



Summer 2019

Down Syndrome Association of Central Kentucky

Support • Educate • Celebrate



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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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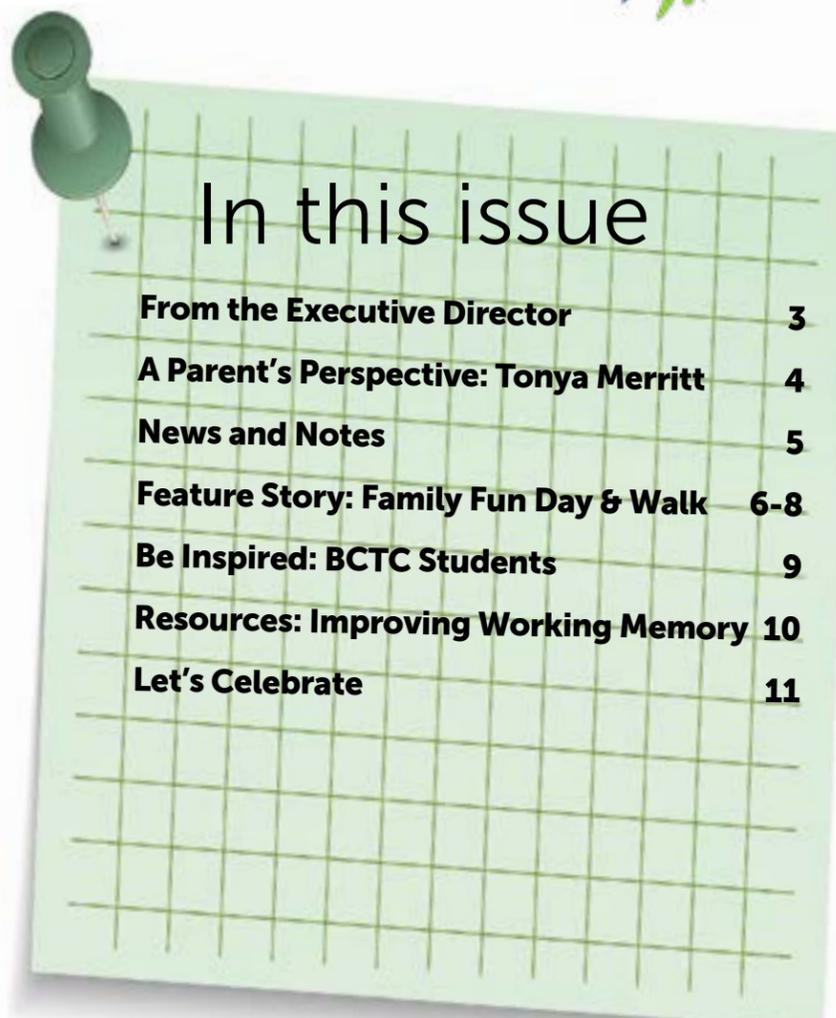
CONTACT INFORMATION

Down Syndrome Association of Central Kentucky
1050 Chinoe Road, Suite 204
Lexington, KY 40502
859-494-7809
website: www.dsack.org
email: dsack.org@gmail.com

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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Give back to DSACK by turning your walk team into a fundraising team

By Traci Brewer

I have a question for you:

How has DSACK impacted your life?

Did your child go to Healthy Movement classes or participate in World Down Syndrome Day festivities? Did he or she participate in our Learning Program? Did someone accompany you to an IEP meeting or help you navigate the Medicaid maze? Did you participate in our play group or go to dinner with other DSACK families? Did you attend our BCTC public speaking course?

Now, let me ask you this:

How would life be different without DSACK?

As for me, I truly can't imagine life without DSACK. From the time our Emily was born,



DSACK has been here to support, educate and celebrate every step of the way.

