

DSAM insights

bimonthly newsletter to support people with Down syndrome and their families



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DSAM INSIGHTS IS FOR INFORMATIONAL PURPOSES ONLY. IT WANTS TO PROVIDE INFORMATION THAT WILL HELP TO BETTER UNDERSTAND DOWN SYNDROME. THE DOWN SYNDROME ASSOCIATION OF MEMPHIS AND THE MID-SOUTH CANNOT GUARANTEE THE ACCURACY OF ANY INFORMATION

DSAM

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From the desk of the Executive Director...

I am amazed everyday how fast 2011 is flying by! It is June already and we are well into summer vacation. School will be back in session in just a few short weeks. Our lives are so busy that there never seems to be enough time.

The same is true for DSAM. This has been a wonderful year so far. Midway through 2011 and we have accomplished so much! We will expand our educator program, Down Syndrome Education Connection, in the fall to include 45 educators from Memphis City, Shelby County and Desoto County schools. Kids on the Block and the skits including Ellen Jane Peterson are booked all school year. Did they visit your school last year? We have a wonderful partnership with Bright Beginning and are so happy to be able to bring you the Bright Steps and Summer Steps programs.

We have so much more on the horizon including programs for teens and adults with Down syndrome, continued healthcare outreach, increase in social media and of course great things to come as we prepare to STEP UP for Down Syndrome in October.

As we create services and programs offered to our families we want to be sure they are the things that are needed in our community. In order to do that we need to hear from you. What do you need from DSAM? More social outings, educational workshops, conferences, programs for individuals with Down syndrome, monthly support meetings? We are here to provide the resources that the Mid-South needs. Please let us know how we can assist you by contacting me at 901-547-7588 or alyson.edwards@dsamemphis.org.

Sincerely,
Alyson Edwards
Executive Director

WE NEED YOUR HELP! DSAM strives to provide programming, education and advocacy for individuals with Down syndrome, their families and the Mid-South community. Please help us by completing an anonymous online survey. The feedback we receive from this survey will help us to determine what our organization can do better. Your honest and constructive feedback will help us to provide what YOU want from the organization.

PLEASE GO TO <http://www.surveymonkey.com/s/P7HK7T9> to complete the survey. The survey should take about 10 minutes to complete. We appreciate your help and support!

Board Bio

Holly Holt



I am an attorney here in Memphis, Tennessee and I focus my practice primarily in the areas of family law and domestic relations. While in law school, however, I did a great deal of research during a clerkship regarding the Individuals with Disabilities Education Act (IDEA), which sparked my interest in,

and eventually led to my desire to become more involved with DSAM.

I was drawn to the DSAM community, like many others, by former DSAM Director, Jawanda Mast. She and her husband, Jonathan, and their daughter, Rachel were close family friends, and my family routinely participated on Rachel's team in the Buddy Walk (now known as Step Up for Down Syndrome). A few years ago, Jawanda asked me to write a few short pieces for the DSAM newsletter, one of which included a lengthy interview with Marie and Precious Dodson, who were so gracious to me when I had no idea what I was doing! Last year, I was contacted by Board Members Aggie Fratta and Mark Price with the opportunity to join the DSAM Board of Directors, and I jumped at the chance to become more involved. I joined the Board in January of 2010, and am now serving in my second year with the organization. The passion exhibited by these Board members and families associated with DSAM is contagious and I am so happy to be a part of a program that educates the Mid South community about Down syndrome.

My husband, Billy, and I recently became parents to our precious son, Carter. He will be one in July, and we are so blessed to have him as the newest addition to our family. As a new mom, I am even more excited about being a part of this organization. It is my sincerest hope that we are able to continue to effectuate the mission of DSAM, "to support and empower individuals with Down syndrome by providing families and our communities with up-to-date information and education, enhancing public awareness about the inherent worth, value and contribution of these individuals to society and fostering positive attitudes regarding people with Down syndrome."



In January 2011 DSAM partnered with Bright Beginnings to bring you the Bright Steps program.

Bright Steps is a family-centered training program focusing on ther-a-play. Parents and caregivers of infants and toddlers, up to 18 months old, with Down syndrome are learning teaching and therapy techniques they can use during daily activities while caring for and playing with their children. Several families are enjoying their time together on Thursday mornings as they work with their children and network with each other while they learn about things such as music & movement, positioning for play and reaching & grasping. Join us for upcoming sessions. We meet at the DSAM office every Thursday from 10:30 a.m. – 12:00 p.m. For more information contact DSAM at 901-547-7588 or admin@dsamemphis.org.

