



Buddy Walk

October is National Down Syndrome Awareness Month and Buddy Walks are held across the nation to celebrate individuals with Down Syndrome.

In South Carolina there are Buddy Walks in Aiken, Anderson, Columbia, Greenville and Spartanburg. These events are hosted in celebration of individuals with Down syndrome, to promote awareness and understanding, and to raise funds to support local parent-to-parent programs and research through the National Down Syndrome Society.



CSRA Buddy Walk - Sunday, October 16th at the Roberto Hernandez Stadium in Aiken. Registration - 12:30 pm. Call Jenny Hall at Upside of Downs of AIKEN - 803-648-1652.

Anderson Area Buddy Walk - Sunday, October 9th at the Anderson University Athletic Campus. Registration at 2 pm. Fun, food and games from 2 to 5 pm. Contact Sherry Fields at SherryFields@FamilyConnectionSC.org or 864-231-8100.

Columbia Area Buddy Walk - Sunday, October 23rd at Saluda Shoals Park. Registration at 1 pm. Fun, food and games from 1 to 5 pm. Contact Vanessa Clark at VanessaClark@FamilyConnectionSC.org or 803-252-0914.

Greenville Down Syndrome Buddy Walk - Saturday, October 2nd at 12:30 pm at Furman University. Presented by the Down Syndrome Family Alliance of Greenville - www.DSFAGreenville.org.

Spartanburg Area Buddy Walk - Saturday, October 15th at the School for the Deaf and Blind. Registration at 2 pm. Fun, food and games from 2 to 5 pm. Bring your own picnic, chairs & blanket. Snacks & drinks will be provided. Contact Lisa Anderson at LisaAnderson@FamilyConnectionSC.org or 864-585-5462.

Come on out and show your support for our 'Special Buddies' with Down syndrome.

Guardianship

In South Carolina, when your child reaches age 18, he is considered an adult under the law. Legal adults are presumed competent to make decisions, whether or not they have a disability, unless proven otherwise.

Parents do not automatically retain the decision-making rights they had prior to child's 18th birthday. For parents to continue to have decision making authority for their young adult, they must file for "guardianship."

Obtaining guardianship is a necessary step in the transition from being the parent of a child who has a disability to being the parent of an adult (age 18 or older) who has a disability and is unable to make appropriate decisions for himself.

But guardianship is not necessary for every person with a disability. Parents should carefully analyze their unique situation to determine if guardianship is necessary and in the best interest of their child. They must ask themselves and others such as relatives, teachers, attorneys and other professionals, "How limited is my child? Is there some necessary reason for guardianship? What alternatives are there to guardianship?"

When considering these questions, parents need to understand what guardianship can and cannot do. It is necessary to know the different kinds of guardianship and the terminology used. Here are some of the more common terms:

Guardianship - A court-approved legal relationship where a competent adult is appointed to protect, manage and control the person and rights of another person who is a minor child or an incompetent adult with a disability.

Guardian - The competent adult appointed by the court to carry out the duties of the guardianship.

Ward - The minor child or incompetent adult with a disability who is the subject of the guardianship.

Full Guardianship (Plenary) - Total guardianship of an individual who lacks the ability to make any important decision on his or her own behalf. This involves the loss of such rights as the right to marry, enter into a contract, vote, consent to surgery, make a valid will, or choose a residence.

Continued on p 2 ...

Family Connection Parent-To-Parent

What Family Connection Offers:

- ✓ Support Parents, parents with children with special healthcare needs, are matched with parents who have children with similar diagnoses and needs. Support Parents, because they have faced similar life circumstances, are an invaluable source of emotional support and encouragement.
- ✓ Family Partners, parents of children with special needs, are trained to provide help to families whose child(ren) have developmental delays and are eligible for services through BabyNet, South Carolina's early intervention program for infants and toddlers up to age three. This early intervention program is designed to prepare young children for pre-school.
- ✓ Neonatal Intensive Care Unit Support: one-to-one support for parents who have a newborn in NICU.
- ✓ Parent Connections: Support Groups organized around specific disabilities or interests for parent-to-parent support.
- ✓ Family Social Events: celebrations and activities to recognize seasons and holidays.
- ✓ Project Breathe Easy: information and support for parents who have children with asthma.
- ✓ Hispanic Outreach: information and support provided for the Hispanic community en Español.
- ✓ Medicaid Managed Care Information Resource Liason: provides information about Medicaid Managed Care options.
- ✓ Awareness: The Key to Friendships: an Educational program teaching students understanding and sensitivity towards people with disabilities.

Guardianship

... continued from p 1

Limited Guardianship - Involves a partial substitution of personal decision-making by the ward. The court determines that the ward is incapable of making certain types of decisions in his or her personal life but preserves the freedom of independent decision-making in all other areas.

Conservatorship - A term used to refer to a form of limited guardianship. A conservator is appointed to care for and manage the property or estate of a ward. The ward is otherwise free to exercise his or her own decisions concerning personal matters.

Testamentary Guardian - A person appointed as guardian of a minor or incapacitated person under age 18 by the child's parents or by the spouse of a married incapacitated person through a provision in their will. In probating the will, the probate court will normally support the provision.

HOW TO OBTAIN GUARDIANSHIP

In South Carolina the judge of probate court has the authority to appoint and monitor guardians or conservators for minor children or incompetent adults with disabilities. The only exceptions are testamentary guardians, since they are named in the parent's will, or guardians ad litem appointed by courts other than the probate court.

