



# CRS Parent Connection

Alabama Department of Rehabilitation Services

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Summer 2013

## Opelika CRS 'School's Out Bash' a hit

### CRS ends school year, welcomes summer months with a smile

by Sharon Henderson, Parent Consultant

With beautiful skies overhead, the Opelika Children's Rehabilitation Service opened the summer vacation season with this year's School's Out Bash for children with special health care needs.

Families from Lee, Tallapoosa, Macon, Chambers, Randolph, Russell, and Montgomery counties attended the event co-hosted by CRS Youth Consultant Miracle Woods and Sharon Henderson, parent consultant for Opelika CRS.

Additional volunteers from Montgomery CRS, Vocational Rehabilitation Service's Opelika office, and the Opelika Achievement Center all assisted in making the event a huge success.

The party featured music from DJ Catalyst, balloon art from Dwayne "Dr. Magic" Reynolds, a petting zoo courtesy of Jubilee Farms, face painting by Sweet Cheeks, and appearances from McGruff the Crime Dog, Auburn University mascot "Aubie" and University of Alabama mascot "Big Al."

Children and their families were able to dance and have their photos taken with Aubie and Big Al while other children were excited to check out the big yellow dump truck provided by Thompson's Carriers. The Opelika Police and Fire departments also brought vehicles for the children to explore. Hungry children and adults



*Cindy Sue and Heather Salm get their photo taken with Big Al and Aubie at the School's Out Bash*

enjoyed hot dogs, chips, popcorn, cotton candy, cupcakes, juice, and water.

Special thanks to the many vendors that contributed to the event's success: Robert's Frozen Delights, Yogurt Mountain, Lee Nail Spa, Irish Bred Pub, Storybrook Farm, Alabama Artificial Limb and Orthopedic Service, Quality Care Nursing, Chik-fil-A, Flower's Bakery, Harvey's

Orthopedic Service, Photographer Earl Thomas, and Opelika Sportsplex.

If you missed out on the fun this year, don't worry. Plans are already under way for next year's celebration. Big kudos and an even bigger "Thank You" to everyone who made this day special for the children and families served by CRS!

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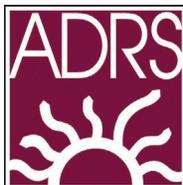
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# From the Director's Chair



Hello Parents and Caregivers,

Moving into the start of school and into the fall, I encourage you to read your newspapers, listen to the radio and TV, and surf the internet for information on TWO IMPORTANT TOPICS that may impact you, your families, and services to your child/children with special health care needs. These topics are Medicaid regional care organizations (RCOs) and the Federal Health Insurance Marketplace.

In May of this year, the state Legislature passed SB 340, a bill to restructure Alabama Medicaid, which will impact the way children and families with Medicaid insurance receive services. This bill allows managed care to be provided through RCOs for the Medicaid population. It appears that the state will be divided into five geographic regions where RCOs will be established. There may be one or two RCOs in each of these regions. You will be able to stay updated about RCOs by going to the Medicaid website at [www.medicaid.alabama.gov](http://www.medicaid.alabama.gov). When you enter the homepage, click on "Newsroom," then find and click on "Regional Care Organizations" to find all information that has been made public since May of this year. There you will find a map of the regions and will be able to determine which region your child/children will eventually be assigned to. The regional care organizations are on a timeline to be established by Oct. 1, 2016; however, some of them may be established prior to that time. Medicaid will notify you about these changes and give you instructions that must be followed. So, please be sure to read all information that comes to you from Medicaid so you will be well informed.

You may know that the state of Alabama decided not to establish a state health insurance exchange. However, the federal government is in the process of establishing the Federal Health Insurance Marketplace. This federal health insurance exchange will launch Oct. 1, 2014, and be available to qualifying Alabamians. Information may be found on the website [www.healthcare.gov](http://www.healthcare.gov). You will be able to find "a list of coverage options you and your family may qualify for – specific plans and prices available Oct. 1," "answers that will help you make good decisions," and "a personalized checklist to help you get ready to apply." This website is easy to follow, and you will be able to find answers to many other questions as you navigate through.

In the coming months, CRS care coordinators will participate in webinars and/or other trainings in order to assist you with questions/concerns you may have about the Medicaid RCOs and the Federal Health Insurance Marketplace. Also, CRS State Office staff and district supervisors/office coordinators will participate in state level or local meetings, so CRS can be a part of any change that may impact you, our families.