Building Bridges

The beginning of the 2011/2012 school year will mark the fourth year of our partnership with Memphis City, Shelby County and Desoto County schools to bring resources on best practices for educating students with Down syndrome. The Parents and Schools in Partnership program will undergo a minor name change to more closely reflect the purpose of the program. The program will now be called the Down Syndrome Education Connection. The goals and implementation of the program will remain the same. This program has been greatly received by the educators and administrators in the three school districts. Next year we will have 45 educators attending the workshops offered to learn about best practices. We appreciate your support of this program and your help in letting others know about it and how it benefits students with Down syndrome. If you know of an educator that would like to be involved in this program please have them contact the DSAM office at 901-547-7588 or admin@dsamemphis.org.

Black Jackets for Southaven Wildcats, Lynx's!

By Toneka Buntyn-Kelly, mom to Gianni

Hooray, we did it! Who would have thought all our hard work would get "us" esteemed "Black Jackets?" "When I told my mom I wanted to cheer, it was not for a black jacket. It was because I love to dance and socialize!" said Gianni.

The Lynx's Squad left for Florida during 2011 Spring Break! Our family was in Florida for 5 days. We were busy from the time we landed. Gianni asked "when are we going to have fun?" No fun for the Lynx! At least not until the competition was over. The stage is set! Lights, camera, action! Gianni said "Mom, this looks like something from a movie." I must admit, I was amazed as well.

The competition was on! The Lynx's looked super. To be fair, so did the other teams. They all worked very hard. "Wow, mommy, this is fun, but I'm tired of all this walking!" The squad competed at ESPN Zone. By chance, it was during a major league game. We really did have to walk about a half mile to get to our destination. Mommy and granny were tired, too. "Mom, I'm done cheering, is it time to have fun yet?" Fun she did have! I want to do it all over again!



Gianni Kelly is 7 years old. She attends Pleasant Hill Elementary. This is her second year to cheer with the Southaven Wildcats Lynx Squad.

Do you have a success story about an individual with Down syndrome that you would like to share? We want to share your stories with other families and the community! Please contact kelli.polatty@dsamemphis.org with your ideas.

I am a Runner

Jonathan Mast

Reprinted with permission from the Down Syndrome Guild of Greater Kansas City Connections newsletter.

Jonathan Mast and his wife Jawanda, past DSAM Executive Director, live in Kansas City, Kansas with their daughter Rachel.



I am a runner. I run a lot. Sometimes, up to 50 miles in one day! A lot of people ask me what I am running from

and why I chose to go to such extremes. I am not running from anything. I am running to something. How did I get started and why? I started out like anyone else. I ran a mile one day and then progressed to marathons and then on to what is called an ultra marathon. I have many reasons for running, but my one driving inspiration and my end goal for climbing out of bed when it is dark, cold and snowing is my daughter Rachel.

Rachel is my amazing daughter who is almost 11. This year she received an award for reading 6,000 minutes at school, and I was there by her side for most of those minutes. She has been in countless plays, choir concerts, and soccer games and appeared on TV shows just to name a few of her accomplishments. If she had a Facebook page, she would have a huge following.

Though of less importance Rachel has Down syndrome. So some people find this list of achievements quite unbelievable. I live with her so it is just everyday occurrence for her to raise the bar beyond what the world expects her to be able to accomplish because of this label.

Since she was born, I have watched as she pushed past one goal after another. She has left behind a trail of skeptics who wanted to set the standards so low that if equated to my running program would mean that I would just stay in bed every morning and not lace up my shoes.

My most recent race was a distance of 40 miles through miserable muddy conditions around Lake Clinton, KS. My legs hurt toward the end. I was facing the usual mental opposition of why should a 46 year old man be out here doing this seemingly crazy hobby? As always my mind drifted to Rachel and the visual image of her waiting to run those last 100 yards with me. My ultimate prize was that sparkling smile, beautiful, contagious smile that would join me as I crossed the finish line. She will be saying did you win daddy? I will answer no but I finished. She will say that's great daddy - you did your best. She's heard us tell her a million times - just do your best.

