



Connections

Information + Support
Families of Children with Special Needs
Alleghany, Ashe, Avery, Mitchell, Watauga, Wilkes, & Yancey counties

Late Summer
2010

FAMILY SUPPORT NETWORK OF THE HIGH COUNTRY

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An Affiliate of
Family Support Network-
North Carolina

With Support From

Appalachian State University
Children's Developmental Services
Agency—Blue Ridge
High County United Way
Friends of Family Support
Network—High County
Avery Partnership for Children
Mitchell-Yancey Partnership for
Children



A Chromosome of Love

Kim Buchanan

Cody was born on August 1, 2008. I had a normal pregnancy. Everything was ok until after he was born. Cody's oxygen rate wouldn't come up to normal. It was only about 4 hours after his birth that he was on the road to Brenner Children's Hospital. After the tests were completed it was determined that Cody had a heart condition called double outlet right ventricle (DORV). He would have to have open heart surgery to fix the problem. The only problem was he was too small to do the surgery. We were also told that Cody has Down syndrome.

When Cody was 12 days old we were told we would be able to go home soon. Then he took a sudden turn for the worst. His oxygen level dropped down into the low 40's and he stopped breathing. The cardiologist was in the room with him when this happened and knew exactly what to do. She grabbed him up and squeezed his knees up into his chest and doing this made the air in his lungs expand and then he started breathing again.

After all this had happened they decided he wasn't going to be able to wait and grow to be big enough for the repair without a shunt being placed into his heart. He was only 13 days old and he was going in for his first open heart surgery. Our world was already turned upside down and now they were taking our baby in for heart surgery. We were so scared and so worried. We had all kinds of thoughts running through our heads...Would he make it through surgery? Is he strong enough? Will we ever get to go home as a family?

Cody came through the surgery and recovered quite well, but was still very small and not growing well. Cody had a feeding tube that went in through his nose and down into his stomach. He couldn't have a bottle because he was aspirating and his heart was so weak that he would wear himself out trying to suck a bottle.

We were home for 2 weeks. We were really busy getting all the things lined up that Cody would need to help him with his special needs. We had a home health nurse that came to the house to check on him and also got set up with the CDSA (Children's Development Services Agency). Cody would have physical therapy and also a nutritionist that would come out to see him and help him with his development. The CDSA got us in contact with the Parent to Parent Family Support Network (FSN) group. All this was overwhelming at first. When we finally got him home after 3 weeks in the hospital we just wanted to have some family time but we also wanted to do what was best for Cody and get him all set up with the things he would need to help him developmentally.

The Parent to Parent FSN group is such a wonderful organization. They have tons of information and resources that have really helped us along our journey. They also gave us the option of being connected with a Support Parent that we could talk to either by phone or email that has been through similar situations with their children. We were connected with a wonderful family with 3 children with Down syndrome and they have been such a blessing in our life. If we have had any questions about anything with Cody they have always been there for us to talk to. They have already been through all of the things we were going through and thanks to Parent to Parent FSN we were able to have some piece of mind with the challenges we were facing.

After 2 weeks had passed we were back at the hospital for the checkup. Cody was going to have to have the feeding tube took out of his nose and put into his stomach. This meant he would have to have another surgery! Deep down we knew this was coming but we still weren't prepared... but we had to do it for Cody if he was going to have a chance at life. After his feeding tube surgery and 11 days in the hospital we were going home again. It seemed so good to see our little boy's face without the tube coming out of his nose. Now he had a mickey button in his stomach and he was hooked up on 24 hour feeds with his feeding pump. The feeding tube in the stomach did the trick. He was finally growing!

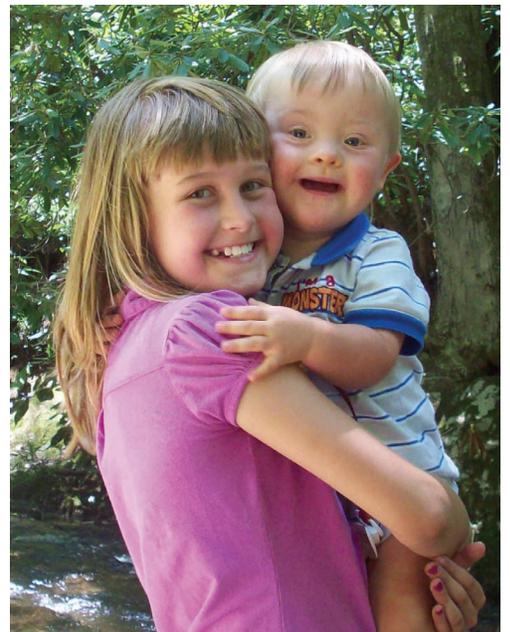
At 9 months old they said he was ready and surgery was scheduled for May 20, 2009. We were once again scared and worried because we had 9 months to bond and love this little guy and now we have to hand him over again to have yet another heart surgery. We wanted to take him and run away and leave this all behind us but in reality we knew he had to have this surgery to get better. The dreaded day finally came and after a 5 hour surgery he was in recovery, he had made it through the second heart surgery. Eleven days later we were on the road home.

After a few weeks of recovery time we had a brand new little boy! He had so much energy and was able to play and stay awake so much longer than he had ever before. He will still have to have a third heart surgery sometime in the future to have a valve replaced.

