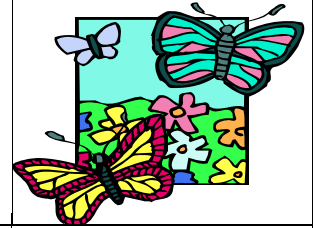


THE CIRCUIT

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Spring 2003

A Newsletter for Families of Ventilator Assisted Children

Volume 11 Issue 2

Nurses Who Foster Resiliency in Critically Ill Children

By Deborah S. Boroughs, RN, MSN

Happy Spring! I hope, as I'm sure you do, that the weather soon catches up with the season. The challenges of a difficult winter can be especially trying for families of ventilator-dependent children. Power outages, frozen pipes, nurses unable to report for work, and inflated utility bills are a few of the inconveniences that affect our families harder than the average family. As we look forward to warm weather, we also anticipate a wonderful event for our families, our annual Family Day on June 7. This year should be the best ever, and detailed information is forthcoming. Be sure to put the date on your calendar. In this issue, I have included the following article, "Nurses Who Foster Resiliency in Critically Ill Children" that was published in the *Nursing Spectrum* a few years ago. It is my hope that the article will assist you in training your nurses to help your children reach their full potential. The article is a tribute to our wonderful nurses who always managed to keep our child's best interests at heart. They were competent, compassionate and consistent, and they set a standard for all nurses who would subsequently care for our child. It is my hope that your homecare nurses are caring for your child in the same way. If not, why not lend them the article? You won't offend them. Genuinely good nurses always want to "raise the bar" of their professional practice

"Debby, I'm so glad to run into you. I have a little boy I want you to meet," pediatrician Maureen Fee said enthusiastically as we met in the lobby of The Children's Hospital of Philadelphia. "I'm sorry, Dr. Fee, but we have no plans to adopt more children," I replied apologetically. "Oh, I just want you to meet him. He's one of the most remarkable children I've cared for." Reluctantly, I followed her to the third floor of The Children's Hospital of Philadelphia, where Children's Seashore House was located. There I met Zee, an amazing, three-year-old, ventilator-dependent child, who was holding court for his equally amazing group of nurses. Little could I have imagined how these nurses would influence and enhance my personal life and professional practice in the years to come.

Dr. Fee introduced me to Zee's primary nurse, Joan McNichol. Joan, in turn, introduced Zee's other nurses: Cathy McNabb, Kathy Glass, Cathy Donahue, and Sue Vitek. As Joan provided a medical and social history, Zee eyed me with shy curiosity. Zee's trust in Joan was evident; initially, he would only speak to me through her, but with her encouragement, he began to warm up to me. The other nurses watched protectively from a distance. I was astounded at Zee's obvious intelligence and adorable, charming personality despite his extreme physical limitations. His verbal articulation was that of an adult, and his apparent joy in the midst of a hospital setting intrigued me. I was smitten! So began the journey of adopting the child who would become my son. Over the six months of training and preparation to bring Zee home, I observed a new model of nursing that moved from a purely medical model of sickness, disease, and rehabilitation to a resilient model of health, adaptation, and habilitation or "making the most of what a child has and can do."

During this time, I read a fascinating study entitled "Children of the Garden Island," which explored the nature-versus-nurture formula in comparing biological and environmental risks with behavioral outcomes of children. The study documents the innate and environmental influences that are the protective factors that contribute to resilience in children at risk and make a difference for children in overcoming sizeable odds. The study could just have easily been entitled,

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“The Children’s Seashore House Nurse Practice Model for Fostering Resilience in Critically Ill Children.”

During the last few years, I have researched the topic of resiliency and have come to believe that resiliency development is a practice component that all pediatric nurses should embrace. Research estimates that there are more than 30,000 medically fragile children who rely upon mechanical assistance for life. Protective and resilient personality traits begin to form early in life. Some traits may be mainly genetic, but others are greatly affected by social influences. Therefore, it is essential for pediatric nurses to understand this broader notion of nursing practice in order to optimally foster the physical, psychological, and social development and confidence of their patients with chronic illness and disability.

Personality Traits of Resilient Children

Longitudinal studies have identified several personality traits of resilient children that help them thrive amidst negative circumstances. The following traits are central to the ability of these children to grow into emotionally healthy, productive adults:

- **Social Competence:** The ability to establish positive relationships, be empathetic toward others, and maintain a sense of humor.
- **Problem-Solving Skills:** The ability to plan, resourcefully seek help from others, and think creatively, critically, and reflectively.
- **Autonomy:** The ability to maintain one’s own sense of identity, act independently, and exert some control over one’s own environment.
- **Sense of Purpose:** The ability to maintain a vision of an attainable, bright future that is supported by achievement and aspirations, persistence, optimism, and spiritual connectedness.