The appointment of a guardian is initiated by filing the appropriate documents with the judge of probate court in the county where the proposed ward lives. The probate court must appoint a guardian ad litem to protect the ward's interests during the legal process. Such interests include, but are not limited to, representation by counsel, notice of proceedings, opportunity to present evidence and to cross-examine opposing witnesses, and opportunity to be present during proceedings. The petition is presented at a hearing before the judge of probate court. There is no jury and the proceedings are closed to the public.

The person filing the petition (the petitioner) must have some relationship to the proposed ward, such as, parent, custodian, relative or other interested person. A state agency may petition for the

appointment of a guardian for someone in its care and custody when there is an immediate need and no family member is available to assist the disabled individual.

At the hearing, clear and convincing evidence that the proposed ward needs a guardian must be presented to the judge.

If the proposed ward is physically or mentally disabled, the court will need evidence to prove this: this evidence usually comes from qualified professionals. The judge may also talk with the proposed ward to find out what he or she would like to do.

If the probate court finds it is in the person's best interest to have a guardian, the judge will usually appoint the person nominated in the petition as guardian. But the court is required to give priority to the ward's parent or other close relative, such as an adult child, unless someone else would better serve the ward's interest.

If the judge finds the ward incompetent, the guardian will have plenary (full) guardianship powers. If the judge decides that the ward can take partial care of himself or his property, the guardian will have limited guardianship. If the petition was initiated for a special purpose such as applying for admission to an institution or consenting to surgery, then the appointment would generally be limited to that purpose. Any party may appeal the probate court judge's decision to the Court of Common Pleas in the same county.

DUTIES OF THE GUARDIAN

Guardianship is a trust of the highest and most sacred character. The guardian is not permitted to gain any personal profit or advantage from dealings with the ward or the ward's property or estate. Under South Carolina law, a guardian of the property or estate, more commonly known as a conservator, must file a bond with the probate court at the value of the ward's personal estate. The judge may waive the bond if funds are deposited with a domestic financial institution in a restricted account.

The guardian/conservator must report to the court, on an annual or more frequent basis, all transactions affecting the ward's estate. Although the court may not ask for information during the year and it may

Guardianship

not be necessary to get the courts approval before spending money from the ward's estate, the guardian/conservator should get the consent of the court before large sums of money are spent on benefit of the ward.

The guardian/conservator may be personally liable for improper expenditures. A guardian may be removed by the court for malfeasance (wrongful conduct). The guardian may also petition to the court for release from this position.

The guardian-ward relationship should be one of trust. If the form of guardianship is limited and the ward is capable of making certain independent decisions, the guardian should know when not to interfere with the ward's opportunity to choose a personal course of action. The guardian should encourage independence and self-sufficiency. The guardian or conservator must always act in the best interest of the ward.

Guardianship, when used properly, may be of real assistance to your child with a disability. When used improperly, guardianship may hinder the individual's development and independence. Effective estate plans drawn by the parents of the son or daughter with a disability may eliminate the need for a legal guardianship arrangement.

ALTERNATIVES TO GUARDIANSHIP

Guardianship is not necessary for every person with a disability - many are able to manage their own affairs with appropriate services and support systems. However, some additional alternatives are:

Generic Services - In the community, various state and local agencies provide services for persons with disabilities, such as protective services, homemaker services and foster care homes. In an institution, the general care and treatment of residents is the responsibility of the institutional agency. The agency has the duty to act in the residents' best interest with due regard to their individual rights.

Protection and Advocacy for the People with Disabilities - These agencies provide advocacy services for persons with disabilities and seek to ensure that adequate services are provided to their clients.

Trusts - The trustee of a trust has no authority to act as a guardian; however, as a provision of the trust, the trustee can be required to visit the person with a disability and oversee his well-being. The trustee may be empowered to expend the trust to provide a certain standard of living for the individual.

Power of Attorney - Any person may authorize another person to act as an agent in handling certain specific business matters. Power of attorney may be used only if the person granting the power of attorney fully understands what he is authorizing. This may be written, however, so that the agent could continue even if the person authorizing such an agent should later become disabled. In South Carolina this type of authorization is known as durable power of attorney. The authorization or power of attorney should be legally executed.

Representative Payee - A number of government benefit programs such as Social Security, Supplemental Security Income (SSI), and the Veterans Administration permit a representative payee to receive and manage the funds from that agency for another person who has been properly appointed.

MAKING GUARDIANSHIP DECISIONS

The first step in obtaining guardianship is to consult an attorney. The South Carolina Bar referral service will help you find an attorney in your area who specializes in this type of law. Contact them at 1-800-868-2284 or www.scbar.org/PublicServices/FindaLawyer.aspx. An initial 30-minute legal consultation may be less than \$50.

If payment for these legal services is a concern, contact the Legal Aid Telephone Intake Service (LATIS) at 1-888-346-5592. They will help determine if you qualify for free services and refer you to South Carolina Bar ProBono Program to help find a lawyer who offers this service. Learn more about the SC Bar's public services at <http://www.scbar.org/PublicServices.aspx>.

Family Connection can also connect you to another parent who has gone through this process with their adult child(ren). Call Family Connection's state headquarters at 1-800-578-8750 for more information.