If your life has been greatly impacted by the programming, events and services that DSACK offers, then you're no doubt aware of the importance of raising the funds needed to keep them viable. Frankly, there would be no DSACK without

the money raised from events like Fall Family Fun Day and Walk, which is fast approaching (read more on pages 6-8). Or at the very least, we'd have to charge for all our programs and services.

That's one reason we keep "upping our game" with Fall Family Fun Day and Walk, adding more attractions and fun each year so we can attract more people. Attracting more people means more money raised. It's really that simple.

So what can you do differently from what you're already doing to help DSACK be fully funded each year? This year, there's a big something you can do. You can encourage your friends and family to do more than just join your Walk team; you can encourage them to become fundraisers, as well.

With our new Walk team software platform, it's easier than ever for your "walkers" to set up their own fundraising efforts and help us raise tens of thousands of dollars more. Just think, if every walker raised \$100 for your team, that would be \$200,000! That would help us far exceed our \$160,000 goal and set us up to take DSACK to the next level.

It's all about thinking big – big in terms of effort, big in terms of results.

With the Fall Family Fun Day and Walk coming soon, let's go ahead and put on our fundraising hats and make this the best one yet. What better way to give back to an organization that has such a huge impact on individuals, families and our community.

Coming up!

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



Down with Dares	June 7
Fall Family Fun Day & Walk Kickoff	June 13
Summer Enrichment Program	June 18-July 25
Strider Bike Camp	July 1-July 31
Fall Family Fun Day and Walk	Sept. 14
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.

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



Tonya and Will Merritt

A team approach can make a real difference

By Tonya Merritt

When Will was born, we were blessed with the support and presence of our friends and family. After Will's surprise diagnosis, people filled our hospital room with laughter, stuffed our refrigerator with lasagna, and covered us in prayers. We were lucky to have a wonderful tribe of people cheering us on who were eager to help.

At one of our first DSACK 0-5 parent group meetings, Courtney Elbert spoke about Sam's walk team. We knew that our friends and family were hungry for information that would help them better understand Down syndrome. The walk seemed like a good opportunity to update people on Will's progress, share the important role DSACK plays for families, and provide some basic information about Down syndrome.

We used the "Christmas card letter" concept that Courtney had recommended and sent out invitations to our whole Christmas card list. We also tapped into our school communities, inviting our colleagues, our schools' service clubs, and our own students to participate with Team Will Power. We put up donation tanks in our school libraries and at activities. And then we waited.

And, boy, did our tribe ever come through. Donations and registrations came rolling in. People wanted a way to do something, to show support for our family, and to help a grassroots organization that had helped us navigate life with Ds. They just needed to be asked. They needed to hear our story and see how important DSACK had been to us.

Over the years, our tribe and our methods have shifted. But the power of a personal appeal has never lost its impact. And it has made a difference.

While we love DSACK, we would never have been able to make a large enough donation each year to impact DSACK's scope of services. Instead of trying to make a big personal contribution, we put our money into invitations and swag for our team. We have some team members who make donations in the \$50-\$100 range, but most of our team members just do the standard registration cost. Our motto has always been "we don't know people with a lot of money, but we know a lot of people with \$20."

Over 10 years, Will Power has raised over \$50,000 for DSACK, most of it \$20 at a time. While most of our team members are not huge philanthropists, many of them have given each year because they see how important

DSACK is to our family.

Although there have been many factors that have helped DSACK grow over time, we are proud that the money raised by Team Will Power has made a real difference in the level of support DSACK offers. Ten years ago, DSACK was meeting in borrowed spaces and powered completely by volunteers. Now, we have a space, a staff, outreach, policy engagement, a wide variety of programming that serves all ages.

Now is the time to think about how to build your team. Help your tribe understand how important it is to have connections with people who are walking your path, mentors who have been there before you, and access to the specialized information you need to navigate the services and needs of a family member with Ds. Show them how important it is for your typically developing children to make friends who also have a sibling with Ds. Let them know that, by joining your team, they can make a real difference in the life of your family and many others like you. Tell your story. Build your team.