Now Cody just turned 2 years old on August 1st. He is so full of life and so full of energy! He has speech therapy, physical therapy, a CBRS person once a week (this is a general teacher), and a nutritionist once a month. He is now able to eat and drink most of his nutrition by mouth and only uses the feeding pump at bedtime. Cody even surprised us shortly after his second birthday and started walking!

Cody has a big sister Brook. She is his world. He loves her more than anything. She is the best big sister that anyone could ask for and also a huge help to us! Cody is the sweetest loving child, as are all children, but Cody has a little something extra. His extra chromosome that came with his Down syndrome must just be a chromosome of love.

We would like to thank the CDSA, First in Families, Parent to Parent FSN-HC, Dr. St Clair and Boone Pediatrics as well as Dr. Hines and Brenner Children's Hospital. Without you all we wouldn't be where we are today with our little angel!



WHERE HAS ALL THE ASSISTIVE TECHNOLOGY GONE????

In recent months, access points for assistive technology (AT) equipment libraries and services have changed. Loan libraries are valuable with Assistive Technology because you want to try items before you pursue funding, especially with expensive items, and because some AT needs are short term. Here are a few starting points to help you obtain needed items:

Resources for All Ages:

The North Carolina Assistive Technology Program (NCATP) is a state and federally funded program that provides AT services statewide to people of all ages and abilities. They offer device demonstrations and device loans free of charge. Check out their website for more information at <http://www.ncatp.org/>

Contacts for our area:

Bonnie Center

100 Bonnie Lane, Suite B
Sylva, NC 28779
Phone (828-631-9461 (Voice/TTY)
Fax (828-631-9259
Staff AT Consultant: Rae Bachus
Staff AT Specialist: Mary Kay Dulin

Enola Center

200 Enola Road
Morganton, NC 28655
Phone: 828-433-2431 (Voice/TTY)
Fax: 828-433-2288
Staff AT Consultant: Shelby Kennerly

The NCATP also has a Technology Exchange Program for device reutilization. You can list items to give or needed items for children and adults. There are several items for children currently listed such as walker, gait trainer, and wheelchair to name a few. Contact: Carol Williams, (919) 850-2787, ext. 222.

Partnership in Assistive Technology (PAT) is a non-profit organization dedicated to increasing access to assistive technology and information technology for North Carolinians with disabilities through training, equipment recycling, advocacy, and technical assistance. Their big event, the AT expo will be November 17-19th 2010 in Raleigh, NC. Go to www.pat.org for more information.

Ages 4 years and older

The Generations-Tadpole Lending Library is a private rehabilitation agency serving children and adults with disabilities. At one time, they were able to USPS mail devices all over North Carolina. The Lending Library is now available for use by employees of Central Regional Hospital and Murdoch Developmental Center only. It is no longer available to consumers across the state due to budget deficit. It may be a good idea to check with them periodically to see if restrictions have been lifted. Contact: <http://tadpole.org>

Birth to 3 years old

“The Family, Infant and Preschool Program (FIP) at the J. Iverson Riddle Developmental Center in Morganton has been selected by the North Carolina Early Intervention Branch Together We Grow program to provide statewide AT services for infants and toddlers with disabilities and their families through a memorandum of agreement for \$550,000. The purpose is to develop and implement a statewide AT loan and technical assistance system to provide support for children with disabilities from birth to three years of age and their families who are served by the Children’s Developmental Services Agencies (CDSAs) across North Carolina. The project will fund 3 full-time and one part-time staff positions as part of the American Reinvestment and Recovery Act. Services are scheduled to begin in August, 2010.”
M’Lisa Shelden, Director, Family, Infant and Preschool Program, Phone: (828) 430-7953, Email: mlisa.shelden@dhhs.nc.gov

Locally, the CDSA of the Blue Ridge has a loan library. The primary focus is on the birth to 3 population but we will loan items for people over 3 when the items are available. The majority of this library is in the Boone office. The number is 828-265-5391 to inquire about accessing this library.

If anyone knows of other useful Assistive Technology resources please share them with the Parent to Parent FSN-HC office. Happy Hunting!

Article submitted by CDSA Assistive Technology Team members Shana McCurry and Mary Wilkie

We're on the Web & Facebook Check us out!
www.parent2parent.appstate.edu

Love and Logic Helpful hint....

When we describe what we will do or allow, that's setting a limit. When we tell a child what he/she should or shouldn't do, that is a possible fight.

Examples of Turning Your Words Into Gold

Unenforceable Statement

mine. Don't talk to me in that tone of voice!

when For Pete's sake! Take out the trash!

try

try

Enforceable Statement

I'll listen when your voice is as calm as

I'll be happy to do the extra things I do for you
your chores are done.

Area Support Groups: Contact Information

Ashe County Support Group: Norma Bouchard at 336/246-3222 or toll free: 866/812-3122 or bouchardnj@appstate.edu

Mitchell County Support Group: Teresa Emory at 866/448-5781 or emorytd@appstate.edu

Watauga County Support Group: Kaaren Hayes at 828/262-6089 or toll free: 866/812-3122 or hayeskl@appstate.edu

Wilkes County Support Group: Norma Bouchard at 336/838-0977ext. 212 or toll free: 866/812-3122 or bouchardnj@appstate.edu

Yancey County Support Group: Teresa Emory at 828/682-4772 or emorytd@appstate.edu



PLEASE SUPPORT OUR PROGRAM !



ONLINE:

www.parent2parent.appstate.edu

MAIL:

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