



CONNECTIONS

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Family Support Network of the High Country

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FSN-HC is proudly sponsored by Appalachian State University, Children's Developmental Services Agency of the Blue Ridge, Family Support Network of North Carolina, & High Country United Way

Family Support Network of the High Country

Information and Support for Families of Children with Special Needs
Serving Alleghany, Ashe, Avery, Mitchell, Watauga, Wilkes, & Yancey
Services are Free and Confidential

Welcome to the Family Support Network of the High Country!

Our program:

- Provides information and support for families who have a premature infant, a child with a disability or chronic illness or a family who has experienced the death of their child.
- Can match a family one-to-one with a trained, volunteer Support Parent who has a child with special needs. These volunteer families provide emotional support and share the expertise of their own experiences.
- Supports professionals working with families caring for children with special needs.
- Sponsors workshops, trainings and support groups.
- Promotes collaboration among parents, families and service providers.

Down Syndrome in Watauga County

We have been helping families who have children with developmental delays find resources, educational materials and service referrals since our founding in 1988. And as Kate Brinko knows firsthand, FSN-HC also links these families up to a "support family," which has already gone through similar experiences with their own children.

Kate Brinko and Jon Kwiatkowski are the parents of Mieszko Kwiatkowski. This unique name is quite fitting for a young man who was grown

up experiencing challenges that only about one in 1000 people face. Mieszko has Down Syndrome.

Down Syndrome is the most common chromosomal condition associated with mental retardation. Being born with one extra chromosome (47 as opposed to the typical 46) can cause problems such as delayed cognitive functioning, health risks and physical irregularities.

But as Kate commented, "Some are short, some are tall. Some are sweet, some are rude.

They're just people like everybody else."

While most people with Down Syndrome live with a mild to moderate range of mental retardation, there are many different levels of intellectual aptitudes, behavior and developmental growth. However, providing children with Down Syndrome early on with special attention that encourages the growth of their language, social, cognitive and motor skills can greatly aid in their development.

"Like everyone else,

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Anchors Away!

The past couple of years have been difficult ones for Family Support Network of the High Country. FSN-HC struggled month to month with financial obligations while several longtime key advisors drifted away. Our ship was adrift with the tide. Things needed to change.

In January 2004, the Advisory Board and Executive Director of FSN-HC sat down to begin the process of charting the program's future course. What we thought would take two days turned into a series of meetings over the next five months, resulting in a renewed vision for FSN-HC with a strategic plan to see that we get there. Creating a map for success was difficult work, but following this route will require even greater efforts, collaboration, and commitment.

Already, however, we are seeing the beautiful signs of success in our journey. You are currently reading the first newsletter published by our organization in many, many years. Did you notice the new logo? How about the new website- have you checked it out? We have also begun a process of reconnecting our valued Support Parents/Families to each other and the larger Parent To Parent program. Have you met our new staff? That's right, staff! We have three new members on the team helping Kaaren Hayes keep the course. Melanie Cashion is the new

Training Coordinator, Jessica Powell is the new Volunteer Coordinator, and Jeannie Wellborn is the Family Support Coordinator.

In October, Kaaren, Board Chair Chris Goodrich, and myself attended a retreat of all programs in the Family Support Network of North Carolina (FSN-NC). FSN-NC has also had a change at the helm and is steering a new course as well. It was a wonderful opportunity to share and learn with the other Family Support Network programs across the state. We acquired a greater respect for the larger network of which we are a part, and learned more about our many state resources (such as the Central Directory, which you can learn more about in this newsletter).

You will soon see other changes on the near horizon. We are in the process of acquiring a new database that will allow us to serve more efficiently and effectively, as well as expanding our website. We are also creating a new model for support/share groups that empowers families with the information they need to succeed. You should start to see and hear more about FSN-HC in the community as part of a targeted awareness campaign. And following my theme here, what seafaring adventure would be complete without a treasure chest? As part of our plan, we have already had some success in

creating a strategy for funding FSN-HC long into the future. FSN-HC started fiscal year 2004-2005 with the first balanced budget in the history of the program!

Imagine with me for a moment, a day when no High Country family with special needs is frustrated for lack of understanding, information, contacts, or help. A day when they have all the directions they need to plot their own course, lift those heavy anchors, set sails, and make way. What a beautiful voyage it will be. Well, we can make it happen. With your help, Family Support Network of the High Country can provide the resources families need to take control of their lives, move forward with confidence, and as our vision statement puts it "... create lasting waves of positive impact."