**Melinda M. Davis**  
*Assistant Commissioner, CRS*

# For parents: Helping children with special needs thrive

by Carrie Summers

Complex Child E-magazine (reprinted with permission)

Caring for a child is a hard job; it takes flexibility, consistency, patience, endurance, and love. Caring for a child with special needs adds a whole new layer of challenge to an already hard job. The stress of constantly worrying about your child's health and well-being can quickly take a hard toll on any caregiver.

Which is why taking care of your own mental health is of paramount importance. We can best care for our children when we're not overwhelmed and drained.

Our story: Living with severe food allergies

My sons have a motley crew of food allergies and intolerances. Between them, we deal with food protein induced enterocolitis syndrome (FPIES), milk protein intolerance (MPI), and a traditional antibody allergy to egg. I have to vigilantly watch every bite that goes into my children's mouths – even with non-food things like art supplies and shampoo – to ensure they are not sickened by what they eat. Because we have conflicting dietary needs, I cook two meals for every mealtime from scratch (almost no pre-packaged food is safe for us). Eating out is not an option for us; I've yet to find a restaurant that can safely feed both our children.

We carry compounded diphenhydramine (Benadryl) and an Epi-Pen with us wherever we go; our oldest child's egg allergy can have deadly consequences.

Our youngest son is almost 10 months old and has not been able to eat any foods. He survives solely on my breast milk; so far, every formula we've ever tried for him has caused him to get sick. Consequently, I eat an incredibly restricted diet: grass-fed beef, Russet potatoes, carrots, onion, garlic, sea salt, black pepper, olive oil, decaf tea, and stevia. This is safe for him, for now, but it is stressful to know that your milk production is the only thing keeping your baby alive. There is no reprieve from his demands for food – not now, and not in the foreseeable future.



I don't resent any of it; I know there are far scarier things my children could suffer from. However, food is such a vital part of life ... every social activity, every gathering revolves around food in some way. My guard is always up; my stress never really goes down.

It gets tiring, you know?

So, these are some things I've learned to help deal with the stress, to help make being my children's caregiver more pleasant and manageable.

Find a 'tribe'

Look online or ask at your doctor's office, but find other people dealing with the same situation as you (or as close as possible). These other caregivers will understand what you deal with in a way that no one else ever possibly can. I'm not exaggerating when I say that I would be completely lost without the other FPIES parents I've met; they don't disbelieve me the minute I claim my son is having a strange reaction to hand cream. They understand and can offer solutions to problems I'm encountering, and if nothing else, I know I have a group of like-minded parents in my corner

offering me support and cheering us on when we have a food victory.

So find people that "get it," and hold on to them for dear life. Even if you never meet in person and only ever interact online, they will help make your life better.

Find good doctors

As much as possible, within the limitations of your finances and insurance plan, find a good doctor. Find a doctor who makes you feel satisfied: that your questions are not being ignored, that your child's needs are being met, that you are not a nuisance because your child doesn't fit into a mold which makes you ask so many questions. Find a doctor that will make you feel like you are doing a good job taking care of your child.

If you have to visit 10 different specialists to accomplish this, it will be worth the effort. When you realize your child is going to have to go to the ER – again – you will be far less stressed out about that scary proposition if you know your regular doctors will not write you off as a paranoid parent. Good doctors are worth their weight in gold; find the best one for you through whatever means possible.

Reduce your circle of friends and family

This may sound harsh, but it is sometimes sadly true. There will be people in our lives who do not understand our children's complex medical needs, who think we are exaggerating the dangers they deal with, and who may even sabotage our efforts to keep our children safe.

*Eliminate them from your life.*

It doesn't matter who they are – your own mom or dad, your sibling, the best friend you've had since first grade – stop calling them. Don't invite them over. Avoid them at every opportunity.

They are not only a potential threat to your child's health (and perhaps even your child's life), but they are a serious drain on your mental health. Having someone you love – who is supposed to love you – constantly second-guessing your

*Please see Tips, Page 7*

**For more information about Children's Rehabilitation Service and to stay in touch with Parent Connection, please visit us on the web at [rehab.alabama.gov/CRS](http://rehab.alabama.gov/CRS) and [www.facebook.com/CRS.ParentConnection](http://www.facebook.com/CRS.ParentConnection)**

# Friendship Circle's Great Bike Giveaway

by Sharon Henderson, Parent Consultant

For many parents of a child with a significant disability, going to Walmart or Toys-R-Us to purchase a \$100 bike for their son or daughter's birthday is not an option. Thankfully, there are several companies throughout the country that realize the need for accessible bikes for kids and produce specialty bikes and trikes for those who need more support than what is offered by the traditional bicycle or tricycle.

