

# Down Syndrome Association of Central Kentucky Support · Educate · Celebrate Spring 2019



# Keeping Up with DSACK



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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.



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

# From the Executive Director

# Building relationships key to carrying out DSACK's important mission

#### By Traci Brewer

Within DSACK's mission to educate, support and celebrate is the very important responsibility to build relationships – relationships with families, relationships with medical providers and relationships with schools, churches, businesses and others throughout the community. In fact, we must make the connections and build relationships before we can even carry out our mission.

Until recently, DSACK's outreach efforts fell primarily to volunteers. But two years ago, thanks to the vision of our board of directors, DSACK placed a high priority on outreach and created a medical and community coordinator position. The board felt it was important to make connections beyond just asking individuals and groups to donate money.

As the name of the position



implies, our outreach efforts are two-fold. On the medical side, we are striving to make connections with a broad range of medical providers in our community in the hopes that they will refer us to families with a prenatal or postnatal diagnosis. Making contact with these families, then, helps ensure DSACK can educate, support and celebrate throughout the lifespan.

The medical and communi-

ty outreach position is held by Courtney Elbert. So far, through Courtney's hard work, DSACK has made great progress in this effort, the results of which can be seen day in and day out.

For instance, for our World Down Syndrome Day celebration, we are partnering with Lexington's Safety City to provide children with Down syndrome a course on pedestrian and fire safety (see more on page 10). Safety City is a joint project between Eastern Kentucky University's College of Justice and Safety and the Lexington Police Department. Courtney and I met with them to customize a presentation just for us.

At the same time, DSACK has been busy forming relationships with the Lexington Police and Fire departments in the hopes of presenting information to first responders about dealing with individuals with Down syndrome.

And that dance salsa class that started in February? Also the result of reaching out to businesses - the Salsa Center in this case - to see if they would work with DSACK. As Courtney says in the story on pages 6 and 7, it's so much fun to see what develops when connections are made.

Beyond helping DSACK to better educate, support and celebrate our families, building relationships has an added bonus. It helps others to see the value and worth of people with Down syndrome, which of course, opens doors to all kinds of possibilities.

You, too, can help in this effort. Who do you know that would benefit from being a community partner with DSACK? Pass along your ideas and contacts to us. Together, we can fulfill our vision to create communities where people with Down syndrome are valued and included throughout every stage of their lives.

# Join **Club 21** today and help keep these programs and events free for everyone! For as little as \$5 a month, you can make a big difference. Start giving today at www.dsack.org/club21.



Learning Program \$6000



Healthy Movements Program \$2,000



Summer Enrichment \$3,500



Social Events \$10,000



We Work!



Dinners \$1,500



Adult College Classes \$4,000



Outreach to Community Priceless!





# A Parent's Perspective

Our largest fundraisers are on the calendar - two tried and true ones and one that's brand new. The fund-raising fun kicks off May 18 with the Nothing Down About It Gala. This year's Gala will be held at the 21C Museum Hotel in downtown Lexington. Once again, there will be a live and silent auction (Bill Menish returns as our awesome auctioneer), cocktails and dinner. The Gala is followed by the inaugural Down

with Dares scavenger hunt June 7 in downtown Lexington. It's a photo scavenger hunt in which participants are "dared" to take photos of specific things. Additional information will be shared in the coming months.

Family Fun Day and Walk. This year, it will be Sept. 14. Thanks to the success of last year's event, we will return to the Masterson Station

May 18 Nothing Down About It Gala

> June 7 Down with Dares Scavenger Hunt

Sept. 14 Fall Family Fun Day and Walk

Park fairgrounds with all the carnival-like activ-

More details on all these events will follow, so keep your eyes open for emails and social

## Welcome to three new board members

Three new members have been added to the DSACK Board of Directors. They are Laura Yost and Matt Shorr, both DSACK parents, and Jonathan Wright, a sibling.

Yost is a stay-at-home mom of four children. Shorr is a financial adviser at Wells Fargo. And Wright is the compliance officer with Colonial Claims. All three live in Lexington.



It's Salsa time! DSACK's salsa classes have been a big hit. The Sunday classes are held through March 24 at the Salsa Center in Lexington.