Environmental Factors That Contribute to Resiliency

There are a number of ways a child’s environment can promote resiliency and help protect chronically ill children from experiencing negative adult outcomes:

- The environment should provide social supports in the form of belonging, stability, and continuity.
- The environment should have special adult caregivers with whom the child can develop trust, autonomy, and initiative.
- The environment should have parental support in the form of nurturing parental roles that offer formal and informal guidance as well as a forum for collective action.

The Special Role of Nurses in Fostering Resiliency

Nurses who care for critically ill children greatly influence and play a key role in developing a child’s resilience and adaptation to physical limitations. Resilient children can find a great deal of support in their “home away from home” if their nurses properly assist them in developing resiliency. Nurses will foster resiliency when they –

- accept them for who they are and lend support and encouragement
- understand their reality and provide experiences that challenge rather than overwhelm their ability to cope
- encourage them to develop competency through special interests and activities
- invite them to reach beyond their own families for contacts, activities, and sources of fulfillment model constructive thinking and the conviction that life can be wonderful

Critically ill children who spend long periods of time in hospital environments do not inevitably experience poor adaptations to adult life. Pediatric nurses who provide consistent, resilience-inducing care help their patients develop protective factors that perpetuate resilience into adulthood.

Zee, now 16 years old and still ventilator-dependent, attends a regular high school where he impacts the lives of his able-bodied classmates and teachers daily. The charming social skills and remarkable sense of humor and self-confidence he developed during his first four years of life under the insightful care of his Children’s Seashore House nurses have equipped him for a joyful life. We are indebted to Joan, Cathy, Kathy, Cathy, and Sue for the magnificent start in life they gave to an exceptional young man.

Deborah S. Boroughs, RN, MSN, is the administrative Director of the Ventilator Assisted Children’s Home Program. She is the biological mother of two sons and the adoptive mother of six medically fragile children.

Helping Students Develop Their IEP

What should I do if I want to help develop my IEP?

Five Basic Steps

- ❶ Talk to your parents and teachers
- ❷ Review last year's IEP
- ❸ Think about your strengths and needs in school.
- ❹ Write your goals for this school year.
- ❺ Practice what you want to say at the meeting.

Writing your IEP

- ❶ You will need pen or paper, computer, tape recorder, or a friend to take notes. Whatever works best for you.
- ❷ Start by describing your disability.
 - a. What is your disability called?
 - b. How does your disability affect you in school and at home? (i.e. What things in school are harder because of your disability?)
 - c. What do you think is important for others to know about your disability?
- ❸ Look at your old IEP.
 - a. Review the IEP form to become familiar with what information is included in each section and why.
 - b. Look at the IEP goals and put a check next to the ones that you have met.
- ❹ What goals or objectives have you not met? These goals/objectives might need to be included in the new IEP.
- ❺ What are your strengths and weaknesses in each class or subject?
- ❻ Show the goals in your old IEP to your parents and your teachers. Do they think you have met these goals? What goals haven't you met? Add their ideas to the list that you made in Step 4.
- ❼ Ask your teachers what they believe your strengths and needs are in each class or subject. Write these down.
- ❽ Develop new goals for this year using the list of strengths and needs you and your parents and teachers developed.
- ❾ Describe the accommodations you may need in each class to meet these goals and objectives.
- ❿ Think about your plans for the future and what you will do after you have finished high school. What should you be doing this year to get ready?

How a student can identify strengths and needs.

- ❶ What classes do you take? Make a list
- ❷ Which is your best class?
- ❸ What can you do well in this class?
 - a. These are your strengths. Example: read, write, listen, work in groups, work alone, draw, do your homework. .
- ❹ **What helps you do well?**
 - a. These can also be your strengths. Examples: Your interest in the subject, your memory, patience, determination, effort, the help of others (be specific), the way the teacher presents information.
- ❺ What class is hardest for you?
- ❻ What's the hardest part of this class for you?
 - a. These are the areas you need to work on during the school year. Examples: paying attention, reading the book. Listening, staying in the seat, remembering new information, doing homework, doing work in groups. .
- ❼ What accommodations would help you do better in this class?
- ❽ What do you need to work on in your other classes?
 - a. Go class by class and make a list of what is hard for you in each one. Be specific - i.e. In math class you might find word problems very difficult.
- ❿ What accommodations would help you in each class?

