



## September e-Newsletter

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### September is Childhood Cancer Awareness Month

By Melissa Dedic – ASK parent liaison

I didn't know of September's designation until a few years ago when our then 3-½ year old daughter was diagnosed with Stage 4 Alveolar Rhabdomyosarcoma Cancer. It was the last thing we expected when we found a lump on her side. She was premature and was in and out of the hospital for her first 3 years. She spent 3 weeks in the NICU, had liver issues, an underdeveloped left lung and left pulmonary artery. She was hospitalized 8 times with recurrent pneumonia in her right lung. We were living in the world of the unknown, trying to find a diagnosis. We were living in the world of developmental delays, feeding issues, NJ tubes, speech and occupational therapy, dietitians, primary care doctor, pediatric specialist, the Aero-Digestive team at Cincinnati Children's, and had just signed our first IEP.



Just as we were getting answers; the pulmonologist found a hemorrhage in her right lung. We were referred to a cardiologist. Then a lump showed up on her right oblique muscle; it grew quickly. It had already spread to 4 lymph nodes and to 1% of her bone marrow. We were now in a world where 4 out of 5 children with this specific cancer diagnosis do not survive past 5 years. It was a very rare cancer with less than 100 cases in the US each year. *I soon became aware of many new things about childhood cancer.*

Here are 4 awareness facts:

1. There are dozens of types and many subtypes of pediatric cancer and all are very different from adult cancers. The causes are unknown and not linked to lifestyle or environment.
2. Funding for research is needed as it generally only comes from small pediatric cancer foundations.
3. 80% of the survivors have health problems later in life because of the toxic treatments (e.g. infertility, cognitive issues, heart disease and lung issues). Potentially the cruelest side effect is the risk for secondary cancers caused by treatment.
4. 46 kids are diagnosed each day in the US and 1 out of 5 do not survive. It's the leading cause of death by disease in children.

*We spent almost a year going through chemotherapy treatments (which were developed 30-yrs ago); she was sedated 20 times for her radiation treatments alone. We were living in a nightmare but tried to make the best of it. Our children deserve to have something done to change these statistics; less toxic treatments need to be found. Our daughter is currently doing well with No Evidence of Disease (NED) for 3-years. We have scans every 4-months and we don't take anything for granted, savoring every moment in life. Unfortunately, today, another 46 families will also realize how precious and fragile life is, so please **Go Gold in September** and spread awareness about the #1 disease killer of children.*

### A Season of Giving



This time of year, many companies offer their employees an "opportunity" to give to their favorite charity through an easy payroll deduction. This is an effortless way to show your support for About Special Kids. If ASK is not listed – you can simply write "About Special Kids" in the space provided.

Thank you for helping empower families of children with special needs.

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### **Trending at ASK**

**School is back in session – How is it Going?** Has your child adjusted to the new rigors of the schedule? Is the IEP being followed or need adjustments? Do you know what your rights are under Indiana's Special Education Law?

If you have questions or communication with the school isn't going well – give us a call! ASK can help you work through these issues to make sure your child receives the education and school services your child is entitled to receive.



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### **Upcoming Workshops**

#### **Roadmap to Special Education: Laws and Process**

September 22  
8:30 – 4:00 pm  
Mad Anthony's Children's Hope House  
7922 W Jefferson Blvd.  
Ft. Wayne, IN 46804

September 22  
8:30 – 4:00 pm  
Wabash Center  
2000 Greenbush Street  
Lafayette, IN 47903

September 28  
8:30 – 4:00 pm  
Harsha Behavioral Center  
1420 E Crossing Blvd.  
Terre Haute, IN 47802

**[Register Here](#)**

#### **Life with Stress, Balance and a Plan**

September 30  
10:00am – 12:00pm  
Ronald McDonald House  
11109 Parkview Plaza Drive  
Ft. Wayne, IN 46845

October 13  
10:00am – 12:00pm  
Wabash Center  
2000 Greenbush Street  
Lafayette, IN 47903

**[Register Here](#)**

#### **My Child has Special Needs: Now What?**

October 15  
10:00am – 12:00pm  
Parkview Noble Hospital  
401 Sawyer Road  
Kendallville, IN 46755

September 29  
6:30 - 8:30pm  
Northside Christian Church  
4407 Charlestown Road  
New Albany, IN 47150

#### **ASK & Learn**

ASK Office  
September 30  
2:00 - 3:30pm  
&  
October 12  
8:30 - 10:00am

**[Register Here](#)**

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### **And Now a Word from a Sponsor**



Now that kids across the state are back to school, MHS is geared up for another great year of the *Adopt a School* program. This initiative provides interactive programming to schools to educate students and their families about the importance of healthy living. All programs are free and tailored to fit the needs of each school, with an emphasis on exercise, nutrition, bullying prevention, and access to healthcare.

Programs include:

**Rosie's Rockin' Recess** – This energetic presentation for grades K-3 includes dance contests, exercise demonstrations, giveaways, and lots of fun with MHS mascot Rosie Roo.

**Healthy Lifestyle Events** – A comprehensive event for parents and faculty that includes health screenings, cooking demonstrations (with free samples and recipes!) and information on Medicaid and health insurance marketplace coverage options.

**School Nurse Support** – MHS can provide your school nurse with fully stocked nurse kits, health education resource materials, and educational books for the waiting area.

**Bully Prevention Reading Event** – The "No Bullying Zone" event features a reading of a new anti-bullying book, with copies of the book and a proactive parent guide given to each student.

**Parent and Community Events** - The MHS Community Outreach team can help coordinate events including back to school fairs, health fairs, parent engagement nights, health insurance education and enrollment events and more.

**School Based Health Center Support** – MHS can assist with developing School Based Health Centers – a model that offers health provider services on school grounds while coordinating with the child's primary provider.

**Behavioral Health Education** – In partnership with community mental health centers, MHS can provide behavioral health training and resources to school staff and to students in grades 3-5.

In addition to the *Adopt a School* program, MHS is proud to work with ASK to bring their training sessions to the MHS adopted schools to help educate and connect with parents.

Want more info? Contact MHS at Sarah Thompson at [sarthompson@cenpatico.com](mailto:sarthompson@cenpatico.com). Here's to a happy, healthy, safe school year for all kids and families!

**About MHS:**

Managed Health Services (MHS) is a health insurance provider that has been proudly serving Indiana residents for two decades through Hoosier Healthwise, the Healthy Indiana Plan and Hoosier Care Connect.

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