UPDATE

Winter 2003

SCAS to Offer Service Coordination

The S.C. Department of Disabilities and Special Needs has awarded contracts to seven providers, including the S.C. Autism Society for service coordination

It will be SCAS's first contract with DDSN for services, and the first time SCAS has offered service coordination.

"We are happy to be part of the movement toward more choice in providers," SCAS President and CEO Craig Stoxen said. "We have long advocated for options, and now we can be an active participant in choice."

SCAS will offer service coordination beginning in 2004 to individuals with autism who are at least 3 years old and have been qualified for services by DDSN.

Initially it will be offered in the Midlands, most likely including Richland, Lexington, Fairfield, Newberry and Kershaw counties, according to Craig. He added that the organization has been approved for service coordination statewide and will gradually move in that direction.

Service coordination includes identifying and obtaining needed services for individual children and adults; monitoring and evaluating those services; constructing lifelong plans; coordinating resources; and assuring lifelong plan achievement.

See page 14 for information about the other contracts DDSN awarded. See page 2 for a message about changes in membership dues from SCAS President and CEO Craig Stoxen.

Other components are providing information and support; creating and developing opportunities; and educating the broader community.

Most service coordination in South Carolina is currently provided by Disability and Special Needs Boards in the various counties, although a few independent providers have begun to offer it in some areas.

"We are pleased to have been approved," Craig said. "We already are experienced in advocating for individuals with autism and have worked closely with families for 31 years now."

Chapter to Collect Only Its State Dues

Effective Jan. 1, 2004, the S.C. Autism Society will collect only its state dues and no longer collect national dues for membership in the Autism Society of America.

Not all SCAS members may have realized it, but the bulk of their dues was forwarded to ASA. About a third stayed at SCAS for local programs.

SCAS members will be directed to ASA if they opt to join the national organization. ASA contact information will be included on SCAS membership forms and linked on the website at www.scautism.org.

Approved by the Board of Directors in November, the change will eliminate the work of soliciting for and collecting ASA dues, as well as monitoring national

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From the Desk of the President

Dear Friends:

Recently, at church, we had a guest preacher. He was a minister who had left the parish ministry to pursue pastoral counseling. During his sermon he made an interesting observation. He was talking about change and how we all need to change and that different people take to change differently. It's a lesson we all know well in the autism community.

One thing stood out for me as he spoke. He said confusion was part of the change cycle. That when someone was confused about an issue, this was a sign that they are starting to process the new idea, even though it may have been contrary to the idea they previously held.

I found this interesting when I was thinking about all of the new changes happening at SCAS. These changes can sound confusing. After many years of doing things one way, starting the new year, some things will be done differently.

For many years, we have always collected the dues for the Autism Society of America. But last month the SCAS Board of Directors elected not to continue doing so. There are many reasons for this, but the main reason was to preserve the integrity of both databases.

This is where the confusion kicks in. In the past we would collect the dues along with all of the data on members. At the end of the month, we would fill out a submittal form and send the form and the National dues to ASA. They would receive that data and input it into their system. ASA has recently gone to electronic transmissions, but their form is not compatible with our database, and we have to type the information twice. Also, dates of membership often do not match between the two organizations, because ASA inputs the data at a different time. This leads to considerable confusion among those who join both groups, but we can do little about it.

This process is costing us money at the local level. Also, the bulk of the membership fees was being forward to ASA. By only retaining the local dues, and ASA collecting national dues, we will eliminate our having to enter everything twice and hopefully eliminate some of the membership expiration date confusion. This may be confusing at first, but other ASA chapters have found that in the long run, things have run much smoother this way.

The second change next year is that SCAS will start providing service coordination. We have been approved as a qualified provider by the Department of Disabilities and Special Needs. This is a positive change because previously families have had little choice in who would coordinate services. In almost all cases, it was the local disabilities board, which meant no options.

But as DDSN moves more toward choice, SCAS decided to apply to offer this service. We are planning to start in the Midlands area and then expand according to need and request. The SCAS philosophy is that service coordination is about advocating for the individual's needs.

These are some big changes for SCAS and unfortunately, not all of the details have been worked out yet. So if you are confused, or if we sound confused at points, please know that we are moving toward serving you and your family better.

We look forward to these changes. As we move forward and work out all of the details, things will become clearer and any confusion will lift.

Craig C. Stoxen
President and CEO

Thank You, for Making Golf Tournament a Success!

