

The Heated Circuit

**The Newsletter of the Pediatric Home Ventilator Program
University of Michigan Medical Center
Summer 2010**

Nurse Practitioner Notes

By Ann Marie Ramsey, RN, MSN, CPNP

Many consider fall the “new year” with the start of school and the start of our fall and winter routine. School sports, dance classes, bowling leagues are all getting started. For our “vent family”, the approach of the cold months signals the end of the summer medication holiday and getting back to the preventative winter regimen. We still have a few weeks of summer weather left, so now is the time to pull out the equipment and medications and make sure you are ready for “old man winter”.

Many of our kids are growing rapidly. Check the fit of your “shakey” vests and make sure the fit is still good. If the vest is looking too small call the company (either SMARTVEST or Hill Rom) and ask for the next size larger. Pull out your cough assist machines and revve them up. Check the tubing for any tears or holes and make sure the mask still fits. If you identify any problems or your child needs a mask refit call your durable medical equipment company. Finally, check your supply of bronchodilators, and pulmozyme. Make sure you have enough medication to get through several days just in case your child gets sick on the weekend (which they ALWAYS do!!). Check expiration dates and discard any expired medication. Contact the office if you need refills.

Those who know me, know I truly believe “an ounce of prevention is worth a pound of cure”. An important part of keeping healthy during the winter is immunization and good hygiene practices. All the children in the program are encouraged to get the seasonal flu shot. This year the annual flu shot will include H1N1 virus coverage. Flu vaccine is expected

in early September. Contact your primary care doctor and find out when the vaccine is expected and make an appointment. All our children should receive the flu “shot” which contains “killed” virus. The nasal spray vaccine contains live virus and is not recommended for persons with chronic illness. Infants and children who are receiving their first flu shot will need a second booster 4 weeks after the first dose. Children who have received flu shot in previous seasons will need just one dose.

I often get questions about the “pneumonia shot”. This refers to the 23 valent pneumococcal polysaccharide vaccine. This immunization protects high risk persons from pneumonia and other disease caused by certain types of pneumococcal bacteria. The CDC’s Advisory Committee on Immunization Practices (ACIP) recommends a single dose of this vaccine for all people 65 years and older and for persons 2 to 64 years of age with certain high-risk conditions (including our vent kids). A single shot is all that is needed for most of our kids. People with no spleen, have certain cancers or HIV may need a second dose.

This is a good time to remind all parents to talk to your child’s primary care doctor about immunizations and to make sure your child is up to date. Sometimes illness can cause delays in receiving routine immunizations, so always good to check. Remember, immunization has been hailed as the single greatest discovery to promote health and prevent disease. Please, please, please give this protection to your children.

Planning for Our Future

By Penny Canada, mother of Drew

Before my 40th birthday, my husband asked where he could “take me away to” to celebrate my big birthday. With three small boys, including one with muscular dystrophy, I realized the Will & Special Needs Trust that had been on our ‘to-do’ list was what I wanted most as I celebrated ‘40’. I wanted the peace of mind that if something happened to us, our boys -especially Drew, would be able to maintain their quality of life and care after we were gone.

Due to medical advancements and a revised diagnosis, Drew has gone from an expected life span of 2 years old to ‘anything is possible’ (I recently read about a 50 year old man with a similar type of muscular dystrophy).

Now, I am closer to 50 than 40, and our future financial needs seem to be growing: How to plan for our retirement (without a corporate pension) and possible long term care expenses; how to fund college for our three sons – including the hours of care needed if Drew, who is very sharp mentally, is able to realize his dream of going away to college at U of M or another university; as well as how to provide for lifelong care for our son with a disability.

My financial interests and concerns have led me to a 2nd career in financial planning, where I am enjoying an internship this summer and learning a tremendous amount. I once thought of financial planning as a luxury, but as a parent of a special needs child, I see it as a roadmap to our future. In order to help your special needs child today and in the future, your finances must first be secure. Here are a few things to consider if you are ready to take ‘create a special needs trust’ off of your to-do list:

Work with a credentialed financial professional who specializes in Special Needs Planning and is knowledgeable and experienced regarding:

- Coordination of State and Federal Funding and Eligibility for Government Benefits.
- Creation and Funding of a Special Needs Trust.
- Maximizing Quality of Life & Quality of Care while preserving/protecting parents’ assets.
- Future Residence Options for your child with a disability.
- Designation of Future Trustees, Guardianship and Conservator if needed.
- Creating the best solution that you can afford.