Unfortunately, these same bikes are not exactly affordable for most families; they usually start at \$1200 and go up from there, depending on the need of a child.

Realizing that bikes for children with special needs are prohibitively expensive for most families, Detroit-based Friendship Circle hosted a national accessible bike giveaway April 16 to May 10, appropriately named "The Great Bike Giveaway." For the event, Friendship Circle teamed up with adaptive bike companies to hand out bikes and trikes to more than 25 children with special needs nationwide.

I had already been following Friendship Circle on Facebook because the group provides great articles and information for families who have children with special health care needs. When I first saw a posting on their website for the contest, I assumed it was something only for Michigan families and did not read the article. Later, when I was doing more research on their website, I came across the banner again and decided to give it a closer look. That is when I realized the giveaway was a national contest, not for Michigan residents only. That's also when I entered my son, Dallas.

Dallas is a 14-year-old boy who has neurofibromatosis type I and an unknown form of dwarfism and skeletal dysplasia. He uses a wheelchair and walker for mobility.

He received a tracheotomy in 2010 after a dentist appointment went horribly wrong.



Sharon Henderson entered this photo of her son Dallas in the Friendship Circle bike giveaway

Since then, because of the significant damage to his trachea, Dallas has required constant supervision and around-the-clock nursing care.

When I read the article about the bike giveaway, I thought it would be a great way for him to get back some of his freedom and independence and a fun way to strengthen his legs. Also, Dallas's birthday happens to be May 11, the day after the conclusion of the contest, and I knew this would make a great birthday present for him if he won.

Signing Dallas up was quite simple. There were several types of bikes from several different companies to choose from. You choose the bike you think would best match your child's ability, and then post a photo of your child along with a brief summary of your child and how getting a bike would help him or her.

We needed 50 people to nominate Dallas to win the bike, so I posted it to Facebook and emailed friends and family to encourage them to vote for Dallas.

The support we received was phenomenal! Every one of our friends got right on it and voted. After he had received the 50 necessary votes, people were still emailing, texting, and

calling me to find out how they could still vote for him.

A few days later, I checked the site and discovered that Dallas had won! I danced, shouted, and leapt for joy! My baby had won a bike!!! It was totally awesome!!!

After Dallas won, I was contacted by Friendship Circle and told that I needed to submit a physical therapist's measurements of my son to ensure we received a bike that was properly sized. We didn't expect to get it so soon, but the bike was shipped directly to my house for free within two weeks of us submitting my son's measurements. Dallas has been happily riding ever since.

What I appreciated the most about the contest is that you didn't have to fund-raise or anything like that for your child to have a chance to win. You could, however, ask friends and family to make a donation to allow for the purchase of more bikes so there are more contest winners. For each \$1,000 they raise, another bike is added to the contest for another child to win. This is money very well spent as I would love to see every child with a disability win a bike.

Think about this: Every year we give money for research for cures to help kids with

Please see Bike, Page 5

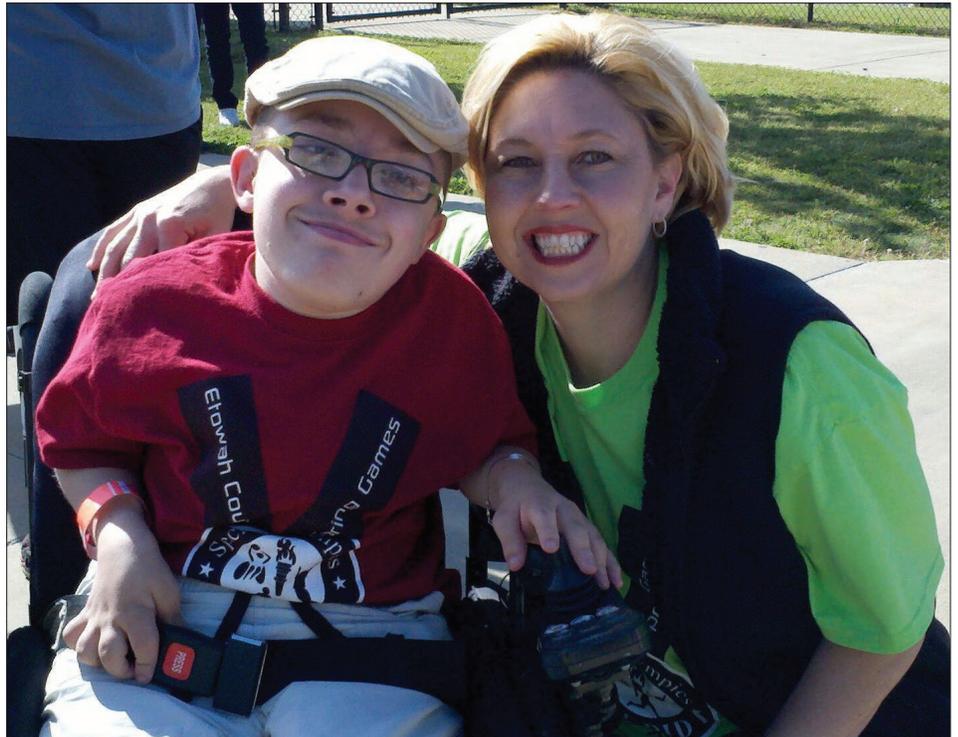
# Olympics made more special for Gadsden CRS hearing aid recipient

