



Fall 2020

Down Syndrome

Association of Central Kentucky

Support • Educate • Celebrate

Lindsey Greer



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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The DSACK newsletter is published quarterly by the Down Syndrome Association of Central Kentucky, 1050 Chinoe Road, Suite 204, Lexington, KY 40502

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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.

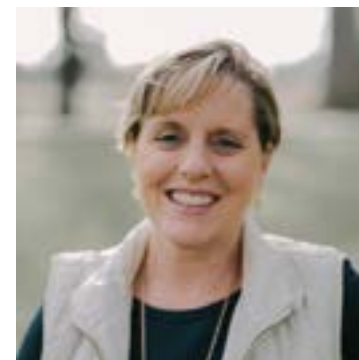
Visit our calendar on www.dsack.org to see current events, activities and educational opportunities!

Adults with Down syndrome brighten, enrich lives

By Traci Brewer

Over the past seven years, DSACK has been growing to offer programs for people with Down syndrome across the lifespan. It was really quite easy to come up with programming for younger children and elementary-age children. We asked parents what would most help their children, and built programs to meet that need. However, when it came to adding something for teens and adults, we didn't want to just ask parents; we wanted input from the people we would be serving. About three years ago, we held a focus group study for parents of teens and adults, and another focus group for teens and adults (with no parents allowed). We really wanted to hear from the individuals with Down syndrome. We didn't want to assume that we knew what they wanted or needed.

That focus group unveiled a lot! First it showed us that parents of teens and adults with Down syndrome have concerns, of course, but that their adult with Down syndrome continues to brighten and enrich their lives. Yes, they are serving as chauffeurs and still have health and lifestyle concerns for their adult son or daughter, but not one



parent felt their son or daughter was a burden on their lives. So once again, the myth that having a child with Down syndrome is burdensome was totally debunked! Secondly, when asking the teens and adults with Down syndrome who participated in our focus study what they wanted for their future, we discovered several commonalities across the board:

- 1) They wanted to go to college.
- 2) They wanted to be in a rock band.
- 3) They wanted to date and/or get married.

I was honest with them and told them that DSACK could work on getting them to college, that DSACK could in no

way afford to put together a rock band to tour the world, and that dating and getting married were tough for everyone, but that DSACK would find a way to help. I'm proud to say that DSACK is entering their third year collaborating with BCTC for college classes on campus, (pre-COVID 19, and now online due to COVID 19). They have taken two public speaking courses, an art class, and are now starting on a course of study over the next few semesters on health and nutrition. I'll be honest, we are not working on a touring rock band, but who knows what the future will bring! We still want to find a way of offering a workshop on dating and marriage and have been exploring speakers, books, and resources to hopefully do this in 2021.

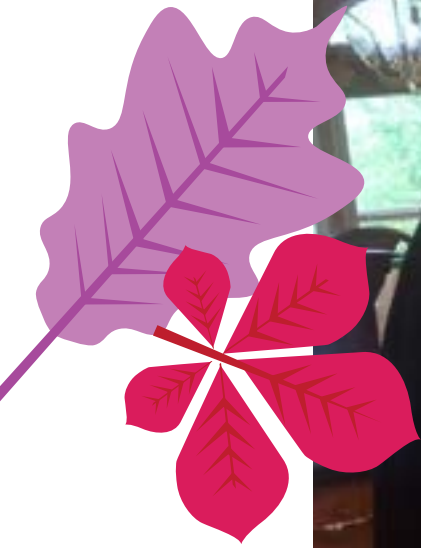
My daughter, Emily, is now 22. She is the fourth of five children. Yes, I worry about Emily's future, her health, and making sure she has a full and rich life of friends and opportunities. Guess what, I have the same worries for my other four children! Keith and I see our friends becoming empty-nesters, and yes, their retirement years will look different than ours. For now, Emily chooses to live at home and that is the best place for her. She

may always live with us. Does that "cramp our style"? Absolutely not! We have the privilege of enjoying Emily every single day, watching her continue to grow, and keeping up with her friends such as the DSACK college group. (By the way, Tuesday nights are my favorite night of the week as I get to hang out with them on their Zoom call until Emily tells me to "leave so she can talk".) These are truly amazing adults!