Family Connection Parent-To-Parent

What Family Connection Offers:

- ✓ Kid Connection: workshops for siblings of children with special needs.
 - ✓ Father's Network: A network for informational support for fathers.
 - ✓ Family-to-Family Health Care Information and Education Center: help for families of children with special health care needs seeking objective, family-friendly health care information.
 - ✓ Physicians Education Awareness Program (PEAP): opportunities for professionals to learn from families, such as medical student visits in homes of families who have children with special needs.
 - ✓ Family Respite Cooperatives: volunteer program to give parents a break from in-home care.
 - ✓ Couples' Communication Retreats: a getaway for the enrichment of communication in relationships.
 - ✓ Virtual Library: InfoAble brings research and information right your own computer. Books can be sent to you on loan with a pre-paid return envelope. There is no cost to use this service! Developed by the Center for Disability Resources Library in partnership with Family Connection.
 - ✓ EConnection: Email distribution lists that keep you informed of events, news, workshops, and support groups in your area. To join, send an email to info@FamilyConnectionSC.org.
- To participate in these activities, or receive additional information, contact Family Connection at 800-578-8750 or info@FamilyConnectionSC.org.

Safety Tips

Poison Prevention For Families With Children With Special Needs

Unintentional poisoning can happen in any home. It's important for every family to take the proper precautions to prevent this common household danger. For families of children with special needs, this is especially true. Making the home a safer place in preventing poisonings requires a few simple steps.

For any family, preventing unintentional poisonings is important and with a few easy steps, your home can be safer.

POISON PREVENTION TIPS

Store medicines and toxic household products out of sight and reach.

Install locks on cabinets and drawers, making sure you choose ones that work to keep your child out of harm's way.

Go over the differences between what products are safe and not safe in your home.

Avoid taking any medications in front of your children.

Put up visual reminders such as stickers on dangerous and poisonous household items.

Remind your child regularly about avoiding these items, using stories or pictures to ensure that they understand.

Post the poison control center number by every phone: 1-800-222-1222

Remember: For any family, taking the proper precautions to prevent poisoning is an essential part of ensuring a safer home.



www.safekids.org/safety-basics/special-needs/poison-prevention/

All Are Welcome

A faith inclusion training program for places of worship.

An individual's spiritual life is an important area of one's life. Having a disability does not take that importance away. Unfortunately, many families affected by a disability often feel unwelcomed in the faith community. All Are Welcome is a project of the South Carolina Autism Society (funded by the SC Developmental Disabilities Council) that works to develop resources to help faith communities to become inclusive and welcoming. In the first year of this grant, we created a training video and curriculum for church and ministry leaders.

After all, if we can not have inclusion in God's house, what chance is there for the rest of society?

In order to reach as many places of worship as possible, the All Are Welcome faith inclusion training program is available online at no cost.. Please forward this email to any members of your faith community who may benefit from this valuable training.

For more information on All Are Welcome go to www.scautism.org/index.php?option=com_content&view=article&id=46&Itemid=68.

The All Are Welcome project is funded through a grant from the South Carolina Developmental Disabilities Council.



Statewide Events

Anderson area

864-231-8100

Buddy Walk - October 9th. (see front page)

Bluffton area

843-556-5010

Picnic & Playdate - September 24th, 4:00 - 6:00 pm - Jarvis Park. Call Meagan for details at 843-556-5010.

Charleston area

843-556-5010

Family Fishing Rodeo & BBQ - Saturday, October 29th, 10:00 am - 12:00 pm, at Sewee Visitor Center, 5821 hwy 17 N in Awendaw (13 miles north of IOP Connector.) REGISTRATION is required. Bring your own fishing rod or some will be provided. The East Cooper Fishing Club will teach us all how to fish. The BBQ includes water, chips and hot dogs.

Cookies & Cocoa with Santa - Sunday, December 4 at the Children's Museum of the Lowcountry . Two parties - one at noon and one at 1pm. More details to follow.

Columbia area

803-252-0914

Support Parent Training - September 17th, 9:00 am - 12:30 pm. If you would like to offer support to other parents call Susan at 803-252-0914. Free training.

Columbia Fall Festival - October 15th, 10:00 am - 1:00 pm. Call Kim for location and registration - 803-788-6164 xt3010.

Buddy Walk - October 23rd. (see front page)

Welcome Workshop - October 27th, 6:00 - 7:30 pm. Food, and information about Family Connection and Resources. Call 803-252-0914 to Register.

Camden Fall Festival - October 29th, 4:00 - 6:00 pm, Bethel Worship Center, 814 Fair St, Camden. Games, inflatables, horseriding.

Special Needs Wills & Trusts Workshop - November 10th, 6:00 - 7:30 pm. Call 803-252-0914 to Register.

Four Sisters Farm - November 12th, 10:00 am - 12:00 pm, at 1357 Horsehead Branch Rd, Lugoff. Petting zoo, inflatables.

Greenville area

864-331-1340

Autism Connection - September 12th, 6:30 pm - Center for Developmental Services, 29 North Academy St., Greenville. A forum for connecting with other parents of children with autism and learning about therapies and area resources to help members of impacted families.

Buddy Walk - October 2nd. (see front page)

SC Autism Society Annual Conference - Saturday, October 15th - Columbia Conference Center. See www.scautism.org for details.

Myrtle Beach area

843-556-5010

Breakfast with Santa - Date/time TBD. Call Meagan for details at 843-556-5010.