by Emma Hereford, CRS Social Work Administrator

Several staff from the Gadsden CRS office joined more than 500 volunteers at Gadsden City High School sports fields to participate in the Etowah County Special Olympics on April 26. About 350 people from Etowah, Attalla, and Gadsden City Schools as well as various group homes and adult care services throughout the county competed in the events.

The most exciting part about Special Olympics is being able to see many CRS clients and their families from Etowah County at the event, and this year was no exception. In particular, Jacob Sanford, who is served by the Gadsden CRS office, was not only happy about participating in the Special Olympics, he was thrilled to be able to finally “hear” all of the excitement, having just received his first pair of hearing aids the day before the competition.

Jacob and his care coordinator, DeAnna McMurtrey, talked and posed for pictures before the event began and the look on his face was proof he was ready for a fun-filled day. Jacob is seen in the Gadsden CRS orthopedic, hearing aid, and seating/positioning clinics.



Jacob Sanford with CRS Care Coordinator DeAnna McMurtrey at the Etowah County Special Olympics



Dallas rides the bike he won from Friendship Circle's Great Bike Giveaway

## BIKE

Continued from Page 4

disabilities, but what – if anything – has ever actually been cured? Don't get me wrong – I'm not saying people shouldn't donate money for research because research is very important for improving treatment options. However, here is a way to know, without a doubt, your donation directly contributed to bringing a smile to a child's face for at least one day. Besides, what parent doesn't dream of his or her child riding a bike? Here is a way to make that possible.

While this year's contest is officially over, Friendship Circle will have another bike giveaway in 2014. Be sure to check out their website at [www.friendshipcircle.org](http://www.friendshipcircle.org) and become a member while you are there. Also, be on the look out for the next Great Bike Giveaway contest, and tell everyone you know to support this cause, because every kid should have a chance to ride his or her own bike.

# Let's YAC about it!

## What is best for *your* health?

by Miracle Woods, CRS state youth consultant

Health care. It's one of the biggest issues being discussed this decade, and it was one of the single most-debated topics for President Obama's first term in office.

Whatever your stance is on the matter, health care is very important. It's important for the American people; however, it's just as important, if not more so, for those of us who face disabilities in our everyday lives. Not because we're so different or special, but because some of us encounter a multitude of issues the average person doesn't usually deal with. My advice? Take charge of your own health care. Become involved in your doctor's visits. Take steps to voice your own concerns. After all, you are the patient, and it concerns your own well-being. It's important to try and learn as much as you can about your disability and how it impacts you and your health.

Focus on you and find out enough information about your disability to be able to fully explain it to someone who may know nothing at all about it.

Learn to speak confidently and also find out what it takes to maintain good health. Take aim at these goals now, because when you are an adult, you will need to know the steps to take to receive proper health-care coverage and services.

I urge you to learn now the services your doctor provides, so if and when the need rises, you can find a physician who best suits your individual health-care needs.

All of this may sound daunting, but you can do it. It will take some time, but taking charge of your health now will greatly benefit you in the future, especially because it could easily become your responsibility in the not-so-distant-future. Healthcare

transition can be difficult for anyone, but youth with special health-care needs must take steps to see the transition through without harm, if possible.