Keli and Carter Blankenship

## After a storm, there is always a rainbow

### By Keli Blankenship

There are so many unique stories about discovering your child has Down syndrome, but the overlapping similarity I have observed is that the negatives seem to come before the positives. It only took six words spoken by my husband for my entire life to change, "They think he has Down syndrome."

I could share the unbelievable trials we took to conceive him, the worry we had along the way and the unexpected shock that came with his diagnosis, but we have all just begun or experienced this journey so I won't. While our story is unique to us, yours are unique to you.

Some of it is difficult to reflect upon and admit. To feel sadness over a child you wanted in the worst way, who has no idea of life, genetics, health risks and abilities, surrounds me with guilt at times. Carter is only 3 ½ years old, but one day, I will have to explain his birth, his diagnosis and the feelings we experienced when he arrived.

The fears, the unknown, the disappointment in a child that we considered a "disability" will have to be outlined. Some may suggest we skip over that part to minimize his hurt, to focus on the positives. However, as a parent

I value truth despite potential hurt, because being untruthful would take away from our experience. He will likely experience his own emotions toward his birth and our response, as well as his understanding of Down syndrome. No matter what, his family will be there to hold his hand.

The good, I could shout from the rooftop. Some might consider my statement of "my entire life changed" as my life became less, sad or more difficult. In actuality, once the initial diagnosis came and we got through it, there were so many changes. Within our family, we valued one another more, we increased family time, and little disagreements became insignificant.

In review of my parental self-growth, which I will also get to share when he asks questions, his birth, despite the initial feelings, has made me a better human, mother, wife and professional. Despite our fear of the unknown, our reality is far beyond our wildest expectations. There are now unimaginable friendships, opportunities, a purpose as well as a spirit and so much more. While the truth will likely have hurt, the good far outweighs it.

The good and bad is a normal occurrence in

a family, we just all have our unique journeys, which includes families without a differently abled child/family member. I would be lying if I said Carter does not have challenges, that I don't get frustrated, that I don't want him to do things similar to his peers or to "catch up." That is the challenging stuff that comes with this journey, but after a storm there is always a rainbow. Initially, the rainbow was the realization of just how LUCKY our family is to have Carter.

Along this path there will be several storms, but the rainbows that come with them are full of beauty. Every achievement along the developmental spectrum is a celebration, and despite six words initially changing my world, one word can do that now, "Momma." It makes me smile every time.

As a parent of a child who happens to have Down syndrome, I don't look at it as "I have to be his mom" or "I am strong for being his mom." I see it as, I get to be his mom and that's the most positive thing of all.

Keli Blankenship is a psychologist at the Lexington Veterans Affairs Medical Center, as well as a mother to Carter. She has two other children, Carson and Corbin.

## Fundraisers galore! Grant funding

And then last but certainly not least is the Fall

# approved

News and Notes

Two more grants were approved for 2018 – a Blue Grass Community Foundation grant for \$3,700 for DSACK's Summer Enrichment Program and a \$5,000 grant from Rite Aid Foundation's KidsCents program to be used however needed.

The grants topped off a phenomenal year for grant funding. More than \$32,000 was awarded through seven grants. The funds were used for the Summer Enrichment Program, We Work!, Learning Program, Strider Bike Camp and more.

Grant funding is important to DSACK. If your company offers grants or you know of other grant possibilities, please let us know

## Next Coffee Chat on Connect the Dots

The next Coffee Chat will be April 13 from 10 a.m.-1 p.m. at the DSACK office. Brooke Gill of Kentucky Child Care Health Consultation will present a program on Connect the Dots, which addresses challenging behaviors of young children (ages 2-5) in a positive

Among the strategies discussed will be: setting clear expectations, modeling appropriate behaviors, using the "Flip-It" technique and actively ignoring inappropriate behaviors.

Child care will be provided, but reservations are required. Registration information will follow soon.







Courtney Elbert has been DSACK's medical and community outreach coordinator for two years. Her role is to make connections in all areas of the community.

# Reaching Out

# DSACK takes seriously its goal to make vital connections throughout the community

#### By Terri McLean

Meeting with families who have just welcomed a baby with Down syndrome is like a "sacred experience" for Courtney Elbert, DSACK's medical and community outreach coordinator.

"It's a special thing to meet someone in that place," Elbert said, "such a personal and vulnerable place."

She should know. She and her husband Dennis found themselves there 14 years ago when their son Sam surprised them with a postnatal diagnosis. "So, we know this moment is a powerful moment in these families' lives."

