to find anyone who enjoys visiting the dentist, patients with sensory issues, including some with down syndrome, can have a greater fear of going to the dentist. For example, someone who is generally wary around new people and does not like to be touched may find that having a stranger's hands with tools in their mouth may be an overwhelming situation.

Finding the right dentist for those with additional support needs is extremely important. There are a number of things to consider when searching for a dentist, and it is important to be diligent in your search and to not give up until you've found someone who is a good fit for your loved one. Talking with a dentist prior to a visit is a good first step in preparing everyone for the visit. Some questions that you may ask when deciding on a dentist for your loved one include:

1. Are you comfortable working with someone who has Down syndrome?

The dentist you choose should be comfort-



and ensure their visit goes well. Some accommodations that you may want to request may include being able to stay near the patient throughout their visit or requesting a specific flavor of toothpaste. These may seem like small requests but can make a difference in the overall experience.

It is important to find a dentist who will allow family members or others providing support to be involved with the visit. They should also encourage you to ask questions. The more information you have, the better the appointment will be for all. Finally, ask your friends, family, doctor, or someone you know with a loved one who has additional support needs for recommendations.

Once you've chosen a dentist and scheduled an appointment, it will be time to prepare for the visit. It is important to prepare ahead of time so your loved one has an idea of what to expect during their visit. To help the patient feel more comfortable and prepared for their appointment, consider the following.

1. Find ways to visualize what happens at the dentist.

Using visuals is a great way to see what happens at the dentist. This can be done with books or videos and gives the future patient a way to make a connection between the visual and their dental appointment.

2. Visit the dentist early.

Scheduling an introduction visit with the dentist prior to the visit can be beneficial. It allows patients to familiarize themselves with the environment, such as seeing the lights and hearing the sounds. You and your loved one can meet the office and staff members and go over any accommodations that may need to be made prior to the appointment so that everyone is better prepared.

The best way to avoid trips to a dental urgent care center or (worse) an emergency room is to begin practicing good oral hygiene habits at home. Instilling habits from a young age is best, but it's never too late to start practicing good dental hygiene.

able working with patients with additional needs. If the patient is a child, start by searching for pediatric dentists. They have two to three years of extra schooling and may be better at providing needed accommodations.

2. What experience do you have working with patients with Down syndrome?

When asking a potential dentist this question, it's best to listen for specific examples of when they worked with patients with additional needs. A dentist with previous experience is more likely to know how to ensure a visit runs smoothly and that your loved one is at ease.

3. Can any special accommodations be made?

A good dentist should answer yes to this question. It should be their goal to make the patient as comfortable as possible

Adoptive parents relish life with Charlotte

With five children from previous marriages, one adopted son and 13 foster children having passed through their door, Matt and Abby Olmstead are used to "going with the flow." So, when they were asked if they would be interested in adopting another baby, they didn't hesitate to say yes.

When they learned that the baby had been diagnosed with Down syndrome and that she had a hole in her heart, the Olmsteads remained steadfast. "It just felt like it was meant to be," Abby said.

That was four months ago and Charlotte's adoption is official. She's "lucky No. 7" in the Olmstead clan, joining Marcus, 20, Emma, 19, Phoenix, 18, Leah, 16, Memphis, 16, and Bryson, 3.

The couple likes to say the stars aligned when they adopted baby Charlotte, a.k.a. Charlee. But the story of how she came to the Olmstead home is not quite that simple. It has its beginning in the Olmstead's nearby Kroger.

"We had made friends with somebody that works at our local Kroger and she'd seen a bunch of our foster kids and she'd seen Bryson since he was itty bitty," Abby explained. "So, one Saturday we went to Kroger, and we had just adopted Bryson ... and our friend said, 'I have a really good friend who's pregnant and I just have some questions about adoption because she's chosen to put the baby up for adoption.'"

One of those questions produced "instant tears."

"She said, 'Would you guys be interested?'," Abby said.

They immediately wrote down their names and phone number on a napkin and asked the woman to pass it along to her friend. They were interested, if the mother was interested. Then they waited for her to call.



Charlotte Olmstead

When she did, they set up a time to meet her and talk. Shortly after meeting the birth mother, Matt and Abby got busy learning everything they could about Down syndrome. One of the first things Abby did was call another friend of hers who has twins, one of whom has Down syndrome.

"I said, 'Tell me everything good and bad, just tell me honestly how it is - everything about it,'" Abby said. "What are the struggles, what are the best parts of it. ... I had her on speaker so Matt could listen to her, too. We just looked at each other and we were like let's do this."