Tonya Merritt is administrative dean at Paul Laurence Dunbar High School. She and her husband Brent have two boys, Eli and Will.

Fundraisers recognize World Ds Day

In honor of World Down Syndrome Day this year, two DSACK friends went the extra mile to create awareness and make an impact.

Madison Beckett, with the aid of her mother Marina Kennedy, decided to sell Down syndrome awareness t-shirts throughout their Pike County, Kentucky/Mingo, West Virginia community. Instead of the 20 or so shirts they thought they'd sell, they ended up selling 100. As a result, they donated \$321 on 3/21 to DSACK.

"I'm honored to be able to make this donation. DSACK was wonderful to reach out to us when I had

my girl," Kennedy said.

In addition, Bryce Vinson once again held his 3/21 fundraiser at Common Grounds Coffee Shop in Lexington, where he works. With the help of a friend who donated stainless steel coffee mugs, he donated the first 21 drinks to customers that day, and in return his customers filled a tip jar. Customers, friends, family and others helped Vinson raise \$600 this year, according to his mother, Becky Vinson.

"Common Grounds was so nice to let Bryce come in on his day off and make it a big event," she said.



Bryce Vinson; Marina Kennedy and Madison Beckett

Global Recognition

DSACK was one of eight member organizations to be awarded an Employment Initiatives grant from the Global Down Syndrome Foundation recently. The grants were started in 2016 and have provided nearly \$65,000 to programs for 33 local Down syndrome organizations across the country and supported a total of 75 employees with Down syndrome.

The DSACK grant was awarded to underwrite the administrative position held by Emily Wright. It also enables Emily to speak on behalf of the organization at public events like the Nothing Down About It Gala, which she emceed.

"This grant is so important because it enables us to hire and empower an individual with Down syndrome. And she (Emily) is such a valuable part of our staff," said Executive Director Traci Brewer.



Photo by Paul Martin

We threw ourselves a Gala - and 130 people attended and more than \$57,000 was raised. This year's event was held at the 21C Museum Hotel in Lexington.





Photos by Maggie Mae Photography, Poteet Photography and Mahan Photography

Walk Kickoff
June 13
DSACK office
6 p.m.

New this year is the software platform used. It's more user-friendly and easier for people who join a team to become full-fledged fundraisers themselves.

"Our new software will enable us to take fundraising to the next level," Brewer said. "Imagine if every person who joined a team shared it through social media and raised an additional \$100!"

The day gets started with registration and tailgating at 9 a.m. The walk, which follows a one-mile route throughout the fairgrounds, is at 10 a.m., and family fun day activities begin at 10:30 a.m. The event will end at 1 p.m.

Once again, plenty of parking will be available in the grassy area across from the fairgrounds. A drop-off area will be available for those who need handicap access, as well as for those who want to drop off tailgating or other supplies.

The cost of participating on a Walk team remains at \$18 and gets people "in the door" of the Fall Family Fun Day events. Members of the community who do not participate on a Walk team can get into the event for \$18, as well.



2019 Fall Family Fun Day and Walk FAQs

When, where, what?

The 2019 Fall Family Fun Day and Walk is Sept. 14 at the Masterson Station Park Fairgrounds located at 3051 Leestown Road in Lexington.

What should we expect?

Registration and tailgating begin at 9 a.m. (if you already registered online, no need to stop at registration). We'll begin our day at 10 a.m. with a short walk (about 1 mile) to celebrate people with Down syndrome. The fun concludes at 1 p.m.

There will be a designated area to set up a tent (no ground stakes allowed) or to simply throw down a picnic blanket. Although vehicles are not allowed to park within the fairgrounds area, you can pull your vehicle up to a designated drop-off zone. Golf carts will be available to help bring supplies to the tailgating area. (No alcohol is permitted and will be confiscated.) Don't want to tailgate? No problem. Plan to arrive at your convenience.