SCAS greatly appreciates all the contributors who made the "Fun in the Fall' Golf Tournament such a big success. The tournament was held Sept. 27 in Columbia. See page 7 for the contributors to the silent auction at the 2003 conference in October.

Platinum golf sponsors ($1,000 and up) were West Columbia Evangelical Church, through Roy Williams; Progress Energy Solutions and Montone Trailers, LLC. Practical Energy Solutions was a gold sponsor ($500 and up). Bronze sponsors ($300 and up) were Richland Northeast Family Dentistry, Carolina Diabetes and Kidney Center and Midlands Pediatrics.

Corporate hole sponsors were Midlands Pediatrics; Capital City OB/GYN; NBSC; New Capernaum Life Services; New Capernaum Church Ministries; Robert Capers- State Farm Insurance; Palmetto Pediatrics; Pat Blake - Russell & Jeffcoat; Specialties and Etc. Distinctive Promotional Items; and Carolina Women's Health Care, PA.

Holes were sponsored in honor of Sommer Bauerle, Jessica Yoder, Bill Weeks, Megan Weeks, Matthew L. Pate, Ryan Marquis, Mike Shippy, Ryan Holbert, Cole Highes, Gabriel Diaz and Buddy Reames. In-kind sponsors were the Pepsi Bottling Group, the Golf Club of South Carolina at Crickentree, Putt-Putt Fun Center, Budweiser of Columbia, Adams Mark Hotel, the Mills House through John Edwards, and Specialties and Etc. Distinctive Promotional Items.

Dues

cont. from p. 1

memberships on behalf of ASA.

Craig Stoxen, SCAS president and CEO, said ASA has agreed to directly collect its own membership dues. The national organization has said it will begin mailing its renewal notices in January.

SCAS will continue to mail its own notices the month before the recipient's membership expires. Because the national dues will not be included, the SCAS renewals will be for smaller amounts than before.

Benefits of joining ASA include national advocacy, a discount to attend the ASA national conference (in Seattle next July), and a subscription to *The Advocate* magazine. Research is funded by a separate foundation.

"State memberships are an important part of our funding," Craig said. "Overall, I can say

For the Record

Congratulations to the following winners at the fall golf tournament on Sept. 27:

1st Place (scored 62)
RCR Associates
Carlisle Reames, Bobby Hornton,
Dick Woodward, Brent Mattox

2nd Place (scored 63)
Montone Trailers
Jerry Owens, Tim Smith, Monty Barfield,
James Cox

Closest to the Pin
Dick Woodward (#4)

Longest Drive
Scott Thompson (#18)

The Update

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. Guest articles are welcome for possible publication. Information or points of view contained in the *Update* are not necessarily endorsed or held by SCAS, its directors or staff, but may be presented simply to keep readers informed about options. SCAS maintains offices in the Palmetto Office Building at 652 Bush River Road, Suite 203, Columbia, SC 29210. Call us at 803-750-6988 or 800-438-4790; fax us at 803-750-8121; or e-mail us at either scas@scautism.org or www.scautism.org.

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Rett Syndrome More Complex Than Once Thought

by Ruth K. Abramson, Ph.D.
Department of Neuropsychiatry and Behavioral Science, USC School of Medicine

Editor's note: Ruth is a Fellow of the American College of Medical Genetics and a regular contributor to the Update. *She is part of the University of South Carolina-Duke University team that is researching the genetics of autism spectrum disorders.*

All of us who work in autism research and many family members look forward to the day when there is a laboratory test for autism. Currently, there is only one disorder in the autism spectrum for which a physician can order a DNA test from a laboratory accredited for clinical testing. That disorder is Rett Syndrome, a relatively rare disorder which affects 1 in 12,000 to 15,000 girls. As initially described, Rett Syndrome is a neurogenetic developmental disorder that presents in girls with a developmental regression that results in a loss of skills, autistic-like behaviors, microcephaly (small head circumference), development of hand stereotypies such as hand wringing and hand washing behaviors, seizures, increasing spasticity, gait ataxia, scoliosis, and marked breathing problems that can include hyperventilation and periodic apnea and breath holding (Hagberg et al, 1983; Percy, 1995; Naidu, 1997). Previously it was thought that Rett Syndrome affected only girls, with boys who had a mutation in the Rett's gene being stillborn or lost during pregnancy.

