



FAMILY SUPPORT NETWORK

of Eastern North Carolina

Fall 2005

Irons Building - ECU Campus
Greenville, North Carolina 27858

www.fsnenc.org

Email: bboberg@pcmh.com

Please note phone number change

252-328-9332

Physical address has changed to:

**2780-B Dickinson Ave.
Greenville, NC 27834**

Mailing Address:

**FSN-ENC
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Greenville, NC 27858**

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"A continuous healing
relationship"
by
Dr. Charles Willson

All parents would like to have a physician or group of physicians who will "be there" for them when their child gets sick or they need medical advice. The national institute of medicine listed "a continuous healing relationship" as the first desired characteristic of the doctor/patient relationship. We pediatricians call it a "medical home." A medical home is more than a physician or

an office; it is a system of care that meets the medical needs of its patients and parents no matter what time of day or day of the week. The most rudimentary medical home is simply a physician carrying a pager when the office isn't open, with the final result of a visit to the emergency room if the problem can't wait until the office is again open. Fortunately many pediatric practices are evolving into more sophisticated medical homes that foster the continuous healing relationship desired by their patients and valued by their doctors. Children with special health care issues need a well prepared medical home more than healthier children. So, as a parent, ask yourself "is my child's doctor's office a medical home? And if not, will the doctors work to make it a better medical home for my child?"

Here are some questions to ponder as you assess the "medical homeness" of your child's doctor.

1. Does the practice have office hours other than 8 A. to 5 P.M. Monday through Friday?
2. If my child needs to be seen when the office is not open, will the doctor see us in the office or is the ED the only option? If the ED is the only option, will the ED doctor see us or will the pediatrician see us?
3. If my child has special needs, does the office have

accommodations to meet those needs (wheel chair ramps, large rest rooms, staff who are skilled in measuring and weighing children who cannot stand)?

4. Does the office schedule longer visits for children with special needs and complex issues?
5. Can I see the physician of my choosing for pre-scheduled visits?
6. After addressing the main reason for the visit, does the doctor ask if I have any other issues to discuss?
7. Will the doctor call me back if I have a question the nurse can't answer?
8. Does the doctor seem comfortable taking care of a child with special needs?
9. Does the doctor develop, with my input, an on-going care plan for my child?
10. Does the doctor ask if our family can carry out the care plan?
11. If we'd like a second opinion on an issue, is the doctor receptive and willing to arrange one?
12. If we need to meet with a doctor to discuss our child's health care needs, can we schedule a conference at a time that my wife or husband doesn't need to miss work?
13. Do I have access to my child's medical records?
14. If I made a suggestion on how the practice could be a better medical home for my child, would the suggestion

be considered and appreciated?

- 15. If English is not my first language, does the practice have someone I may speak with in my native tongue on the phone and during the office visit?
- 16. Does my doctor know what community resources are available to help me care for my child? Will the doctor communicate with the school system about my child's special needs?
- 17. Can my doctor or staff direct me to appropriate educational materials on new issues as they arise?
- 18. Does the doctor address legal and societal issues that make caring for a child with special needs so difficult?

I know that these are high standards for a typical primary care office or physician to meet consistently for every child and family. But, these are the characteristics of a true medical home that will have the best chance of developing a continuous healing relationship and ensure the best outcome over time for you and your child. If you approach your physician with these questions in a kind and caring manner, you can help your doctor evolve her practice toward the ideal medical home.

Food Lion Shop & Share

Family Support Network of Eastern NC is participating in the Food Lion Shop & Save program again this year. Each time you shop at Food Lion and use your MVP card, a portion of your total grocery purchase will be donated to FSN-ENC. To register or re-link your MVP card go to

www.foodlion.com In the left hand column under "In the Community" click on Lion Shop and Share and follow the instructions to link your card to FSN-ENC. Thank you in advance for your support!

Family Support Network of Eastern North Carolina (FSN-ENC)

Update By
Brenda Boberg
Executive Director

Can you feel the beginning of fall in the air? Time seems to fly! And can you believe FSN-ENC is finishing our 18th year of providing one-to-one parent matches and resource information to families who have a child with a disability, chronic illness, premature birth, or experienced the death of a child. Our program started within the Greenville Children's Developmental Services Agency (used to be called the DEC, Developmental Evaluation Clinic) and has expanded due to the passion and vision of the board and staff of FSN-ENC. This year from Jan. 1 through Aug. 31, our Parent Coordinators and volunteer support parents have seen over 1500 new referrals to the program.

A big thank you goes to United Way of Pitt County who believed in the vision set forth by parents and professionals in 1987 when they gave us our first grant. United Way of Pitt County has continued to be one of our supporters over the years.

Martin Pitt Partnership for Children gave us a grant in 1999 to fund two more parent

coordinators. During the last six years we have been able to expand our outreach and help more parents due to their support. So, we also say a huge thanks to Martin Pitt Partnership for Children. We are also affiliated with the state Family Support Network who gives funding to our program allowing us to reach out to an even broader section of eastern N.C. Parent Coordinators are in Wilson, Johnston, Northampton, Halifax, Bertie, Beaufort, and Hyde counties due to the funding from the state FSN.