This issue is focused on adults. Chad Bell's mom, Susan, shares her parent's perspective; UK Sanders Brown research team answers our questions about aging and Down syndrome; and DSACK volunteer Terri Rue shares more about the weekly College Hangout Zoom calls. We've also asked several adults with DS to give us a one-line quote about their lives, and they're sprinkled throughout the magazine.

As with every issue, you'll find out about the amazing things that took place at DSACK over the summer and what's coming up for the remainder of 2020. If you want to help coordinate a rock band tour for DSACK in your spare time, let me know. I've got some musicians ready to rock!

Check the DSACK calendar at www.dsack.org for information and to register for events and activities.



Chad Bell makes snickerdoodles during DSACK's recent cooking class.

Grateful for this phase of life and all it offers

By Susan Bell

Did you know that you can ask Alexa to tell you a joke, and another joke, and yet another joke, and she literally never runs out of jokes!! Do you have someone in your life who enlivens each dinner time with the latest news stories and weather predictions? Do you have an avid sports fan who lets you know about each game day, time, and opponent? Do you know how to make pineapple pizza or cheese quesadillas?

These are just some of the many ways in which we continue to be enriched through sharing our lives with Chad, our adult son with Down syndrome. Chad came into our lives as a frail infant who was not expected to live beyond his first few months. His therapies and medical appointments quickly dominated our daily schedule, and we didn't dare to think much beyond the next day or week. Our worries centered around his health and development, and the way in which our 3-year-old daughter would adjust to less time and attention.

Thirty-seven years later our pandemic-narrowed lives are full to brimming with an energetic and curious young man who continues to delight us with his sense of hu-

mor and to surprise us with his compassion and insight. Pre-COVID-19 closings, Chad's life outside our family was full of his work at our local McDonald's restaurant, his role as a deacon in our church, recreational opportunities like horseback riding through Lexington-Fayette County Parks and Recreation, and his community college classes with DSACK. When the pandemic narrowed his outside activities, Zoom became a big part of our lives. Chad has his own computer and is now on Zoom about three to four times a day, interacting with friends and learning new skills. He lives in his own apartment on the lower level of our home, makes his own breakfast and lunch, oversees his personal care, and walks, feeds, and otherwise independently cares for his golden retriever, Max. He uses his smartphone just as we all do – as an alarm, to monitor his daily steps, to Facetime with his sister, to keep up to date with weather and news, and to text us from downstairs to ask about dinner! These are skills that we would never have dreamed about when we waited years for that toilet training to take effect!

However, what we never could have predicted was the lovely young man he would become. He is so very compassionate and

kind – I still remember the day that I found a note in my home office that said, "I'm sorry they hurt your feelings at work. Love, Chad" This was his unsolicited response to overhearing about a particularly difficult day.

There are still some really bittersweet times. As an example, one day he asked us, "Can a single man adopt a child?" I know that he longs for the close relationships that most of us take for granted. He is acutely aware that other people get promoted and take leadership positions, and he often tells me that after McDonald's he is going to become the manager for DSACK (sorry Traci!) His hair is turning gray (as is ours), and his cardiologist has reminded us that his heart condition is not immune from lifestyle-created damage, so, just like all mid-life adults, he needs to start watching his snacks. Thankfully, DSACK and BCTC are providing a course on nutrition! Originally, we feared he would not live to age with us; now we are sometimes exhausted by the transportation and oversight he requires. All in all, we're grateful for this phase of life with all of its promise and challenge.

Susan Bell is a professor of psychology at Georgetown College. She lives in Paris with her husband, Jeff, and son, Chad.

Summer programs a 'virtual' success

As with everything else, COVID-19 wreaked havoc on DSACK's well-laid plans for the summer. But the staff, led by Education Coordinator Hana Toupin, pulled together to come up with not one but two virtual programs for students with Down syndrome.

The Summer Enrichment Program, which normally meets in person three days a week in June and July, was revamped to include take-home boxes of activities for children ages 8 to 11. The boxes included art projects, math activities, and a life skill project. Then once a week, a virtual "meeting" was held with each family.

