

# Family Support Network of Region A Parent Link



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A Parent to Parent Program Serving Families of Children with Special Needs

## Advocate/aka- mom, dad, caregiver, ect.

Am I dreaming? They must be wrong... I am having a baby and today is the day My husband and I will find out if it is a boy or girl. My excitement turned to terror and unbelief as we sat with the obstetrician. We were supposed to learn the sex of our baby instead we were told our baby had a rare nuerotube defect, an occipital encephlocele. Our vision of coo's and laughter were blurred by the words, your baby has no chance of survival. The next six months were incredibly difficult. Do I fix a nursery or plan a funeral? I remember thinking that I didn't want her to be born. Just stay inside me, safe!

Being an advocate for my daughter began long before she arrived. All the professionals advised me to terminate the pregnancy or have natural childbirth so it would make things easier for me. I didn't want easier for me I wanted what was best for my baby. This was the beginning of being my child's best advocate. I kept insisting and reluctantly my wishes were granted to have a caesarean birth.

On July 11, 1994, anxiety at its peak, Mary Elizabeth Davis was born. I had prayed and believed she would be born a perfect bundle of joy. My faith had never experienced such a test. I didn't understand just yet that Mary Beth was the perfect bundle of joy I prayed for. Those first few days of her life were filled with medical staff not giving her a chance. I quickly realized that I must advocate on her behalf even for the basics of life. On day five we were sent home with Hospice services and told to love her until she died. My reply was simply "That is exactly what I plan to do."

I knew from the moment I held this amazing little baby that I would never give up hope. I prayed for the wisdom and grace to be the parent she needed. I have lost track of all the times I have been told there is no hope but as her mom/advocate, never give up became a way of life. When she was unable to eat, I kept insisting to trying one more thing. When she couldn't communicate and was starting school I held to my hunch that being in a class where she could experience sign language all day would mean that she could learn to communicate. No one thought that was the best placement but soon she began to communicate with sign language. When no one else believed she could learn to read I kept pressing to find a way. Mary Beth just finished her first book of the Edmark reading curriculum.

Being a child's best advocate is really what being a parent or caregiver all is about. No matter whether or not a child has a disability our role is to look out for our child's best interests. The definition of an advocate is a person who speaks up for or in behalf of another. I know that advocating for my bundle of joy has helped her become who she is today. Seeing Mary Beth first as my daughter, not just a diagnosis, allows her to touch hearts every where she goes. I think she knows more people around town than I do. I certainly got my bundle of joy, more joy than I could have dreamed. Mary Beth has taught me that everyone no matter whether or not they have a disability can leave their mark on others' hearts when we see potential that no one else does and advocate on their behalf.

So let all advocates (moms, dads, caregivers, etc.) do what we do naturally-Seeing that our children's best interests are looked out for. Let us also remember that others need to benefit from our experiences and what we have learned while advocating for our child. Even though being your child's best advocate can seem very lonely at times, you are not alone. There are many others who have walked where you are walking and are willing to walk alongside you as you advocate for your child.

Family Support Network is a program of Region A Partnership For Children and an affiliate of Family Support Network of North Carolina, serving Cherokee, Clay, Haywood, Graham, Jackson, Macon and Swain Counties and the Qualla Boundary.



Julie Davis

**CHECK OUT WHERE YOUR LOCAL SUPPORT GROUPS FOR CAREGIVERS OF CHILDREN WITH SPECIAL NEEDS ARE: CHEROKEE, CLAY, GRAHAM, HAYWOOD, JACKSON, MACON & SWAIN COUNTIES**

**Family Support Network of Region A**

**367 Dellwood Road**

**Building D**

**Waynesville, NC 28786**

**828—456-8631 Ext 29**

**Fax: 828-452-4871**

**[www.regionakids.org](http://www.regionakids.org)**

**Program Coordinator**

Julie Davis

[julie@regionakids.org](mailto:julie@regionakids.org)

**828-456-8631 ext. 39**

**828-226-1198**

FSN of Region A is an affiliate of Family Support Network of North Carolina

**Haywood**

Haywood support group meets the 2nd Monday of the month from 6-7:30 at New Covenant Church, Clyde. Contact Michele Holden at 235-0993 or [mommichele2030@bellsouth.net](mailto:mommichele2030@bellsouth.net) for more information!

NAMI Support Group meet the 3rd Thursday of the month at First United Methodist Church, Asbury room in Waynesville. 6pm

**Relatives as Parents**

1st & 3rd Tuesday of the month at 11:30-1 at First Methodist Church, in the Wesley room, Waynesville. Contact Emma Beckner at 456-8995 for more info. Food & child care provided.

**Jackson/Swain**

Autism Support Group meets the 1st Friday of the month at Christ Fellowship Church, Cherokee. Contact Brandi West at 488-1526 for more information.