The first step is opening the conversation with your primary care provider (PCP) to see how the process begins. After talking with your PCP, do some research in your area to find out what adult providers are available. Some things may require parental assistance, and that's perfectly okay.

Once you find an adult physician you feel comfortable with, waste no time and be vocal in expressing your individual needs. After all, this is the only way you will find out if this particular doctor can adequately meet your care needs. As always, if you need a little assistance or direction, I am here to help.

Keep persevering and aim high!



## FUTURE LEADERS

Several Children's Rehabilitation Service (CRS) clients recently attended the 2013 Alabama Governor's Youth Leadership Forum (YLF) held on the campus of Troy University. The forum equips high school students with disabilities with leadership skills so that they can participate more fully in their communities. During the weeklong forum, delegates take a trip to Montgomery for a Mentors Luncheon and a tour of the state Capitol. This year, Gov. Robert Bentley met the delegates and posed for a photo on the Capitol steps.

## TIPS

*Continued from Page 3*

decisions and actions will make you start doubting yourself. Even if you can stand firm in your knowledge that you are doing the right thing for your child, having to battle with your family and friends over your actions is exhausting. No one who is caring for a chronically ill child has the energy reserves leftover to fight such ridiculous battles.

Perhaps, as time moves on, your friends and family will come around and become part of your tribe; perhaps they never will. Even if you lose them forever, though, your child's health and your mental health have to come first. It's hard to do, but it is necessary.

### Remove perfection from your vocabulary

Your house will be messier than you'd like. Laundry may not be done as frequently as it should. The kitchen may not be cleaned to your usual standards (if at all!).

It happens.

There are enough demands on those of us caring for children who are complex that we have no choice but to prioritize. Those things that are vital to keeping your child healthy and safe are important. Everything else will fall on a sliding scale; some days you will have the energy and time to do some of them, and some days you just will not.

We will not have magazine-ready homes, we will not be able to volunteer for activities in a way we used to, and we may not even have time for a bath on some days! It's okay. Focus on the priorities, and let go of perfection. Let "good enough" be your mantra.

### Accept help and take breaks

While you may find friends and family who are



the opposite of supportive and have to be removed from your life, you may be pleasantly surprised to find there are people in your world who were mere acquaintances who begin reaching out to support you. When these acquaintances – or even strangers – reach out to lend a hand, an ear, or in some way offer help, take it. Take any help that is offered to you in any form it comes.

I've had friends come by just to socialize with me because they know that meeting for lunch is impossible, and that I get lonely never seeing other adults. I've had friends come by to clean my house because they know we just got back from the hospital and are overwhelmed. I've had friends simply call to ask if I needed anything at the moment, and sometimes I do. Sometimes I don't. But the fact that they called makes me feel less alone and replenishes my emotional tank.

Also, take breaks whenever you can. I'm not talking "Mom/Dad's night out" kind of breaks – those are probably not going to happen, sadly. But if you have a spouse or family member whom you trust, leave him or her to care for your child long enough for you to go to the grocery store – alone. Just getting to drive somewhere without pre-planning every step of your journey and wandering the grocery store aisles without splitting your attention in three different ways is a welcome reprieve to our highly focused days.

If all else fails, steal 10 minutes to go walk around your house a few times. Some fresh air and movement will recharge you enough to hopefully make it possible to get through your day.

### Pray

Whatever your faith, do it. Pray. Meditate. Repeat mantras. Whatever your belief system, rely on it.

Praying helps connect you; it helps ground you. Praying reminds you of the truth of the world. It can lift your spirits and take the burden of responsibility off your shoulders, because you know you can give that burden to God and He will take it. It's easy to forget that while WE are the parents of our high-needs children, God is the parent of us all ... and He's a whole lot better at handling stress than we are!

If you can't do it throughout the day, then make it a priority to pray first thing in the morning and last thing at night.

Our spiritual faith is an important part of our well-being even in normal circumstances; while



under the constant stress of caring for a child with complex needs, faith and prayer become invaluable tools in our mental health cabinet.

### Remind yourself that 'love' is a verb

Love is not an adjective. It's not descriptive. We don't say, "I pretty you," or "I tall you." We say, "I love you," because love is an action.

Every single thing you do for your child is an ACT of LOVE. Whether it is giggling and laughing with them, or holding them while they lay unconscious in the hospital, it is ALL LOVE.