Rock Hill area

803-366-4839

Breakfast with Santa - December 3rd, 9:00 am - 11:00 am. - Boyd Hill Recreation Center, Constitution Blvd, Rock Hill.

Resource Workshop - 2nd Wednesday of each month, 9:30 am, Family Resource Center, 410 E Black St, Rock Hill.

Spartanburg area

864-585-5462

Buddy Walk - October 15th. (see front page)

SEEYA (Social Events for Exceptional Young Adults)

- September 10th - SEEYA Movie Night, 6:00 pm - New Beginnings United Methodist Church, Rainbow Lake Rd. (up above Wal Mart) Boiling Springs, SC. Contact Cindy at 864-472-8592 to RSVP.

- October 8th - SEEYA Fall Dance, 6:00pm. Contact Cindy at 864-472-8592.

- November 12th - SEEYA Karoke Event - Contact Cindy for details.

- December SEEYA Christmas Event - Contact Cindy for details.

Special Needs Trust Workshop - September 10th - 6:00 pm. Terry Hair, Financial Services Representative from MetLife. Info on Legal Guardianship. PLEASE REGISTER FOR WORKSHOP BY SEPTEMBER 7TH by contacting Lisa Anderson at Family Connection , 864-585-5462 or email cvarner@windstream.net

Christmas Social - December 2nd, time and location TBA. Contact Lisa at 864-585-5462 for details

Statewide Parent Connections

Please call the area office unless another number is listed.

Anderson 864-231-8100	Name	Date	Time	Location	Contact
	A Precious Few	2 nd Wednesday of the month 4 th Thursday of the month	Wed: 11:30 am - 1:30 pm Thurs: 5:30 pm - 7:30 pm	McDonald's Seneca	
	Autism Connection	2 nd Tuesday of the month	6 pm - 8 pm	Family Connection office	
	Children R Special	2 nd Friday of the month	6 pm - 8 pm	Anderson Mall food court	
	Oconee Parent Connection	3 rd Tuesday of the month	6 pm - 8 pm	Open Door Baptist Church Walhalla	

Charleston 843-556-5010	Name	Date	Time	Location	Contact
	Morning Coffee Break	2 nd Tuesday of the month	10:00 am	Atlanta Bread Company North Main Street, Summerville	Meagan 843-556-5010
	Morning Coffee Break - Myrtle Beach	3 rd Thursday of the month	10:00 - 11:30 am	To Be Determined Contact Laura for Details	Laura 843-246-5933
	Spanish Speaking Parent Connection	4 th Thursday of the month	6:00 pm	MUSC Northwoods Clinic	Saritta Vann 843-534-7471

Columbia / Midlands 803-252-0914	Name	Date	Time	Location	Contact
	Asperger/ADHD Connection	1 st Thursday of the month	6:00 pm - 7:30 pm	Family Connection Offices 2712 Middleburg Dr, Ste 103, Columbia	803-252-0914 - Call for childcare
	Asthma Connection	1 st Tuesday of the month	6:00 pm - 7:30 pm	Family Connection Offices 2712 Middleburg Dr, Ste 103, Columbia	Michelle Drayton 803-252-0914
	Autism Connection	3 rd Monday of the month	6:00 pm	Family Connection Offices 2712 Middleburg Dr, Ste 103, Columbia	803-252-0914 - Call for childcare
	Down Syndrome Playgroup	2 nd Saturday of the month (except Nov)	1:00 pm - 3:00 pm	Family Connection Offices 2712 Middleburg Dr, Ste 103, Columbia	803-252-0914 - Call for childcare
	Family Fun Event	Monthly	Varies	Varies	Call to be added to our mailing list
	Lego Club	1 st & 3 rd Thursday of the month	4:30 pm - 5:30 pm	Family Connection Offices 2712 Middleburg Dr, Ste 103, Columbia	803-252-0914
	Mom's Night Out	Monthly	Varies	Call for Location	803-252-0914 - Call for location
	Morning Coffee	Varies	9:00 am	Call for Location	803-252-0914 - Call for details
	NICU Connection	4 th Thursday of the month	6:00 pm - 7:00 pm	NICU classroom of the NICU at Palmetto Health Richland	
	NICU Scrapbooking Group	1 st Wednesday of the month	1:00 pm - 3:00 pm	TV area of the NICU at Palmetto Health Richland	
	Parent Group (for those who have children 12 and over)	2 nd Tuesday of the month	6:00 pm - 7:30 pm	Family Connection Offices 2712 Middleburg Dr, Ste 103, Columbia	803-252-0914 - Call for details
	S.M.I.L.E.S.	4 th Monday of the month	7:00 pm	Meets in Lexington	803-252-0914 - Call for details
	Scrapbooking	4 th Saturday of the month	1:00 pm - 5:00 pm	Family Connection Offices 2712 Middleburg Dr, Ste 103, Columbia	Susan Haney 803-252-0914
Sumter Connection	Last Tuesday of the month	10:00 am	McDonald's Broad St, Sumter	Becky Brown 803-499-2970	
Teens Rock (children 12+ and parents)	1 st Monday of the month	6:00 pm	Gamecock Lanes 817 Broad St, Sumter	Karola Richardson 803-983-8426 to Register.	