I think of how she may not think of what she does every day as hard work. Then again she may based on recent homework conversations. Some days are hard when she suffers the occasional cruel comment from another child or gets frustrated by a math problem and tells us "my brain forgot". Then almost as fast as Usain Bolt in the 100 meters, she rebounds and is making us laugh with her jokes and her crystal clear laughter.

Life is hard for all of us sometimes. Running helps me deal with what life throws at me. So in answer to your question, I am not running away from anything but rather I run toward the hope and joy that my daughter Rachel brings to me. I run because I want her to know that all things are possible. I want to be in good health so I can hopefully enjoy the many more amazing journeys she is going to take her mother and I on in life. God gave me a ticket to an amazing story.

Parent-to-Parent Mentor Training

**Saturday, July 23rd, 10am to 1pm
at the DSAM office**

DSAM welcomes approximately 25 new families each year to the Mid-South. Our goal is to provide them appropriate support and resources during what can be a difficult time as they adjust to the diagnosis of Down syndrome. Research indicates that meeting another family is the most helpful and rewarding experience for our new families. **WE NEED YOUR HELP.**

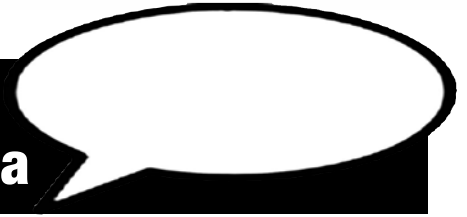
DSAM is offering a Parent to Parent Mentor Training. Do you want to support families with a newly diagnosed baby with Down syndrome? This training provides attendees with a comprehensive overview of best practices and covers the DSAM referral and intake process. Please contact DSAM at (901) 547-7588 or admin@dsamemphis.org to register. Breakfast will be provided!

Tell us what's on your mind!

DSAM strives to provide information that readers will find helpful and useful. Want to share something? WE WANT TO HEAR FROM YOU! Is there anything missing from the newsletter that you would like to see? Then let us know! Contact Kelli Polatty at kelli.polatty@dsamemphis.org with your ideas and suggestions.



Ask the Expert: Snoring and Sleep Apnea



By Dr. Steve Green, DDS
Team Green Dentistry in Fishers, IN
Reprinted with permission from Down Syndrome Indiana

**How do I know if my son or daughter has sleep apnea?
How is it treated?**

Snoring and Obstructive Sleep Apnea are both breathing disorders that occur during sleep due to narrowing or total closure of the airway. Snoring is a noise created by the partial closure of the airway and may often be more problematic than the noise itself. However, consistent, loud, heavy snoring has been linked to medical disorders such as high blood pressure. Obstructive Sleep Apnea is a serious condition where the airway totally closes many times during the night and can significantly reduce oxygen levels in the body and disrupt sleep. In varying degrees, this can result in excessive daytime sleepiness, irregular heartbeat, high blood pressure and occasionally heart attack and stroke.

Individuals who have Down syndrome have a number of risk factors that contribute to this challenge. Some of the anatomical structures of the face can be one contributing factor. Weight is another factor that can affect the flow

of air through the airway and Thyroid disease is another component that can contribute to the level of risk. According to a Journal of Sleep Medicine article (August 2009), children who have Down syndrome have a 30-50% prevalence and adults have even more factors for sleep apnea.

How do you know if you have sleep apnea? A sleep physician needs to diagnose this, based on the results of an overnight sleep study (Polysomnogram). How do I treat it? There are a few ways to improve your condition. A weight management program may be beneficial. Avoiding alcohol and tobacco is also helpful. Sleeping on your side can decrease the severity of the problem.

If it has been determined by a physician that a patient has sleep apnea, medical and dental treatments including Continuous Positive Airway Pressure (CPAP), oral appliance therapy (OAT) and upper-airway surgery may be helpful. If you think you or someone you care about may have sleep apnea, talk with a physician and/or dentist. Do not ignore it! Sleep is good; Proper sleep is great!

Dental Resources

Many families contact the DSAM office to inquire about dentists that treat patients with Down syndrome. You can always check with your regular family dentist first. Some parents feel more comfortable finding a pediatric dentist, and then there are some dentists that specifically cater to patients with special needs.