Rett Syndrome is caused by mutations in a gene on the X chromosome which produces a protein called MeCP2. One theory is that the MeCP2 protein controls gene expression important in the development of normal nerve cells in the brain. Mutations in MeCP2 change the ability to regulate genes during critical stages of brain development. Researchers think that, in part, the problem is related to the normal function of MeCP2. MeCP2 is thought to bind to genes that have become methylated (methyl refers to the chemical group CH3). Methylation is important because it is the way that genes in development are turned off when they are no longer needed. The MeCP2 protein locks onto these methylated genes and prevents them from becoming active again. Abnormal MeCP2 is not able to function properly. There are mice whose MeCP2 gene has been disabled who have Rett-like symptoms (Jaenisch).

Since Rett Syndrome was initially described and the gene identified, more than 100 mutations in the MeCP2 gene have been identified. The clinical picture has become more complicated, with reports of mutations in the Rett Syndrome gene resulting in "classical Rett Syndrome," less severe Rett Syndrome, and boys who have a mutation in the Rett Syndrome gene who have mental retardation. It is also important to know that ***MeCP2 mutations cause some but not all cases of atypical Rett Syndrome*** (Hoffbuhr et al, 2002). In the large Hoffbuhr study of girls with atypical Rett Syndrome and MeCP2 mutations, most showed preserved language, some intact hand use, normal head circumference and good motor ability. Many researchers, including our group, have screened all girls with autism and found that a small number of girls diagnosed with autism really had Rett Syndrome with a MeCP2 mutation being present. Thus, there is great variability in the expression of Rett Syndrome in girls who have MeCP2 mutations.

In girls with Rett Syndrome, several researchers have reported that the position of the mutation within the gene and the kind of mutation may affect the severity of Rett Syndrome, while others have described the same mutation in girls who have classical Rett Syndrome and girls who have atypical Rett Syndrome (Amano et al, 2000; Amir et al, 2000; Cheadle et al, 2000; Auranen et al, 2001; Hoffbuhr et al, 2001; Nielson et al, 2001). In addition, there are girls who have a MeCP2 mutation, but have no symptoms whatever because of skewed X chromosome inactivation. Girls have two X chromosomes and boys have 1 X chromosome. Early in development, one of the two X chromosomes in girls is randomly turned off and does not function in each cell. On average, with Rett Syndrome, you would expect to see half of the cells with the normal MeCP2 gene on one X chromosome and half of the cells with the abnormal MeCP2 on the other X chromosome. However, more often than expected, the abnormal X chromosome is turned off and only the normal X chromosome is left functioning in most cells in the body. This results in a girl who is normal with no signs of Rett Syndrome because most of the abnormal chromosomes are turned off and are not functioning.

Rett Syndrome in boys can be expressed in at least two ways. First is the classical Rett Syndrome, where the MeCP2 mutation is fatal during pregnancy or the fetus is stillborn. The second way is in boys with

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Autism Division Training Has a Long History

by Bruce A. Braswell, M.Ed.
Director of Training and Quality Assurance
Autism Division of the S.C. Department of Disabilities and Special Needs

Editor's note: In 1976 Bruce began teaching at North Charleston Elementary School in a contractual autism program through the S.C. Department of Mental Health (DMH). Eight years later Bruce became a consultant with the DMH autism programs. The program in North Charleston, known as the Program for the Behaviorally Handicapped, was the first DMH contractual autism program in South Carolina. Its first director was Andy Mance.

The Autism Division of the South Carolina Department of Disabilities and Special Needs (DDSN) provides the services of evaluation, consultation and training. We are now making major revisions in the training area. Revisions and updates are underway for classroom teacher training. This is the first of two articles in this newsletter to let the "autism community" in South Carolina know about the revised training. For now we'll look at some highlights of the Autism Division's history. In the next issue specific information about the new training will be provided.

History? Ugh! Why talk about "history"? Well … knowing some things about our past might help you understand the changes we are making. To keep it simple, we'll just look at four main time periods. Those periods are the 70s, 80s, 90s, and from 2000 until now.

1970s: DMH, Classrooms, Contracts & Judevine

The present statewide network of services known as the Autism Division, under DDSN, was originally started in 1973 under the South Carolina Department of Mental Health (DMH). We were known at that time as *Programs for Autistic Children*. DMH contracted with school districts around the state to manage self-contained classrooms for children with autism. In those years, all contractual classes were modeled after the Judevine School for Autistic Children in St. Louis, Missouri. Judevine continues today as a program and service model for people with autism under the direction of its founder, Lois J. Blackwell. (For more information go to www.judevine.org/)

Everywhere in the late 60s and early 70s services for children with autism were limited. Services for adults with autism were pretty much "not there." Around the country, there were places where people were discovering that treatment based on behavioral principles worked. Children with autism responded successfully to the correct implementation of behavior management. Judevine was one program that was teaching children and increasing appropriate behaviors through behavior principles.