Special Needs Planning solutions require an unbiased assessment of your needs and your child’s needs based on a comprehensive understanding of both financial and special needs issues.

Consider checking this off of your ‘to-do’ list and enjoy the peace of mind!

*By Penny Canada
Vent Clinic Mom & Intern in Financial
Planning*

NUTRITION

NOTES

Probiotics

By Emily Freitag, RD

The human intestinal tract is home to millions of friendly bacteria. These friendly bacteria make substances that help keep the cells in the intestinal tract healthy, plus they keep unfriendly bacteria, yeasts and molds in check. Sometimes the good bacteria become out of balance with the unfriendly bacteria, and the bad bacteria, yeast and mold grow unchecked. This can happen with use of antibiotics or with a bad diet.

Probiotics are friendly bacteria found in foods and dietary supplements that can help bring back the balance of good bacteria. Products that are available that contain probiotics, specifically marketed for infants and children, include:

- FlorastorKids with *Saccharomyces boulardii* lyo (do not take if allergic to yeast or on an anti-fungal medication). This is a strain of yeast that is not killed off by antibiotics.
- Culturelle for Kids with *Lactobacillus rhamnosus* GG (100% dairy and gluten free and for kids >1 year of age).
- Baby's Only Essentials Probiotic – a powdered probiotic available in packets that can be added to milk or yogurt (contains three types of friendly bifidobacteria known to be present in a healthy baby's intestinal system).
- Nestle Good Start Natural Cultures Infant Formula with DHA & ARA – a baby formula with probiotics.
- Yo Baby yogurt – includes extra probiotic bacteria.
- DanActive yogurt drink, for kids over age three.

Many of our children are on frequent antibiotics, which may result in antibiotic-induced diarrhea. It is also common for our children to have irregular digestive systems, which may be a result of many different factors. Probiotics have been shown to improve digestive health; however there are no set dosages or types of bacteria to use. If you have questions or concerns that your child needs probiotics ask your dietitian (that's me!) and we will assess if and what is appropriate for your child.

Forms, Letters and Prescriptions for School

School is just around the corner. Please send in requests for any forms for school as soon as possible and don't wait until the last minute. Please allow one week turn-around time for any school forms, since there are many requests at this time of the year. Contact your school early to find out what your child needs and we will be happy to assist you.

Emergency Information Sheets

Your child's Emergency Information Sheet should be updated regularly to reflect any medication changes, trach size changes, etc. The beginning of a new school year is a good time to update the information, particularly if your child will be attending a new school this fall. If your child's Emergency Information Sheet has not been updated in the past year, please contact our office and we will be happy to send you one with more recent information.

Adult Ventilator Clinic

After much planning, on August 3, 2010, we had our first Transition Clinic. This was a clinic that involved members of both the Pediatric Home Ventilator Program and the Adult Ventilator Clinic meeting with patients and their families in the clinic setting. This was a "hand off" from our clinic to theirs for some of our patients 18 years or older. Patients met with physicians, nurse practitioners, respiratory therapists, social workers and dieticians from both teams to discuss the transfer and clarify any questions. After the clinic, patients and their families were given a tour of 6D (Intensive Care) and 8D (Patient Care Unit for Ventilator Patients). After the tour there was a pizza lunch and patients were able to meet the medical staff from both units. Both families and staff felt it was a positive experience and helpful toward putting most of their fears to rest about the "big move" to the adult world.

Medical staff on 6D and 8D in Main Hospital have been working hard to make your stay on their units as smooth as possible, should you require hospitalization. They have listened to comments and ideas from patients and parents of recent inpatients and taken their concerns under consideration. While there will always be differences between Mott and Main and the method of care delivery, the medical team in Main is working hard to make your stay as comfortable as possible.

We plan to have another Transition Clinic around January, 2011. Our plan is to have a clinic every 6 months. If you or your child have already transferred to adult services but would like a tour of 6D and 8D, we can arrange this for you. We can also arrange a tour of the two units following your regular Clinic appointment if you will be transferring your care over before January. Contact April Lo, social worker or Jody Bouchard, RN at (734) 615-3267.

