

# CAP / C NEWSLETTER

AUGUST-SEPTEMBER, 2007

## UP CLOSE AND PERSONAL WITH CAP/C KIDS: A MOTHER'S PERSPECTIVE

by Gavin's mom, Debbie

Gavin was born by planned C-Section on September 19th 2002. I had a normal pregnancy and he seemed healthy and happy at birth. Before we left the hospital I noticed that he did not seem to be sucking well, or for very long. He tired easily and would just stop. I nursed his brother Ryan for a year so I knew what I was doing. Everyone said I was just seeing things and he was fine, but he began to fall off the growth charts and then he started to flat line on the charts and doctors got interested.

Gavin was sent to a "suck" specialist and for \$100 an hour, she fed him a mixture of my pumped breast milk and rice cereal. He did start to gain after that but he still did not eat normally. Doctors tested him for every terrible illness known to man yet he does not seem to have any of them.

In December of 2005, Gavin's doctor decided to put in a G-tube. Since then he has gained some weight, but he still eats only a few bites and then he loses control and becomes disorganized in this mouth and he gags or throws up. He does not speak clearly and not at all for a long time. He is diagnosed with apraxia, a communication disorder.

Because Gavin was not growing and tested low on growth hormone, his physician put him on growth hormone shots last year fall. He is five years old and still the size of a three-year-old, although he has grown an inch.

Gavin is a wonderful child. He has not let his disabilities slow him down. He played soccer with his brother last year and stayed with the pack during the game. He played T-ball this year and although he doesn't really understand which direction to run, he did GREAT! He runs and jumps and pesters his big brother Ryan. Ryan is seven, and he is a WONDERFUL big brother. If you ask him who is his best friend, he will quickly say, "Gavin!"

Last year Gavin attended Louisburg Elementary part-time in a pre-K class for special needs kids. This year he will attend that class on a fulltime basis. Because of his delays (about 18 months) he is not ready for kindergarten just yet.

Gavin has started talking better and REALLY loves his home health nurse (Sherree) who we feel has helped him

make big growths in his connection and communication with us all. He continues with speech therapy, physical therapy, and occupational therapy. Along with all of his other activities we know he will continue develop more confidence and abilities.

A BIG "Thank You" to Gavin's CAP/C case manager April Hill who has made everything SO easy for us and keeps Gavin up-to-date in all of the things he needs. She (and CAP/C ) has been a life preserver in a sea of confusion.



## CCWJFC TRADING POST



CAP/C kids are often in need of equipment that is not covered by their private insurance or Medicaid. In addition to the organizations on the internet and locally where equipment can be exchanged, we have this trading post. We often are given items by a parent whose child is unable to use a piece of equipment any longer and are able to pass the equipment along to another child. Please know that if there is anything your child is in need of that is not covered by CAP/C or will not fit into the budget that you can let your case manager know so that the need can be posted on the next newsletter.

### Items up for grabs:

- Bath Chair
- Walker—to fit a child less than 39 inches tall.
- Walker—was used for a child aged 6-9 years old.
- Stander with tray—was used for child age 5 and under.

Please let your case manager know if you are interested in any of these items.

### Items needed:

- Hoyer Lift
  - Oxygen Concentrator
- Please let your case manager know if you are in need of any equipment.

## THINGS YOUR CASE MANAGER NEEDS TO KNOW

- your child is hospitalized or there are any changes in your child's medical status
- the agency that provides care for your child is not able to provide staff or if you "fire" an agency
- there are any issues with the delivery of supplies
- your child's doctor or therapist suggests a new piece of equipment such as AFO's or a wheelchair
- an IFSP, IEP, or an annual physical exam is scheduled
- there are any changes in you child's primary insurance policy
- Also the case manager will need to see your child's Medicaid card during home visits. We must be sure the CAP indicator code on the card is correct. Be sure to have it available when a home visit is scheduled.

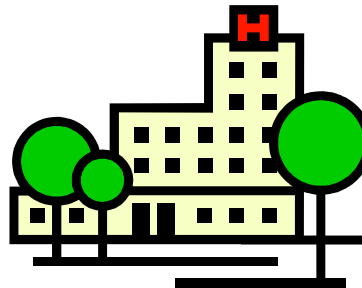
## POLICY REMINDERS



The CAP/C program is designed to provide care for children in their homes. Nurses and nurse aides may travel with the child to medical and therapy appointments while the parent is driving because the child may require care during travel time.