Ken Powell - Advisory Board



Become A Support Family

Become a Support Family! We are looking for parents, guardians, foster parents and grandparents of children with disabilities, health problems, or those who have lost a child who would be interested in being a support to another family.

There is often a common bond between families of children with special needs. Yet, many times families are not able to discover this bond because they don't know where to turn to find other parents facing similar situations.

Volunteer Support Families can bridge this gap.

FSN-HC will begin to offer orientation sessions for new volunteer families this winter. The sessions will provide potential volunteers the opportunity to learn more about our program and the parent to parent matching process. The orientation will also provide support to new volunteers by presenting information on communication skills, listening skills, the process of grieving, confidentiality, and local

resources.

If you feel that you have the time and energy and would like to be a support to someone else, or would just like more information about this opportunity, please call our office at (828) 262-6089 or use our toll free Parent Line at (866) 812-3122. You will be amazed at how rewarding it is to work with other families like yourselves.

We look forward to your call!

Share Groups

Worried about your child's behavior? Come join other families once a month to share knowledge, strengths, hopes and experiences.

We eat together, visit, relax and learn about new resources and ways to help our children and ourselves. We respect each person's right to confidentiality and all agree that any personal information shared at a meeting, stays at the meeting. We believe that both information and fun are important. Topics in the past have been an introduction to the Love and Logic parenting approach, How To Keep Your Stripes On (Stress Relief!) and a family picnic. We strive to take an active part in making services better for our children.

This group is sponsored by FSN-HC and Watauga Youth Network.

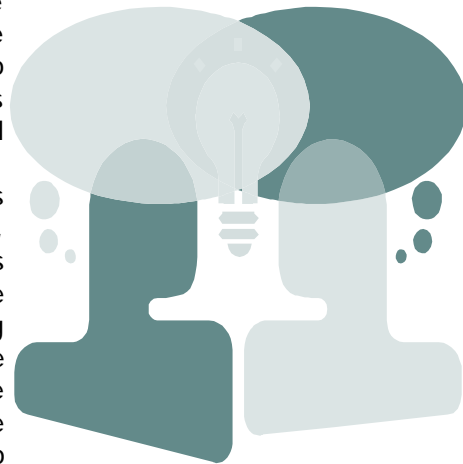
We are proud to also

announce the **Families with Medically Fragile Children Share Group**. This Share Group is a unique opportunity for families to meet and share with others with similar lifestyles and concerns.

Since FSN-HC covers Alleghany, Ashe, Avery, Mitchell, Watauga, Wilkes and Yancey counties, we are looking at meeting formats like teleconferencing, private online chats or phone conferencing to compliment the meetings held in Boone. If we have several families who wish to participate in counties other than Watauga, we will look at expanding the Share Group to have meetings in their county.

Both Share Groups meet the second Friday of each

month at 6pm at the CDSA (150 Den-Mac Drive, Boone).



New families are always welcome! For more information or to RSVP, please call (828) 262-6089. Childcare is provided if requested.

Q & A

Where else can I go to learn more about finding resources for my special needs child?

The Central Directory of Resources (CDR), a part of Family Support Network of North Carolina (FSN-NC), provides information about resources for families with children with special needs across the state.

Resource Specialists offer support and services for children aged birth-21 and their families. Callers can speak with a Resource Specialist about a child's particular needs, find help with advocacy, and get information about services



that are available in their own communities.

The CDR provides printed information and links to websites that provide information about specific disorders and disability-related issues to families and service

providers. Staff can fax, mail and, when available in electronic format, e-mail information to you. The CDR has printed information available in Spanish and one of our resource specialists is Spanish-speaking. All services are provided free of charge.

The CDR also publishes an annual camp directory of camps throughout the state, and some national camps, for kids and adults with a variety of special needs.

Contact the CDR by calling (800) 852-0042 or by sending email to CDR staff: cdr@med.unc.edu

Down Syndrome Continued from Page 1

when they are treated with love, respect and compassion, they will be better able to perform in their lives. Their talents will shine through," Kate said.

People with Down Syndrome can experience medical difficulties such as hearing loss, speech difficulty, and visual and respiratory problems. About one in three babies with Down Syndrome have heart defects, just like Mieszko, who conquered heart surgery at three years of age.