Created to help students avoid regression during the summer months when school is not in session, the at-home version fulfilled the Summer Enrichment Program mission, Toupin said.

"One hundred percent of the students did not regress in any of the areas we were focusing on," she said. "I heard over and over

again how helpful the activities were."

Nine families participated in the Summer Enrichment Program. "We were able to reach new families that may live too far to come to our in-person program. I believe we will continue to have some sort of virtual portion even when we can go back in person," Toupin said.

New this summer was a Book Club for students 12 and above. It was originally slated as an in-person class over four weeks, but DSACK turned it into a virtual offering as well.

"We were able to transition this program into a virtual one very easily," Toupin said. "It turned out to be very successful."

Set up in a book club format, students were charged with reading specific chapters of "Charlotte's Web" each week and then discussed via Zoom what they read. Three different reading levels were provided, so students were able to read according to their skill level. Discussion questions were also



provided for students to answer in advance of their virtual meetings.

"This was the highlight of my week," Toupin said. "They were all so prepared, and that made the discussion so vibrant." Fourteen students participated.

BCTC classes move forward online

Students in DSACK's College Bound program are once again taking a Bluegrass Community and Technical College. However, because of COVID-19, class is being conducted virtually.

The eight-week Health and Nutrition class is being taught by professor Sobhana Ranjan. Thirteen students are participating in the course, as well as a weekly study group via Zoom.

Boutique 21 now open

Visit DSACK's Boutique 21 at <https://www.dsack.org/shop/> for those unique items on your shopping list.

Just added: mood tumblers

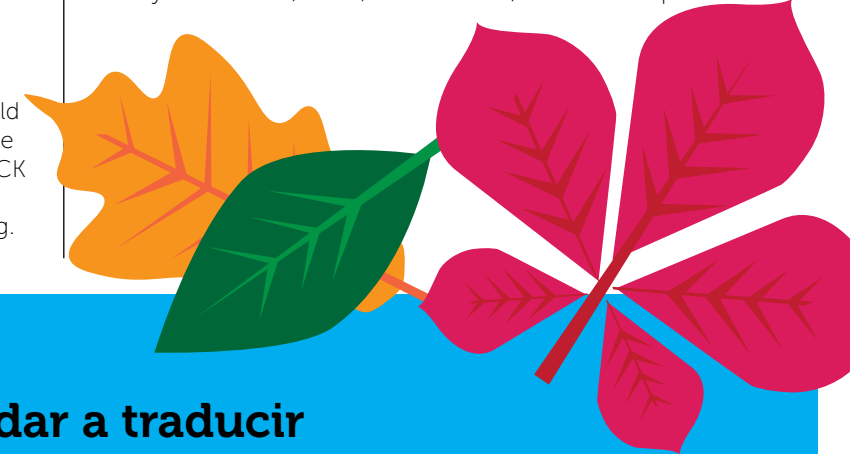
that change color with hot/cold liquids and adult- and child-size facemasks. We also have DSACK hats and apparel. All items are available for pickup or shipping.

Holiday party set Dec. 12

Go ahead and mark your calendars for DSACK's annual Holiday Party. If all goes as planned, it will be Dec. 12, again at the Marriott Griffin Gate in Lexington.

Of course, health concerns surrounding COVID-19 could well change the plans. But we are proceeding as if it's still a go. Stay tuned to social media for updates.

Each year, the Holiday Party brings together DSACK families for a visit by Santa Claus, crafts, refreshments, and fellowship.



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

Aging and Down syndrome: A closer look

A Q&A with the Research Team at the University of Kentucky's Aging and Down Syndrome Research Study

Q: People with Down syndrome (DS) are living longer than ever before. To what do you attribute this?

A: Before 1954, people with Down syndrome generally did not survive beyond the age of 30 years due to a high risk of not surviving infancy and a limited ability to treat childhood diseases. Since that time, improved medical treatments have doubled life expectancy. A child with DS born today can expect to live into their 60s and often beyond. However, adults with DS experience what may be called 'accelerated aging', where they appear to 'slow down' as they enter their 40s and 50s. Therefore, annual health checkups are particularly important starting around age 35.

Q: What are some of the early changes that families and caregivers can be on the lookout for?