Florence 800-578-8750	Name	Date	Time	Location	Contact
	Autism Connection	4 th Thursday of the month	6:30 pm	Theodore Lester Elementary School	Beth Dynan 843-661-5360
	Family Pizza Night	3 rd Wednesday of the month	7:00 pm	CiCi's Pizza - 1945 W Palmetto St, Florence Meet near the game room. Everyone pays for own meal.	Amy Melton - 843-858-1349 Wendy Stokes - 843-332-6291
Family Fun Night	2 nd Thursday of the month	7:00 pm	Burger King - 706 S 5 th St, Hartsville Everyone pays for their own meal.	Amy Melton - 843-858-1349 Wendy Stokes - 843-332-6291	

Statewide Parent Connections

Please call the area office unless another number is listed.

Greenville 864-331-1340	Name	Date	Time	Location	Contact
	ADD/ADHD	Varies		Shandon Forest Presbyterian Church 830 Garlington Road, Greenville	Elizabeth Stuff, Greenville CHADD 864-286-6872, Rstuff6872@charter.net
	Air Buddies For Children with Asthma	Varies	6:30 pm - 8:30 pm	Center for Developmental Services	Pam Kruzan 864-331-1340
	Autism Connection	1 st Monday of the month	6:30 pm - 8:30 pm	Center for Developmental Services	Susan Kastner 864-331-1340
	Down Syndrome Family Alliance of Greenville	Varies	Varies	Varies	www.DSFAGreenville.org
	Mom's Night Out	3 rd Thursday of the month	Varies	Varies	Family Connection 864-331-1340
	Moms' Coffee	Varies	9:30 am - 11:30 am	Varies	Mindy Ramsey 864-331-1340

Myrtle Beach 864-331-1340	Name	Date	Time	Location	Contact
	Morning Coffee Break - Myrtle Beach	3 rd Thursday of the month	To Be Determined Contact Laura for details.	To Be Determined Contact Laura for details.	Laura 843-246-5933

Rock Hill 803-366-4839	Name	Date	Time	Location	Contact
	Autism Support Group	1 st Tuesday of the month	6:30 pm	St. John's Methodist Church	Cindy Tomlinson 803-396-0610
	HITCH UP Hearing impaired toddlers and children	2 nd Tuesday of the month	6:30 pm	St. John's Methodist Church	Melissa Burgess 803-547-0207
	Mom's Coffee Break	1 st Friday of the month (except June, July & August)	8:30 am	Panera Bread Manchester - Dave Lyle Blvd	Cindy Tomlinson 803-396-0610
	Play Date at the Park	1 st Friday of June, July & August	10:00 am	Duranqo Bagels Millwood Plaza, Herlong Avenue	Cindy Tomlinson 803-396-0610
Mom's Night Out	4 th Thursday of the month	7:30 pm	Charanda's 2260 Cross Pointe Dr across from Galleria	Cindy Tomlinson 803-396-0610	

Spartanburg 864-585-5462	Name	Date	Time	Location	Contact
	Especially Ours General Support	Call for Date & Time		Union County DSN 226 South Gadberrry Street, Union	Lauri English 864-427-7700 ext 303
	NICU Connection	4 th Tuesday of the month	6:30 pm - 8:00 pm	Tower 4 Classroom Spartanburg Regional Hospital	Marsha Edens 864-592-2757
	PEP - Parents Empowering Parents	3 rd Saturday of the month	6:30 pm	Cudd Memorial Baptist Church 1301 Boiling Springs Rd, Spartanburg	Andrea Forringer 864-578-9288 - Call for childcare
	SEEYA Social Events for Exceptional Young Adults - 15+	2 nd Saturday of the month	Varies	New Beginnings United Methodist Church Rainbow Lake Rd, Boiling Springs	Cindy Varner 864-472-8592 cvarner@windstream.net
SonShine Club For adults with special needs and their caregivers	Saturday monthly	10:00 am - 3:00 pm	First Baptist Church 140 Metro Drive, Spartanburg	Larry McCollough 864-804-3106 to check dates & RSVP	

Congratulations to the New Family Connection Support Parents!

Sarah Cruz
Amy Lageman
Jennifer Medina
Karen Nesbit
Michele Ruff

Wanda Sutherland
Alison White
Jacqueline Williams
Suzanne Wingard

Support Parent Corner - The Heart of Family Connection

Caring for Yourself

This article is designed to be given to our new parents. But it is equally relevant to more experienced parents, and especially our Support Parents. Since we do forget quickly, it is good to be reminded to take positive steps to “Care for Ourselves.”

Right now, you are very focused on taking good care of your child. But remember that it’s also important to take good care of yourself at this time. Doing so will keep you feeling healthy, strong and well-equipped to deal with your responsibilities as a new parent. Here are some tips many parents have found helpful for reducing anxiety and stress:

- ♦ **Be patient with yourself.** The road to acceptance is a process, so give yourself time to deal with your emotional responses. Your feelings are valid, so be easy on yourself. Allow yourself guilt-free moments of anger, sadness, jealousy and elation.
- ♦ **Build a support system.** It may be tempting to keep to yourself at this time, but doing so can result in feelings of isolation. Reach out to trusted friends or family members. You can always let them know how much help you need or desire, and if you want time alone, don’t hesitate to say so. Join a support group, or form a relationship with a family facing a

similar diagnosis or situation.