"We've shared tears, we've shared laughter," Elbert added. "Afterwards, I walk around with them in my heart."

In her role, Elbert embraces the DSACK

## "We've shared tears, we've shared laughter." Courtney Elbert

mission to educate, support and celebrate - providing families with the most recent evidence-based information, offering a listening ear and shoulder to lean on, and assuming the role of cheerleader. Establishing long-lasting relationships is the ultimate goal.

"You delicately try to meet them wherever they are in this journey," she said, "and that's different for each family. You want to just nurture them and meet them right where they are."

But long before Elbert can establish a rela-

tionship with a family, she must first establish relationships with the medical providers who are working with them – hospitals, physicians, nurses and others who are on the front lines of providing care. The medical providers are the all-important link between DSACK and those who receive a Down syndrome diagnosis.

"Thanks to the work we've been able to do the past couple of years, these medical providers are connecting us more to new families," she said. "That says a lot about DSACK's professionalism and reputation."

Recently, Elbert has been invited to make presentations to therapists at Cardinal Hill Hospital, the University of Kentucky College of Social Work, Kentucky One Health Saint Joseph East Women's Hospital, among others – all part of that effort to connect to health care providers. And DSACK has

been invited to present at the UK Center for Interprofessional Health Education's Grand Rounds, a prime opportunity to reach a broad range of graduate students in the UK Health-Care system. DSACK will make the presentation in conjunction with three physicians, a self-advocate, a therapist, a social worker and a family

"We want doctors and their staffs to understand that we are a lifeline – to realize that not to refer us would be a disservice," said Traci Brewer, DSACK executive director.

Establishing relationships with health care providers and families is only part of Elbert's job. She is also tasked with "building long-term relationships and finding commonalities" with individuals, businesses, churches, schools and other community partners.

"That's where I feel like in a lot of situations I'm on a first date," she said. "I tell them about DSACK, they tell me about themselves, and we find ways that our missions intersect."

Recent examples include a partnership with West Sixth Brewing Co., which chose DSACK as its Pay It Forward charity and raised nearly \$4,000 from sales of the company's Pay It Forward Cocoa Porter. Later, West Sixth became an in-kind sponsor of the Nothing Down About It Gala and hosted the gala's after-party.

"We want doctors and their staffs to understand that we are a lifeline." Traci Brewer

Other DSACK partners include Tiger Kim's Taekwondo, which provided Taekwondo classes this past summer, and the Salsa Center, which is offering salsa dance classes for DSACK families.

In addition, as part of DSACK's World Down Syndrome Day celebration, DSACK has created a partnership with Lexington Police Department's Safety City to teach pedestrian safety skills to children with Down syndrome and with the Lexington Fire Department to teach fire safety. A visit to the 9-1-1 Call Center is also planned.

A New Parent Dinner and Brown Bag Lunch are also part of Elbert's responsibilities – activities she said helps families feel more comfortable reaching out to DSACK. In the future, Elbert plans to develop a mentoring program for families, along with other programs that further enable DSACK to extend its reach.

"It's really fun to see these partnerships develop," Elbert said.



New parents receive a bag with books, information and an infant t-shirt.

# 'We didn't feel alone anymore'

By Sarah Huston

When Patrick and I were handed Markus in the hospital, we knew immediately he had Down syndrome. There really are no words to accurately describe the emptiness we felt. Asking God why us? We were alone with our emotions, and that was such a feeling of despair.

We were in our room, and normally in our previous experiences there were always so many interruptions in the hospital, you weren't able to sleep. But not this time, Markus had been taken to the NICU and we were just alone with no one. Just our thoughts. We didn't even know what to say to each other.

I just laid in the hospital bed and cried. Later that evening we had a visit from Courtney, and that's when our mindset changed. She came to see us when she already had plans that night and she turned around and came back to Lexington to see us. God sent her to us for a reason. ...

She explained about DSACK and what they did and how much they help and what an amazing resource to our family it can be. She cried with us, prayed with us, and it was genuine. She is an amazing advocate for her son, Sam, so therefore we knew that everything was going to be OK. Might not be easy, but we are truly going to have our lives changed for the better because of our sweet Markus.

