



# September 2016 ~ E-Newsletter

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Resource Directory



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## Reflecting and Remembering

By, Andrew VanGordon

September quite naturally makes you reflect and remember. Whether you are doing a personal reflection since the kids have settled back in school and you think of all of the things you were able to do with your family over the summer. Or, as most do, remembering the horror we went through as a nation in 2001.

Like so many of the readers of ASK's e-Newsletter, this summer was yet another summer spent watching my son recover from another big surgery, and getting our other kiddo to all of her social and athletic events. As I reflect on this past summer, I can remember the stress of the surgery, the hassle of coordinating all of the appointments, and having my own health complications. As I do, I can remember it all with a genuine smile on my face. I can smile because I can see the love my kids have for me, their mom, each other, their dogs and the world/family they were placed in. I can remember the moment at Wrigley when my son's favorite player got a hit and he squealed in sheer delight; that is why I can smile.



We also observed the 15<sup>th</sup> Anniversary of 9-11; at my age this is the one of the two events that I can tell you exactly where I was and what I was doing when I heard about the attack. Many of you can too. I remember walking around the living room hugging and holding, my then, three months old daughter. At that time my dormant understanding of the world around me was jolted awake and remains awake still. I also, remember the people of this great nation joining together in love, concern and patriotism.

I apologize if I dredged up bad memories, but I see this as an analogy to what it is like being a parent of a child with special needs. Until you are a parent of a child with special needs you don't understand that world we journey through. Our understanding of the world around us is acute, we tirelessly explore medical/behavioral topics, and we as an organization of your family continually seek the best service that help you help your child.

I have been a dad of my son with special needs for more than 7-years now. We found out he had Spina Bifida at 16-weeks in utero – this was the 2<sup>nd</sup> moment that changed me. We were stunned, you could say traumatized. After the initial shock, we knew that we had to learn more about what we were facing, we felt alone and bewildered. We luckily had a doctor (High Risk OB) who knew many of the specialty docs in our area. She aligned us with them – but as we all know doctors are great but they do not offer the ancillary services that so many of our kiddos require.

A few months after he was born we went to a Spina Bifida Assoc. picnic and we met an ASK Parent Liaison. What a stroke of luck – she helped me connect with ASK. ASK connected, educated and empowered us to meet our son's needs to enable him to achieve what we hope will be his best level of independence.

Recalling that first meeting and how a few years later brought me to work at ASK still makes me smile.

Have a Great September!



**Temporary moratorium on new ASD outpatient referrals for evaluation or treatment at the CSATC (Sarkine)**  
*(From Riley/IU Health:)*

Dear Referring Provider:

Approximately 1 in 68 children in Indiana will be diagnosed with autism spectrum disorder (ASD), and early intensive services can positively affect the course of the disorder. As the demand for ASD-related services has grown, the Christian Sarkine Autism Treatment Center (CSATC) has expanded to better serve our state. The Inpatient Behavioral Health Unit at Riley, which will also serve individuals with neurodevelopmental disabilities, is scheduled to open later this year. However, expanding our services to meet this population's needs has resulted in a decrease in outpatient provider availability. Although we continue to try to recruit highly trained professionals, the reality is that we cannot maintain our current level of services with the providers available.

We therefore regret to inform you that at this time we are placing a temporary moratorium on new ASD outpatient referrals for evaluation or treatment at the CSATC at Riley Hospital for Children for at least the next 6 months.

[Read More...](#)

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## Upcoming ASK Community Workshops

### Public Health Insurance: What You Don't Know Can Cost You

Parents and professionals will get information about public health insurance programs that can be accessed by families caring for children with special needs. It includes information on Medicaid, Medicaid Disability, Medicaid Waivers, Children's Special Healthcare Services, Hoosier Healthwise and SSI.

*September 27 – 9:00 AM - 12:30 PM*

ProKids

6923 Hillsdale Court

Indianapolis, IN 46250

Cost: FREE - Sponsored by Hoover Family Foundation

[Register](#)

### Roadmap to Special Education: Laws and Process

This all-day workshop provides basic information about special education laws and regulations for Indiana children ages 3-21. In addition, this training will provide information on how to prepare for a case conference and write an IEP. This training is a great learning opportunity for family members and professionals who advocate for children with a disability or serious chronic illness.