What to say in the IEP meeting

Prior to the IEP meeting, talk with your parents and teachers about the process of an IEP meeting. Think about what you want to say and practice it with your parents or teachers. At the meeting, you want to be able to:

- ❖ Describe your disability
- ❖ Talk about your strengths and needs
- ❖ Describe your learning style (how you learn best and what gets in the way of your learning)
- ❖ Tell team members the accommodations you need and why you need them
- ❖ Describe any medications you are taking or medical needs you have (if you wish to share this information)

During the IEP meeting be sure to:

- ❖ Ask for additional suggestions
- ❖ Ask questions about any material or information that you do not understand.
- ❖ Share your feelings about the goals/objectives that the other team members suggest.
- ❖ Review your IEP periodically throughout the year.
- ❖ Take notes or have someone else take notes regarding the decisions made during the IEP meeting so that they can be incorporated into the final copy of the IEP.

Camps and Programs

PA Ventilator Camp

June 23—June 27, 2002

PO Box 850

Hershey, PA 17033

Contact: Michael Dettorre, DO

1-877-455-3311

online: www.pedsvent.net

VACC CAMP 2003

VACC Camp treats families with children dependent on oxygen, a tracheostomy, ventilator, C-PAP or BiPAP to *a week of fun and adventure* in Florida in the company of their peers. Interest parents should contact Camp Director Dr. Moises Simpser or Camp Coordinator Bela Florentin at 305-662-8222 to verify eligibility and request an application. You can also visit their website at: www.vaccamp.com

Some picks from: The Delaware Valley Resource Directory for Families with Special Needs

Academy Of Community Music

Community Music Services

Crescendo Program

601 Bethlehem Pike

Fort Washington, PA 19034

215-233-3020

- ◆ Community music therapy and education program
- ◆ Fee is based on sliding scale.

Camelback Adapted Ski Program

Kelly Drive, 4 Boathouse Row

Philadelphia, PA 19130

215-765-5118

- ◆ The group skies at Camelback
- ◆ Fee is on a sliding scale
- ◆ Skier must provide their own transportation

Children's Lokotek of Southeastern Pennsylvania

3905 Ford Road

Philadelphia, PA 19131

215-578-3616

- ◆ A play resource center at Thomas Jefferson University Hospital's Ford Road Campus.
- ◆ Serves children with special needs and their families ages birth-14y.
- ◆ Offers adaptive toys, relaxed play sessions, computer classes, computer camp and a toy lending library.
- ◆ Annual membership; scholarships available.

Houseman Recreation Center

Summerdale and Godfrey Avenue

Philadelphia, PA 19124

215-685-1240

- ◆ Several programs for children with disabilities including a Saturday morning sports program (Fall and Spring) and a 3-day-a-week camp (summer).
- ◆ Primarily serves children in the Northeast districts
- ◆ There is a fee; Bus transportation is provided for day camp.

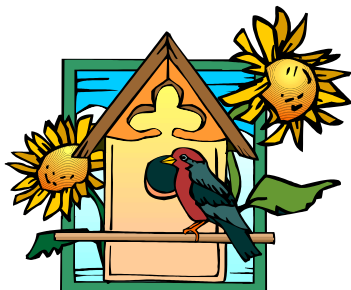
Kardon Institute of the Arts for People with Disabilities

10700 Knights Road

Philadelphia, PA 19154

215-637-2077

- ◆ Individual and Group Music, dance therapy and education for children, teens, adults with disabilities.
- ◆ Programs are available in south Philadelphia, West Philadelphia, Northeast Philadelphia, Germantown, Jenkintown, and Doylestown.
- ◆ Services provided at reduced fee based on financial need.



HOME VENT RESPITE NEWSLETTER

A Newsletter for Families & Respite Providers

Spring 2003

Vol.2 No. 4

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(412) 692-6657(Pitts)

Mailing Address:

100 N. 20th Street
Suite 201
Phila, PA 19103

Website

kidshome-vent.org

- * Send in your updated nursing license and CPR card to avoid delay in payment.
- * Submit you child abuse and criminal clearance. If you work for a nursing agency they can fax us a copy of these documents.
- * Submit all address and name changes in writing to VACHP.
- * If you provide respite to more than one child, we only require one set of updated credentials but we do need a separate Provider Form for each child.
- * Respite paperwork must be mailed to the office. We cannot accept hand-delivered paperwork to the offices.
- * Please post this information so your respite providers can be aware of updates.