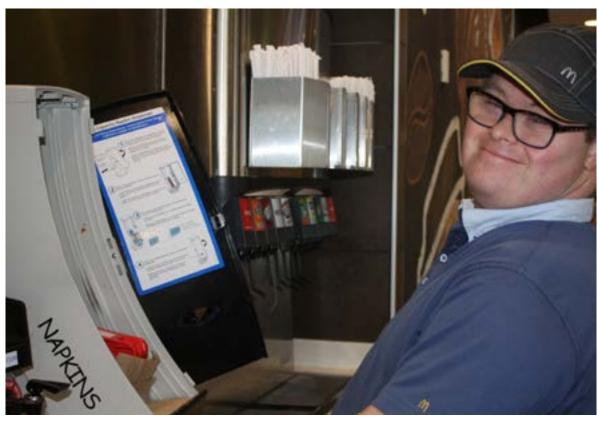
Courtney is the reason we started thinking differently. We didn't feel alone anymore. She gave us information and she gave us two books that provided the tools to tell our 8-year-old daughter and 11-year-old son about Markus and Down syndrome. Those books are what explained the extra chromosome to them. Courtney gave us that!





Be Inspired

# Resources



Chad Bell would rather work at McDonald's Restaurant than anywhere else.

## Chad Bell: 15 years at McDonald's and still lovin' it

If Chad Bell could work anywhere in the world, it would be McDonald's Restaurant – the very place he's worked for 15 years now. That's where he says he wants to be, even in "20, 30, 40 years."

"Going to work at McDonald's is like going to work at Disney World for Chad," Jeff Bell said of his son.

The 35-year-old first donned his McDonald's uniform while still in school at Paris High School. He worked at the McDonald's in Paris as part of the school's work co-op program. Skills learned through the program and experience gained at two other local restaurants and a grocery store made Chad the ideal candidate for a permanent job.

"I would come in and tell them to let me know what he needs to learn at home and we will go over it," Jeff said. "They said, really, he does fine. Every time I've said what do we need to work on, they've said Chad is great." Chad has a variety of duties when he works Monday, Tuesday and Wednesday mornings. "He cleans the bathroom, takes out the trash, mops the floor, wipes the tables ... talks to customers, talks to customers and talks to customers," Jeff laughed. Recently, he began bringing customers' food to their tables.

While Chad loves all aspects of his job, he said his favorite thing about working at McDonald's is "loving the customers." One of his bosses, Lloyd Murray, said the feeling is mutual. "Chad is the sweetest person," adding that many of the customers know him by name.

"He knows more people in Paris than I do," added Jeff, who is a minister at a local church.

Working a regular job has been good for Chad, his father said. "It means he's making

his own way in the world. To a minor extent, he has his own money ... he never spends it all so we let him contribute to family vacations, dinner out and things like that so he feels like he is contributing."

Chad lives largely independently in a basement apartment at his parents' Paris home. He's responsible for keeping his apartment clean, caring for his dog Max and other tasks that come with living on your own.

Work is not the only thing that keeps Chad busy. He's active in his church, participates in Special Olympics basketball and bowling, and enjoys a large collection of movies. Recently, he saved his money from working at McDonald's and took a trip to New York City.

He also loves spending time with his family, which in addition to his father Jeff includes his mother Susan, sister and brother-in-law Sarah Bell and Matt Simpson, his nephew Eli and niece Olivia, and his grandmother Violet Hart.

# Improving quality of life for young adults

This October 2017 article was reprinted from the Global Down Syndrome Foundation website. It also appeared in the foundation's Down Syndrome World magazine.

In the U.S., the life expectancy of an individual with Down syndrome has more than doubled in the last three decades, from 25 years in 1983 to 60 years today.

The reason for this increased lifespan is two-fold. First, the inhumane institutions where the overwhelming majority of people with Down syndrome were forced to live were dismantled in the 1980s and 1990s. This dismantling was a product of the human and civil rights movements of the 1960s and 1970s, which resulted in children with Down syndrome being raised in their homes and receiving education and medical care — basic rights they were deprived of in institutions.

Second, in the 1980s, there were considerable advancements in pediatric heart surgeries, as well as a legal battle that rightly ended with doctors being required to perform lifesaving procedures, including open-heart surgery, for children with Down syndrome.