A: **Sensory Losses** w Cataracts (clouding of the eye lens) are seen in up to 13 percent of persons with DS. Keratoconus, which causes the round cornea to become cone shaped, leading to distorted vision, occurs in up to 15 percent of persons with DS. Both eye conditions can be screened for and detected by most health-care providers, but these should be assessed regularly by an optometrist or ophthalmologist.

There is also a high risk for conductive hearing loss in addition to small ear canals. Hearing losses occur in up to 70 percent of adults with DS. Poor hearing further complicates speech and communication problems. The sensory change associated with hearing loss may, in turn, contribute to delirium (a sudden change in thinking and attention leading to confusion). Routine ear examinations can assess for wax impactions. Periodic screening by an



audiologist can formally assess hearing loss and the need for hearing aids.

Undiagnosed sensory impairments (vision or hearing) are frequently mistaken as stubbornness, confusion or disorientation in adults with or without DS. These conditions are common and, when properly identified, can be greatly improved with cataract surgery, glasses, hearing aids, ear cleanings and environmental adaptations.

Hypothyroidism: The thyroid gland helps control how quickly the body uses energy, makes proteins and regulates hormones. Thyroid dysfunction is common in adults with DS and can lead to symptoms of fatigue, mental sluggishness, weight fluctuations and irritability. Hypothyroidism occurs in 10 to 40 percent of persons with DS and is easily detected via a screening blood test. Treatment usually involves taking thyroid medications that regulate abnormal hormone levels.

“I’m glad to have my whole family in my life.”
– Chad Bell

People with DS are also at higher risk of developing autoimmune thyroiditis, a condition in which the body treats its own thyroid glands and hormones as threats, therefore producing antibodies that 'attack' the gland. There is an associated neurological disorder known as Hashimoto's encephalitis that can be mistaken for dementia as symptoms can gradually emerge. Importantly, this disorder is also known as 'SREAT' (steroid-responsive encephalopathy associated with

“I like to volunteer at the Ronald McDonald House.”
– Julia Steinman

autoimmune thyroiditis) pointing to how this condition is often treated.

Sleep Disorders: Children and adults with DS are at increased risk for sleep apnea, a sleep disorder that involves pauses in breathing that lead to poor quality, non-restorative sleep. Obstructive sleep apnea is estimated to occur in 50 percent or more of persons with DS. It is not always associated with obesity and may be related to the hypotonia (muscle relaxation) and structural differences in the tongue and neck associated with DS. Signs of possible sleep apnea include snoring, gasping noises, daytime sleepiness, morning fatigue (difficulty getting out of bed), excessive napping and fragmented sleep. Undiagnosed or untreated sleep apnea leads to symptoms of irritability, depression, poor concentration, behavior changes and impaired attention and can put a strain on the heart and lungs. Untreated sleep apnea can also cause and/or worsen cognitive changes, such as memory difficulties. Sleep apnea can be detected via a sleep study performed at a sleep lab or sleep testing can be arranged in the home. If diagnosed, this condition can be treated with devices that improve breathing during sleep.

Osteoarthritis: People with DS are typically hyperflexible and the large joints in the hips and knees suffer increased wear-and-tear. Adults who are or previously were overweight are at increased risk. Arthritis is painful and can lead to decreased mobility and decreased willingness to participate in activities. A recent study from Ireland suggests that arthritis is at least two times greater in children with DS (see: <https://rmdopen.bmj.com/content/5/1/e000890>).

Osteoporosis: Osteoporosis is a thinning of bone mass that can lead to fracture. People with DS are at higher risk for this condition, especially if there is immobility, low body mass, family history of osteoporosis, early menopause or longtime exposure to certain anti-seizure medications. A bone density test will identify this condition. Osteoporosis is treated with medication, exercise and lifestyle modifications.

Celiac Disease: Celiac disease is a condition where the body cannot digest wheat

“I like to hang out with my family. We just made tie-dye shirts together!”
– Lindsey Greer

gluten and wheat products, causing damage to the intestine and preventing absorption of certain nutrients. When celiac disease is present, it can cause gastrointestinal distress, nutritional deficiencies, diarrhea, and sometimes general irritability or behavior changes. There is a greater (3 to 6 times higher) risk of this condition in individuals with DS (see: <https://www.beyondceliac.org/celiac-disease/related-conditions/down-syndrome/>). Celiac disease can be screened for by a blood test but requires a biopsy and evaluation of the small intestine to confirm the diagnosis. A visit with a gastroenterology specialist is usually needed to formally make the diagnosis.