Judevine was, and still is, an innovative approach. Blackwell and James F. Budde took behavioral technology and put it into "easy to understand" language. Correct applications of behavior principles were presented in everyday family and classroom situations. Blackwell and Dr. Budde developed a deceptively simple, yet systematically thorough, training curriculum for parents and teachers. Training lasted three weeks. It was a blend of lecture and observing or working directly with children. Some of the "founding parents" of the present day S.C. Autism Society helped to make Judevine the model for autism services here. The resulting South Carolina contractual school programs had the double purpose of, (1) providing treatment, and (2) training family members, teachers and other professionals. From our beginning, training for professionals and families has been an integral feature of the Autism Division.

In addition to the Judevine model, the DMH autism programs continued to explore other avenues to improve education and treatment. One of several in the later 70s was Mark Gold's "Try Another Way." Dr. Gold was a pioneer in effectively teaching vocational skills to people with mental retardation. He used task analysis to teach complex skills to those once considered "unteachable," including people with autism. Professionals from his program came to South Carolina to train staff in the DMH autism programs.

1980s: NPT, Functional Curriculum, Community Training & Discrete Trials

A major milestone in our history occurred in the early 80s. The DMH autism programs received National Personnel Training (NPT) endorsement. The original name of the Autism Society of America (ASA) was the

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Autism Division Training

cont. from p. 5

National Society for Autistic Children (NSAC). NSAC got a grant to develop "state of the art training" for professionals serving people with autism. The official name was NSAC-NPT. Highlights were the content and a two-step approach to staff training. Step one was to train a group of direct service staff and supervisors to set up a model site. The second was to train some of the supervisors to be trainers. Some of the professionals involved in the NPT project were Dr. Lou Brown of the University of Wisconsin-Madison, Dr. Barry Prizant of South Illinois University, and Dr. Gary LaVigna of the Institute of Applied Behavioral Analysis (IABA), Los Angeles, California.

Condensed, here are three significant topic areas of the NSAC-NPT curriculum. "Functional programming" – doing things that have a clear purpose – helps people with autism to learn. With a functional approach, inappropriate behaviors decrease. The second topic area is "community training." People with autism have problems generalizing. They learn something in school, but have a hard time doing it at home. Teaching students in community settings was, and is, an effective long-term strategy to aid generalization. Our third example is discrete trial training (DTT).

When people think of DTT, Ivar Lovaas usually comes to mind. They also get a mental picture of a young child learning skills such as identification, matching and imitation. The NSAC-NPT trained a version of DTT that is broader and more versatile than that "typical picture." Discrete trial training at its core is: Stimulus – Behavior – Reinforcement. NPT taught a discrete trial format that could be used for teaching most skills across all settings and with all ages. (***Important*:** DTT is not appropriate for ***all*** people with autism. Deciding to use discrete trial training should always be based on the individual person and the skills to be taught.)

In the later 80s the DMH autism programs kept some elements from Judevine, but incorporated the NSAC-NPT into three-week training. We continued to seek additional approaches to benefit people with autism. One was the Job Coach training model developed by Paul Weyman at Virginia Common Wealth University. As in the previous decade, the DMH autism programs continued to provide training. In addition to the three-week format for classroom teachers, we developed specialized workshops.

During this period the DMH autism programs started providing residential services. Initial residents were some of the children from the contractual school programs. Serving them residentially created a new avenue for training. We developed training for staff in these DMH autism residential programs.

1990s: Expanded Services, New Training, New Agency — DDSN

As we moved into the 1990s several issues forced the DMH autism programs to change their approach to service delivery. Identification of people with autism was increasing, and the increase was not just in young children. Adolescents and adults were being diagnosed for the first time. Requests for evaluations, consultation and training were increasing. There wasn't enough staff to handle requests for training and consultation from outside the contractual school programs. Planning for and establishing new positions for Autism Consultants started in the late 80s. But it was not until the 90s that the current slate of statewide Autism Division Consultant positions was established.

In 1991 the DMH autism programs mapped out a plan to revise its training approach. Part of the plan was to restructure the three-week training and develop a series of one- or two-day workshops. The three-week training was shortened to eight days and named Applied Treatment Strategies. New, shorter training workshops were later developed. The strategy was to be cost effective by having Autism Division Consultants conduct training, as well as to offer shorter sessions to make it easier for people to attend.