- ♦ **Practice “living in the moment.”** While it is important to plan ahead, worrying about the future can easily lead to anxiety. Focus on the joys and accomplishments of today.
- ♦ **Take care of your physical health.** Healthy eating and exercise can reduce fatigue, irritability and make you feel better. Be sure to get regular medical check-ups as well.
- ♦ **Don’t lose sight of the important things in life.** Nurture your relationships with your partner, children, friends and family. Communicate with each other, laugh, do fun things together, celebrate traditions, and be sure to spend quality time with your child that doesn’t focus on his or her special needs. The fact that your child has special needs is life-changing. But it doesn’t change the things that are truly important in life!

In Loving Memory

To the precious friends we have recently lost, we miss you deeply.

Joseph Knight, son of Doug and Colleen Knight
Cyrah Vess, daughter of Lacy Spradlin

If we have missed your loved one or someone you know who has been supported by Family Connection, please let us know of your loss.

	Name	Date	Time	Location	Contact
Respite Sites	Charleston Harbor Bible Church	Last Saturday of the month	5:30 pm - 9:00 pm	Charleston Harbor Bible Church Charleston	Peggy Carr 843-224-1817
	Mt Moriah Missionary Baptist Church	Last Friday of the month	6:30 pm - 9:30 pm	Mt Moriah Missionary Baptist Church Charleston	Family Connection 843-556-5010
	Crowfield Baptist Church	3 rd Friday of the month	6:00 pm - 9:00 pm	Crowfield Baptist Church Goose Creek	Angie Beard 843-821-6579 or 843-708-0859
	Epworth Early Intervention Center	4 th Saturday of the month	4:30 pm - 7:30 pm	Epworth Early Intervention Center Columbia	Kay Richardson 803-212-4757
	Central Baptist Church	2 nd Saturday of the month	10:00 am - 1:00 pm	Central Baptist Church Columbia	Wanda Brown 803-788-1199
	Saxe Gotha Presbyterian Church	1 st and 3 rd Saturday of the month	4:30 pm - 7:30 pm	Saxe Gotha Presbyterian Church Lexington	Ginny Aldinger 803-629-5212
	Discover Church	2 nd Saturday of the month	5:30 pm - 8:30 pm	Discover Church Mauldin	Laura Beth Cajar 864-335-8526
	Pine Street YMCA	2 nd Saturday of the month	3:30 pm - 6:30 pm	Pine Street YMCA Spartanburg	Shannon Batson 864-414-9577

The Zaffutos ...

My story begins with the birth of my third child, Matthew, in the spring of 2008. Matthew was a full-term, seemingly healthy baby and we went home with no idea of the journey on which we would soon embark. At six months of age, Matthew was diagnosed with global developmental delays and we began a search for answers. Over the course of the next 18 months, countless vials of blood were taken as doctors tested for this disorder or that disorder—most with names I couldn't pronounce, and all terrifying. I learned about low muscle tone and failure to thrive. Maybe it was Fragile X, maybe muscular dystrophy, maybe a metabolic disorder, but all the tests came back normal. I searched the internet constantly, researching symptoms and reading message boards, but nothing sounded like my son. It was heartbreaking, terrifying, frustrating, and exhausting.

As Matthew approached his second birthday, a neighborhood chat ended up changing the course of Matthew's medical treatment. A concerned neighbor asked about Matthew because she knew of his struggles. She suggested that I call her husband, Dr. Dominic Gault, Medical Director of Pediatric Sleep Medicine at Greenville Hospital's Children's Hospital. I had felt for some time that Matthew had ENT-related issues, and I hoped Dr. Gault could recommend a pediatric ENT. Upon a request from his wife, Dr. Gault called me a few days later. In a 20-minute telephone conversation, Dr. Gault would end up changing Matthew's life.

Matthew was always a noisy breather. He often sounded congested and sick. In fact, many doctors commented on his congestion, and I myself would jokingly tell them he snored like an old man. What I, and other perfectly competent physicians, failed to recognize was the significance of his snoring. At Dr. Gault's request, I recorded Matthew sleeping and sent him the recordings. Immediately after he reviewed the tapes, Dr. Gault scheduled a sleep study. The results of the first sleep study were nothing short of shocking to my husband and me. The following day, Matthew was diagnosed with severe obstructive sleep apnea.

Obstructive sleep apnea occurs when the airway collapses and disrupts the normal amount of air from moving in and out of the body during sleep. This results in acute drops in oxygen levels and increases in carbon dioxide. The body has to awaken repetitively throughout the night in order to reopen the airway. These issues place stress on the body and result in worsening health and daytime performance.

Matthew's abnormally large tonsils and adenoids were originally deemed the cause. His low muscle tone was a contributing factor as well. Matthew's body would wake him up an average of 34 times per hour. Because of the remarkable sleep disruption that had prevented him from having a solid night of sleep in his whole life, his body was not secreting the growth hormones it so desperately needed. Matthew was immediately scheduled for surgery in April of 2010 to remove his tonsils and adenoids. His surgery went well, and



Matthew Zaffuto

after a week of recovery, he quite literally woke up a different child. Dr. Gault told me to expect a "growth spurt" and Matthew did not disappoint.

While Matthew's surgery was definitely considered a success, it did not totally cure his sleep apnea. A follow-up study showed that he still had some degree of sleep apnea, and Dr. Gault ended up prescribing Continuous Positive Airway Pressure, or CPAP therapy. Matthew needed to sleep with a mask attached to a long hose that blew air into his airway and effectively keep it open. I left Dr. Gault's office the day we were prescribed CPAP therapy feeling confident that we could do it! What I didn't realize at the time, however, was how challenging and frustrating the transition would be.