Atlantoaxial Instability and Cervical Spine Concerns: The region of the spine located in the neck is called the cervical spine. In adults with DS, there is increased risk of instability between the first and second spinal bones in the cervical spine (located directly below the base of the head). This is known as atlantoaxial instability. If instability is present and arthritic changes also occur, there is an increased risk of damage to the spinal cord in that region. Gradual narrowing of the spinal canal can also occur due to development of severe arthritic changes in the bones of the spine. This is called spinal stenosis. When these changes arise, they affect the spinal cord resulting in symptoms such as weakness in the arms or hands, walking abnormalities, neck pain, or incontinence. Scans of the cervical spine can show this condition if any signs or symptoms are present.

Q: In what ways can families and caregivers be proactive regarding these early changes?

A: Clearly, regular visits with pediatricians in early life and later family medicine and primary care providers can serve to establish patterns of growth and development along with a 'baseline' for adults. These visits can identify many of the conditions mentioned previously such that effective treatment can be started. In order to observe change effectively, one must be informed about what the individual could do at his or her very best. This could be considered the individual's 'baseline.' The importance of having a good description and understanding of an individual's best capabilities is that this information can be used for comparison if changes are observed as the individual grows older. It is extremely helpful to record baseline information throughout

“I like all my friends.”
– Emily Brewer

adulthood – noting basic self-care skills, personal achievements, academic and employment milestones, talents, skills and hobbies. A baseline can also be established formally through an office visit with different specialists, where these capabilities can be reviewed, and mental abilities can also be tested. Formal screening for memory, behavior, and day-to-day function should become a priority throughout mid- to later-adulthood.

Q: What are some of the signs that indicate a mental health disorder and what should families and caregivers do when they are concerned?

A: As adults with DS grow older, there is increased risk of experiencing certain common mental health disorders like depression, anxiety, obsessive-compulsive disorder and behavioral disturbances. A thorough medical assessment is recommended to look for any new (and potentially treatable), physical or medical conditions that may contribute to behavior or mood changes. However, some research has suggested that behavioral and psychiatric symptoms often precede a dementia diagnosis in adults with DS.

Psychiatric illnesses can have different features in adults with DS. Therefore, an evaluation from a mental health provider with specialized training or expertise in adults with intellectual disabilities is recommended. In addition to medical and psychological contributors to mood changes, it is important to be sensitive to any significant change in environment or social structure. Paying attention to recent emotional upheavals such as the loss of a parent, loss of a housemate, departure of a beloved staff member, conflict at the workplace, etc. is important as individuals may experience great difficulty coping with these changes.

Q: A key concern for aging adults with DS is the increased risk for Alzheimer's disease. What is the connection between Alzheimer's and DS?

Continued on page 8

“I like spending time with my family and playing the drums in the Great Danes rock band.”
– Conor Healy



Continued from page 7

A: As many DSACK members know, DS involves a full or partial third copy of chromosome 21. This chromosome plays an important role in the DS - Alzheimer disease (AD) connection. Chromosome 21 carries a gene that produces one of the key proteins (amyloid precursor protein; APP) involved with changes in the AD brain. The buildup of abnormal protein 'clumps' known as beta-amyloid (or neuritic or senile) plaques is promoted by too much APP. Additionally, scientists have located several genes on chromosome 21 that are involved in the aging process and that can also contribute to the increased risk of AD. It is this unique property of chromosome 21 that makes the disease a greater concern for people with DS. Excellent resources on AD and DS can be found on the National Institute on Aging website (www.nia.nih.gov/health/alzheimers-disease-people-down-syndrome) and National DS Society website (www.ndss.org/resources/alzheimers/).

"I like my job at DSACK and want to keep going to college."
— Emily Wright

Q: What is the difference between Alzheimer's and dementia?