Matt, Abby and Charlotte Olmstead

She also made a connection with DSACK, thanks to the fact that when the birth mother received the baby's diagnosis, her doctor gave her DSACK's medical outreach materials. "She gave us that new parent packet to kind of prepare us," Abby said.

In addition, Abby made connections with other DSACK parents. "I think the connections with the moms right now has been the biggest help," she said. "I feel like we have so much support we didn't know was out there."

Because they are both trained paramedics (Abby is now a stay-at-home mom), the potential medical issues Charlotte could experience did not frighten the Olmsteads. Charlotte has had two heart surgeries already, and she is still receiving supplemental oxygen.

Now, both Matt and Abby say they cannot imagine their lives without Charlotte in it. Aside from the fact that she still has some medical issues, "she's developing and she's learning and she's interacting with us. ... She knows her parents, she smiles when she sees us. She's a beautiful little baby," Matt said.



Happy 12th Birthday Brianna!
Love,
Daddy, Samantha,
Joshua and Scarlett



Congratulations Conor on your graduation from Tates Creek High School! We're so proud of you!



Happy birthday Louisa!
You are our sunshine!



Tarenne Maher graduated from West Jessamine High School. She will be attending Asbury's Connection program in the fall.



Happy 14th birthday, Anna! We love you, Dad, Mom and Maria



Happy birthday Harley Townsend (Aug. 31).



Happy 12th birthday to our Tori Tornado! We love you more than words can say! Mom, Dad and Karl



Congratulations to Conor Healy and Tarenne Maher! Their photo was chosen to be part of a NDSS video that will be shown in Times Square on Sept. 14.



Happy 3rd Birthday Scarlett on Oct. 27! You are absolutely amazing! Thank you for being ours!!



Happy 7th birthday Huck!
Love, Mom, Dad, Owen and Lena



Happy birthday to our sweet Emily who turned 5 on Aug. 27! What a gift she is to her family!



Happy 9th birthday Jeremiah.
You are such a blessing to everyone. You are loved.



Congratulations Brianna Orihuela and Kennedy Bradley! Both girls made the West Jessamine Middle School cheerleading team. We are so proud of you!!
Love, John, Samantha, Joshua and Scarlett Orihuela & Heather Bradley

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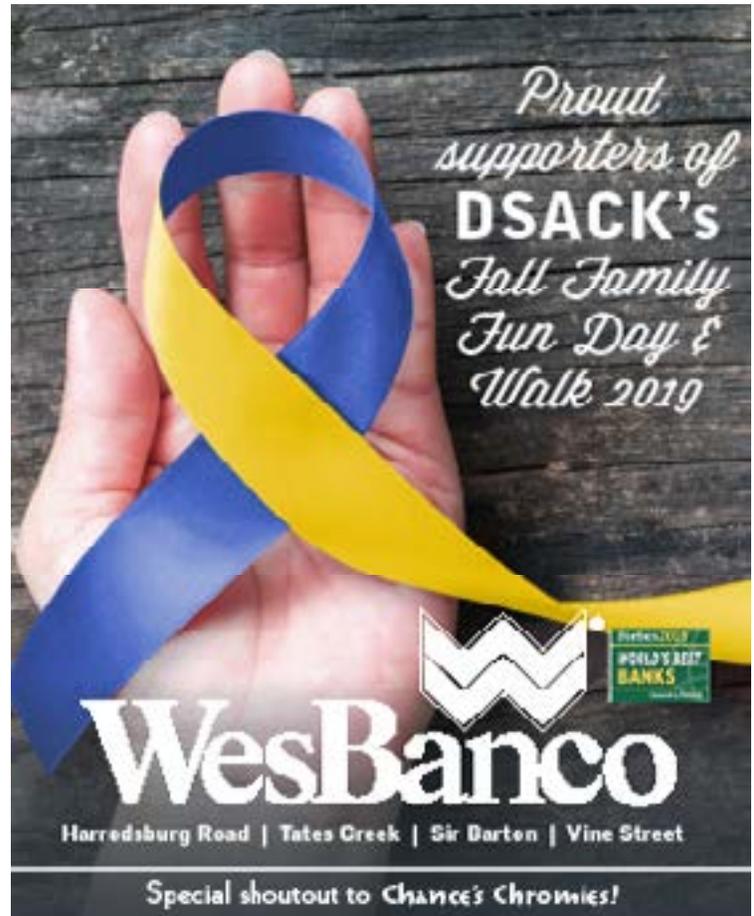


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Special shoutout to **Chance's Chromies!**

WORLD'S BEST BANKS



**MISSION
STATEMENT**

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