Where can we park?

There will be free parking in a grassy area across from the fairgrounds. For those in need of handicap accessibility, there will be a drop-off area within the fairgrounds before parking.

Why do we walk?

This is our 15th year to host a walk for Down syndrome. It is a time for family, friends and community to celebrate people with Down syndrome. DSACK families work hard throughout the year to raise money for their walk team, with all funds raised going toward the services and programs DSACK offers free throughout the year.

What if I am unable to join the walk?

For those unable to walk the 1-mile route, you are welcome to remain at the fairgrounds and rejoin your party afterward. If you're unable to join us at 10 a.m. but still want to come to our family fun day portion, that works, too. Join us any time before 1 p.m.

How will we know when the walk begins?

Listen for the firetruck siren, then make your way to the firetruck and continue along the walk route.

Continued on page 8

Fall Family Fun Day and Walk promises more fun, more food, more memory-making moments

The 2019 Fall Family Fun Day and Walk is just around the corner - believe it or not. And that means it's time to start making plans.

The date: Saturday, Sept. 14.

The place: Masterson Station Park Fairgrounds in Lexington.

The time: 10 a.m.-1 p.m. (registration and tailgating begin at 9 a.m.).

Once again, this year's Fall Family Fun Day and Walk will feature carnival-like games, food trucks, inflatables, Cambo the Clown, live music, face-painting and, of course, our one-mile fund-raising walk. New this year: the Bubble Car, Teasley's Rolling Video Games and more food and fun.

"We just keep adding more fun things to do," said DSACK Board Chair Katie Gilley.

"It's a day set aside for the whole family to enjoy."

While last year's event went down as the most successful yet, "that just means we work harder to make this year even more successful," said Traci Brewer, DSACK executive director. "We totally believe we can top last year, bringing in more people to enjoy all the fun and, as a result, more funds to support DSACK's important programming and services."

Specifically, the funds raised from Fall Family Fun Day and Walk go toward keeping all of DSACK's programs and events free for families.

"A successful event is more important than ever as we continue offering more," Brewer said. "More importantly, we still believe that everyone should be able to participate in these life-changing programs

and events, regardless of financial circumstances."

This is the second year for the "family fun day" to be added to the annual event.

"We decided that the only way to increase our attendance numbers, which had plateaued over the previous years, and our fundraising numbers is to offer more attractions," Brewer said. "It seems to have worked, with more than 2,000 in attendance last year and \$156,000 raised."

It's also the second year the event is at the Masterson Station Park Fairgrounds, located at 3051 Leestown Road in Lexington.

"Masterson Station offers such a wonderful spot for our biggest event of the year," Brewer said. "It was a no-brainer to schedule it there again."

Continued from page 7

Do I have to be part of a team to enjoy the fun?

You do not. We have a lot of fun and friendly competitions for those who form a team, however. We want everyone to join us for our day of fun. You can register for the general event and share in our day of family fun at your convenience.

What is the Fall Family Fun Day and Walk registration fee, and what does it include?

The fee is \$18 per person, which includes a t-shirt, carnival games, inflatables, face-painting, kids' activities and more. This year we will have a mobile gaming truck and a bubble car. There will be some things not included in the registration fee, such as food truck purchases and purchases from a few vendors.

Where can I get a sign for my team?

Some teams choose to have a sign professionally made, while other teams make their own signs out of poster or foam board. Signs can be as simple or as elaborate as you choose. If you need the DSACK logo, just email us at dsack.org@gmail.com.

Is a sign for my team required?

It is totally up to each team. We enjoy seeing the creativity of our teams, however, it is not required. We do have a contest for "Best Sign," and the winning team will lead off our 2020 walk for Down syndrome.

Can our team sit together?

Because our venue is completely outside, the only seating will be in the tailgating area. Watch for team contests to win the best spots closest to the activities and vendors. For those who do not win the best spots, plan to arrive early to claim your team area. Gates open at 9 a.m.