In a perfect world, Matthew would have immediately started sleeping through the night. Unfortunately, it was a struggle to get him used to it. At first, he was fine as long as it was off, but would start screaming as soon as we turned it on. The air blows out with surprisingly strong pressure, and it is a rather unnatural feeling to have air blown up your nose. There were many tears shed—by him and me. It would have been easy to give up, and there were times I was tempted, but Matthew had a condition that was treatable and my determination to help my child won out. We began to see improvements that fueled our efforts to support him. After he got used to sleeping with the CPAP, Matthew was more alert, required less daytime sleep, and his vocabulary began to expand.

Dr. Gault and his team were all incredibly supportive and helpful during this time. They offered advice and

Continued on p 11 ...

New Learning Opportunities

Institutions of higher education in South Carolina now offer some amazing opportunities for students with intellectual disabilities. South Carolina currently has five such post secondary education programs. There is the College of Charleston REACH Program; the LIFE (Learning is For Everyone) Programs at The University of South Carolina, Clemson University, and Coastal Carolina University; and the Transition to College Program at Winthrop University, which is a dual enrollment program for current high school students in the Rock Hill area.

CarolinaLIFE is a two-to-four year postsecondary program for students with intellectual disabilities. CarolinaLIFE offers students the opportunity to immerse themselves in college life through inclusive participation in University courses, competitive employment, student organizations, and residential learning communities. The CarolinaLIFE program is an individualized program where each student chooses a major, takes regular college classes in his/her area of interest, receives individual instruction, and is coupled with peer academic coaches. Current students are studying Business, Education, Theatre, Music, Culinary Arts, Hospitality and more. The goal of CarolinaLIFE is to increase employment opportunities. Students participate in career seminars, internships, and paid employment in their area of interest to provide a range of opportunities for work and to hone their interests and skills. Students also take advantage of the various enrichment opportunities offered at USC through student organizations and interest groups. Students also have the option to live in University housing (apartment style dorms) where they receive independent living and life skills instruction. Our students share rich and meaningful experiences that allow them to grow, learn about themselves, develop lasting friendships, celebrate independence, and build skills necessary to ensure independent living and competitive employment after they graduate. For more information or to schedule a campus visit, contact Dr. Tony Plotner at 803 777-7664. To register for the open house on December 2nd visit us on facebook or www.sa.sc.edu/sds/carolinalive/.

ClemsonLIFE is a postsecondary program designed for students with intellectual disabilities. We are located on campus at Clemson University and provide a range of instructional topics by certified staff, including job preparation, social skills training, independent living skills, community living skills, nutrition, personal safety, banking, budgeting and more. This program currently serves 15 students per academic year.

For 2011-2012, Clemson LIFE has an impressive array of staff consisting of 4 special education teachers, a transition coordinator with a background in clinical counseling, an employment coordinator who is also a certified special education teacher, a volunteer coordinator, over 100 volunteers, and a director with a background in school psychology and applied behavior analysis. Please visit online at www.clemson.edu/culife/index.html.

The **R.E.A.C.H** (Realizing Educational and Career Hopes)

program at the **College of Charleston** is a four-year non-degree, inclusive program for students with mild to moderate intellectual disabilities who want to partake in the full college experience, including participation in regular college classes, living independently on campus, engaging in professional internships, and enjoying an active social life with friends. Students who complete the program receive a REACH certificate, and have training and experience necessary for successful competitive employment.

Students in the REACH Program are full members of the College of Charleston campus, and they prepare for independent, successful futures in the same way traditional students prepare for adult life. Students in the REACH Program take regular college courses each semester, with assignments and assessments modified so that they are appropriately challenging at an individual level. Students have access to the same academic supports utilized by traditional students as well as individualized supports provided by peer mentors.

The REACH Program includes the option of an inclusive residential experience in which students with and without disabilities live together in a historic home in the heart of campus, with walking access to all that campus life offers. Students in the REACH Program are encouraged to explore the social organizations, intramural sports, sororities and fraternities, sporting events, and clubs.

Students in the REACH Program prepare for competitive employment by learning skills for a job search and participate in paid internships both on and off campus that allow them to explore different professional interests and prepare for successful employment upon graduation.

Come visit the campus and meet with the REACH Director, Edie Cusack. REACH will be hosting an Open House on Friday, December 9th. To learn more visit the REACH website (www.reach.cofc.edu) or contact Edie Cusack (cusackel@cofc.edu; 843-953-4811).

Coastal Carolina University LIFE™ Program is a four year post-secondary education program for students with intellectual disabilities. The LIFE Program is designed to provide both residential and non-residential options to enrolled students. The purpose of the program is to promote a smooth and effective transition from secondary school to a four-year higher education institution and provide post-secondary opportunities on a college campus. This program will allow for the students' full inclusion within the campus community, as well as provide supportive and developmentally appropriate scheduling and coursework.

The program is designed to emphasize student independence and personal development, choice making, individualized work environments, communication skills, money skills, integration within the University community, and transition to an integrated work environment. The program is structured around a schedule that includes college classes, career exploration, functional living skills training, campus events,

Parent to Parent

... continued from p 9

encouragement, patiently answered my countless questions and calmed my nerves. Throughout the experience, however, I longed to talk to another parent who been through the same thing. It was apparent that I, and others in my circumstance, could use a support group. Dr. Gault spoke with Dr Schmidt, Medical Director of Children's Hospital of Greenville Hospital System University Medical Center, who suggested that this new support group would be a perfect fit with Family Connection. Dr Gault consulted with Family Connection staff in Greenville and then introduced me to the organization. I immediately knew they could help us achieve our dream.