Our contract with Pitt County Memorial Hospital also gives us the opportunity to work with families in the 29 counties of eastern N.C. Each year we receive over 1500 referrals from the Neonatal Intensive Care Unit, Pediatrics, Pediatric Intensive Care, Pediatric Rehabilitation and Women's Center and the community.

I say all of this because we are proud of the organization that we have become. We are celebrating the success of our program and the contribution of time and money that many individuals have given over the years. Unfortunately, North Carolina has been hit hard this past year with funding cuts to many agencies, resulting in FSN-ENC having to cut some of our Parent Coordinators. How can you help?

*Contribute your time volunteering to help others in a similar situation. A training will be provided on communication skills, listening skills, and the grieving process.

- *The Festival of Trees is approaching and we need volunteers to help set up trees, decorate trees, and take down trees.
- *Say thank you to the local businesses that sponsor our holiday trees at the Greenville Convention Center. Let them know you appreciate their business and support of families who have a child with a disability or experienced the death of a child.
- *Sponsor a holiday tree or provide an item for our live or silent auction held on Dec. 2, 2005.
- *Contribute to the United Way through payroll deductions.
- *Call your legislators about the cuts made to FSN programs, Early Intervention, Smart Start and other agencies providing services for children with special needs.
- *Sign up for the Food Lion Shop and Share program mentioned in our newsletter, and have a portion of your money come to Family Support Network of Eastern NC.
- *Sew or knit infant quilts and gowns for our premature infants.
- *Donate items for our Tender Memories Scrapbook meetings on Wed. at PCMH.
- *Be a board member for FSN-ENC.
- *And of course, contributions are always accepted.

Call Linda, administrative assistant to sign up to help our organizations, or find other areas to volunteer with our program. Call 252-328-9332

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**Inclusion Is More Than a
 Place**
By
Sandy Steele

Drew, my 20 year old son was born with Down Syndrome. From the beginning I was encouraged by friends and professionals to “include” him in our family activities. At that time, those activities were our routines at home: meals, naps, diapering, playing, watching TV, and taking walks. They also included activities outside the home: child care, shopping, visiting family and friends, attending the basketball games my husband was coaching, going to church, and taking trips to the park. During these activities I would watch Drew interact with his surroundings and ask myself “What am I supposed be doing? How am I helping Drew grow and learn?”

I want to share two important lessons about inclusion I have learned over the years that helped me answer those questions. First, it’s not just the places we take Drew—it’s what we do with him while we’re there or while we’re getting there. The second important lesson is that activities we do with Drew should be natural and intriguing to him. It should not be therapy plopped in the middle of my living room that

he’s uninterested in doing and won’t be done again until the next time the therapist comes to my house. Let me give you a few of our stories to illustrate.

In taking Drew to the basketball games, he was held, cuddled, and talked to by so many people. They loved him at an early age and were advocates for him as he grew older. This was the beginning of long and lasting friendships for Drew and our family. It became only natural that Drew be included in community activities. Soon children were explaining to other children about Drew and how he learned a little differently than they did but he should not be left out. They showed each other how to support or adapt what they were doing so he could participate.

Grocery shopping can be such a tedious task but with Drew it became our biweekly speech therapy. He wanted to know the names of everything he could get his hands on in the store. We would have a shopping cart full of things not needed but we knew the names of each item! He also wanted to hold, feel, smell and taste each one. We would practice it again when we returned home as he helped unpack the grocery bags. What wonderful things he was learning that many parents take for granted but was so essential in Drew’s learning process.

Our backyard baseball games became our favorite physical therapy and social skill building sessions. We used a big plastic bat and an

oversized tennis ball so that Drew could hold the bat and make contact with the ball. When it was Drew's time to hit, another child from the neighborhood helped him bat by standing in back of him and assisting him with his swing. Everyone would get on their knees to field the ball and give Drew extra time to run the bases. The children adapted the rules for Drew's success without adult input. Many times we adults just need to get out of the way.

These ideas spilled over into the classroom for Drew. In fifth grade the students were studying weather. Drew loved to watch the weather channel but knowing what a cumulus cloud was very difficult for him. His teacher embraced his love for weather and renamed the clouds so that Drew could remember them. The cumulus cloud became the "pillow" cloud. Drew took his love for weather and what he had learned and put it to practice. When he went to high school Drew became the weatherman for his local high school TV station.

Drew's success wouldn't have happened without the support and assistance of his teachers and therapists along the way. Sometimes it took a little urging to get them out of their comfort zone—providing adult directed therapy in quiet, secluded areas—to consulting with us on how to embed his goals in everyday, natural activities without us turning into therapists. It was a learning process for everyone involved and through their collaboration and competence it has

worked.