Will there be enough t-shirts to go around?

We make every effort to have enough t-shirts of every size. However, to be sure you get a t-shirt, please have your team members pre-registered by Aug. 18. If a walker is not registered by this date, we will not be able to guarantee a t-shirt on the day of the walk. However, we will do our best to have extra shirts available. We order a lot of extra shirts every year, but we often run out. After Aug. 18, it is first-come, first-served.

Can I pick up my team's shirts in advance?

We do have t-shirt pickup dates so that team

captains can pick up the shirts in advance. The dates will be announced. The pickup location is the DSACK office at 1050 Chinoe Road, Suite 204, Lexington, KY 40502.

What if our team has designed their own t-shirt?

Many teams choose to do this. The registration fee of \$18 includes a t-shirt, so each member of your team will still receive a shirt. However, your team members can choose to decline a walk t-shirt to help offset expenses. Just choose "No shirt needed" when registering.

Are there team contests again this year?

We will once again have the exciting Grand Champion team level for those who raise \$10,000 or more. Grand Champions will win travel for three to a national Down syndrome conference in 2020. Other team levels include different perks as well, including a drawing for your child's picture on a billboard for teams raising \$5,000 or more. We will also offer a billboard for teams raising the most money and registering the most walkers. Many other contests will be available, so check the Facebook page and read your emails! Team levels and prizes are also listed on the Fall Family Fun Day and Walk homepage, which can be reached through www.dsack.org after June 13.

What if I can't attend but want to join a team or make a donation?

You will be missed! However, you can still join a team and get a t-shirt, even if you are unable to attend. Of course, donations are always welcome, too. You can even have a team of "virtual walkers."

How can I volunteer?

It takes many volunteers the day before and the day of to make this event fun and safe. If you or your group are interested in volunteering, email DSACK at dsack.org@gmail.com. We usually ask volunteers to be there by 8-8:30 a.m. and wrap it all up by 1 p.m. Volunteers are needed for everything from assisting in activity areas, lining the route and cheering on walkers, set-up and clean-up. Volunteers 16 and younger must be accompanied by a parent or guardian.

What are some ideas to help my team raise money for DSACK?

- First and foremost, encourage everyone who joins your team to become a fundraiser. Our new software makes it incredibly easy to share on social media as a fundraiser. Imagine if every team member raised an extra \$100 simply by sharing!
- 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. Last year, one elementary school raised nearly \$2,700 doing this!

- Of course, you can also ask your employer, local businesses, doctor's office, etc. to sponsor your team. There are several different levels of sponsorship; a sponsorship form can be found on the Fall Family Fun Day and Walk homepage at ??????. Be sure to let us know if you have a gold, silver or bronze sponsor so we can make sure they get the benefits of their sponsorship package. Email us at 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 Fall Family Fun Day and Walk and/or donate. List your child's accomplishments. How has your family grown through this experience? How have you grown? How has DSACK supported you? Mention what the funds will be used for (see below) 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.

Have fun with this. You will find that most people want to give and just need to be asked.

How does DSACK use funds raised from the Fall Family Fun Day and Walk?

As far as we can tell, DSACK is the only Down syndrome affiliate that does not charge its families for programs or activities. Our board believes strongly that financial circumstances should never prohibit a family from participating in our life-changing programs and events.

Our annual Fall Family Fun Day and Walk allows our families to give back to DSACK by raising money to continue to offer all of our services and programs free of charge. One hundred percent of all money raised for our event is used to continue programs and services such as The Learning Program, We Work! job skills classes, bike camps, Coffee Chats, new parent packets, medical outreach and so much more.

Fall Family Fun Day and Walk proceeds are also used for our social events, including the pumpkin patch outing, holiday party and World Down Syndrome Day events. Learn more at www.dsack.org.



