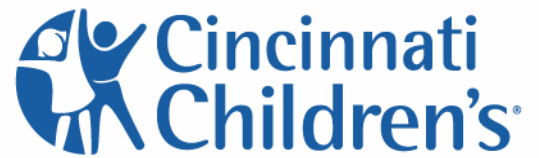


The Center for Infants and Children with Special Needs Family Newsletter April 2008



Spring is Here! 

"Be like the flower, turn your face to the sun."

— Kahlil Gibran

HELP US HELP YOU

Due to the increase in patients and our pending location change we are asking families that:

- Any refills, especially monthly refills, of their medications that we are given at least 24 hour notice before they need to be picked up.
- PLEASE refill all medications during business hours (M-F) unless urgent.
- Give at least 1 week for all faxed forms and 2 weeks due to the mail system for any forms being mailed to our office. (any letters, school forms, FMLA forms, guardianship paperwork, Plans of Care, and anything else that requires review and a signature of a physician.)

Thank you for your understanding, this allows us to make sure that all the orders and procedures are correct.

"If You Receive a High Bill for Services"

Our practice is committed to advocating for the needs of all of our families. While we believe the work we do is valuable and deserves compensation, we do not wish any of our families to be burdened with unexpectedly high medical bills. If you receive a bill that you were not expecting, or which would be a burden to pay, please call our office to discuss it. Often times, the matter can be resolved by a simple phone call. Other times, we can connect you with hospital or community resources to assist you with your bills. Please do not feel that you have to do it alone. We want to help.

Come support our team at this year's Golf Outing at Tournament Players Club at Rivers Bend
September 15, 2008

2008 Golf Outing Update

The 5th annual event golf outing benefiting our clinic, Center for Infants and Children with Special Needs, is approaching.

Join us for 11am shotgun start, \$250 per golfer not only includes 18 holes but also lunch, dinner and silent auction.

We are looking for sponsorships and silent auction items. Please let us know if you or anyone you know would like informational packets mailed with more details.

If you would like to a volunteer or knows someone who wants to be a part of the fun please contact

Della or Sally at 513-636-3000.

Fun includes being able to appreciate Dr. Levin's poor golf swing and knobby knees.





Summer Programs & Camps

It is important to start planning early for summer programs, as many have limited availability. The Center for Infants and Children with Special Needs at Cincinnati Children's Hospital Medical Center offers resources to patients and families to help in the planning process.

When searching for a summer program for your child, it is important to find a program that focuses on your child's interests and can meet your child's developmental and medical needs. Specialty programming that serves children with specific medical conditions or diagnoses and traditional programming with integration are both available.

Visit our website at www.cincinnatichildrens.org/special-needs and click on Recreation. Here you will find several online camp directories and information about how to obtain printed directories. We also recommend consulting with your MRDD worker about available opportunities.



Preparing Your Child - and Yourself- for Camp

- ✓ Visit the camp if possible, make sure you get as much literature about the camp, including a description of the layout and a video if the camp has one.
- ✓ Tell your child that you'll be checking in regularly with the camp staff and stress that he or she can always let the staff know if his or her needs aren't being met.
- ✓ Talk to your child about his or her feelings. Find out if your child has any concerns, and do your best to reassure him or her that you and the camp staff will take every precaution to make sure he or she stays safe.
- ✓ Provide the staff with any information that would be helpful in meeting the physical, behavioral, health, social and communicative needs of you child.
- ✓ Provide staff with strategies of what to do if your child is having a difficult time or ways to calm them down.
- ✓ Send equipment that would help your child participate in activities and communicate with each other.
- ✓ Talk about why your child is attending camp and what some of his or her goals might be, such as to try a new sport, to make new friends, or to just enjoy a break from doctors' appointments and therapy sessions.
- ✓ Give the staff a list of emergency phone numbers and email addresses, and make sure they know how to reach you at all times during your child's camp stay.
- ✓ If your child takes any medication, include the phone number of your child's doctor, in the event the prescription is lost and needs to be refilled by camp staff. Check whether the camp infirmary stocks your child's medication, too. If it doesn't, make sure you send extra medicine with your child in case of an emergency.

If your child is intimidated by the thought of attending a residential camp you might consider starting him or her off in a day camp or a sports team for kids with special needs. This step can give your child the skills and confidence to feel comfortable about camp. Start with regular sports activities and day camp. Then use a special-needs camp to get your child used to being away before sending your child to an inclusionary camp. Another option you might consider is sending your child to camp with a friend or a sibling to reduce stress.

Struggling with your Child's Anxiety while at Children's?