Sandy Steele is an inclusion specialist for Partnerships for Inclusion, a project out of UNC-Chapel Hill and lives with her family in Greenville.

Upcoming Events

**10th Annual
Festival of Trees
Greenville Convention
Center**

Thurs., Dec. 1 9am-5pm
Fri., Dec.2 9am-1pm
Sat., Dec. 3 11am-5pm
Sun., Dec. 4 12noon-5pm

Bedtime with Santa

Thurs., Dec 1 6pm-7pm

For reservations call-328-9332
\$8, \$10 for 2, \$12 for 3
children. Each child receives a
gift from Santa.

Storytime with Santa

Sat., Dec. 3 3pm-4pm

For reservations call 328-9332
\$8, \$10 for 2, \$12 for 3
children – Each child receives
a gift from Santa.

Preview party

Fri., Dec. 1 6pm-10pm
Silent and live auction
And hors d'oeuvres'
\$30 per person/\$50 per couple
For reservations call 328-9332.

If you would like to be a
sponsor or decorator for the
festival of trees fundraise
please contact the FSN-ENC
office at 328-9332.

This event would never come
to pass without the assistance
of hundreds of volunteers. If
you would like to volunteer for
this event, please call 328-

9332.

Home Builders Company has
FSN-ENC on their web page
along with a picture of their
holiday tree from last year. Go
to homebuildersnc.com and
click on Community on the left
hand top corner of the page.

FSN-ENC Staff

Brenda Boberg
Executive Director
252-847-5120

Linda Clark
Administrative Assistant
252-328-9332

Parent Coordinators
Portia Richardson
PCMH, PEDS, PICU,
Rehab
252-847-5068

Sylvia Barrett
Pitt County
252-383-0724

Cheryl Adams
PCMH, NICU & Women's
252-847-0192

Pam Allen
Martin County
919-917-2503

Candace Lang
Wilson & Johnson
Counties
919-880-5053

Deen Rightmyer
Northampton & Halifax
Counties
252-532-5644

Dana White
Beaufort, Hyde & Bertie
Counties
252-917-7029

**Martin County
Smart Steps**

Funded by Martin-Pitt Partnership for Children

Meets every Wednesday
Call Pam at 252-917-2503

Pam Allen
Parent Coordinator

Upcoming speakers:

Sept. 21 – **Sandy Steele**
Partnership for Inclusion

Sept. 28 – **Donna Austin**
Power Point Presentation on Medical Cover/Medicines

Oct. 5 – **Pam’s House**
Fact Finding Workshop on Internet

Oct. 12 – **Kid’s Activity Day**

Oct. 19 – **Tanya Wynne**
Martin Co. Extension Agency – Taking Care of Yourself with Diabetes

Oct. 26 – **Sandra Nobles**
Martin County Community Action – Head Start

Nov. 16 – **Kid’s Activity Day**

Nov. 23 – **No Meeting**

Dec. 7 – **Tonya Wynne**
Martin Co. Extension Agency – Holiday Cooking

FSN-ENC has a wish list and some items needed are:

- Small stuffed animals (beanie baby size)
- Receiving blankets (small and full size)
- Newborn outfits (boy

- & girl)
- Scrap booking supplies such as:
Stickers
Decorative edge scissors
Double sided tape
Glue Sticks
Decorative paper
Small books

FSN-ENC Board Members 2005

- Diana Antonacci
- Jackie Cannon
- Bettie Ann Carroll
- Steve Engelke
- Joi Hadnott
- Georgia Hennessy
- Debbie Iams
- Angela Lamson
- Carol Irons
- Kaye McGinty
- Kathy Preville
- Jim Smith
- Tammy Song
- Gary Stainback
- Sheri Strickland
- Rosalie Trotman

The activities of the Family Support Network of Eastern NC are made possible by:

- United Way of Pitt County
- FSN-NC
- Martin-Pitt Partnership for Children
- Family Support Network of Eastern NC (DSS funding, CDSA funding, state appropriations)
- University Health Systems of Eastern Carolina, PCMH
- Festival of Trees fundraiser

- Generous donations of individuals and families

Mission Statement of FSN-ENC

A Parent-to-Parent support program designed to provide emotional support and resource information for families of children with developmental, physical or medical needs and families who have experienced the death of a child.

The Family Support Network of Eastern North Carolina (FSN-ENC) needs your support.

Contributions may be made in the form of:

- Cash Donations
- Monetary Pledges
- Materials and Supplies
- Equipment
- Volunteer Manpower
- Stocks/Bond Donations
- Memorial Bequests
- Other Gifts

FSN-ENC periodically has a FREE workshop designed for brothers and sisters of siblings with special needs. We know there are times when these children feel the need to talk about their feelings and to have that “special attention” that is

given during the 6-week course. This workshop is geared toward the 6-12 year age group and meets once a week. If you would like to have your child attend, please call 328-9332 and the secretary would be glad to add their name to the list for the next available workshop.