A: Dementia is an umbrella term for many brain disorders. Clinically, dementia involves progressive losses in mental abilities and daily functioning. AD is one type of dementia that gradually destroys brain cells, affecting a person's memory and their ability to learn, make judgments, communicate and carry out basic daily activities. Research with amyloid-PET scans shows that there is a significant buildup of beta-amyloid in people with DS over the age of 50. While some research suggests that AD is not inevitable in people with DS, it has also been argued that it may affect over 90% of people with DS over the age of 60. However, some adults with DS will not show Alzheimer's symptoms in their lifetime. Estimates show that AD affects about 30% of people with DS in their 50s. By their 60s, this number comes closer to 50% or higher.

Early symptoms, in addition to memory loss,

that have been described include:

- Reduced interest in being sociable, engaging in conversation or expressing thoughts.
- Less enthusiasm for usual activities.
- Declines in attention.
- Sadness, fearfulness or anxiety.
- Irritability, uncooperativeness or aggression.
- Restlessness or sleep disturbances.
- Seizures that begin in adulthood.
- Changes in coordination and walking.

Q: Is there anything families and caregivers can do to prevent Alzheimer's or slow down its progression?

A: Studies suggest that one of the best ways to keep the brain functioning optimally is a healthy lifestyle (It has often been said that what's good for the heart is good for the head). Scientists and clinicians believe that many of the risks associated with developing AD in the general population (examples are diet, obesity, cardiovascular problems, diabetes) can potentially be modified to reduce the impact that genetics have on developing this disease. There is growing evidence from studies of aging and the risk of AD in people without DS supporting lifestyle changes. As research progresses, there is hope that some of these promising lifestyle changes can be encouraged in adults with DS.

A healthy diet, rich in fruits and vegetables that contain many antioxidants is associated with a reduced risk of developing AD. It is interesting to note that eating well seems to provide greater benefits than taking supplements or higher doses of vitamins, which may be associated with side effects. There is also evidence suggesting a Mediterranean diet (including foods like fruits, vegetables, nuts and grains) lowers risk. A healthy diet

"I like to spend time with my family and friends. My favorite food is mac and cheese."
— Aliyah Clay

"My life is centered around God."
— Joshua Landeene

may be particularly beneficial for people with DS as several genes on chromosome 21 can lead to higher levels of inflammation and oxidative stress in the brain, which may be modifiable with a diet rich in antioxidants. Benefits of antioxidants may be greater when ingested in food as studies looking at antioxidant supplements in older people with DS lead to limited if no improvements.

Physical exercise is another avenue that can lead to benefits for both the heart and the brain. Exercise can promote a healthy body weight, which is important given recent studies that higher body mass index is associated with a higher risk of type II diabetes, which in turn has been associated with higher risk of AD. There are several studies in younger people with DS showing functional benefit from an exercise program.

"I want to be an actress and on You Tube."
— Blair Osborne

Use your brain! Some evidence suggests that the more active your brain is, the greater your protection from AD. Published reports suggest that activities like reading, playing games, solving puzzles, and cognitive training can slow the development of AD or reduce risk. The brain reacts to mental activity by growing more connections, growing new neurons and releasing molecules that keep neurons in the brain working well.

Keeping socially active also appears to be protective against AD. People who have lots of friends, interact frequently with friends and family, and are engaged in social groups (e.g. church) tend to have less of a risk for developing AD while having a fuller, richer life as they get older. The molecular benefits in the brain due to social enrichment have not been well characterized but being socially active is associated with physical exercise and cognitive engagement, both of which may improve brain function.

As described before, the higher prevalence of obesity in DS along with orofacial anatomical variations lead to a high frequency of obstructive sleep apnea (OSA). The incidence of OSA in children 2 to 4 years of age with DS is as high as 57 percent, and other studies suggest that it is even higher. In some studies, the frequency of OSA has been as high 94 percent with people with DS showing varying levels of OSA severity. OSA impacts cognition both in childhood and adulthood in DS. Repeated episodes of depriving the brain of oxygen can lead to problems with parts of the brain (particularly the hippocampus) that are involved with short-term memory. Therefore, OSA is a risk factor, once identified, that can be treated to benefit the brain.