From left, Conor Healy, Blair Osborne, Emily Brewer, Chad Bell, Callie Baesler, Jason Smitha, Emily Wright, Troy Lovich, Kate Boudreaux, Joshua Landeene, Lindsey Greer, Julia Steinman, Hunter Bowden and Olivia Ash.

DSACK students excel in college class

Baseball.

Forgiveness.

Celiac disease.

Professional wrestling.

Pacemakers.

These were just a few of the topics presented by the students on the final day of DSACK's Public Speaking course at Bluegrass Community and Technical College. The 14 students enrolled in the spring semester course were required to give an informative speech about a topic of their choice.

"To see the DSACK students present their final presentation was such an exciting experience," said Dr. Kimberly Ross-

Brown, who teaches the class. "These students have grown tremendously since last semester. They are extra bright, very outgoing and there has been a lot of personal and professional growth."

The participants spent eight weeks in class preparing for their final speeches, including learning about the oral communication process and the importance of listening in the public speaking process. They also had to complete and interpret an audience analysis, as well as conduct research about their chosen topics.

To aid in what they learned in class, the students also spent one night a week in study group. Students from the University of Kentucky Speech Pathology

Program attended study group and assisted with topic research.

"We were determined to give the students all the tools they needed to succeed in this course," said DSACK Executive Director Traci Brewer, who led the study group.

The course is part of DSACK's efforts to give adults the experience of going to college. It came about after several adults with Down syndrome told a focus group last spring about their desire to be on a college campus, to be part of a community and to be in a classroom learning like many of their peers.

The first course – an introduction to public speaking – was held during the fall semester. The students were also required

to give a speech at the end of that course.

Talks are already underway about the next course offering this fall.

"I believe all students can learn if they have the right environment and if we engage them appropriately and if we meet them where they are," Ross-Brown said.

"This has been such a positive experience for everyone involved," Brewer added. "Going to college is a dream come true for the students, and for the rest of us who have watched and aided their progress, it's a reminder of the amazing potential every person with Down syndrome possesses."

Working memory boosters can be built into your child's daily life

By Amanda Morin
Understood.org

At a glance:

- Working memory refers to how we hold on to and work with information stored in short-term memory.
- Kids use working memory to learn and follow directions.

Does your child have a hard time keeping one bit of information in mind while he (or she) is doing something else? For example, if he's helping make spaghetti and the phone rings, does he forget he needs to go back and keep stirring the sauce? If he often has trouble with such tasks, he might have working memory issues.

Working memory refers to the manipulation of information that short-term memory stores. (In the past, the term "working memory" was used interchangeably with the term "short-term memory.") It's a skill kids use to learn. It's needed for tasks like following multi-step boosters into his daily life.

1. Work on visualization skills. Encourage your child to create a picture in his mind of what he's just read or heard. For example, if you've told him to set the table for five people, ask him to come up with a mental picture of what the table should look like. Then have him draw that picture. As he gets better at visualizing, he can describe the image to you instead of needing to draw it.

2. Have your child teach you. Being able to explain how to do something involves making sense of information and mentally filing it. If your child

is learning a skill, like how to dribble a basketball, ask him to teach it to you. Teachers do something similar by pairing up students in class. This lets them start working with the information right away rather than waiting to be called on.

3. Suggest games that use visual memory.

There are lots of matching games that can help your child work on visual memory. You can also do things like give your child a magazine page and ask him to circle all instances of the word "the" or the letter "a" in one minute. You can also turn license plates into a game. Take turns reciting the letters and numbers on a license plate and then saying them backwards, too.

4. Play cards.

Simple card games like Crazy Eights, Uno, Go Fish and War can improve working memory in two ways. Your child has to keep the rules of the game in mind. But he also has to remember what cards he has and which ones other people have played.

5. Encourage active reading.

There's a reason highlighters and sticky notes are so popular! Jotting down notes and underlining or highlighting text can help kids keep the information in mind long enough to answer questions about it. Talking out loud and asking questions about the reading material can also help with this. Active reading strategies can help with forming long-term memories, too.

