The Chronicles of Nemours:
The Lion, a *Twitch*, and a Need for a Wardrobe

By Lisa Stammerjohann

A primary goal of the Family Advisory Council at Nemours/Alfred I. duPont Hospital for Children is to help promote family-centered care. Parents want their child to be treated by compassionate, expert staff, while being respected as a partner in their child’s care. This standard is demonstrated to all families who come to the hospital.

Parents have the right and responsibility to advocate for their children when they are in need. For some, advocating is as second nature as fighting off hyenas from your lion cubs in danger. For others, it can feel as daunting as giving a speech in front of thousands of people in your underwear. Having experienced both feelings, I can say it’s easier to fight the hyenas.

When our child is in medical trouble, we want an expert to tell us what’s wrong and what to do. Sometimes, however, we know more about what our child needs than a professional. We sense that something’s not quite right, or have a feeling that the diagnosis given doesn’t seem to fit. This is the time to be the lion—when you are encouraged to participate fully in the discussion about treatment and ask questions until you are satisfied.

So how do you move from giving a speech in your skivvies to raising the hair on your mane? Here are a few tips I’ve found successful to alleviate that twitch of anxiety, apprehension, or downright fear:

- **Write things down.** Keep a three-ring binder or notebook with sections for different specialists. Keep a blank piece of paper in front of each section to write down questions you want to ask during the appointment. Then you can stay focused, write down the doctor’s answers, and keep a record for the future.

- **Bring a loved one with you for support.** If you are facing a difficult appointment it is always good to have someone by your side. They can

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**CaringBridge**

CaringBridge is a free, personalized website allowing families and friends to stay in touch and share information, love, and support during a health crisis, treatment, and recovery.

For more information, please visit www.CaringBridge.org

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Is It Contagious?

Available for free on the iPhone, this app by KidsHealth allows parents to look up different symptoms, learn more about the symptoms, causes and treatment, and if a condition is contagious.

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Facebook

Help spread the word about the hospital’s Facebook page: [www.facebook.com/aiduponthospital](http://www.facebook.com/aiduponthospital). “Like” this page, then share it with family and friends.
What is the Family Advisory Council?

Founded in April 2005, the Family Advisory Council (FAC) of Nemours/Alfred I. duPont Hospital for Children is a group of approximately 20 families and members of the Nemours staff who meet monthly. The FAC is led by Parent Co-Chair, Jim Burrows, and Staff Co-Chair, Ed Woomer. The Council’s family members have experience with the duPont Hospital for Children in both inpatient and outpatient settings and in almost every specialty Nemours offers, providing great insight into the care Nemours delivers. The mission of the FAC is to contribute to the development and enhancement of family-centered care at the Nemours/Alfred I. duPont Hospital for Children and Nemours Children’s Clinics.

For more information, please call (302) 651-4014.

Pardon Our Appearance

Please pardon the hospital’s appearance and excuse any construction noise as we clear the way to a healthier future for children. We are committed to creating a children’s hospital like no other in the region, giving our patients and families the promise of even better days to come. Get regular updates on the Hospital Expansion Project at Nemours.org/expansion or call our hotline number at (800) 842-1900.

Safe Sleep for Your Baby

In 1992, the American Academy of Pediatrics (AAP) recommended that all babies be placed on their backs to sleep. Since then, deaths from Sudden Infant Death Syndrome (SIDS) have declined dramatically. However, sleep-related deaths from other causes, like suffocation, entrapment, and asphyxia, have increased.

To address these issues, the AAP has expanded its guidelines on safe sleep for babies with added information for parents on how to create a safe sleep environment. Three important additions include:

- Breastfeeding is recommended and is associated with a reduced risk of SIDS.
- Infants should be immunized. Evidence suggests that immunization reduces the risk of SIDS by 50%.
- Bumper pads should NOT be used in cribs. There is no evidence that bumper pads reduce injuries, and there is a potential risk of suffocation, strangulation, or entrapment.

To review all the AAP’s recommendations on safe sleep for babies, visit www.healthychildren.org/safesleep.

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MyNemours

At Nemours, one of our goals is to improve the delivery and coordination of health care to children. As part of this effort, Nemours has developed MyNemours, a confidential, easy-to-use, Internet-based tool that gives parents and legal guardians secure electronic access to specific portions of your child’s medical records. Best of all, MyNemours can be used from the comfort of your home.

MyNemours allows you to review your child’s clinical information (such as laboratory and imaging results), health concerns, immunization records, and upcoming appointments. This free program is available to patients and their parents or legal guardians.

Feedback from users of MyNemours:

- I love MyNemours… It has been a wonderful tool for us.
- This is the best and most useful site that I have ever used! The information available is so helpful and the easy access to my son’s doctors is unheard of. This is a great help, because I am overwhelmed with paperwork. This simplifies my life.
- I really love how everything is set up and how easy it is to use… and how quickly everyone responded too.

To learn more, visit Nemours.org. To get started on enrollment, discuss the MyNemours tool at your child’s next doctor’s visit.

Family Members Needed for Hospital Committees

Family is the center of all that we do at Nemours/Alfred I. duPont Hospital for Children. We invite families to join key hospital committees to represent their point of view as we work together to improve our facilities and our care. Listed below are some committees that would welcome family involvement.

- **PICU Satisfaction** – Work to develop and implement strategies to improve patient and family satisfaction
- **Ambulatory Surgery Satisfaction** – Work to develop and implement strategies to improve patient and family satisfaction
- **Family as Faculty** (a subcommittee of the Family Advisory Council) – Share the story of your experience with Nemours as a teaching tool for New Hire Orientation, Resident Orientation, Nursing Panel Discussions, and other groups

If you would like to volunteer your time to work with any of these groups, please contact Abby Frelich: (302) 651-4014 or afrelich@nemours.org.
The Chronicles of Nemours (CONTINUED)

offer another set of ears and eyes, as well as a shoulder to lean on. If your spouse or significant other is not available, have a friend accompany you.

- **Remember, YOU are your child’s best advocate.** No one else knows your child as intimately as you do. You don’t need to KNOW all the answers, but you can help find those who might.

- **Finally, BREATHE.** Really, take a deep breath whenever you are facing something scary or difficult. It will help calm the nerves, allow you to take a moment to regroup and to more calmly and assuredly make the best decisions for your child.

The Nemours slogan, “Treating your child as if they were our own,” means that the hospital staff needs YOU to help them know your child like you do, so that they can best treat your child. Now it’s time for you to find the strength and power of the lion within yourself. Because your child deserves a voice.

Resources Available at Nemours/Alfred I. duPont Hospital for Children

**Free Car Safety Seat Checks**

Don’t just think your child’s car seat is safely installed…know it is! Every Wednesday evening from 5:00 – 8:00 p.m. safety experts are on site to check your child passenger safety seat and make sure it is installed properly. The Car Seat Safety Checks are done by appointment only in the duPont Hospital for Children Parking Garage. To schedule your appointment, call (302) 651-5437.

**Nemours Safety Store**

Need a new car seat? Maybe your child is ready for a booster seat or a new bike helmet. All of these items are available for very reasonable prices at the Nemours Safety Store. Open Monday through Friday, 10:00 a.m. – 3:00 p.m., the Nemours Safety Store is located in the duPont Hospital for Children, near the cafeteria. Not only will you find a great selection of safety items, you will learn about injury prevention and proper use of the items from safety experts. Whether you have an infant, toddler, tween, or teen, you’ll find low-cost items to keep your family safe. Call (302) 651-4279.