However, Medicaid does not allow payment for services provided by nursing staff once the child arrives at the medical facility (doctor's office, emergency room, hospital, clinic, rehab center, etc.). Care provided by the nurse/aide while in a medical facility is considered a duplication of service and is not reimbursed.

The nurse/aide's paid time stops upon arrival at the facility and begins again upon departure.



Therefore, please give your nurse/aide advance notice of upcoming appointments so they can decide whether they will be able to accompany you to the appointment.

**Under no circumstance is your child's nurse/aide allowed to drive your child in any vehicle. This is a strict Medicaid rule that must be followed by family and staff.**

## CAP/C STAFF ADDITIONS

More children are enrolling in the CAP/C program and we are keeping pace by hiring some wonderful new case managers.

Joy Crabtree, RN, came to us from Duke as a nurse in the intensive care nursery. She is a new mom to a little boy born in May 2007, and she is excited to be part of CAP/C.

More about Joy to come in a future issue!

### NEW MAILING ADDRESS:

**Community Care of Wake, Johnston & Franklin Counties  
2500 Blue Ridge Rd,  
Ste 330  
Raleigh NC 27607**

### NURSE/AIDE STAFFING NOTE:

**Referrals for staffing are sent each week for children who are without a nurse/aide or who are not fully staffed.**

**Let your child's case manager know if you interview a nurse/aide that you want to hire.**

## APRIL HILL: WIFE, MOM, NURSE, TRAVELER

*This column features a different CAP/C case manager each issue. Stay tuned to learn more about your own child's case manager.*

April Hill, RN, is no stranger to nursing. April's 17 years of experience bring many valuable contributions to the CAP/C program.

April began her nursing career caring for patients on the medical-surgical floor and in the emergency department at Franklin Regional Hospital. She later transferred to WakeMed, working on the labor and delivery unit, the cardiac unit, and then case management on the trauma unit, giving her valuable experience setting up home health needs for patients. While working, she continued her education and completed her bachelor's degree in nursing through East Carolina University.



April joined CAP/C in May 2005. She says the best part of being a case manager is "being able to successfully connect clients with the services they need and being able to provide the needed support to families so their child will be able to thrive in their home environment."

One of April's biggest challenges is trying to find community resources for her clients in Franklin County because of the limited resources available.

Outside work, April is a wife and mom. She and her husband, Willy, stay busy raising four beautiful daughters and one yellow labrador puppy named Waylon. April loves spending time with her girls, visiting the water parks in Virginia and making trips to the mountains. She looks forward to her biannual vacations with her husband, a cardiovascular technician and paramedic through WakeMed. They enjoy relaxing at various Sandals resorts such as the one in Jamaica and the Bahamas.

## SHINING STARS!



Through Make-A-Wish, **Harrison** attended a Boston Red Sox game and threw the first pitch! Way to go Harrison!

**Asher** received his much anticipated lung transplant in July 2007. He is now decannulated, completely oxygen-free, without a wheelchair, and getting all his nutrition by mouth. Keep making strides Asher!

**Michael & Christopher** are the Make-A-Wish Foundation Ambassadors for 2007! Great Job to both of you!

**Is your child a Shining Star?** Let your case manager know about your child's accomplishments, big or small, so that we can celebrate your child's success with you!



## CAP/C STAFF DIRECTORY

If email works for you, feel free to communicate with your case manager that way. **Remember that anything sent via email is not encrypted and can potentially be viewed by anyone.**

**Liz Ackerman, RN**  
Office: 919-303-8488  
Fax: 919-303-8489  
lackerman@wakedocs.org

**Lori Banks, RN**  
**CAP/C Coordinator**  
Office: 919-461-3999  
Fax: 919-461-0334  
lbanks@wakedocs.org

**Joy Crabtree, RN**  
Office: 919-934-4271  
Fax: 919-6315  
jcrabtree@wakedocs.org

**April Hill, RN**  
*CAP/C Parent Newsletter Contributor*  
Office: 919-562-7990  
Fax: 919-554-1990  
ahill@wakedocs.org