**Cherokee Support Group**

Meets the 3rd Tuesday of the month. Contact Kathy Norris at 497-3682 for details.

**Support Group for people with food allergies and those trying a wheat-free diet** Contact Karen White, nutritionist at WCU, at 227-2088 for more information.

**Macon**

**Macon support group**

Meets the 4th Thursday of the month from 6-7:30. Refreshments and child care

provided! [Contact Ellen Hodgins at 828-421-7750](mailto:Ellen.Hodgins@regionakids.org) for more information.

**Community Early Learning Groups**

Opportunity for structured play with your child 0-5. Groups meet weekly. To find out the day & time the group meets in your county [call 586-0661](tel:586-0661) or [emma@regionakids.org](mailto:emma@regionakids.org) or [kristi@regionakids.org](mailto:kristi@regionakids.org)

**Care to Share?**

**Families sharing their experiences and stories bringing hope and encouragement to other families who may be facing what they have already experienced.**

**The biggest challenge with having a child with a disability is:**

**The day to day challenge of maintaining as much normalcy as possible.**

**The greatest joy this child has brought to our lives is:**

**Watching them overcome their personal challenges to become individuals, not just a child with a disability.**

**Shasta Vough**

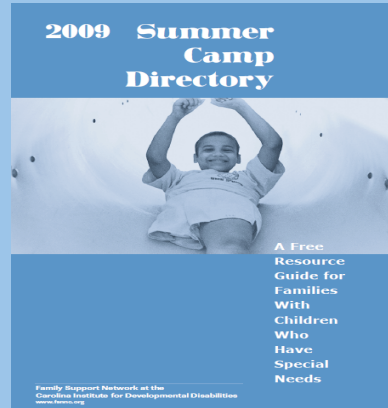
## Carolina West Dental

205 Waynesville Plaza

Waynesville, NC 28786

Carolina West Dental is a private group practice dedicated to providing quality dental care to Western North Carolina. The practice accepts patients from any county in North Carolina, ages 1-20, who are enrolled in the Medicaid and NC Health Choice programs.

Carolina West Dental is located in the Waynesville, Plaza. The hours of operation are Monday –Friday 8am -6pm. Patients do not need a referral. Call **828-452-5656** for an appointment



Go to [www.fsnn.org](http://www.fsnn.org) to check out all the camps! For a hard copy contact Julie Davis at 456-8631 ext. 39.

## Workshops and Conferences

**Love and Logic** March 17– April Learn how to get your child out of bed, stop the bickering and how discipline on public. New Covenant Church, Clyde, NC Light evening meal at 5:30 free of charge and childcare will be provided also. Course meets every Tuesday.

### Autism Society

March 18 & May 13–Newly Diagnosed Workshop, workshop for families with a child recently diagnosed. 10-12 pm

April 15 & May 27-What is Autism? Basic introductory workshop about Autism Spectrum Disorder 9:30-11:30am

April 18-Transition to Adulthood. Most helpful for parents of children ages 11-17 who have an IEP. 9:30-11:30am

May 16-Autism Spectrum IEP. Provides information on the IEP process, how to prepare and advocate for your child. 9:30-12:30pm

Registration required for workshop. Workshops will be held at the Asheville office. Contact Jean Alvarez at 828-236-1547 or email [jalvarez@autismsociety-nc.org](mailto:jalvarez@autismsociety-nc.org).

**2009 Autism Society Conference**, March 27-28 Sheraton Chapel Hill Hotel

**22nd Self Advocate Conference**, March 27-29 Benton Convention Center, Winston Salem [www.asa-nc.org](http://www.asa-nc.org)

**NC Foster & Adoptive Parent Association Conference**, May 1-3 Renaissance Suites Hotel, Charlotte [www.ncfapa.org](http://www.ncfapa.org)

**2009 Smart Start Conference** May 5-8 Greensboro [www.ncsmartstart.org/conference/](http://www.ncsmartstart.org/conference/).



**Family Support Network of  
Region A Partnership for Children  
116 Jackson Street  
Sylva, NC 28779**

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### **Upcoming Support Parent Trainings!**

**Friday, March 27      Haywood County      10-3**

**Saturday, March 28      Jackson County      10-3**

Are you interested in offering support to “new” parents of children with special needs? Who better to provide support to others than a parent like yourself who has been through a variety of challenges and joys raising your child. This training will help to:

- orient you better to the “network” of Family Support,
- help you to more fully understand your role as a “support parent”,
  - expand your knowledge of resources and,
- provide you with an opportunity to meet other parents

***Lunch and snacks will be provided.***

***Stipends available for childcare. Please contact Julie Davis for more information and to register for the workshop!***