Although people with Down syndrome are enjoying a significantly increased lifespan, their longevity is revealing some challenging age-related medical diagnoses. For example, it is estimated that approximately 70 percent of people with Down syndrome will develop Alzheimer's disease. As they age, they are also at increased risk of many immune system disorders and obesity. Conversely, they are highly protected from several diseases, including most solid tumor cancers, such as breast cancer, as well as certain

types of heart attacks and strokes. It is clear that people with Down syndrome have a different disease spectrum than typical people.

The American Academy of Pediatrics does an excellent job of periodically updating guidelines pediatricians should follow for their patients with Down syndrome. However, the last medical care guidelines for adults with Down syndrome were published in 2001. They provide many excellent insights and recommendations but are in need of updates based on the increased lifespan of people

Initially, the new guidelines will cover medical care across multiple disciplines, including cardiology, immunology, behavioral and mental health, and obesity/metabolism.

with Down syndrome and advances in medical science.

In 2015, the Global Down Syndrome Foundation's Task Force for Adults with Down Syndrome, a team of more than 60 self-advocates, their family members and medical professionals, unanimously voted for Global to make updating medical care guidelines for adults with Down syndrome a priority.

"The primary purpose is to improve the physical and behavioral health of, and medical care for, people with Down syndrome. That's absolutely why we're doing this," said Dennis McGuire, Ph.D., LCSW, senior consultant at Global. He helped create the first adult medical care guidelines and is tasked with helping galvanize some of the leading medical professionals in adult care to establish new, comprehensive guidelines. "When we're talking about health care and behavioral health, we're talking about improving people's quality of life. That's our goal."

## Empowering doctors to provide better care

The new Medical Care Guidelines for Adults with Down Syndrome will provide medical professionals with updated information about adults with Down syndrome and a checklist of recommended screenings and tests that cater to the unique medical profile of this special population.

There are only a few clinics in the entire country serving teens and adults with Down syndrome," Dr. McGuire said. "So there are huge numbers of them without access to specialty care. They go to local doctors, who may see just a few people with Down syndrome over the course of a year. The guidelines can provide those physicians with a resource they can trust, which will help them deliver better care."

## Addressing key areas of medicine

Initially, the new guidelines will cover medical care across multiple disciplines, including cardiology, immunology, behavioral and mental health, and obesity/metabolism.

"We want to eventually cover many more areas," said Michelle

Sie Whitten, president and CEO of Global. "Unfortunately, Down syndrome is still one of the least-funded genetic conditions by our federal government. As a result, we won't have enough evidence-based research to provide definitive quidelines in some areas but will rather be able to make recommendations. However, in identifying the research gaps, we can also prioritize such research so when we go back to update the guidelines in five years, we have targeted, more comprehensive research to rely on."

"New health guidelines could prove beneficial for many reasons," said Dr. McGuire, who worked for 25 years as a behavioral health expert at the Adult Down Syndrome Center at Advocate Lutheran General Hospital in Chicago. "For example, we've found that people with Down syndrome have a tendency toward depression. We also know there's an overlap between physical and behavioral health. If people have thyroid problems, those can present as behavioral change. When people come in with changes in behavior, behavioral health professionals will recommend a thorough physical exam to make sure there are no physiological issues. If we're treating depression without treating its physical causes, we're not really helping [someone with Down syndromel."

## Vetting the data

The first step in the creation of the new guidelines is a rigorous research process by the ECRI Institute, a nonprofit organization that conducts research to create evidence-based medical guidelines. ECRI works closely with the U.S. Department of Health and Human Services' National Guideline

Continued on page 10





## World Down Syndrome Day events span three days

World Down Syndrome Day is home." March 21, and this year DSACK is celebrating with three days of exciting events instead of one.

First up, on Wednesday, March 20, is a community safety/awareness event for families at the Lexington Police Department's Safety City. The event, from 4-5:30 p.m., will feature partner presentations from the police department, the Lexington Fire Department and Safety City itself.

"Our presenters will touch on fire safety and pedestrian safety in a really fun environment," said Courtney Elbert, DSACK's medical and community outreach coordinator. "They'll get to practice pedestrian safety on the course and have take-home items to practice safety signs at

Located at 1160 Harry Sykes Way in Lexington, Safety City is a joint project between the Lexington Police Department and Eastern Kentucky University.

Then, on the same day from 5:30-6 p.m., we will visit Lexington's 9-1-1 Emergency Call Center, located just across the street from Safety City. There, families can see how the center operates and learn more about Smart 9-1-1 – a free service you can register with to help first responders better address your emergencies.