Here are some of the dental groups and dentists that we provide to families when they ask. DSAM is happy to connect you to another family that may use one of these resources, if you'd like to find out more.

Pediatric Dental Group
Dr. John A. Acosta, DDS
7675 Wolf River Cr., Ste 102
Germantown, TN 38138
(901) 363-8191

Dr. Billy W. McCann Jr., DDS
5885 Ridgeway Center Pkwy #230
Memphis, TN 38120-4012
(901) 767-9200

Bartlett Pediatric Dentistry
3071 Kirby Whitten Rd.
Bartlett, TN 38134
(901) 382-1564

Audubon Dental Group
2059 Houston Levee Street #126
Germantown, TN 38139-6970
(901) 853-9800

Children's Dental Center of West Tennessee
2028 West Poplar Ave., Suite 110
Collierville, TN 38017
(901) 861-9668
www.dentistjustforkids.com

The Smile Center
Dr. Mehdi Sadeghi, DDS
6750 Poplar Ave, Suite 612,
Forum 1
Memphis, TN 38138

Alliance for Full Participation Survey on Tennessee's Employment Scorecard

Give your opinion! Please join us in rating the state policies, practices and strategies that promote employment in TN using the national scorecard from the Alliance for Full Participation. Go to <http://j.mp/gyh4oN> or call The Arc at (800) 835-7077.

Your answers will help the TN team:

- ① Identify priorities
- ② Set goals for employment initiatives
- ③ Outline a strategy for doubling TN's rate of integrated employment by the year 2015

Who can take this survey?

Any adult in TN can take this survey. We really want to hear from people with disabilities, family members and care providers, professionals who work with adults with disabilities, like teachers, therapists, employment professionals, etc...

Who is collecting this information?

The leaders of Employment initiatives from the TN Developmental Disabilities Network <<http://kc.vanderbilt.edu/kennedy/TNDD/>>, The Arc-TN <<http://www.thearc.org/>> and the Department of Intellectual Developmental Disabilities <http://www.tn.gov/didd/consumer_services/index.html> and Division of Rehabilitation Services <<http://www.tn.gov/humanserv/Disability.html>>, the state government agencies that promote employment are all very interested in this information.

What will they use it for?

Feedback will be used to examine what policies, practices and strategies can be changed to improve the percentage of people with disabilities who are in employed.

New Incentives for STEP UP Team Building Goals

DSAM appreciates your support and effort to grow the Step Up for Down Syndrome event. As an incentive for all your hard work, team captains that meet each month's fundraising goal will be entered into a drawing for a chance to win an American Express gift card. Winning team/team captain will be announced through Happenings, DSAM website and in newsletter. Winning team captain will be notified via email/phone call. Each Team can only be entered once each month. Funds raised are cumulative. Drawing dates and details are:

May Goal is \$1,000 -

Drawing date is June 2nd for a \$100 AmEx Card

June Goal is \$1,500 -

Drawing date is July 4th for a \$100 AmEx Card

July goal is \$2,500 -

Drawing date is August 1st for a \$200 AmEx Card

August goal is \$5,000 -

Drawing date is September 1st for a \$200 AmEx Card

Congratulations to STEP UP Team **For the Love of Luke** for going above and beyond the April Team Fundraising goal of \$500! Team Captain Amy Folkerts won a \$50 AmEx card. Her team raised \$2,000 during the month of April. Check the DSAM Happenings email and website for the May Team Fundraising winner.

Don't forget...The STEP UP Team goal for June is \$1,500. All team captains that reach this goal will be entered into a drawing on July 4th for a \$100 AmEx card. Contact Jennifer Atkeison at 901.547.7588 or jennifer.atkeison@dsamemphis.org to find out more. Registration is open! Go to www.dsamemphis.org/suds

Let's Get Social!

If you haven't already, it's time to get social with DSAM! Like us on Facebook and join our group on LinkedIn! Just look up Down Syndrome Association of Memphis & the Mid-South and get involved in conversations and networking.



LinkedIn



Lose the Training Wheels

Camp Dates: Monday through Friday, July 25-29.
75 minute sessions each day at Bartlett Station Municipal Center. To register and find out more, go to



www.scenichillsumc.org.
The bike camp is for children with disabilities, ages 8 and up. DSAM is offering reimbursable \$100 stipends for individuals with Down syndrome that apply and are accepted, on a first come, first served basis. Limited stipends available.