*October 6 – 8:30 am - 4:00 pm*

ProKids

6923 Hillsdale Court

Indianapolis, IN 46250

Cost: FREE

Sponsored by Hoover Family Foundation

[Register](#)

*October 13 – 8:30 am – 4:00 pm*

Mad Anthony's Children's Hope House

7922 W. Jefferson Blvd.

Ft. Wayne, IN 46804

Cost: (\$40 – Family Member / \$75 – Professional)

[Register](#)

### My Child Has Special Needs: Preparing for the Journey

Finding out that your child has special needs can be overwhelming. Some common reactions can be "What do I do now? Where do I start?" This training provides families with a brief overview of how to find support for your child and family, find appropriate information and services, ways to pay for services, and will help you start thinking about the future. This training is geared to help parents map out the next steps for their child and family.

*October 24 – 6:00 - 8:00 PM*

We Rock the Spectrum Kids' Gym

210 S Emerson, Suite D

Greenwood, IN 46143

Family Member – Free

Professionals - \$25

[Register](#)

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**Hungry?**

## Pumpkin Waffles

This month's recipe comes to you from Lisa Kutschera; ASK parent liaison since 2007. [Check out her bio.](#)



### Ingredients:

1-Cup	White Flour
1-Cup	Wheat Flour
3	Eggs
3-Tablespoons	Sugar
1-1/2 Teaspoons	Baking Powder
1-Teaspoon	Baking Soda
To Taste	Salt
1/4-Cup	Butter (Melted & Cooled)
1-Carton	Buttermilk
1/2-can	Pumpkin

### Directions:

SPRAY waffle maker with no-stick cooking spray.

WHISK all dry ingredients in large bowl. Whisk together eggs, butter, buttermilk, and pumpkin in small bowl. Add buttermilk mixture to flour mixture; whisk just until blended. Do not over mix. Let batter rest 15 minutes before baking.

HEAT waffle maker according to manufacturer's directions. Ladle batter into waffle maker. Cook until golden. Repeat with remaining batter.

NOTE: Lisa suggests you double the amount to freeze so you can just pop them in the toaster like Eggo® waffles, for those busy school mornings. And you won't waist the leftover pumpkin ☺

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## ASK (About Special Kids) is an Invaluable Resource for Any Child with Special Needs

Editor's Note – Story by IU School of Medicine Community Peds Community Newsletter – Curated by Andrew VanGordon

Dr. Colin Rogerson thought he knew everything about ASK as he had been told what kinds of resources they could provide families. However, he didn't realize the scope and variety of questions parents would ask nor how parent liaisons and ASK could help. After witnessing firsthand the interactions parent liaisons and families had, Colin was able to further appreciate the roles of parent liaisons at ASK.

By updating the Resource Directory, Colin was able to help ASK employees keep their information current. This directory gives very specific resources for medical conditions as well as general information like camps for children with special healthcare needs. Colin had the opportunity to interview a family about the services ASK provided. The mother told him that even though she was a social worker, she didn't know about the much larger community for kids with special healthcare needs. Colin reflected, "I learned that even families with knowledgeable parents can still benefit from contacting ASK and seeing just what else is available."

In addition, Colin accompanied a child and his family to a doctor's visit. Even though the child had autism, a congenital heart defect, and prior cerebral infarctions, Colin was struck by how functional the child was given his medical conditions. He said that this case was a testament to how well kids with special needs can do when they have the resources they need and a family that knows how to access them. Colin now sees ASK as invaluable to families.

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## Its Festival Time in Indiana



Find one near you – <http://www.indianafestivals.org/>

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## Job Opportunity

Do you want to work from home, set your own schedule, learn about different destinations and help people with special travel needs?

If so, you can join the Special Needs Travel Agent Webinar – on Sept. 28th, 2016 at 8:00 pm EST to learn what being a travel agent for The Greater Go is all about. No commitment at the time, just information!

Sign up [here](#) and you will be sent the link to join the Webinar on Sept. 28th. If you are unable to attend due to a schedule conflict, please email Becky Kirby at [rkirby@thegreatergo.com](mailto:rkirby@thegreatergo.com).

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## Giving Tuesday

This year, on Tuesday, November 29, About Special Kids is participating in #GivingTuesday, a global day dedicated to giving.

Last year, more than 45,000 organizations in 71 countries came together to celebrate #GivingTuesday. Since its founding in 2012, #GivingTuesday has inspired giving around the world, resulting in greater donations, volunteer hours, and activities that bring about real change in communities. We invite you to join the movement and to help get out and give this November 29

[Stay Tuned](#)

<https://www.facebook.com/AboutSpecialKids/>  
<http://www.aboutspecialkids.org/>

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