| Payment Schedule for Quarter 4 | | |
|--------------------------------|--|---------------------------------|
| Billing Cycle: | Paperwork must arrive at VACHP by this date: | Paychecks mailed out this date: |
| Apr. 1/15 | 4/23/03 | 4/30/03 |
| Apr. 16/30 | 5/8/03 | 5/15/03 |
| May 1/15 | 5/23/03 | 5/31/03 |
| May 16/28 | 6/10/03 | 6/17/03 |
| June 1/15 | 6/24/03 | 7/11/03 |
| June 16/31 | 7/9/03 | 7/16/03 |

These dates may be Subject to Change. However,

Parents

- * For Quarter 4 (April May, June) there will be 56 hours respite care available. Please adjust your hours if you borrowed hours from quarter 3. Please call if you have any questions about your hours
- * You can now print your respite paperwork from the VACHP website (www.kidshome-vent.org).
- * WE WILL NOT ACCEPT ANY PHONE CALLS from nurses regarding respite issues or payment. All inquiries must be submitted via fax, written, called in by parents or email.
- * Please continue to submit the respite paperwork immediately after respite care.
- * We cannot process incomplete paperwork for payment. Please review all paperwork for completion of information and required signatures before sending to VACHP.

Nutrition by the Numbers
by Althea Zanecosky, RD

March is National Nutrition Month — a time when many of us focus on what we are eating. Is there a simple way to eat healthier? Yes! Try eating by the numbers.

5-A-Day

Eating fruits and vegetables is a good thing to do. Leading health authorities — the National Cancer Institute, the U.S. Department of Health and Human Services (DHHS), the U.S. Department of Agriculture (USDA), and the National Academy of Sciences — have urged Americans to eat 5 or more servings of fruits and vegetables daily.

Eating more fruits and vegetables may reduce the risk of getting cancer and other chronic diseases. A serving is less than what most people think.

Here are adult serving sizes for fruits and vegetables:

- 1 medium piece of fruit
- 1/2 cup fruit or vegetables (raw, cooked, canned, or frozen)
- 1 cup of leafy salad greens
- 1/4 cup of dried fruit
- 3/4 cup or 6 ounces of 100% juice.



Children are also encouraged to eat five or more servings of fruits and vegetables per day. For

children ages 2 to 3 years, portions that are at least half the adult size should be nutritionally adequate. Because many children don't eat a lot all at once, try to serve smaller portions more frequently throughout the day.

There are quick and easy ways to add fruits and vegetables into your diet. Try these:

- Add fruit to your breakfast cereal or oatmeal (bananas, apples, grapes, berries, peaches or mandarin oranges).
- Snack with 100 percent juice.
- Eat mini-carrots or dried fruit at work as a snack.
- Supplement your take-out dinner with fruits and vegetables from home.
- Try a glass of 100 percent juice, a salad, microwaved vegetables, or some fruit for dessert.



4-A-Week

Do you know beans about legumes? The American Heart Association encourages consumers to include more plant-based foods in their meals and recently made a statement advising Americans to include beans and other legumes in their meal plans 4 times a week.

Research from Tulane University reported that eating beans and other legumes at least four times a week lowered heart disease incidence by 19 percent compared to those who ate legumes less than once a week.

Legumes are plants that have pods with tidy rows of seeds inside. They include beans, peas, lentils, and peanuts. All are high-quality protein sources that are usually low in fat and high in dietary fiber.

Peanuts are higher in fat (though it's a healthy fat) than the other legumes (2 tablespoons have 190 calories, 16 grams of fat).

There are many ways to include more legumes in meals. For example, start a meal with lentil or split pea soup, spread toast with peanut butter instead of margarine or serve baked beans.



Chick peas and hummus (made from chick peas) are good sources of protein and fiber and low in fat. 1/4 cup chick peas has 70 calories, 0.5 grams fat while 1/4 cup hummus has 100 calories and 5 grams of fat. Also try chili with kidney beans or black bean soup.

3-A-Day

Got milk? Americans' low calcium intake is recognized as a major public health problem. The USDA recommends two to three daily servings of dairy products. A new study reaffirms that milk really does do bones and bodies good. Results indicated that the children who didn't drink milk had significantly lower calcium intakes, were significantly shorter, had smaller bones and lower bone mineral density, and sustained a higher number of bone fractures than the children who regularly consumed milk.

Eating 3-A-Day means eating three servings of milk, cheese and yogurt.

A dairy serving is:

Milk: one serving is 8 ounces (1 cup) or three-fourths the size of a can of soup and contains up to 300 milligrams of calcium.

Cheese (natural e.g. cheddar, mozzarella): one serving is 1-1.5 ounces, the size of a matchbox, and contains up to 300 milligrams of calcium.