The Bible says that:

*Love is patient, love is kind. It does not envy, it does not boast, it is not proud. It does not dishonor others, it is not self-seeking, it is not easily angered, it keeps no record of wrongs. Love does not delight in evil but rejoices with the truth. It always protects, always trusts, always hopes, always perseveres.*  
(1st Corinthians 13:4-7)

Lao Tzu says, "Being deeply loved by someone gives you strength, while loving someone deeply gives you courage."

We protect our children. We hope for our children. We courageously persevere through untold battles for our children.

Remembering what love is somehow makes me feel stronger and braver and reminds me of the selflessness involved with living that action. And it gives me the strength to carry on through another day.

So remember, YOU are LOVE.

Take care of yourself, so you can continue to Love your children with every fiber of your being. Don't let yourself get so drained that you can't go on; taking care of yourself is, in a very real way, another form of taking care of your child.

# The marvel of Miracle League baseball

by Ree Clark, Parent Consultant

Playing ball is an uncomplicated rite of passage for most kids, but for children with special health care needs, there can be many barriers to this summer past time. Families of children with special health care needs not only have to find accessible areas to play, but also keep in mind that every aspect of the environment must address the children's special need. For some children, the need might relate to sensory issues; for others, it might be orthopedic issues. Miracle League ball addresses and meets those needs, giving individuals with special needs the opportunity to play ball. The team members enjoy a time of recreation in an environment that is physically safe and promotes acceptance and awareness.

My son, Alex, started playing Miracle League ball two years ago. Alex has Langer-Giedion syndrome, which causes orthopedic issues, intellectual impairment, speech/language delay, and sensory issues. I can distinctly remember the first team picture. Everyone stood close together, their blue shirts seemingly blending into a unified little wall. Alex stood slightly off to the side. He did not want anyone to stand close



to him or get in his space. It took a few games for him to relax, but slowly he gained a sense of comfort and excitement. He was on a team, and he had never been on one before. He was wearing a uniform, and he had never worn one before. He was proud to see it said "Alex" on the back. No one made him feel like he ran too slowly. No one made him feel like an outsider. He eagerly looked forward to each Saturday and the ritual of eating pizza after the game.

This year, he returned to that same ball park. He gave out countless hugs. He encouraged his friends. He spent time petting the therapy dogs. In the team picture, he sat in the middle, huddled with his team members and smiled

proudly. Miracle League is a safe place for him, not just because of accessibility, but because he can relax and be himself. No one looks at him and thinks about what he cannot do; they celebrate all that he can do. Because of the league's structure, each child on the team is a star player. According to the National Miracle League Association (2008), leagues follow this general format:

1. Every player bats once each inning.
2. All players are safe on the bases.
3. Every player scores a run before the inning is over (last one up gets a home run).
4. Community children and volunteers serve as "buddies" to assist the players.
5. Each team and each player wins every game.

Miracle League comes with many blessings, including the chance for increased socialization, exercise and networking and connecting for parents, but it also celebrates the abilities of children with special health care needs. When the children run those bases, it's about ball, but it is also about the joy and awe of getting to play the game!



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## Beyond the rhetoric: *what the ACA means for my family*

by Rylin Rodgers, Family Voices Indiana

*This story first appeared in the Summer 2013 issue of the Catalyst Center Quarterly e-newsletter*

On June 28, 2012, the U.S. Supreme Court ruled that the Patient Protection and Affordable Care Act (ACA) was constitutional. As the first anniversary of the court's decision approached, I took a step back from the rhetoric and controversy that continue to overshadow what this historic legislation means for my family and other families raising children and youth with special health care needs.

My two children – Matthew, 16, and Laura, 13 – have mitochondrial disorders, complex neuromuscular conditions. From birth, they have required extensive medical care. That care was costly, so costly that we quickly met the annual and lifetime caps imposed by our health insurance. Because of their medical conditions, Matthew and Laura joined the ranks of Americans whose pre-existing conditions made them uninsurable. My young family was locked into a world of limited choices. Fearing a gap in insurance coverage, we could not change jobs. We experienced financial hardship because once the annual and lifetime health insurance caps were met, we paid the tremendous cost of their medical services out of pocket. Luxuries like dinner out or cable television were unthinkable as bills for necessities – including our own medical bills – sometimes went unpaid. We survived, just barely, by making painful choices about treatment priorities. We lived under the shadow of deep concern for the future. How would our children successfully transition to adult life when life-saving treatment was outside of our reach?