Please contact the DSAM office at 901-547-7588 or admin@dsamemphis.org.

The 39th Annual NDSC Convention

August 5-7, 2011 in San Antonio, Texas
There is still time to register for this year's NDSC convention. The convention will be deep in the heart of Texas – in San Antonio, home of the Alamo, Sea World, Six Flags Fiesta Texas, Morgan's Wonderland, and, of course, the world-famous River Walk. For more information about the 39th Annual NDSC Convention, and convention registration information, go to www.ndsccenter.org.

Save the Date

7th Annual Down Syndrome Awareness Picnic
Saturday, September 10, 2011, 11 A.M. – 2 P.M.
Goodman Oaks Church of Christ, 1700 Goodman Rd. East, Southaven, MS
Come celebrate the abilities of individuals with Down syndrome with music, food & fun! Proclamations will be presented declaring October "Down Syndrome Awareness Month". If you have any questions, are interested in helping out beforehand or volunteering the day of the picnic, please contact the DSAM office at 901-547-7588 or admin@dsamemphis.org

Christmas In July

Join DSAM Thursday, July 28th from 5 pm – 9 pm at Lexus of Memphis, 2600 Ridgeway Rd., Memphis for our 4th Annual Christmas in July. For a \$5 door donation you'll enjoy live entertainment, food from Goodnight Gracie Specialty Foods and incredible shopping with exciting vendors.



Despite the rain, last year's event was a huge success with close to 40 vendors participating. This year there will be over 60 vendors selling one of a kind custom made specialty items. You don't want to miss this shopping opportunity! SUPPORT, EMPOWER, SHOP!!! For more information on vendors or how you can participate, please visit the DSAM website <http://dsamemphis.org/christmasinjury> or contact Jennifer Atkeison at 901.547.7588.



Thank you to all the volunteers that helped make DSAM Family Day at the Memphis Zoo a huge success. Over 350 attended this annual event. The weather was great! There was lots of food and the face painters did an incredible job. Be sure to join us next April for this fun annual event!



Community Group spotlight

On May 4th the Women's Guild at Our Lady of Perpetual Help in Germantown invited DSAM to attend their annual spring mass and luncheon. Over the past 60



years the guild has raised more than \$200,000 for the church and Mid-South community. DSAM is honored to receive a grant from the OLPH Women's Guild to support Amigos de Syndrome de Down. If you'd like to find out more about Amigos de Syndrome de Down, please contact Sandra De Tuya at 901-229-6749 or detuyagomez@hotmail.com.

CAMP HIGHLIGHTS

Is your child attending one of the summer camps offered? Please be sure to let us know! We'd love to receive camp stories and pictures that we can use for newsletter highlights! Contact Kelli Polatty at kelli.polatty@dsamemphis.org.

D.A.D.S.

(Dads Appreciating Down Syndrome) is an organization that was founded to assist and support, through fellowship and action the fathers and families of individual with Down Syndrome. Meetings are the last Thursday of every other month from 6 to 7 pm at the DSAM office and will be announced in the newsletter and correspondence by email with those who have signed up. We firmly believe that the DAD being involved and engaged in the life of your child with special needs is a role that is so very important. The Attitude of the father becomes the Attitude of the family. Please contact us if you would like to know more about our local Chapter. John E. Stamps (Brooke's DAD) 901-230-7901.



Looking for a unique gift for Dad?

DSAM has our exclusive 21 X's 3 t-shirts for men!

Designer Mike Womack explains his inspiration for the shirt design: As a father, having a child with Down Syndrome would be much like being lost in the woods. Being submersed in the outdoors is one of your favorite places in the world to be, but once those familiar landmarks are gone, you tend to panic, you aren't prepared for this! Where do you go, what do you do? During your search you find a road, it'll be full of twists and bumps, up hill and down, but it will take you all the way home. It's not the easy road you got here on, it's definitely the road less travelled, and you find comfort and pride in knowing that you've just embarked on one heck of an adventure!



Shirts are brown long-sleeve with white design for \$20 each, or grey short-sleeve with dark green design for \$15, in different sizes. Contact the DSAM office if you'd like to purchase a couple of these great shirts for the men you know!