**Cindy Mackvick, RN**  
Office: 919-553-6944  
Fax: 919-553-6870  
cmackvick@wakedocs.org

**Andi Phillips, RN**  
Office: 919-875-2425  
Fax: 919-875-2426  
aphillips@wakedocs.org

**Amy Price, RN**  
Office: 919-387-3313  
Fax: 919-387-3314  
aprice@wakedocs.org

**Tara Robinson, RN**  
*CAP/C Parent Newsletter Editor*  
Office: 919-477-1439  
Fax: 919-477-1459  
trobinson@wakedocs.org

**Heather Stewart, RN**  
Office: 596-3366  
Fax: 919-596-8231  
hstewart@wakedocs.org

**Kelly White, RN**  
Office: 919-557-9934  
Fax: 919-557-9978  
kwhite@wakedocs.org

## INTERVIEWING A POTENTIAL NURSE OR AIDE

Here is a checklist that may be helpful when interviewing a nurse or aide.

- Name of agency
- Agency phone number
- Name of nurse/aide
- Scheduled interview time & date
- Is the applicant timely for interview?
- Professional dress and demeanor?
- Did the applicant notice my child, play with and address my child comfortably?
- What experience with children does the applicant have?
- Does she or he have experience with technology that my child uses (trach,

ventilator, g-tube/j-tube feedings, venting g-tube, catheterizations, braces, etc)?

- Is the applicant comfortable with my emergency plans (what to do for seizure, choking etc.)?
- Does the applicant understand and can carry out our daily routine?
- Does his or her availability fit my scheduling needs?
- Once the interview in completed, whom do I call at the agency to provide feedback?



## CAP/C PARENT SUPPORT

Listed below are "Web Sites of Interest" with a brief description of what each site has to offer. Please browse the websites you find interesting. They are all bursting with information and resources.

**comeunity.com/disability** Contains a wide range of articles and resources for parenting children with special needs or disabilities.

**familyvillage.wisc.edu** This site describes itself as a global community that integrates information, resources and communication opportunities on the Internet for persons with cognitive and other disabilities, for their families and for those that provide them services and support. Resources on specific diagnoses, communication connections, adaptive products and technology as well.

**our-kids.org** A "Family" of parents, caregivers and others who work with children with physical and/or mental disabilities and delays. Its members consist of over 800 people representing children with varying diagnoses; everything from indefinite developmental delays and sensory integration problems, to cerebral palsy, to rare genetic disorders. You'll find discussions about children's accomplishments and obstacles, knowing that the audience includes others who know what they are going through. Members can also get some idea of

how others address specific problems/concerns with feeding, learning, schools, medical resources, techniques and equipment, as well as describing the problems to friends and family, or just coping.

**groups.yahoo.com/group/CAP-C** This email group is for families in the CAP/C program in North Carolina, or those who are on the waiting list to begin services. The purpose of this group is to provide a positive and supportive forum for families of children who are medically fragile, to share ideas, and help each other as only other parents can. Here you can discuss your favorite nursing agencies or DME providers, places that easily accommodate our kids, even trade or share extra supplies. Membership is restricted to parents (which includes foster, adoptive, grands, guardians, etc.) of CAP/C kids.

**pat.org** The mission of PAT (Partnership for Assstive Technology) is to increase knowledge about and access to assistive technology and information technology for North Carolinians with disabilities. This site includes an equipment trading post.

**Caregiverssupportandwellness@yahoo.com** Support email group for parents who have children with special needs.

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Every month we announce birthdays of our CAP/C kids, using the child's first name only.

Please let your case manager know if you DO NOT want your child's birthday announced in future newsletters.



**HAPPY BIRTHDAY TO YOU!**

### AUGUST BIRTHDAYS

Alexa  
Alexander  
Carissa  
Eleora  
Grace  
Harrison  
Mackenzie  
Quandre  
Tyson  
Victoria

### SEPTEMBER BIRTHDAYS

Aiden  
Amy  
Asher  
Benjamin  
Craig  
Diavian  
Joshua  
Kathleen  
Malek  
Michael  
Niamya