The early years were the most difficult for Kate and her family. She had numerous questions as to what his life path would be, how he would

develop, how he would be accepted in the community, and whether or not Watauga County could provide all the resources they needed. She wondered whether he would be invited to birthday parties.

Kate's association with Parent To Parent during the beginning of her son's life helped to ease some of these fears. In addition to helping her find informative material about Down Syndrome and services around the High Country specializing in the disabilities, she was also linked up to a family that had dealt with the syndrome. Meeting them and consulting with them on the phone gave her some of the support she

needed.

After surviving the uncertainty of those early years, Kate volunteered to become a support parent herself. Since then, she has guided three families with Down Syndrome children through the trying times that she herself experienced.

The support Kate has received from the Family Support Network and other services in the High Country has helped her to realize that life is what you make of it.

"Raising a child with disabilities has extreme highs and extreme lows. While it's really hard, it's also really—and I mean *really*—fabulous!"

Ananda Janowiak

Upcoming Events

Mark Your Calendars Now!

Saturday February 26, 2005
Adam's Mark Hotel
Winston-Salem, NC

ALL Aboard... to the Future!

A conference for **parents** and **families** with children with disabilities, **educators** and **youth** with disabilities

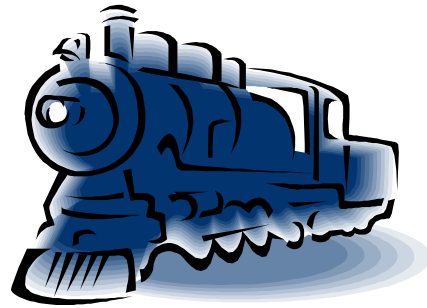
- Conference sessions will include:
 - Positive Behavior Supports and the NCDPI Initiative
 - Effective Practices for use in school and community such as:
 1. School-based Mental Health Services
 2. Student Directed IEPs
 3. Effective Advocacy Skills
- Sessions FOR youth ages 15 and above

The conference is brought to you by the:

Exceptional Children's Assistance Center

in collaboration with The North Carolina Positive Behavior Support Initiative
Divisions of mental Health, Developmental Disabilities and Substance Abuse
NC Families United Governor's Advocacy for Persons with Disabilities
Other NC Parent and Disability Organizations

Conference brochures will be available in late December. Watch our website www.parent2parenthighcountry.org or call our office: (828) 262-6089 or toll free Parent Line (866) 812-3122



Mardi Gras Marathon 2004

Appalachian State University hosted their Second Annual 24-Hour *Mardi Gras Marathon: Making Miracles Happen* on October 9 & 10 at Legends. Over 125 students and friends boogied all day and all night long! Over \$15,000 was raised for FSN-HC and Watauga Youth Network. That's twice the number of students and money raised than last year!

Participants also danced their way amongst cheers and honking cars to Kidd Brewer Stadium to watch ASU's football game vs. Furman. Even while watching the game, they never

stopped rocking. At half time, the dancers provided an amazing show of a dance they had learned that morning.

Thank you to Appalachian and the Community Together (ACT), Appalachian Popular Programming Society (APPS), The Pan Hellenic Council (PHC) and

ASU Athletics Department for all their effort in making this marathon happen. Thank you to Wachovia who made a generous donation to the Marathon. A very special thanks to the ASU students for all of their long, hard work to make this event such a success.



"Over 125 students and friends boogied all day and all night long!"

HATS OFF!



Dana Willett of Advertising Design Systems for creating our new logo!

Jim Williams for creating our new website!

Dr. Melissa Barth and her English 4300

class for creating this newsletter and revamping our brochure!

Mr. Dennis Hayes for his contribution to our program which funded the printing and mailing of this news- letter!

Looking For a Unique

Having a difficult time finding the perfect holiday gift for someone? Why not make a donation to FSN-HC in their honor. Simply send us a donation along with the name of the person you are honoring. We'll give you a holiday card to give to the honoree. Or make a donation gift in the memory of a loved one.

These memorials will be published in the next edition of *Connections*. If you would like to send a donation, please see the form we have provided below.

Remember, your gift is 100% tax deductible as we are a nonprofit organization.



Please support our project so that we can continue to serve our parents and the community. Detach this form and send donations to the address below and help continue this much needed program.

Name _____

Address _____

City _____ State _____

Zip Code _____ Amount \$ _____

Name of Honoree(s) _____

Thank you for valuable contribution.



FSN-HC
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