Pharmacological interventions to slow or prevent AD in people with DS are either actively being tested or have been proposed. The primary target at this point is the buildup of beta-amyloid due to too much amyloid precursor protein in DS. The hope is that beta-amyloid can be cleared from the brain using a vaccine against beta-amyloid. While this approach has not been very successful in treating AD, the genetics of DS have suggested to some scientists that this is important to try. However, since impairment of the immunological system is often seen in DS (in part due to related genes on chromosome 21), careful study of vaccines as well as drugs that modify inflammation and the immune response in DS will be needed if effective therapies are to be developed in the future.

"I like good food."
— Hunter Bowden

Q: Are there conditions for which people with DS are at lower risk as they age?

A: While adults with DS are at risk for several medical conditions described earlier, they are also at low risk for other medical conditions. In a review of cancers among individuals with DS, malig-

"Life is grand. I like hanging out with my family and friends."
— Jason Smitha

nant solid tumors were less common as were epithelial tumors, breast, uterine, digestive, genital, skin, bronchial, ear/nose/throat and urinary tract cancers.

People with DS appear to be 'protected' from atherosclerosis and hypertension. In a study of 70 adults with DS aged 40–66 years, atheroma (degeneration of the walls of the arteries caused by accumulated fatty deposits and scar tissue) was completely absent, in contrast to similarly aged adults without DS. Further, young adults with DS aged 13–42 years seem to have low blood pressure compared with age- matched controls, and a study of 86 people with DS from 18 to 56 years of age found no systematic increase in blood pressure (hypertension) with increasing age.

"I love having my Christian Young Life friends."
— Callie Baesler

Given the health-related challenges of living with Down syndrome, regular checkups are important for monitoring development as well as risks for dementia. Now more than ever, research is important to understand how the brain changes in DS across the life span in order to improve and maintain the quality of life for people with DS. It is also hoped that the understanding of this genetic condition can open new therapeutic opportunities for people with DS as well as other individuals at risk for or with Alzheimer's disease.

To this end, several large-scale studies of aging and DS are currently underway or starting soon (regularly go to the NDSS, NIA and other websites for updates). Our team of clinicians and researchers at the Sanders-Brown Center on Aging, Kentucky Neuroscience Institute, and the University of Kentucky are committed to being part of these important efforts while serving families in Kentucky and the surrounding region.

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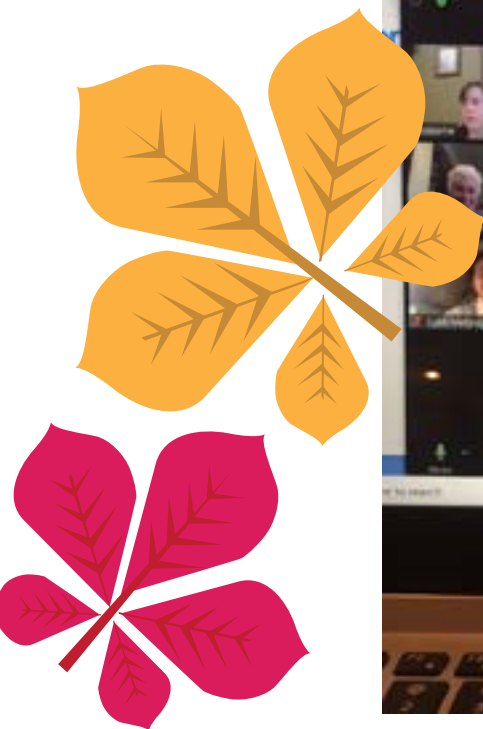
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Happy Hour: Hanging out with DSACK's college crowd

From 6:30 to 7:30 every Tuesday night, Terri Rue is at her happiest.

That's when she hangs out via Zoom with a group of young adults who participate in the DSACK College Bound program. Officially, she's the moderator of the so-called College Hangout, but she's really just part of the "family" that makes up this enthusiastic group.

"To be honest, it's probably the happiest hour of my week every week," said Rue, a behavioral therapist who works with individuals with Down syndrome and other intellectual disabilities. "They have such love for each other and for me. That's why I keep doing it."