6. Chunk information into smaller bites.

Ever wonder why phone numbers and Social Security numbers have hyphens

in them? Because it's easier to remember a few small groups of numbers than it is to remember one long string of numbers. Keep this in mind when you need to give your child multi-step directions. Write them down or give them one at a time. You can also use graphic organizers to help break writing assignments into smaller pieces.

7. Make it multisensory.

Processing information in as many ways as possible can help with working memory and long-term memory. Write tasks down so your child can look at them. Say them out loud so your child can hear them. Toss a ball back and forth while you discuss the tasks your child needs to complete. Using multisensory strategies can help your child keep information in mind long enough to use it.

8. Help make connections.

Help your child form associations that connect the different details he's trying to remember. Grab your child's interest with fun mnemonics like Roy G. Biv. (Thinking about this name can help kids remember the order of the colors in the rainbow.) Finding ways to connect information helps with forming and retrieving long-term memory. It also helps with working memory, which is



what we use to hold and compare new and old memories.

Memory-boosting tricks and games are just some of the ways to help your child with executive functioning issues. If your child continues to have significant difficulties with working memory, it might be a good idea to get an evaluation for possible attention issues. You may also want to explore tips from experts on topics like getting organized and managing attention.

Key takeaways

- Teaching your child ways to visualize thoughts can help improve his working memory.
- Card games and other fun activities can help build working memory.
- Finding ways to connect information can help your child with long-term memory as well as working memory.

Amanda Morin worked as a classroom teacher and as an early intervention specialist for 10 years. She is the author of "The Everything Parent's Guide to Special Education."

This article was reviewed by Thomas E. Brown, Ph.D.



Kayden turned 7 on May 9. Our lives are fuller because of this spunky, red-headed, sweet boy! Happy Birthday Kayden! We love you very much! Mom, Dad, & "Bubbers" (Ginger, Mimzie and Blue too!)



Happy Birthday Kylie, you are such an amazing girl. We are so proud of you! Keep being true to your smart, spunky, sassy self. Dad, mom, and sissy!



We blinked our eyes and Harrison Mizell turned 5 on April 21! He loves life and is enjoying every minute! We love this little guy so much and can't imagine life without him!



Congratulations to Kate, who graduated high school. She plans to go to BCTC and be an assistant dance teacher with Allegro Dance Project.



This is Charlotte Elaine Olmstead, born 3/7/19. Parents, Matt and Abby Olmstead



Lawton Chance, you have changed the lives of everyone around you and we cannot wait to see you do great things in your life! We love you so much. Happy 1st birthday! Mom, Dad, Grumpy & Gran Gran

Congratulations Kennedy! She scored 2nd place for her DARE speech and was awarded a medal! Way to go!



Happy 15th birthday, Sam! You are a treasure - always have been and always will be! We love you! Love, Mom, Dad, Ethan, Sydney & Jade



Jayla, it seems like yesterday that you graduated from kindergarten now you're graduating from 5th grade & heading to new adventures at middle school. Mommy is so proud of the young lady you are becoming.



Happy 4th birthday little man! We love you very much!



Happy 4th birthday Carter! You, my boy, are truly one of the best treasures we have ever received! Love, Momma, Dadda, Carson and Corbin



Happy birthday to Toby Baker June 11!

Jonathan will turn 5 in June. He is getting ready for kindergarten and has blossomed most in his talking and signing. He brings us laughter and joy every day.



Happy 14th birthday Trey Blair on July 11! Trey lights up our lives with his infectious laughter and his loving heart!



Happy 4th birthday Chance!! We are so proud of you! You amaze us and fill us with gratitude every single day!!!



Molly Mahoney celebrated her 7th birthday on May 11.



Happy 5th birthday Chelsey Coleman on Aug. 1! Mommy and daddy love you baby girl.



Happy 6th birthday Gabe!

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