Yogurt: one serving is 8 ounces (1 cup) or one container of yogurt and contains at least 200 milligrams of calcium.



2-A-Week

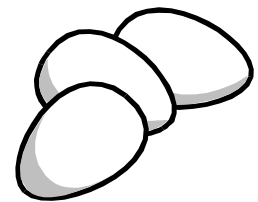
Go fish! Since 2000, the American Heart Association's dietary guidelines have recommended that adults eat at least two servings of fish per week, particularly fish with Omega-3 fatty acids such as mackerel, lake trout, herring, sardines, albacore tuna and salmon. Omega-3 fatty acids make the blood less likely to form clots that cause heart attacks and they protect against irregular heartbeats that cause sudden cardiac death. Fish is a good source of protein without the high saturated fat found in fatty meat products.

However, some types of fish can contain high amounts of mercury. Public health officials are advising pregnant women, nursing mothers and children under age 12 to refrain from eating the following marine fish because of high chemical concentrations: swordfish, tuna steak, king mackerel, shark and tilefish.

1-A-Day

Beyond the basics. Last year, reversing a long-standing policy, the American Medical Association (AMA) advised all adults to take one multivitamin pill each day. It now appears that people who get enough vitamins may lower their risk of developing chronic illnesses such as cancer and heart disease. Because foods contain thousands of vitamin-like compounds that may be important for good health, vitamin supplements should not be a substitute for a balanced diet. A child over age 2 should only take a children's multivitamin. Your child's pediatrician is the best source of advice about supplements.

When choosing an over-the-counter supplement, avoid those that supply more than 100 percent of the recommended levels of any substance; at the least, it is a waste of money, and at worst, it could be harmful. In 1996, poison control centers received more than 50,000 reports of children age 6 and under swallowing excessive doses of supplements. Fruit-flavored, cartoon-shaped chewable vitamins entice young children to eat them like candy in amounts that can cause poisoning. Among the most toxic supplements are those containing 30 milligrams or more of iron.



Happy Birthday

December

Josie Badger
Jose Burgos
Lauryn Carter
Jacob Clontz
Norberto Cora
Phillip Hetman
Tyler Hudson
Brian Iannetta
Steven June
Brian Kendter
John Kravitz
Delilah Leonardi
Austin Manz
Emily Olup
Marybeth Reber
Derreck Taylor

January

Jeremiah Black
Sean Brown
Isabella Coulter
Nickolas Drane
Sierra Fagan
Kristine Joseph
Nicholas Jordan
Faith King
Erica Madge
Emily Mong
Amber Naples
Justin Neal
Adam Ortiz
Eric Perry
Edgar Santos
Scott Savage
Maria Skeriotis
Sara Theil
Sharif Tyson
Melanie Ward
William Watkins

February

Nicholas Burns
Christian DeRiemer
Nataya Dublin
Blaze Tres Foster
Miguel Frezzell
Krysta Godowicz
Bailee Heim
Spencer Leibowitz
Seth Millhouse
Byron Nethery
Miguel Principe
Nathan Roop
Rachel Schmucker
Steven Sebastianelli
Emma Starr

Breath of Your Spirit

Jackie Arrington contributed this poem to our Newsletter. Jackie is an active participant in chamber music, orchestra, choir, acapella and theatre. Jackie looks forward to her endeavors in the Eastern European tour with the Philadelphia Sinfonia Orchestra. Jackie joined the social worker/ nurse team at Children's Hospital's Ventilator Assisted Children's Home Program. She had the unique opportunity to help organize the programs Annual Family Day and accompany the teams on home visits. After a truly awakening experience, Jackie hopes to take her memories of her Junior Project with her in future endeavors

O Tawa, Creator, Giver of life. Grandfather of the children of Maya earth. Giver of blessings, I lay, in my strife. Cursing my birth

Calling to You with my heart song, longing to be caressed by the breath of your Spirit.

With the gentle breeze, of its creative power, I ask, in my life's darkest hour for the healing energy of Your Divine light.

To see the answer of prayers in the creation of life, the eagle, the hawk, yes, even the sparrow.

The bark of a dog, or the growl of a bear.

As I lay here, in my bed. Take me away. To the forest of life. Floating above me, in my head

The healing power of Your, Breath of life. The creative power of my mind.

Given to me, From You Devine, To call upon all the creatures of life.

To share again with them in Your ether, in the healing power of Your Breath.

THE CIRCUIT
VENTILATOR ASSISTED CHILDREN'S HOME PROGRAM

FROM:
Ventilator Assisted Children's Home Program
100 North 20th Street, Suite 201
Philadelphia, PA 19103

TO:

