



South Carolina Autism Society

Together We Can Solve The Puzzle

The purpose of the South Carolina Autism Society is to enable all individuals in South Carolina with autism spectrum disorders (ASDs) to reach their maximum potential.

SCAS News

Strides For Autism 2009



We are off and “walking,” although some are “running,” as we take **Strides For Autism**. **Greenville, Columbia, and Myrtle Beach.** Volunteers and committees have been working hard to recruit for committees and to help develop teams and individual walkers. It is a great experience to learn the many facets of a walk, plus it is lots of fun and a great way to meet new friends and families throughout SC.

Susan Leiby, our co-chair of the Greenville Strides, is committed to doing *all three walks* with her family. *Awesome!* I know there are more of you out there who want to join her!

Remember, it will be lots of smaller gifts/donations that make up the volume as we work toward our goal of raising **\$100,000** by the summer. With the state government’s critical budget cuts, the need at SCAS is vital so we can continue helping our families.

We are off to a great start with several sponsors including **Blue Cross Blue Shield, Greenville Hospital System, Early Autism Project, Eastman**, and the **AT&T Telecom Pioneers**.

This year, some autism researchers here in SC are lending us a hand and their good names, including: **Dr. Desmond Kelly** of Greenville Hospital System, **Dr. Harry Wright** of USC, and **Dr. Ruth Abramson** of USC.

If you need help with Strides, just get in touch with me! Looking forward to hearing from you!

Barbara MacWilliam
Director of Development
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barbara@scautism.org

Strides Locations and Dates

<i>Location</i>	<i>Date</i>
Greenville Tech. College, Greenville	April 25, 2009
Finlay Park, Columbia	May 23, 2009
Grand Park, Myrtle Beach	June 13, 2009

2009 Rolling for Autism Awareness

Don’t miss our annual Bowling fundraiser in Lexington, SC at **JC’s Lexington Bowl**, at 11:00 a.m. on Saturday, April 18, 2009.

Help SCAS - Payroll Deductions

We want to remind you that the SCAS is now a member of **Community Health Charities of SC (CHC-SC)**. What does that mean to you? It means that you may now enjoy the convenience of donating to SCAS via payroll deduction at your workplace. We are one of twenty-four charities that are members of CHC-SC. Our Number Designation is 925. For over 28 years, CHC-SC has been providing financial support for the fight against disability and disease and is the largest workplace giving program devoted exclusively to supporting health care organizations. CHC-SC will forward your contribution to SCAS once it receives it from your employer’s Human Resources Department. Sometimes, your employer may match your donation, so please ask about that at work. In these right economic times, this is an effective way to help SCAS and be able to figure out your “personal budget comfort level” to insure our programs to families continue. Any questions or if you need help with your HR Office, please contact Barbara. **Thanks for all you do!**

SCAS Newsletters

We will be distributing *semi-annual printed* newsletters to reduce costs (**\$8,000-\$10,000/year**) with *emailed* newsletters distributed alternately. Please send us your information via fax, postcard or online to update our database

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From the Desk of the President...

For information about autism and the many activities of our organization, visit scautism.org or in Columbia call 803-750-6988 or 800-438-4790.

Making Strides...

This is more than a tag line for the South Carolina Autism Society's **Strides for Autism-Walks Across South Carolina**. SCAS has been working hard to continue building on the progress made over the past few years. Even in light of declining budgets.

SCAS is so excited to be working with **WACH Fox 57** and **Thermal Technologies** on a public awareness campaign that airs in the midlands in March and will run through December. We had a lot of families volunteer to be a part of this campaign.

Working in partnership with the **Center for Disability Resources**, we have put together a group of stakeholders to look at autism and early intervention as part of a national program: **Act Early**. We had a meeting in Nashville with other SE states. From this meeting, we are developing a logic model on how to improve services. Several first goals includes **developing a service road map** to help families navigate the service delivery system, **applying for a professional autism development grant for teacher preparation** and **working to develop a "mini fellowship" for pediatricians**.

SCAS continues to expand our service area for **Service Coordination**. SCAS believes strongly that individuals with autism and their families deserve to have a choice in service providers. Watch for expanded counties soon.

The **Parent-School Partnership** program continues to reach out to families to assist in the educational process. Last year we worked with more than 1400 families. Even though we have received a budget cut to this program's funding, we continue providing this service without a waiting list.

Through this tough budget year, SCAS continues to be a presence at the statehouse, advocating for people with autism spectrum disorders. The State's budget forecast is not looking very good; but, we need to continue to promote **the need for essential and vital services to those with an ASD**.

SCAS can only make strides **with your support**. We are holding our **Strides for Autism** this year in **Greenville, Columbia** and **Myrtle Beach**. All of you can support this effort: No matter the size of your contribution, **together we can make a huge difference**.

Sign-up your team now at StridesforAutism.org. There are more details on Strides on page 1.

I am looking forward to seeing you at one of our events!



Craig C. Stoxen
President and CEO

Mission Statement: South Carolina Autism Society

Our purpose is to enable all South Carolinians with autism spectrum disorders to reach their maximum potential.

SCAS is a chapter of the Autism Society of America, a United Way participant and a Community Health Charities participant.

SCAS News --Continued from page 1

if you would like to continue to receive the UPDATE each quarter. You can also elect to have only emailed newsletters to further reduce our costs. **Privacy is important to us and your information will not be shared**. You can let us know if you want to be notified of events, workshops and other SCAS events as well. See page 16.

Bordertown BBQ Cook-Off is scheduled for March 28, 2009 at Clover Community Park, 256 Community Park Drive, Clover, SC 29710. Part of the proceeds from the 2009 Cook-Off will go to support the SC Autism Society.

Visit www.BordertownBBQCookoff.com.

SCAS will be honored as **Friends of Earth Fare** in April again. Make plans to visit during the month, see our display board and check the website for scheduled SCAS events to join in.

First Annual **Cruising Through Autism**: Four-Day Bahamas Cruise from Jacksonville, FL aboard Carnival Fascination, August 13-17. Visit www.scautism.org/calendar.html for more information. Fee includes fundraiser for SCAS.

New Research

by Ruth K. Abramson, Ph.D. FACMG

Department of Neuropsychiatry and Behavioral Science, USC School of Medicine

Editor's note: Dr. Abramson is a Fellow of the American College of Medical Genetics and a regular contributor to the Update. She is part of the USC-Duke University team researching the genetics of autism spectrum disorders.

In this difficult time when funds for services for individuals with autism and funds for research are at almost record lows, I thought hard about whether to discuss a research controversy that has been going on for over ten years. At the heart of this controversy are a number of issues that face both researchers and families who depend on the outcome of the research to direct the best treatment for their loved ones.

When I carry out research or when I write about a research study for this newsletter, there are certain unstated truths that must underlie the research effort. First, there must be an attempt to minimize the risk to the patient and maximize the benefit. Second, the design of the study must be sound so the conclusions drawn are accurate. Third, the researcher must accurately report the data and not slant the data to support a hypothesis that the researcher wants to prove. Sometimes, a researcher has a hypothesis that seems to explain a clinical situation. Then, the research study data does not fully support what he feels is true. There then may be a temptation to select part of the data that supports the hypothesis and report that data because the researcher has a gut feeling that this is the right trail. This is unethical and can be potentially harmful.

This is leading up to the issue...**is there a link between MMR immunization and autism** that would affect the development of autism in a large number of children with autism?

1. **In February 1998, the Lancet publishes the paper proposing the link between MMR and autism with Wakefield making no disclosure of his interests and supporting single vaccinations at yearly intervals.**
2. **In February 2004, the *Sunday Times* reveals Wakefield's legal funding and the fact that 11 of the 12 original children who participated in the original study are litigants.**
3. **In March 2004, 10 of the 1998 Lancet paper's 13 authors, but not Wakefield, retract the claim of a possible MMR-autism link, with the Lancet stating the paper was fatally flawed and apologizing for publishing it.**

4. **In July 2007, the *British General Medical Council* opened a professional misconduct case against Wakefield and two other colleagues concerning ethical issues over the treatment of the children.**
5. **On February 9, 2009 the *London Sunday Times* published an investigative report, having gotten permission from the parents of the 12 children to examine their medical records. Upon examination of the records, the newspaper reports that several of the children had problems noted by their usual doctors prior to receiving the MMR vaccine.**

Vaccination in England is at an all time low. In 1998 there were 56 cases of measles in England and Wales. In 2009, there were 1,348 cases with two deaths, meaning measles is now endemic in England. The risk posed by this research may outweigh the benefits.

The ethical questions that I have, after reading the investigative report, are as follows:

1. **Was the study design sound so that the conclusions were accurate?**
2. **Did the researcher report only that part of the data that supported his hypothesis and not the full data that might have shed a different light on his conclusions?**

I leave the conclusions up to you. I will leave copies of the investigative report at the SC Autism Society so that you can decide for yourself. If nothing else, it is interesting reading.

Once again, **Dr. Harry Wright, Dr. Alicia Hall, Elizabeth Wilkinson, Sarah Ravan, and Dr. Shelly Holstrum** and I would like to thank you for your support of both research and the SC Autism Treatment Network. Together that we can make a difference. If you have questions or comments, I can be reached by e-mail at **Ruth.Abramson@uscmed.sc.edu**. I look forward to hearing your comments or your interest in a particular area of research.

Autism: My Story

My Story is a little different this quarter: Ron Dozier has been working with SCAS and families throughout the state to develop a plan to create self-directed support corporations (SDSCs), aka microboards, in South Carolina. This will be a tremendous change for self advocates and their families regarding how services are managed or provided. This article was a contribution to the SC Developmental Disabilities Council, who provided funding via a grant to SCAS to develop SDSCs in our state.

Self-Directed Support Corporations

Consumer/Family Ownership of Supports and Services

In 2006, the South Carolina Autism Society submitted a proposal to the SC Developmental Disabilities Council to fund a grant to develop a self-direction model based on the Microboard models in Canada and Tennessee. The grant staff spent a considerable amount of time studying the models available throughout the US and Canada. What we learned was much different from our initial understanding. Microboards are not formed simply to own property, receive money or support surrogate decision-makers. Microboards allow consumers and families to own and control their supports and services. The concept is not widely supported by the professional community, as professionals are concerned with the possibility of misuse of public funds and abuse of the person receiving services. We have become convinced that for some consumers and families, this may be the only option that will work for them.

Groups & individuals who received information

During the first few months of the grant period, we researched the Microboard model and decided with our advisory council that elements of the Vela Microboard Association and the Tennessee Microboard Association were essential to the development of the program here. Those elements were Person-Centered Planning, the legal framework, the Board selection, Board training and development, and becoming a provider. The grant staff presented the concept of Microboards to more than 50 individuals and groups from the Upstate to the Pee Dee and the Lowcountry. The response was overwhelming: people stated repeatedly, ***"This is what we are looking for...we will be in charge—not the provider network."*** Then, we asked four individuals and families to look at the model in detail and see if it would work for them.

Families that volunteered to look at the model

The volunteers worked with us for five-seven months, reviewing person-centered practices, incorporation, board development and the process of becoming a provider of services—either direct services or service coordination.

What they learned

These volunteers learned that there is a lot of time involved with the ownership and control of supports and services.

The consumer/family has to recruit committed volunteers. On the surface this sounds easy, but the reality is that you need a process. The people recruited to serve on a Board need a compelling reason for wanting to serve. Among these reasons is love for the person, a desire to participate in real system change and a desire to assist the person to attain control of his/her life.

The consumer/family assumes responsibility for the supports and services. A question that surfaced repeatedly

was, "Am I liable?" The answer is yes. This one question will separate the serious consumer/family from those who have a passing interest.

The process exposed the consumer/family to the details of Service Coordination and the Band funding. SCDDSN provided the grant staff with up-to-date information about the funding band system. We in turn explained the system to the consumers and families. In all cases this was the first time the families had a conversation about the Band with their service coordinator. With additional information everyone began asking questions about how to use the band more effectively.

An unintended result was that consumers/families were better educated, asked more questions, and in two cases accessed respite care. Previously, they had not known to ask. We included a PATH planning session with each family, both the consumer/family and service coordinator got to know each other better; and we were able to resolve service issues locally.

What we learned

In SC, we created a Self-Directed Support Corporation (SDSC) model. This allows for the development of a Board that serves one person or a Board who comes together to assist up to four consumers/families with the management of their supports and services. We continue to present the idea of self-direction to individual consumers and groups whenever possible.

The initial meeting with a consumer/family was an intense session with many questions. We allow consumers and families to ask questions while we documented them. We then scheduled a second meeting to provide answers after thorough research. We needed a way to determine the motive for wanting self-direction, and to inform the consumer or family about the necessary time commitment. We needed a way to communicate the steps in the process—as best we can—considering the different needs for each consumer, and to prepare consumers/families for the rigors of Board development.

The SDSCs are subject to the same laws, regulations and oversight as a SC provider, which addressed the concerns of the professional community. The Board will have to meet the same performance criteria set by regulatory agencies, which is critical to the development of self-direction.

The influence of the Tennessee Microboard Association (TMA) and the Tennessee Developmental Disabilities Council (TDDC)

Through our collaboration with the TMA, we were able to get assistance with several issues. We established a ***Why Test***, a self-test of why a consumer/family would want to develop a SDSC. We created a Board selection process. It

Autism: My Story - Self-Directed Support Corporations *Continued from page 5*

is a “long list” and interview, then a “short list” and make an offer to serve.

We also used the TMA Step-by-Step Guide as a model for SC. Our SDSC Step-by-Step guide shows a six- to eight-month process that includes initial information session, the Person-Centered Planning, Incorporation, By-Laws, Phases of Board Development, Board Training, and Becoming a Provider. The TMA and the TDDC helped us develop information that would inform, educate, and prepare the consumer/family.

We wanted to ensure the integrity of the process. Why we are doing this? We are developing the Board to help the consumer own and control his/her supports and services. We are not developing the Board as a surrogate decision-making authority. There is a temptation that has played out in other states to use the Board to control the person and not the supports.

The TMA provided us with invaluable training on details in several months that could have taken a year to resolve through trial and error. We are grateful for the collaboration with the TMA and the TDDC.

South Carolina State Agencies

The SC Materials Management Office and the SC Department of Disabilities and Special Needs assured us of their intent to assist when our Boards are at the point of applying for Provider status. We have a close working relationship with the staff at SCDDSN, and they worked with us to make the new model fit alongside other providers in South Carolina. An example of our collaboration was the updating of the SCDDSN’s Administrative Standards. In fact, SCDDSN included SDSCs as a provider option in one of the new Medicaid Waivers.

The Consumers/Families moving forward

We now have four families moving forward; however, they are not the pilot families. One consumer/family lives in Myrtle Beach. The consumer is a person with autism. The Board that is forming is very strong and an Ad Hoc member is the Executive Director of the Horry County DSN Board. This first Board will be a springboard for other SDSCs in the Myrtle Beach area.

A second Board is forming in Jasper County. The person receiving services has a spinal cord injury, is highly motivated, lives in his own home, and wants to return to work. He wants to control all the services and supports and is surrounded by a strong group of friends with similar circumstances. He recruited local community leaders and family to serve on his Board.

A third Board in Clemson is in the beginning phase. The consumer is a young adult with autism. The young man has social skills issues but is exceptionally skilled with higher mathematics and computer code. He and his family want to control his services to point him toward a career in computer science. The challenges will be finding committed Board members, since these people are new to SC; overcoming the funding barriers; and building a working relationship with the local DSN Board.

A fourth Board is forming in the Greenville area. The consumer, a person with Pervasive Developmental Disability, and her family are in the beginning stages. We will be working to complete the beginning steps, the *Why Test*, the PATH, introduction to Boards, introduction to becoming a provider and the SCDDSN standards.

Finally, we have several consumers/families awaiting introduction sessions. By the end of the fiscal year, we hope to have between nine to twelve “Boards in progress.” We will be at a place to begin forming a SC Microboard Association, which will allow the members to support each other. The idea of ownership and control of supports and services is gaining national momentum.

There are several states, including SC, that have Microboard initiatives among them are; TN, GA, IL, and VA. There are many individuals in several other states working toward self-direction through the Microboard concept. In 2008, this group of states and individuals formed a national Microboard steering committee. The goal is to promote self-direction through Consumer and Family Ownership and Control of Support and Services. The National Microboard Steering Committee intends to: encourage Microboard development in other states, advocate with the Centers for Medicare and Medicaid Services for a faster pace of system change, and coordinate education and training at national conferences. At a recent meeting in Murfreesboro, TN, there was a consensus agreement that Microboards (Consumer and Family Ownership and Control) are a significant system change.

As with any change, there have been success stories and failures. There are key differences in this idea for change. The “Microboard” idea comes through the consumer/family, and not from state agencies or visionary thinkers. Then there is the real probability that consumer and family ownership and control will succeed because of its elegant simplicity.

In 1997, SCDDSN embraced the idea of person-centered programs to provide choices to people with disabilities. Nine years later, SCAS and the DD Council have created the opportunity for consumers and families to develop the means to maintain and support these choices. The thoughtful decisions of the SCDD Council give hope to consumers and their families. Self-Direction through ownership and control of supports and services is a meaningful and significant opportunity. As SC interacts with TN and other states that are embracing this extraordinary change, we will also have the opportunity to influence how other states and their consumers can adopt this approach, which empowers people with disabilities and their families as never before.

Submitted by Ron Dozier. For inquiries, please contact DiDi at SCAS at 803-750-6988 ext 102 or didi@scautism.org.

*We welcome stories of living with autism, which will be used as space permits. Submit to tim@scautism.org with Subject line *Autism: My Story*.*

Keep informed! Don't miss any of your SCAS UPDATES. See Page 16!

Asperger's Syndrome

A Guide for Parents and Teachers, Part II

Jim Garvey M.A., LPC,LPC/S, NCCBT

Editor's note: This is an ongoing guide by Dr. Garvey, a Nationally Certified Cognitive-Behavioral Therapist at the Cognitive Behavioral Clinic, 920 Mt. Gilead Rd. Mt. Gilead Executive Offices Building C-Suite 3 Murrells Inlet, SC 29576 (843) 450-2918.

Emotional Regulation

Children with AS have the intelligence to compete in regular education, but they lack the emotional resources to cope with the daily demands. Their self-esteem is generally low and they are often very self-critical and are unable to tolerate making mistakes. Children and adults with AS may be prone to a high level of depression. The suicide rate is very high with individuals diagnosed with AS. It is very important to educate this population on their differences and through cognitive therapy try to fill in the gaps. Rage reactions/temper outbursts are common in response to stress/frustration. Children with AS rarely relax and are often overwhelmed when things don't fit their rigid view. Interacting with people and coping with the ordinary demands of everyday life takes continual Herculean efforts.

Suggestions:

- Prevent outburst by offering a high level of consistency. Prepare these children for change in daily routine, to lower stress. Children with AS frequently become fearful, angry and upset in the face of forced or unexpected changes.
- Teach the child how to cope when stressed to prevent outbursts. Help the child write a list of very concrete steps that can be followed when he or she becomes upset. **Example:** Breath deeply three times, count the fingers on your right hand slowly, ask to take a walk, ask to talk to a counselor, etc. Include ritualistic behavior that the child finds comforting on the list, like special interests or solitude. Write these steps on a card and keep it readily available.
- Affect, as reflected in the teacher voice, should be kept to a minimum. Be calm, predictable, and matter-of-fact in interactions with the child with AS, while clearly indicating compassion and patience. Hans Asperger, the psychiatrist for whom this syndrome is named, remarked that "the teacher who does not understand it is necessary to teach children with AS seemingly obvious things will feel impatient and irritated."

- Do not expect the child with AS to acknowledge that he or she is sad or depressed. In the same way that they cannot perceive the feelings of others, these children can also be unaware of their own feelings. They often cover up their depression and deny its symptoms. Because of the abstracts in the language associated with emotions, it may be very difficult to express what they are feeling.
- Teachers must be alert to changes in behavior that may indicate depression, such as even greater levels of disorganization, inattentiveness, isolation, decreased stress threshold, chronic fatigue, crying, suicidal remarks, and so on. These may be red flags that the student is feeling so overwhelmed. Do not assume that he/she is OK.
- Report symptoms to the child's therapist or make a mental health referral so that the child can be evaluated for depression and receive treatment if needed. Because these children are often unable to assess their own emotions and cannot seek comfort from others, it is critical that depression be diagnosed quickly.
- Be aware that adolescents with AS are especially prone to depression. Social skills are highly valued in adolescence, and the student with AS realizes he/she is different and has difficulty forming normal relationships. Academic work often becomes more abstract, and adolescents with AS find assignments more difficult and complex. In one case, the teacher noted that an adolescent with AS was no longer crying over math assignments and, therefore, believed he was coping much better. In reality his subsequent decreased organization and productivity in math was believed to be a function of his escaping into his inner world to avoid the math, and thus he was not coping at all.
- It is critical that adolescents with AS who are mainstreamed have an identified support staff member with whom they can check in at least once daily. This person can assess how well the student is coping by meeting with them daily and gathering observations from the teachers.

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- Children with AS who are very fragile emotionally may need placement in a highly structured special education classroom that offers an individualized academic program. These children require a learning environment in which they see themselves as competent and productive. Accordingly, keeping them in the mainstream where they cannot grasp concepts or complete assignments only serves to lower their self-concept, increase their withdrawal, and set the stage for a depressive disorder. In many situations, a personal aide that is trained on Asperger Syndrome is all it takes to keep the student in with typical peers. The aide offers effective support, structure and consistent feedback.

Children with Asperger's Syndrome Disorder are so easily overwhelmed by environmental stressors and have such profound impairment in the ability to form interpersonal relationships, that it is no wonder they give the impression of "fragile, vulnerable, and are often the targets of severe criticism." (Wing, 1981, Everard 1976) When these youngsters are compared with their nondisabled peers "one is instantly aware of how different they are."

Jim Garvey will share more great information in the next edition of the SCAS UPDATE.

Bravo Awards

John Tatara
Richland School District One
Autism Itinerant Teacher

John Tatara is a caring and competent professional who provides strategies and creative ideas to general and special education teachers to better support students with ASD. He is currently working on the ***Strides for Autism Walk Committee for Columbia*** scheduled for May 23, 2009. John strives to keep students with ASD successful in all facets of school life and will go the extra mile for families. We want to offer special recognition for all his efforts.

Submitted by Tim Conroy

Simon Keyes
Horry County Schools
Former Special Education Teacher

Simon Keyes is a teacher who always put his students first. Now I have the great pleasure of working with him as an **Autism Consulting Teacher**. Mr. Keyes, in my opinion, still puts the needs of the students first. He has done an outstanding job.

Submitted by Denise Garvey



Watch WACH Fox 57 for Public Service Announcements

WACH Fox 57 and **Thermal Technologies** are sponsoring several public service announcements for SC Autism Society to bring awareness of autism in our state. These spots will begin airing in March and continue through December.

SCAS wishes to thank the families who shared their time and stories and these outstanding sponsors for their advocacy efforts on our behalf. Special appreciation goes to **State Superintendent of Education, Jim Rex**, for his time and effort supporting students in South Carolina with ASDs. Visit **MidlandsConnect.com!**

2009 Strides For Autism Registration Form

My Information:

Walk Location: **Greenville** **April 25** **Columbia** **May 23** **Myrtle Beach** **June 13** **ALL Walks!**

Your Name:				
Address 1:				
Address 2:				
City:	State:	Zip:		
Phone: with area code	Your Email:			

SCAS respects your privacy and will not share or sell your personal information without your permission.

I'd like to participate as:

(Please indicate Team Name below if you are contributing to a team's goals!)

Team Name: _____

Individual (no team)

I'm Team Captain I'm a Team Member

I'm a Walker I'm a Donor

Fundraising Goal: \$

This is a TEAM Goal This is my Personal Goal

Waiver and Release of Liability: I hereby waive all claims against the South Carolina Autism Society or any personnel for any injury during this event. I attest that I am physically fit and prepared for this event. I grant full permission for organizers to use photographs of me and quotations from me in legitimate accounts and promotions of this event.

Signature: _____ Date: _____
(must be 18 or parent or guardian to sign)

Name Above: _____
(typed/printed)

Registration fees for each Walk is \$25 per person or \$50 per family of 4 (fees include t-shirts).

Donation (optional): \$ _____ Individual Walker \$ 25.00 _____ Family (4) \$ 50.00 _____ (please list names of walkers)

<i>Family Walker 1</i>	<i>Family Walker 2</i>	<i>Family Walker 3</i>	<i>Family Walker 4</i>

Enclosed is Check or Money Order OR Charge Visa / Mastercard / Discover

Name (on card):	Exp Date:	V-Code:	
Card Number:			
Signature:			

Please mail checks/money orders payable to **SCAS**, along with completed form to our address:
SC Autism Society, 806 12th Street, West Columbia, SC 29169-6142
 OR register at www.stridesforautism.org.

Service Coordination News

AT&T Pioneers support SCAS and our Families

January 6, 2009



Upstate

On December 13, more than 85 parents, children and young adults with Autism and their siblings and friends attended the 2008 Christmas party in the Upstate SCAS office. The office was decorated for the holidays including a beautiful Christmas tree full of ornaments hand made by the **AT&T Pioneers** representing their various projects. Participants enjoyed refreshments and had their picture taken with Santa. Everyone also enjoyed the craft project of making Christmas tree ornaments including their picture. **Linda Portwood**, with the AT&T Pioneers, said “we sincerely enjoyed being apart of the day and sharing in the fun.”

Bob Martin, Chapter VP of the AT&T Pioneers, greeted the families and then shared goodie bags. He said “the Pioneers look forward to doing it again next year.” Thanks to all of the AT&T Pioneers for making this party possible for our families and to **Bill Neary** for photos.

Midlands

Thanks to the Midlands area **AT&T Pioneers**, over 50 people with ASD that we serve and dearly love enjoyed an afternoon with **Santa** and his elves, who helped create art projects. **Clowns** also visited and did great face paintings and balloon art to make it a true celebration.

The Pioneers graciously brought handmade teddy bears and goodie bags for all who attended the SCAS Midlands Christmas drop-in on December 20th. This was an awesome way for many of our families to get together and have pictures made of their loved ones with Santa. Yummy snacks were provided by the Pioneers as well. Many thanks for the hard work of the Midlands Pioneers and special thanks to: **Linda Ridenour, Gail Davis, Joan Steele, Mary Williams, Camilla Ferry, Debbie Christy**, and guest from the Edisto Club, **Walter Weeks**. We hope their day was brightened as much as ours by the many gleeful faces who enjoyed the festivities.

Dear Family Member/Loved One,

Greetings! I am writing to let you know of some upcoming changes in service coordination here at SCAS. SC Department of Disabilities and Special Needs notified us on December 23 that we are being forced to place 182 of our current cases on **Level 2 service coordination** due to budget cuts. SCDDSN provided a list of consumers that they want placed on Level 2 service coordination, and you or your loved one was chosen for Level 2. Level 2 service coordination means we will only call you once a year to check on your loved one to see how they are doing, if anything has changed with your address or if you have any critical needs. A person on Level 2 can still call us and request respite and family support funds. However, these funds have been cut as well, and there is very little money left in either of these areas. Nevertheless, we will be happy to advocate on your behalf for either of these services, should the need arise. Please know that this is not something we want to do, nor is it something in which we have a choice. Times are tough all over the country, especially here in SC with state budget cuts affecting all agencies. However, SCDDSN is taking one of the biggest cuts.

Any time during the year that you need our assistance or if critical needs arise, by all means give us a call. With approval from SCDDSN, we can take your loved one off of Level 2 service coordination and put them back on Level 1. If for some reason you don't feel your loved one should be placed on Level 2, we will happily give you the procedures to appeal this decision. We can appeal at the district level of SCDDSN, given you provide us with the circumstances that warrant keeping your case on Level 1 service coordination. With us losing 182 cases to Level 2 service coordination, we also have to cut service coordination staff. I'm doing everything I can to make the cuts in staff minimal. However, we have already let go of 3 service coordinators and may have to let go of an additional 2 if we can't stay afloat with such major cuts. It is important to note that we do not get paid any funds from SCDDSN for Level 2 service coordination. This is why our budget is hurting so badly at SCAS.

I want to sincerely apologize for any inconvenience this is going to cause you and your family. I have incurred many sleepless nights since getting this news, as I do not feel it is fair to make people go on Level 2 – it should be a choice – nor do I like having to let go of staff that have been so dedicated to the consumers that SCAS and SCDDSN serves. I would recommend that if you are upset with the budget cuts to **contact your local state legislators and let them know how these budget cuts are directly affecting you and your family** as well as to **contact SCDDSN to voice your concerns with the budget cuts**. Do not hesitate to let me know if you have any questions or concerns. We should all hope for better times ahead!

Respectfully,

Kim Thomas
SCAS Director of Service Coordination
 803-750-6988 ext. 111
kim@scautism.org

SC Autism Society Workshops 2009

Please visit www.scautism.org for online registration and a current list of available workshops.

Writing Measurable Annual Goals in the IEPs of Students with Autism Spectrum Disorders

**Saturday, March 14 (CHARLESTON) or
Saturday, March 21 (AIKEN)**
9:00am-4:00pm

Workshop Fee: \$25

Instructor: **Mitchell L. Yell, Ph.D.**

One of the most important, but least understood, elements in developing the individualized education programs (IEPs) of students with disabilities is the requirement regarding measurable annual goal. The purposes of this presentation are to (a) present a four-step process for developing educationally meaningful and legally correct IEPs and (b) discuss on how parents and teachers can develop annual goals that are ambitious and measurable.

Participants will be able to :

- * Identify the four steps in developing educationally meaningful and legally correct IEPs
- * Distinguish between goals that are measurable and meaningful and annual goals that are neither.
- * Use effective strategies to develop measurable goals.

Autism 101

Target Audience: Everyone is welcome: this session best suited for participants new to autism, whether you are a parent, teacher, instructional assistant or transition staff, this is your opportunity to learn more about autism, the services and the service delivery systems in South Carolina.

Instructors: **Melissa L. Metts, M.Ed., NBCT or
Alisia Carey, BS/M.Ed in Sp.Ed.,
NBCT, BCBA**

**Wednesday, April 22 - 6:00 pm-8:00 pm or
Wednesday, June 17 - 6:00 pm-8:00 pm or
Wednesday, September 16 - 6:00 pm-8:00 pm**

Workshop Fee: FREE

Everyone is welcome! Ask your questions and gain a better understanding about autism. *Each individual session repeats on each of the days above--this is not a workshop series.*

OH! That Makes Sense! Understanding the Sensory World of Autism

Target Audience: Everyone is welcome: this session best suited for participants newly learning about sensory issues.

Saturday, April 4
10:00 am-12:00 noon

Doors open at 9:30 a.m.

Workshop Fee: \$25. *This workshop is free for SCAS Service Coordination families.*

Instructor: **Shelley Ionescu, MS, OTR/L**

"I wish he would stop flapping!"

"Why does she have to lick everything?"

"He rocks constantly."

"Well of course he acted-out, I forgot to cut the tag out of that shirt."

Believe it or not, there is a reason your child engages in these and other behaviors. Shelley Ionescu will explain how sensory processing impacts your child's behaviors, attention and social interactions. A brief description of our seven sensory systems and how they interact will be given. Sensory strategies/tools will also be recommended, demonstrated and described for use in sensory diets. There will be an opportunity for open discussion and questions/answers at the end of this presentation.

Basic Teaching Strategies and Support for Students with ASD

Tuesdays, May 5 - June 2 (5 sessions)
5:00 pm-7:00 pm

Workshop Fee: \$25

Instructor: **Alisia Carey, BS/M.Ed in Spec. Ed.,
NBCT, BCBA**

Participants will identify, develop and practice strategies and interventions to support persons with Autism Spectrum Disorders in the home,

HAVE YOU REGISTERED YOUR STRIDES FOR AUTISM TEAM?

Visit www.StridesForAutism.org Today!

2009 Workshops Registration Form (for workshop details, visit www.scautism.org)

Name:					
Address 1:					
Address 2:					
City:		State:		Zip:	
Phone: with area code	<input type="checkbox"/> H		Your Email:		
	<input type="checkbox"/> W				

SCAS will send email confirmations only. (Make sure your email address is correct.)

Session Name	Location	Date	No Refunds after date **	Fee includes Lunch:	Registration Fee:
Writing Measurable Annual Goals in IEPs of Students with ASDs	Charleston	03/14 9am-4pm	02/26	no	\$ 25
Writing Measurable Annual Goals in IEPs of Students with ASDs	Aiken	03/21 9am-4pm	03/05	no	\$ 25
OH! That Makes Sense! Understanding Sensory World of Autism	SCAS-HQ	04/04 10am-12pm	03/19	no	\$ 25
Autism 101	SCAS-HQ	04/22 6-8pm	na	no	No-Charge
Basic Teaching Strategies and Support for Students with ASD	SCAS-HQ	05/05-26 5-7pm	4/21	no	\$ 25
ABA workshop: Evidenced Based Practices THIS JUST IN!	Columbia	06/08 <i>see website</i>	5/25	yes	\$75
Autism 101	SCAS-HQ	06/17 6-8pm	na	no	No-Charge
Autism 101	SCAS-HQ	09/16 6-8pm	na	no	No-Charge

Are you a member of the South Carolina Autism Society? Yes No

Are you a Parent of a child with autism? Yes No

Enclosed is Check or Money Order OR Charge Visa / Mastercard / Discover / Am Exp

Name (on card):		Exp Date:		V-Code:	
Card Number:					
Signature:					

***Cancellation Fee of \$20 will apply (if cancelled before "no refunds" date above) .**

Please mail checks/money orders payable to **SCAS**, along with completed form to: **SC Autism Society, 806 12th Street, West Columbia, SC 29169-6142** OR register at www.scautism.org. SCAS's needs-based Workshop Scholarship Application is available at www.scautism.org for parents only for applicable workshops.



Community Health Charity of South Carolina improves the lives of people affected by a disability or chronic disease by uniting caring donors in the workplace with our nation's most trusted health charities. SCAS is a member of the Community Health Charities-**designation code #925** or <http://www.healthcharities.org/index.asp?sid=18&StateID=41>

Join SCAS Today!

If you're not a member of SCAS, remember that becoming one will save you money on the SCAS Conference in October. Contact SCAS at 803-750-6988 or 800-438-4790 or visit www.scautism.org.

BASIC Individual - \$10 Family - \$20
State conference discount; Receive THE UPDATE, state chapter quarterly newsletter; personalized membership card; SCAS membership magnet; voting privileges during annual meeting (Family level gets two votes).

FULL-TIME STUDENT Individual - \$10
Basic (individual) benefits

SUPPORTING Individual - \$35 Family - \$50
Basic benefits plus: exclusive limited edition member coffee mug (Family level receives two mugs).

BENEFACTOR Individual - \$75 Family - \$100
Basic & Supporting benefits plus: Exclusive "Solving the Puzzle" ribbon lapel pin (Family level receives two pins); Personal invitation to special events.

www.scautism.org

The UPDATE is published four times a year by the South Carolina Autism Society, one of more than 200 nonprofit chapters of the Autism Society of America (ASA) and the only ASA chapter in South Carolina. SCAS is a United Way participant and a Community Health Charities participant. Guest articles are welcome for possible publication. Information and points of view contained in The UPDATE are not necessarily endorsed by or held by SCAS, its directors or staff, but may be presented to keep readers informed. Visit our website for a current calendar of events: including training opportunities, meetings, events, and more!

2009

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Dr. Don Wouri, Columbia

Donna Jarrell +, Coastal

* denotes parent of child with an ASD.
+ denotes relative of person with an ASD.

SCAS Board Meetings

2009

May 16 at SCAS-10:00 am

August 22 at SCAS-10:00 am

October 9 at Columbia Conference Center-4:00 pm

Minutes to SCAS Board Meetings can be found at
www.scautism.org/minutes.html

SCAS Programs

For more information, visit our website.

- Family Support/Information and Referral
- Annual conference, workshops for parents and professionals
- Service Coordination for DDSN consumers with autism
- Self Directed Support Corporations SDSCs (aka microboards)
- Parent-School Partnership-parent mentors assist families
- Providing autism books & DVDs to libraries
- SCAS advocates for quality services for children and adults with ASDs as individuals and statewide.

South Carolina Autism Society

SCAS Staff	* denotes parent of child with an ASD. + denotes relative of person with an ASD.	Ext.
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Melissa Shope	Lead Service Coordinator (Upstate)	
Nita Toler	Lead Service Coordinator (Charleston)	
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PSP Mentors All ext.		103
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SCAS Forums
SCAutismForum@yahoo.com <i>for SC Parents/Families only</i>
SCHighFunctioningASD@yahoo.com <i>SC Parents/Families only</i>
AutismSouthCarolina@yahoo.com <i>For Professionals and Families</i>



Please support your local United Way.

Allocations & designations are an important part of the SCAS budget.

Thank you for giving.

SC Autism Society's Main Office (HQ)
806 12th Street West Columbia, SC 29169
803-750-6988 • 800-438-4790 • (*extensions above*)
Fax: 803-750-8121 • e-mail: scas@scautism.org

SCAS Upstate Office
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SCAS Low Country Office
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SCAS Coastal Office
3254 Holmestown Road, Unit A
Myrtle Beach, SC 29588
Office: 843-650-0129 • Fax: 843-650-2105

Sign-Up to Receive SC Autism Newsletters via Email

Name:

Address 1:

Address 2:

City: State: Zip:

Phones: H with area code W C

Your Email:

Are you a member of the South Carolina Autism Society? Yes No

Are you a Parent of a child with autism? Yes No

Please email me about **all** SC Autism Society events, newsletters, workshops & campaigns (*default option if nothing is checked*).

Or if you prefer: Please **only** send me newsletters.

Don't MAIL me any copies-just email me instead.

South Carolina Autism Society respects your privacy and would never share or sell the private information that you make available to us. To remove SCAS notifications at any time, email unsubscas@scautism.org

If you wish to share any other comments, notes or additional email addresses, just write that information below. Many Internet Service Providers filter emails from unknown senders, so please be sure to add scas@scautism.org to your contacts or address book in order to receive notices.

Don't Miss an Issue!

Budget cuts are forcing SCAS to reduce printing costs. Send us your current contact information today to receive all quarterly SCAS UPDATES!

Please choose...	MAIL	SC Autism Society 806 12th Street West Columbia, SC 29169-6142
	ONLINE	www.scautism.org
	FAX	SCAS at 803-750-8121

Volume 37
Issue One
March, 2009

806 12th Street
West Columbia, SC 29169

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U.S. POSTAGE
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South Carolina Autism Society
Together We Can Solve The Puzzle



SCAS UPDATE