



## Hydranencephaly Newsletter January 2008

This is the third edition of what I hope will be a monthly newsletter for anyone who has, knows of, or is interested in a child with Hydranencephaly. Its purpose is to share information on the various aspects of Hydranencephaly as well as to show case our beautiful children. Much of the information presented in the newsletter will originate from the Hydranencephaly Mailing list or group which is hosted by Yahoo groups.

### Topic of the month: Preventing illnesses in our children

There are several illnesses our children are prone to and that may be dangerous for them. They are the "common" cold, influenza and RSV. I am including a basic over view of each of these conditions and information on prevention as well.

#### RSV

##### **What is respiratory syncytial virus (RSV)?**

Respiratory syncytial virus (RSV) is a viral organism that can cause upper and lower respiratory tract infections. It commonly causes bronchiolitis (inflammation of the lower airways) and pneumonia in children and infants under the age of 1.

##### **What are the symptoms of RSV?**

The following are the most common symptoms of RSV infections. However, each child may experience symptoms differently. Symptoms may include:

- Lethargy and inactivity
- Irritability
- Poor feeding
- Episodes of apnea (more common in infants; an event where an infant may not take a breath for longer than 10 seconds)
- Nasal discharge that is usually clear
- Fever
- Wheezing (a high-pitched sound usually heard on expiration, breathing out)
- Rapid breathing
- Cough
- Retractions (pulling in) of the chest wall
- Nasal flaring
- Rattling in the chest that may be felt over an infant's back or chest

The symptoms of RSV may resemble other problems or medical conditions. Always consult your child's physician for a diagnosis.

#### "Common" Cold

##### **What is an upper respiratory infection (URI)?**

An upper respiratory infection (URI), also known as the common cold, is one of the most common illnesses, leading to more doctor visits and absences from school and work than any other illness every year. It is estimated that during a one-year period, people in the US will suffer one billion colds.

Caused by a virus that inflames the membranes in the lining of the nose and throat, colds can be the result of more than 200 different viruses. However, among all of the cold viruses, the rhinoviruses and the coronaviruses cause the majority of colds.

#### **The difference between a cold and the flu**

Cold	Flu
Low or no fever	High fever
Sometimes a headache	Commonly a headache
Stuffy, runny nose	Sometimes a stuffy nose
Sneezing	Sometimes sneezing
Mild hacking cough	Cough, may progress
Slight aches and pains	Often severe aches and pains
Mild fatigue	Fatigue, may persist
Sore throat	Sometimes a sore throat
Normal energy level	Exhaustion

### How is a cold different from the flu?

A cold and the flu (influenza) are two different illnesses. A cold is relatively harmless and usually clears up by itself after a period of time, although sometimes it may lead to a secondary infection, such as an ear infection. The flu can also be harmless but may progress to a more complicated illness, such as pneumonia and even death. What may seem like a cold, could, in fact, be the flu. Be aware of these differences.

### Treatment for colds

To help relieve the congestion and obstruction in the nose for younger children, consider the following:

- Saline nose drops may be used.
- Use a bulb syringe to help remove the mucus.
- Place a cool mist humidifier in the room.
- Analgesics, such as acetaminophen, are sometimes helpful in decreasing the discomfort of colds. Consult your child's physician before giving any medication to your child.
- There are other medications for congestion, cough, or runny noses. Discuss your options with your child's physician.

### Treatment for RSV

- Keeping your child well hydrated by encouraging fluids by mouth. If necessary, an intravenous (IV) line may be started to give your child fluids and essential electrolytes.
- Bronchodilator medications administered in an aerosol mist by a mask or through an inhaler (to open your child's airways)
- Supplemental oxygen
- Bulb suctioning baby's nose before being laid down to sleep and before feedings, which helps the baby be more comfortable

### Treatment of Influenza

Typically, there is little that is done to treat the flu in otherwise healthy people.