During the presidential campaign of 2008, it seemed possible that policymakers might be ready to tackle the brokenness of a health care system that painfully threatened so many Americans, including my family. The candidates spoke about the issues I was living with; we were part of the national conversation. I was thrilled that then-Sen. Obama's presidential campaign was the first to have a Disability Policy Committee. As election day neared, I was asked to speak on behalf of the campaign at the headquarters of Eli Lilly & Co., a major pharmaceutical company headquartered in Indianapolis. The audience was conservative, but they were listening thoughtfully and receptively to why health care and disability rights issues mattered to families in Indiana. It was then that I knew that America was ready for



*To the Rodgers family, the ACA means Matthew and Laura will be able to choose careers based on their aptitudes and interest, not their coverage options*

health-care reform.

Could anyone have predicted that passage of the ACA would come in the midst of a complex fiscal crisis, following the loss of its strongest supporter in the Senate with the death of Senator Edward Kennedy? At the time, it felt like anything that could go wrong would go wrong, a familiar feeling for parents of children with special health care needs. When the final floor debates and votes were happening in March of 2010, I found myself yelling at the TV, not for the NCAA March Madness, but for the madness on C-SPAN. It felt so personal. When the final bill was passed, I read every word. I am aware that knowledge is power and that knowing exactly what the ACA held would allow me to support my family and others in accessing its protections.

My family celebrated Sept. 23, 2010, the day on which my children would be permanently insurable throughout their lives despite their pre-existing conditions. I took a full-time position and enrolled my children in coverage, something that would have been impossible just a few months earlier. With the successive increases in annual caps, mandated by the ACA, which my children (finally) did not exceed, our new insurance covered their medical services. The reality of the ACA changed the reality of my family's life. Economic stability was within

*Please see ACA, Page 10*

**For information about Family Voices, please contact the Alabama state coordinators, Susan Colburn, 334-293-7041, [susan.colburn@rehab.alabama.gov](mailto:susan.colburn@rehab.alabama.gov) or Jerry Oveson, 251-438-1609, [oveson@bellsouth.net](mailto:oveson@bellsouth.net).**

# Building toys into Funderful Times

by Rita Hutcheson-Cobbs, Parent and Lego collector

Legos. Who knew that one could do more than simply build ships, cars, homes, and tiny people with them. I thought the large plastic box of pieces that was tucked under the bed of one of my sons was just going to collect dust until I had grandchildren someday. My children range from 18 years old to 26, all boys, but Madison, who is 16, comes to my house after school and during the summer to visit. Each one of them, has his or her interests, but Legos hasn't been one of them – not until Lego Camp.

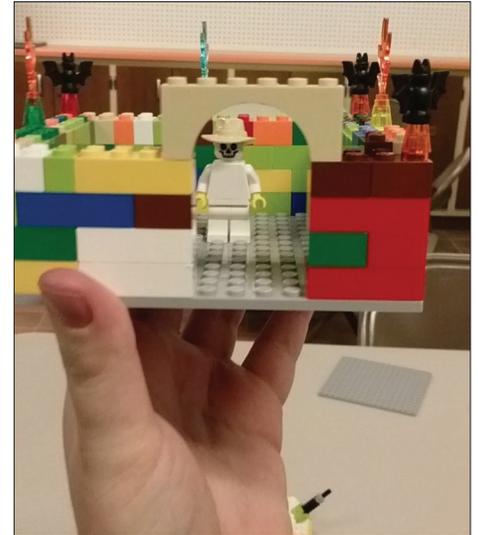


*Garrett Cobbs and Madison Walker work diligently on a construction project with building toys after attending Lego Camp*

While planning summer activities for our oldest son, Garrett, and Madison, I found a fun class called Lego Camp that was held Friday afternoons in June at Decatur's T. C. Almon Recreation Center. This particular class was for individuals with special needs. Garrett has multiple health care needs including fine motor cerebral palsy and Asperger's, and Madison has autism. To say I thought we were wasting our time going is putting it mildly, but I dragged Garrett to the first session, with him a bit unhappy because he thought it was for little kids. After I promised him that we would go to Starbucks afterwards, he willingly went. Madison was just all about the party; she didn't care where we went.

During their first session, the class of four (including the instructor) moved from table to table as they advanced levels of game boards built from Legos. Seriously. Game boards? Yes. Game boards. Garrett and Madison fell in love with not only Lego Camp, but Legos themselves. The next week, they were following instructions and building specific items. By the last week of camp, they were building robotic pieces that developed from one table as manual spinning tops to robotic tops. Garrett and Madison cannot read or write to the level of robotic elements, but they built these devices. All of us were excited!