In 1993 the state legislature mandated that some agencies restructure. The autism programs were moved from the Department of Mental Health (DMH) to the new Department of Disabilities and Special Needs (DDSN), which had been know as the Department of Mental Retardation (DMR). New services were established for people with head and spinal cord injuries. So from then until today DDSN has Divisions for Mental Retardation, Autism, and Head and Spinal Cord Injuries.

This was a good and appropriate move. Services for people with autism fit better into the MR service structure than the Mental Health service system. A lot of work was done to smooth the transition. The staff of the "old DMR" was very positive in helping the "new autism staff" come into the restructured agency.

In the mid to late 90s, DDSN contracted with professionals from nationally recognized programs to develop training material. Our goal was to have training of "best practices" for professionals and families in South Carolina. Two examples of contracted authors are Susan Boswell, from Division TEACCH, UNC-Chapel Hill and Dr. Sally Rogers of the University of Colorado. Training curricula developed by Boswell and Dr. Rogers are part of the current workshops offered by the Autism Division.

2000 +

Over the past few years the Autism Division has implemented a procedure to periodically review, and update as needed, its training. A Task Force was formed in the summer of 2002 to review training for teachers. It had been 11 years since such a review was done in 1991. Much change had occurred in how schools provide services to students with autism. Emphasis on the correct use of behavior technology had increased.

Applied Behavior Analysis (ABA) is the formal term for using behavior principles to teach appropriate behaviors. While the use of the term "ABA" has increased since the 90s, the use of behavior principles with people with autism has been used successfully since the late 60s. Since the Autism Division started providing services in 1973 (under DMH) behavior technology has been the foundation for consultation and training. A key issue the Task Force addressed was the greater emphasis schools have placed on ABA.

After several months of meetings the Task Force submitted recommendations for revising training for classroom teachers. In spring 2003 those recommendations were approved. The revisions and updates are underway. We plan to provide a nine-day course for classroom teachers. In July 2004 there will be two separate five-day sessions. Later in the school year we will provide four separate one-day workshops.

And for the rest of the story …

There will be another article in the next issue of the *Update* about the new teacher training. That article will go into a little more detail about its design and content.

Silent Auction Was a Winner, Thanks to You!

Once again the Silent Auction was a big success this fall, thanks to the many people who contributed items. The event is part of the SCAS annual conference held each October.

Thank you to the following contributors:

John Edwards
Holiday Inn Resort Hilton Head
Mills House
Plantation Inn and Golf Resort
Total Life Center
Columbia Athletic Club
Fox Sports
Clemson University
Doug Flutie Jr. Foundation
University of S.C.
Carolina Panthers
Columbia Inferno
Adam's Mark Hotel
Holiday Inn @ USC
S.C. Aquarium
Middleton Place
Ripley's Aquarium
America By Foot
Gilligan's Raw Bar & Steamer

Amy Weeks
SCAS
Jessy Park
Steve Chastain
Maid Brigade
Autism Coalition
Lynn Ragsdale
Walden Books
Boone Hall Plantation
Spirit Line Cruises
Todd & Moore
Ute Anderson
Baby Bumblebee
Bev McCarty
Anne Bishop
Becky Hughes
Tim Conroy
Joyce Nielsen
DeLoache Florist

15 People Win 2003 SCAS Awards

Congratulations to the South Carolina Autism Society's award winners for 2003. The awards were presented in October at the annual conference, held in Columbia. Those who make the nominations actually present the awards themselves.

The complete descriptions can be found on the SCAS website at www.scautism.org.

Do you have someone in mind for an award? If so, you may submit a nomination to SCAS at any time during the year. Mid-September is the deadline. If an existing category does not apply, you may create your own.