When children are in the hospital, they may become anxious about unfamiliar surroundings or unexpected events. A Child Life Specialist is available as a resource during hospitalization, out patient visits/procedures and are located throughout the hospital. By giving patients familiar toys and soothing activities, patients are able to express their fears and concerns through play. A Child Life Specialist can also help a child cope during a particular procedure or treatment using techniques such as distraction, guided imagery, reassurance, and role-playing. We encourage families to plan ahead of time and fill out "All about Me" to help professionals understand your child's needs. This form is in your parent notebook. Additional resources are available on the Special Needs Resource Directory. Please contact our doctors in advance if your child may need medications to reduce your child's anxiety as well.

Extended School Year Services: An Overview

Extended school year (ESY) services are defined in Section 300.309 of the IDEA legislation under "Subpart C Free Appropriate Public Education."

Basically, ESY services are services beyond the regular school year that are necessary for a student with a disability to make educational progress during the school year. Now is the time to discuss EYS services.

In addition, services must be individualized to meet specific objectives in the Individualized Education Plan (IEP) and must be at no cost to the parents of the child.

Determining eligibility for ESY services can be a difficult task because the decision, using general guidelines, is ultimately left to the discretion of the IEP team.

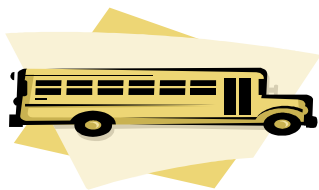
Some important factors to remember and consider in determining whether ESY services are appropriate for your child are:

- EYS services should be considered yearly by the IEP team
- documentation of student performance in relation to IEP goals
- issue of regression with substantial loss and/or ability to recover a loss of critical life skills
- nature & severity of child's disability
- areas of learning that are crucial to the attainment of self-sufficiency and independence
- child's progress, both behavioral and physical
- areas of the child's curriculum needing continuous attention
- child's vocational needs
- ability of the parent to provide in-home educational structure

Our office can assist you in the process of securing ESY services by providing a letter for support and recommendation to the IEP team in advance of the IEP meeting.

Please contact our office a minimum of two weeks prior to your child's IEP meeting to discuss obtaining a letter.

For more detailed information on ESY services check out the on-line Resource Guide under the Education tab.



"Doctor, my child's fever won't go down. What should I do?"



This is one of the more common concerns I hear from parents. And, while it is important to know if your child has a fever, making the fever go away is seldom the goal.

To understand this I think it helps to understand the usual process by which we develop fever. When cells in your body fight infection, they release chemicals to alert the body of what is going on. These chemicals, called cytokines, attract more infection fighting cells and they are detected by the brain which then elevates the body's temperature. It is generally believed that this elevated temperature can inhibit some human pathogens (germs) because they have adapted themselves to work best at body temperature (98.6 degrees F, 37 degrees C) and are therefore less efficient at higher temperatures.

As it is, fever is usually an indicator of infection but is not itself the illness. I compare it to the engine warning light on a car. Although you could paint it over with white-out, and might feel better not having to see it all the time, you've done nothing to fix the car. None of the fever reducers – Acetaminophen (Tylenol), Ibuprofen (Advil, Motrin), Naproxen (Aleve), etc... have any anti-bacterial or anti-viral properties. And, just like the engine warning light, it could mean almost anything. Fever is not a good indicator of severity of illness. I have seen 104-105 degrees in children with colds/ear infections, and 99 degrees in children with meningitis. Except in rare cases of temperatures of 106 degrees or higher, the brain is seldom harmed by fever.

Why treat fever? The goal of fever treatment is almost always comfort. A child who is eating, drinking, active and playful at 104 degrees doesn't necessarily need anything for his/her fever. A child who is miserable at 100 degrees might feel a little better if we treat.

Should we treat fever? I answer, "Sometimes yes." If feeling better means your child will eat and stay hydrated, then reducing his/her fever may well be worth more than merely feeling better. One practice, however, that should certainly be avoided is cold water baths or alcohol baths. Such a sudden change in body temperature can induce seizures, but more commonly will induce shivering which can actually work to raise body temperature even higher.

To finalize, I do think it is important to know when your child has a fever, and it is sometimes beneficial to treat it. On the other hand, I also take into account behavior, activity level, and hydration status in addition to fever, to judge the severity of illness. Finally, I rely on the parent's knowledge of their own child. Many parents will tell me if fever is meaningful in their child, either they run high fevers easily, or only when they are VERY sick. Either way, I am usually more concerned about treating the illness rather than the warning light, which is fever.