College Hangout, which got its start when the COVID-19 pandemic hit and the College Bound program classes at Bluegrass Community and Technical College were canceled, is more social hour than anything. Like everyone else who was sidelined during the pandemic, the students were looking for ways to stay in touch – in a safe way.

"The College Bound students were already used to meeting on Tuesday nights for study hour, so it was only natural to continue their get-togethers virtually after COVID hit," said DSACK Executive Director Traci Brewer. "And it just took off."

Rue, who exudes enthusiasm professionally and personally, took



on her volunteer role after talking to Brewer about things to do with her cousin, Lindsey Greer, who has Down syndrome. Since Lindsey was already participating in the College Hangout, Brewer suggested Rue join her and the others on Tuesday nights.

"It was just a good fit," Rue said. "Now I get to have dinner every Tuesday with Lindsey and then we do College Hangout together."

If Rue wondered whether the group would have much to talk about, it was fleeting. She discovered quickly that they had plenty to say.

"We talk about anything from their favorite foods, favorite vacation spots, favorite dog breeds – anything that they come up with. I don't come up with the questions to ask, they tell me what they want to talk about. I make sure there's not any silences but I also make sure there's not any random conversation going on. We stay on what-

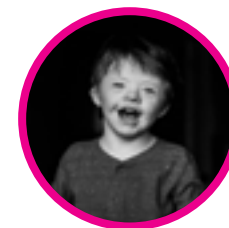
ever the topic of the evening is," she said.

Joining Rue in the moderator role is another volunteer – Luke Niebrugge. "We have such great fun doing this together," Rue said.

There are regularly 12 to 14 people who join in each week. For now, college students are attending online classes through October, but College Hangout will pick back up when their class is complete. Brewer says College Hangout will continue indefinitely.



Happy birthday to Aryana Slaughter, who will be 5 years old on Oct. 5.



Dillon will be a big 5 years old on Oct. 15. He loves dancing, playing outside and helping in the garden. Happy birthday little man! Mommy and Daddy love you so much!



Maya Singleton turned 9 years old Aug. 29. You are the sweetest little girl we know. Happy birthday! We love you. Daddy, Mommy, Sarah, Makayla and Hana



Happy 3rd birthday Woods! We love you so much and are so thankful God blesses us with the sweetest, most lovable boy! We love you. Mom, Dad, and Major



Toni K.L., Nov 13. HAPPY BIRTHDAY baby girl! You inspire us every single day!!!



'21 Days to Do Something Extra' a huge success

By Traci Brewer

DSACK's "21 Days to Do Something Extra" was a lot of things: It was different from anything DSACK has ever done. It was challenging to turn a popular in-person event into a virtual one. And it was exciting to try something new.

But most of all, "21 Days to Do Something Extra" was a success. A huge one. In many ways.

First and foremost, the event was a fundraising success. As of presstime, we were \$2000 OVER our goal of \$140,000. How amazing is that? We'll need to keep up our efforts to raise money in order to make sure all our programs and services free to families. But we got an awesome start.

A couple of things stick out about the fundraising effort. One, for the first time we had an anonymous donor pledge \$3,210 for a team that raised equal to or more than that amount. Several teams reached that point and were placed in a drawing for the matching gift. The winner was Lizzie's Busy Bees.

Also, the creativity behind the fundraising effort was phenomenal. DSACK families did everything from sell fudge to hold Facebook fundraisers to walk 21 miles in honor of individuals with Down syndrome. One family took their story to television in an amazing feature that created awareness about Down syndrome, DSACK, and "21 Days to Do Something Extra" campaign.

Secondly, "21 Days to Do Something Extra" was fun! I've heard from so many of you

who loved the creativity and the opportunity to raise awareness and participate in all the fun events throughout the 21 day. The staff and I certainly had fun! We came together for a sneak peek at all the DSACK learning opportunities, we got moving together, we joined in for an awesome talent show, we honked and shouted and waved during a car parade, and we experienced the talents of some popular area musicians during the music festival.

Lastly, this unique event was a success in creating awareness – awareness about Down syndrome and awareness about DSACK and its mission. We had many first-time team members, donors, and supporters this year – all a testament to all of our efforts to reach out to the community.

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and to educate ourselves and others throughout Central and Eastern Kentucky.