The camp proved to be such a rewarding experience that several positive, fun things happened not only for the instructor, Matthew Hardaway, but also me. Matthew will begin a regular weekly class for Garrett, Madison,



*Garrett Cobbs and Madison Walker work diligently on a construction project with building toys after attending the Lego Camp.*

and their friends this fall/winter so we can continue this learning experience. And I have planned a Lego wall and play station in our home. Garrett and Madison have gotten into the planning and design of this, but my husband, Jerry, said he already knows who is going to be found "on the wall" – me.

I look forward to keeping you posted about this and other fun things we find to do this year. I'm painting two walls with magnet paint then chalkboard paint so that it can be used two different ways for fun, play, and learning. We won't tell anyone about the possibility of learning, will we?

## ACA

*Continued from Page 9*

our reach. Our children could choose careers based on their aptitude and interests, and not by coverage options or by being forced poor in order to stay eligible for Medicaid as adults with disabilities.

Unfortunately, the passage of the ACA did not entirely alleviate our anxiety about the future. We held our breath right up to the moment of the Supreme Court decision. That morning, I was in a doctor's waiting room with my son,

the same boy whose birth 15 years earlier had made health-care reform so important for me. We sat together reading the SCOTUS (Supreme Court of the United States) blog, knowing the decision was so much bigger than us, but at the same time oh so personal. As the "upheld" tweet came, I turned to him and said, "You have a future." He smiled and said, "Yes. I'm going to be a dairy farmer." I cried with relief for my own family and for the generations of children with special health

care needs who would grow up in the new health care reality – what a different world it would be for them.

It's been a wild ride, and it's not over yet. The ACA is not perfect – I have yet to find any law that is – but it is a life-changing, life-saving step forward for our country. I am privileged to have felt its personal impacts and to have stood with so many others for whom this is far bigger than sound bites, rhetoric, and politics.

# Summer Wish Picture Poem Puzzle

Finish the poem with words from the word bank.

I wish you a summer fit for a \_\_\_\_\_,

One with the best of everything,

With camping, kites, and a parade,

With \_\_\_\_\_ cones and \_\_\_\_\_,

With fun-filled trips by \_\_\_\_\_ and \_\_\_\_\_,

A \_\_\_\_\_ if it has to rain,

With apples from an \_\_\_\_\_,

And no bee stings and no scratched knee.



rainbow



ice cream



king



train



apple tree



lemonade



plane





## CRS Parent Connection

Children's Rehabilitation Service  
Alabama Department of Rehabilitation Services  
602 S. Lawrence St.  
Montgomery, AL 36104

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## Check Out What's Ahead ...

### **Aug. 7, 2013**

#### **Selma Wheelchair Wash and Parent Advisory Committee (PAC) meeting**

**Description:** Wash and shine for manual and power wheelchairs, 10 a.m. to 1 p.m., Selma CRS office.

**Information:** Odessa Taylor, [odessa.taylor@rehab.alabama.gov](mailto:odessa.taylor@rehab.alabama.gov)

### **Aug. 15, 2013**

#### **Jackson Annual Wheelchair Cleanup**

**Description:** Wash and shine for manual and power wheelchairs. Representatives from community organizations, including the ARC of Clarke County and Individual and Family Support Council will also be available to share information. 9 a.m to noon, Jackson CRS office.

**Information:** Vivian Spears, [vivian.spears@rehab.alabama.gov](mailto:vivian.spears@rehab.alabama.gov)

### **Aug. 16, 2013**

#### **Birmingham-area CRS Family Fun Day**

**Information:** Tammy Moore, [tammy.moore@rehab.alabama.gov](mailto:tammy.moore@rehab.alabama.gov) (Reservations required for event)

### **Oct. 18, 2013**

#### **Opelika Halloween Costume Party and Wheelchair Wash**

**Information:** Sharon Henderson, [sharon.henderson@rehab.alabama.gov](mailto:sharon.henderson@rehab.alabama.gov)

### **Nov. 18-20, 2013**

#### **Alabama Early Intervention and Preschool Conference**

**Description:** A 2 1/2 day event designed to share information and develop skill for professionals and families who work with children with disabilities from birth to five years of age.

**Information:** Jeri Jackson, (205) 823-9226 or [JBH50@aol.com](mailto:JBH50@aol.com)

***Local PAC meetings/events: Check your local CRS office for dates and times of meetings/events in your area.***