Vent Picnic

The Third Annual Vent Program Picnic was held on August 21 at Gallup Park in Ann Arbor. There was a great turn-out in spite of the rainy weather. Kelly Krawcke's sister, Francie, gave a fascinating demonstration with her birds of prey from the Leslie Science and Nature Center in Ann Arbor. Francie is a Raptor specialist at the Leslie Science and Nature Center. As usual, there was way too much food and a lot of fun and networking.

Patient Advocate

Since his sweet little boy Evan passed away in , Scott Newport has continued to be an advocate for children with special needs. He is a member of the Parent Advisory Board at Mott Hospital. This past June, Scott spoke before the staff of Children's Special Health Care in Lansing.

Scott's endeavors include the production of a four-part video series conveying his family's voice. His mission is to help others see the complex difficulties of raising a child with special needs. In the videos, he talks about private and public insurance issues and outlines some of the methods his family has used to work with the insurance system instead of fighting it. The videos were presented earlier this year in Grand Rapids and the success of that event led to Scott's efforts at the State capital and other potential speaking engagements.

Scott also recently published an article about C.S.Mott Chief Administrator, Pat Warner, in the Summer issue of Children's Hospital Today. The article was entitled "Our Mom."

How God Chooses a Mother

Contributed by Kim Sidlauskas, mother of Ethan

****This can be applied to Dads as well !**

Most women become mothers by accident, some by choice, a few by social pressure and a couple by habit.

This year nearly 100,000 women will become mothers of children with special needs. Did you ever wonder how these mothers are chosen? Somehow I visualize God hovering over Earth Selecting his instruments for propagation with great care and deliberation. As he observes, he instructs his angels to take notes in a giant ledger. "Armstrong, Beth, son. Patron Saint, Matthew." "Forrest, Marjorie, daughter. Patron Saint, Celia." "Rutledge, Carrie, twins. Patron Saint...give her Gerard. He's used to profanity."

Finally he passes a name to an angel and smiles. "Give her a child with special needs." The angel is curious. "Why this one, God? She's so happy." "Exactly," smiles God. "Could I give a child with special needs to a mother who knows no laughter? That would be cruel." "But does she have the patience?" asks the angel.

"I don't want her to have too much patience, or she'll drown in a sea of self-pity and despair. Once the shock and resentment wear off she'll handle it."

"I watched her today. She has that sense of self and independence so rare and so necessary in a mother. You see, the child I'm going to give her has a world of its own. She has to make it live in her world, and that's not going to be easy." "But Lord, I don't think she even believes in you." God smiles.

"No matter, I can fix that. This one is perfect. She has just enough selfishness." The angel gasps, "Selfishness? Is that a virtue?" God nods. "If she can't separate herself from the child occasionally, she will never survive. Yes, here is a woman whom I will bless with a child less than perfect.

She doesn't know it yet, but she is to be envied. She will never take for granted a

spoken word. She will never consider a step ordinary. When her child says momma for the first time, she will be witness to a miracle and know it. I will permit her to see clearly the things I see--ignorance, cruelty, prejudice--and allow her to rise above them. She will never be alone.

I will be at her side every minute of every day of her life because she is doing my work as surely as she is here by my side." "And what about her Patron Saint?" asks the angel, his pen poised in the air. God smiles. "A mirror will suffice."

Tips from Tim, Administration Assistant

I hope everyone had a great Summer, and here's to a hopefully happy and healthy Fall Season. I am writing to inform everyone that the Vent Clinics are, with very few exceptions, full through December 2010. Now, what does "full" actually mean? It means that each Vent Clinic from the time you read this newsletter through the end of December already have the maximum amount of patients that can be accommodated for one day in them, with most already containing an "overbooked" patient. Does this mean if your child comes down with something which may require a Vent Team visit, your child can't be seen? No. When necessary, the team is able to work something out in order to get your child the care he or she needs to get through a situation. But because the clinics ARE full, it is very important that your child's appointment is kept if at all possible. Of course, things happen. Nurses or aides call in sick, vehicles break down, and then there is the weather during our Michigan Winters. However, with Cold & Flu Season fast approaching, a cancellation, especially at the last minute, does two things: 1) it prevents a patient who may be ill from taking that appointment, and 2) it delays care for your child, as the next "available" appointment may be several months out, as this Fall Clinic Schedule clearly illustrates. So, please remember to post the itinerary on the refrigerator, plug the date and time in your PDA or I-Phone, and please call us as soon as possible if you know that you can't make the next scheduled clinic date. As always, I look forward to serving you!

Tim