The following day, which is actually World Down Syndrome Day, will capitalize on DSACK's ongoing outreach efforts



(see more on pages 6 and 7). DSACK's Courtney Elbert, Traci Brewer and Emily Wright will be part of a panel presentation at Grand Rounds for the University of Kentucky Center of Interprofessional Health Education.

"This presentation is a major event for us, as we've been working to establish this important relationship for some time."

said Brewer, DSACK executive director. "We will join doctors. a social worker and a speech therapist in helping graduate students in the UK HealthCare system understand more about Down syndrome."

Finally, on March 22, DSACK staff will attend a Wright's Law seminar in Louisville. Wright's Law is the premier source for accurate, reliable information about special education law, education law and advocacy for children with disabilities.

"Because the Kentucky legislature will not be in session, we are not visiting the capital this year. But we are doing several things to further our mission to support, educate and celebrate." Brewer

## Let's Celebrate



Happy birthday to Talia Baker, who will be 17 in May!



Happy birthday to Joshua Baker. who will be 17 in May!



Raylan "Bubba" Ball will be 8 on April 6. How could this be? Happy birthday to the most awesome little boy we know! Love, Daddy, Mommy and Hunter



Vera James Roberts will be 2 in March. She has a great sense of humor and a laugh that will brighten anyone's day. She is loved more than words can describe.

Joshua is going to be 15! Happy birthday to our favorite super hero. You are such a hard worker, so kind and thoughtful, excellent at whatever you put your mind to and soooo much fun! WE LOVE YOU! Love, Mom, Dad, Ryan, Seth, Ezekiel and Liam





Celebrating the arrival of Rachel Lee Richeson on Dec. 17, 2018. We love you Rachel. Daddy, Mommy, Katie, Laura and Andrew



Happy Birthday Alvin! We are very proud of you! Love you very much! Mom, Dad, Seth, Lucas, Elli and Abbey



Jase Bentlev will be 5 years old on March 18. Happy Birthday to our tractor riding, farm loving little boy!!! Love Mommy, Daddy and Gracie



Clay celebrated his 5th birthday in January! Happy birthday!

Abel, you have changed our family with your precious life. We are over the moon for you! Happy 2nd birthday! Love, Dad, Mom, Razor, and Wells



## Coming up!

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



Safety City, Fire/Police Department Event World Down Syndrome Day Teen Cuisine Cooking Class Coffee Chat All Abilities Bike Camp Nothing Down About It Gala Down with Dares Summer Enrichment Program

March 20 March 21 Starts April 10 April 13 Starts May 1 May 18 June 7 Details to come

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

# Resources continued: Improving quality of life for young adults

## From page 9

Clearinghouse, which validates the guidelines.

"After that, we'll gather information from the researchers and clinicians, put it into the form of actual guidelines, and make certain they are published in medical journals," Dr. McGuire said. "ECRI's role is to make sure that the quality of this process is extremely high."

The project has attracted leading medical professionals from throughout the U.S. who provide clinical care to thousands of adult patients with Down syndrome every year. These clinicians will use the ECRI-vetted data as a basis to apply their vast knowledge in different areas and help craft guidelines and recommendations.

The entire process is expected to take two years, and the anticipated completion date is the end of 2018 with the auidelines expected to be available for publication in early 2019.

## A valuable resource

The goal is to have the quidelines published in maior medical iournals to reach specialty fields and as many medical professionals as possible. The guidelines will be free to parents, caregivers, healthcare providers and local Down syndrome organizations.

"Parents have always been, by far, the best advocates for people with Down syndrome," Dr. McGuire said. "We've made certain to have a version available to families so they can use them to advocate for their sons and daughters."

### Worth the cost

The two-year-long process of creating the new Medical Care Guidelines for Adults with Down Syndrome is costly. Glob-



al Down Syndrome Foundation has committed to funding this important initiative, translating the guidelines into 10 languages and updating them every five years. Global is reaching out to the Down syndrome community for donations, and so far, 28 Down syndrome organizations and multiple individuals have contributed. Their generosity will be recognized in the published quidelines.

"Research is expensive," Dr. McGuire said. "Many groups have already stepped up to help fund the guidelines. They know how important this is and are very excited."

Note: DSACK has contributed to this research.





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