June***STEP UP Team Building Goal deadline!***

June 1st - All STEP UP teams that have raised \$1,000 by June 1st will be entered into a drawing for a \$100 AmEx Card. Drawing will be held at the DSAM office on Thursday, June 2nd. For more details on fundraising goals, please visit www.dsamemphis.org/teamfundraising.

DSAM Night at the Redbirds

June 18th - AutoZone Park

4pm Tour AutoZone Park before the Game! Get a "behind the scenes" look at AutoZone Park, home of the Memphis Redbirds. You'll tour the state-of-the-art press box, scoreboard control room, as well as the clubhouse and training facilities of a first class minor-league baseball team. Tour space is limited. Contact DSAM to reserve your spot!

Game starts at 6pm - Join DSAM for a fun family night out with the Redbirds as they take on the Nashville Sounds. Tickets are only \$5 each and includes a post game fireworks show. There are a limited number of tickets available so contact the DSAM office at 901.547.7588 and reserve yours today!

D.A.D.S. Meeting

June 30 - 6:30pm at the DSAM Office - Dads, this is your chance to get involved! Refreshments will be provided. Contact the DSAM office to RSVP.

July***DSAM Family Bowling***

July 9th - 10am-12pm at Strike Zone Bowling Lanes, 3330 Pine Tar Alley, Southaven - Bring your family for a fun day of bowling, lunch and fellowship with other families. Cost is \$10 per DSAM family and includes two hours of bowling, plus pizza and drinks. RSVP to the DSAM office by July 7.

Mom's Night Out,

Tuesday, July 12 6:30 p.m. at the home of Alyson Edwards. Enjoy a night out without the kids and meet other moms. Bring an appetizer or dessert to share.

Parent-to-Parent Mentor Training

July 23rd - 10am to 1pm at the DSAM office

This training provides attendees with a comprehensive overview of best practices and covers the DSAM referral and intake process. Please contact DSAM at (901) 547-7588 or admin@dsamemphis.org to register. Breakfast will be provided!

Lose the Training Wheels Camp

July 25-29 at Bartlett Station Municipal Center.

75 minute sessions each day. For inquiries, sponsorship opportunities or to volunteer:

losethetrainingwheelsmemphis@scenicillsumc.org.

To learn about this nation-wide program and review the requirements for campers, go to:

www.losethetrainingwheels.org.

4th Annual DSAM Christmas in July

July 28th - 5-9 pm at Lexus of Memphis, 2600 Ridgeway Rd., Memphis - There may be months to go before Christmas, but it's not too early for Santa to stock up on great gifts and goodies! Get a jump start on your Christmas shopping and see what will fit in your stocking! There will be 60 vendors helping spread the joy of shopping, food, beverages, door prizes & more!

August***New Family Brunch***

August 20th - 10am August 20th - 10am at the home of Chandra Evans - Babies two years and younger, along with their parents, grandparents and guardians are invited to come meet other new families. Gifts for babies and parents are provided. There is no charge to attend. Please rsvp to the DSAM office by Aug. 18th.

D.A.D.S. Meeting

August 25th - 6:30pm at the DSAM Office - Dads, this is your chance to get involved! Refreshments will be provided. Contact the DSAM office to RSVP.

DSAM at Children's Museum of Memphis

August 27th - 10am-12pm, 2525 Central Ave., Memphis Bring the family and enjoy a day of education and entertainment. Open play from 10-12, followed by lunch. Cost is \$10 per DSAM family. RSVP to DSAM by Aug. 24.

donations

Donations – 3/16/11 through 4/30/11

General Donations

Maquitta King
Manuel De Tuya
Jeff & Lori Ricketts
Debra Spangle

Honorariums

In Honor of Gio Opp
Edward & Kay Haley
Norberto Valentin
Olivia Opp
Christy Opp

In honor of William J. Greenwald
Martha Cummings

Memorials

In memory of Mary Esta Peeples
Martine, Elliot & Laurie Hobson

Speaker Honorarium

for John Fox
Daughters of American Revolution -
Chickasaw Bluff Chapter

Matching Gift

AutoZone

STEP UP Partner Sponsorship

Cash in a Flash
Pediatrics East, Inc

STEP UP Patron Sponsorship

Fred's

Special Thank you

to Bayer Crop Science for
the Redbirds tickets. Our families
have had a wonderful time this
season enjoying the games.

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Down Syndrome Association
of Memphis & the Mid-South

DSAM

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