- Bed rest
- Drink extra fluids – at least one full glass of water or juice every hour.
- Acetaminophen (Tylenol), or Ibuprofen can relieve head and muscle aches. *Aspirin should be avoided for children.*

### Cough and Cold Remedies for Young children

The FDA has announced that the Nonprescription Drugs Advisory Committee will discuss the safety and effectiveness of cough and cold medication use in children. Questions have been raised about the safety of these products and whether the benefits justify any potential risks from the use of these products in children, especially in children under 2 years of age. With cough and cold medicines for children under 2 being questioned, what are parents of sick infants and toddlers to do? Here are some recommendations from Amy Guiot, M.D., a pediatrician at Cincinnati Children's Hospital Medical Center:

- Cool mist humidifier: A cool mist humidifier makes nasal passages shrink to allow easier breathing. Cool mist humidifiers are recommended over warm mist humidifiers, which may cause nasal passages to swell, making it more difficult to breathe.
- Saline nose drops or spray: These keep nasal passages moist and "running," rather than stuffy.
- Nasal suctioning: Using a bulb syringe to suction nasal passages, either with or without salt water nose drops, works well for infants less than a year old. Older children often don't like the nasal syringe and will fight its use.
- Acetaminophen or ibuprofen can be used to reduce fever, aches and pains. Parents should read the packing carefully and prescribed dosing.
- Drink plenty of liquids to stay well hydrated.
- Nasal sprays containing oxymetazoline, such as Afrin, are not intended for children under 6 years old.

Very young children should not take most over-the-counter cough and cold medicines because they are ineffective and, if too much is taken, can cause serious side effects, such as high blood pressure, hallucinations, erratic behavior and constipation, according to Dr. Guiot. What parents can give their kids is "lots of loving and being held," she says.

### When To Call A Health Professional

- After three days of fever over 102 F.
- If cough brings up heavy mucus.
- If there is increasing difficulty in breathing.
- When a patient seemingly gets better, then gets worse again.

### How is RSV prevented?

Proper handwashing is important to prevent the spread of RSV to other infants, children and adults. If your child is in the hospital, healthcare workers will wear special isolation apparel such as gowns and gloves when they enter your child's room.

Palivizumab (Synagis®), an antibody against RSV, is recommended for babies and children at high risk for RSV to protect them against the serious complications of the illness. This includes children with weakened immune systems, organ recipients and premature infants. Palivizumab is usually given monthly during the RSV "season," from late Fall through Spring. It is not a vaccine and does not prevent the virus. However, it does lessen the severity of the illness and may help shorten the hospital stay. If you have questions about Palivizumab, please consult your child's physician.

### Pneumococcus Prevention

The pneumococcus is a bacteria that causes serious infections in adults and children, including pneumonia, blood infections, and meningitis. This bacteria is also the number one cause of sinusitis and ear infections. The 23-valent pneumococcal polysaccharide vaccine (23PS) protects against many different types of the pneumococcus bacteria and it is recommended that to be given to people over age 65 and children over age two who are at high risk.

Unfortunately, 23PS does not provide protection for children under age two, but a newer version of the vaccine, **Prevnar**, or heptavalent pneumococcal conjugate vaccine (PCV7), is available and can be given to younger children. It was approved by the FDA in February 2000. Prevnar protects against the seven most common strains of Pneumococcus that cause invasive disease, including bloodstream infections and meningitis.

<http://www.keepkidshealthy.com/welcome/immunizations/pneumococcus.html>

### Can I prevent my child from getting colds?

Children suffer more colds, due to lack of immunity to viruses to which they have not been exposed. Taking proper preventive measures can reduce the risk of your child developing a cold. Preventive measures may include the following:

- Keep your child away from a person with a cold
- Encourage your child to wash his / her hands frequently and not to touch his / her mouth, eyes, or nose until their hands are washed
- Make sure toys and play areas are properly cleaned, especially if multiple children are playing together

### What some families do to prevent infections:

#### Signs:

"If you are sick, please do not share your germs with me as my child's life may depend on it."

We did have a sign up on our bathroom door:  
"Please wash hands, germs can travel and Elizabeth doesn't need a trip to the ER. Thank You."