Sweet Dreamers is set to launch in September of 2011 through Family Connection of SC. Our first event will be Friday, September 30 at the Family Connection office in Greenville. Dr. Gault will join us for a "Lunch & Learn" at 11:30 a.m. Sweet Dreamers will provide parents with an opportunity to connect with other parents online, in person, or over the telephone. You can also connect with Sweet Dreamers on Facebook by searching "Sweet Dreamers South Carolina."

Obstructive sleep apnea is more common in children than I ever realized. Considering the possible consequences of undiagnosed sleep apnea, I credit Dr. Gault with saving my child's life. Matthew has made incredible strides in the past year. He is still behind his peers, but he continues to make steady progress and we are hopeful and optimistic about his future. - Abby Zaffuto

New Learning Opportunities

job training, community experiences, and extracurricular activities. The Coastal Carolina University LIFE™ Program will allow students with intellectual disabilities the educational and social development opportunity to address four key primary areas: (1) academic enrichment, (2) socialization, (3) independent living skills, and (4) competitive or supported employment. www.coastal.edu/cec/LIFEprogram.html

The Winthrop Transition to College (WTC) Program provides post-secondary options for students with Intellectual disabilities (ID). The Winthrop Transition to College program includes dual enrollment opportunities that provide and enhance educational and employment opportunities for students with intellectual disabilities. This program will serve six to eight students, ages 18-21 years, in a mixed curriculum that includes classes focused on independent living, academic skills, and campus employment. The WTC students attend a variety of selected college courses. They are employed on campus in a variety of settings. A Winthrop student enrolled in these courses is identified as a mentor to provide support for the student with ID. For more about this program, please visit www2.winthrop.edu/transitioncollege.

The Road Ahead

I was a freshman in college when I first begin to seriously consider how my brother was going to fit into my future life plans. It certainly wasn't the first time I had ever thought about it – I can remember my mother telling me even at a very young age that I should always look out for my brother – that one day he would be my responsibility – but it was in college that I REALLY began to grapple with what that meant. Suddenly I was exposed to whole new range of emotions. Going home from school for breaks and realizing how accustomed I had become to not being around my brother and all his idiosyncrasies and feeling guilty at how much I was enjoying it. Feeling stunned when a young man I had begun spending a lot of time with told me bluntly that he would never consider marrying me because of my brother. Coming to terms with the fact that every major life decision I would make from that point forward – what career to pursue, who to marry, where to live, whether or not to have children – would be impacted by my brother.

What has been most difficult is to develop any sort of concrete PLAN. I first raised my concerns with my parents when I was in college. We talked about it then and have talked about it many times since, but 20+ years later, not much has changed. I'm still grappling with what "being responsible for him one day" really means. My decisions are still largely impacted by this knowledge and the anxiety is always bubbling beneath the surface. As my parents continue to age (the eldest just turned 77) and begin to have their own health problems, the reality that my 42-year brother can't continue to live with them forever continues to sink in.

Don't get me wrong, we've made some good decisions as a family - set up a special needs trust fund, looked at the beneficiary arrangements of various investments, etc. - but the answers to the questions "Where will he live?", "Who would look after him if something then happens to me?" are still unknown. I have long ago come to terms with the fact that life is like a drive on a winding road in the dark. You really don't know what lies ahead until you turn around the next bend and your headlights hit the road in front of you.

The important thing is that my parents and I continue to talk, and to the best of our ability given the changing political and financial climate in our state, we are trying to develop concrete plans.

Fortunately the recently created South Carolina Adult Sibling Leadership Network has provided me with many resources – both emotional and practical – that I can lean on through this journey. "It is a warm and thoughtful online support and information community of adult siblings of people with disabilities." They can be contacted through:

<http://sites.google.com/site/scadultsiblingsleadership/home> or call them at PRO-Parents of South Carolina, Inc. - 803-772-5688 or 1-800-759-4776


Vicki Hamby



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Family Connection of SC is a non-profit which serves families with children with special healthcare needs and depends on the generosity of friends in the community to support its mission.

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Special thanks to the State Department of Education and Blue Cross Blue Shield of South Carolina for helping us provide this resource to families.

Connecting . . .

e-Connection

Receive timely e-mails from Family Connection for you and your family about educational and family events. To sign up go to http://familyconnectionsc.org/join_econnection/.

InfoAble - A Virtual Library

InfoAble brings research and information right to your own computer. Books can be sent to you on loan with a pre-paid return envelope. There is no cost to use this service! Developed by the Center for Disability Resources Library in partnership with Family Connection.

Parent Connections

Parents are making connections all around South Carolina. Parents are making connections in Parent Connection support groups organized around specific disabilities or interests for parent-to-parent support; in family social events; and as volunteer Support Parents. See pages 5 through 8 for details, or call Family Connection. You are not alone.



Family Connection Connections

January 1, 2011 – March 31, 2011

Referrals: 723 ♦ Matches: 647

Not all referrals made to Family Connection are suitable for parent-to-parent matches. These families are referred to appropriate service providers.