Another sign was :  
"If you have a cough, cold or sore throat, please wait outside for the person you came to visit. Elizabeth doesn't want to get sick."



### References

- <http://www.cincinnatichildrens.org/health/info/infectious/diagnose/cold.htm>
- <http://www.cincinnatichildrens.org/health/info/infectious/diagnose/rsv.htm>
- <http://www.healthscout.com/ency/1/251/main.html>

**Child of the Month  
Nicole Trease**



On a warm summer day in August 1998 a miracle came into our lives, her name is Nicole. Born just a couple of months earlier to a single teenage mother, the decision to place her into an adoptive home was difficult. We say Nicole is a miracle as it was predicted that she would not survive birth, nor live beyond three months old. Nicole is now Nine years and seven months old and is amazingly healthy! Nicole has had numerous surgeries including many orthopaedic (legs, hips, arms and a broken femur), a VP shunt placement, gastrostomy tube and fundoplication, 12 sets of ear tubes, port-a-cath and finally a z-plasty to allow her to breathe better.

We were told at placement that our lives would be forever changed by taking on a child with such high medical needs, and the predictions were true! Our lives have been forever changed and we love Nikki even more for that! We look at life as a gift. And we live each day to the fullest, never planning to far into the future as the future is unknown for all of us. We have been very fortunate to have met many new friends through our online support group; Hydranencephaly, Our Rays of Sunshine. Nikki and I have traveled to many US states and have even traveled to Canada and the Uk and are planning a trip to Germany to meet even more families. We feel very blessed to be able to spread the word that hydranencephaly is not a reason to give up

**January Birthdays**

Paris: 1/5/05  
Adrian: 1/7/03  
Brennan: 1/8/02  
Matthew: 1/18/04  
Ailish: 1/25/00  
Justin: 1/25/02  
Kortlyn: 1/27/06

Please remember the families of the children who gained their "wings" in 2007

Neveah Doyle  
Preston  
Jaime  
Josette  
Heather  
Kelly  
Jonathan B.  
Jasmine  
Christian  
Luke Madden  
Malcolm  
Emily  
Keilee  
Jonathan S.

**January**

**"Sadaversaries"**

(birthdays & anniversary dates for those who have died)

Melissa: 7/23/81-1/4/97  
Mariah: 1/8/04-4/23/05  
Daniel: 12/7/95-1/9/05  
Stephanie: 7/31/05-1/10/06  
Jason: 8/16/01-1/12/05  
Elizabeth: 1/17/89-11/12/06  
Emily: 1/18/99-12/11/07  
Jaime: 2/10/83-1/18/07  
Heather: 1/18/01-3/2/07  
Brianna: 1/22/03-12/8/03  
Joshua: 1/22/99-3/2/05  
Preston: 12/13/99-1/22/07  
Ezra: 8/19/00-1/29/03

**"Angel" of the Month**

**Kayda Foster  
12/2/88-6/23/00**



Kayda, a unique name for a unique child. Kayda came to live with me at the age of 4 1/2. At the time she was mostly unresponsive and struggled constantly to breathe. She'd always been one child of many in her previous homes. She had been held so rarely it was uncomfortable for her. Shortly after she came to live with me I discovered that her breathing was better when lying down. That started her road to health.

Over the next few years she showed more and more interest in her surroundings. She learned how to hold on to toys and to explore with her hands. Her hands were always up and exploring. She loved being around other children and attended school with her typical peers. She started to show an interest in listening to stories and quickly developed favorites. As she got older she liked to hear the longer multi tape books. She also loved Star Trek Deep Space Nine and knew what time it was on each day. She'd fuss if I forgot to put it on.

She also had many challenges, illnesses and surgeries. But through it all, her spirit shone through. At the age of 11 she started to change and life became more difficult for her. It became clear that she was tired and it was time to let her go "Home". On June 23, 2000, she slipped from my arms to the arms of Jesus so peacefully I didn't know she was gone. Her smile and her story continue to offer hope for other children with Hydranencephaly. Being her mom has changed my life for the better.