Employer of the Year - Bruce Mills

Bruce Mills, facility director of the physical plant at the Medical University of South Carolina in Charleston, believes in the strengths of persons with autism. Through his friendship with Alan Rose, he hired our son, Olin, to work with the grounds maintenance crew at MUSC. This experiment is a resounding success for Olin and MUSC and validates Bruce's faith in Olin. *—Duncan and Audrey Horne*

Job Coach of the Year - Ron Williams

Ron Williams, a staff person with Carolina Autism Supported Living Systems (CASLS), is far more than just the job coach for Olin Horne. He is a compassionate, loving, well trained young man who is Olin's loyal friend and companion off the job as well. *—Duncan and Audrey Horne*

Sibling Advocate of the Year - Brittni L. Haycraft

Brittni is 12 and has two younger brothers: James, age 5, is nonverbal and profoundly affected by autism. Spencer, age 4, is developmentally delayed with language and articulation difficulties. When friends are over, she teaches them how to socialize with and care for her brothers with love and affection. *—Brande M. Smalley*

Service Coordinator of the Year - Allison Jasinski

Allison works for the Newberry County DDSN Board and has been our Service Coordinator for more than two years. For my son James, Allison has secured a rehab support services slot, a personal care assistant, a computer with a touch screen, software and materials for an ABA program, and a membership to the YMCA. Allison is always searching for ways to make the system work. *—Brande M. Smalley*

Therapist of the Year - Dorothy Wilson

Dorothy began working with my son James one and a half years ago. Over this past summer, James progressed from 4 percent to 29 percent mastery of objectives. Dorothy has incorporated sensory integration and natural environment teaching into her sessions. *—Brande M. Smalley*

Direct Care Provider of the Year - Wilhemina Green

Wilhemina's patience and willingness to love has brought about change in the lives of many people with autism. As a Direct Care Provider for Carolina Autism Supported Living Systems (CASLS), she embraces our mission and is vested in our purpose. It is normal to see Wilhemina buy, sew, cook, find, and fix things for the children she serves. *—Phil Blevins*

Teacher of the Year - Michael B. Walsh

Mike Walsh, "Mr. Mike," teaches an EMD class at Orange Grove Elementary in Charleston. My son James is now in his second year with Mike. In the year and a half that I've known Mike, he has proven to be an intelligent, resourceful, and compassionate team player. —*Ken Boggs*

Peer Advocate of the Year - Justin Wilson

Justin is a very special young man who has been a part of the Camp Good Times peer group for many years. I can't tell you how special he has become to my son Travis. Just to have someone to hang with, that is all our children want. I am so very proud of how he reaches out to everyone and anyone to be a friend. —*Julie Shoemaker*

Bus Driver of the Year - Judy Dunbar

One of the most overlooked individuals in a school district is a bus driver. Mrs. Dunbar is a special driver and a special person to Tres'. I am glad that she takes such an interest in Tres' and the other children on her route. —*Denise R. Long*

Russell Lee Extra Mile Award - Eva Strong & Barbara Carter

Not every duo can handle the task of dealing with autism and other disabilities in one classroom. However, the team of Carter and Strong handles it superbly. These ladies have an amazing relationship with Tres'. They let me know little things as well as major things that are happening in school with him. —*Denise R. Long*

Bridge Builder of the Year - Denice Stout & Babs Bowers

Denice and Babs have worked together to provide collaborative training workshops for families of and professionals working with individuals with autism spectrum disorders (ASD's). The workshops provide participants with hands-on ideas and materials that have immediate, functional applications that promote independence for the individual with ASD. —*Melanie Marquis*

Presidential Citation - Tim Conroy

Tim is an Education Associate with the State Department of Education Office of Exceptional Children. Parents all over the state have told me what a great help Tim has been to them in their quest for information and just lending an ear. Tim is always eager to talk to parents, and if he doesn't know the answer to a question, he will do his best to find one and get back to you in a flash! —*Melanie Marquis*

Nancy Banov Advocate Award - Rev. William Bishop

Bill has worked hard and been involved in every major step South Carolina has taken in providing services for people with autism and their families. Bill thoroughly thinks through ideas, looks at needs, suggests solutions, and always, always has the best interests of people with autism at heart. —*Craig C. Stoxen*

SCAS Offers 4 Options for Membership

There are four types of memberships available for you to join the S.C. Autism Society, if you aren't already a member.

Because of space limitations the entire membership form does not appear here. But you can select the option you like best and either call us at 800-438-4790 or 750-6988, ext. 100, or join us on our website, www.scautism.org.

For membership in the Autism Society of America, which is not included with SCAS membership, try the website www.autism-society.org, or call 1-800-3AUTISM.

BASIC:
Individual $10 Family $20

- Receive the *Update*, the SCAS quarterly newsletter
- Free shipment of SCAS products purchased by phone
- Personalized membership card
- SCAS membership decal
- Voting privileges during annual meeting (Family level gets two votes)

SUPPORTING:
Individual $35 Family $50

- Basic benefits ***plus***
- 10% discount on all SCAS promotional items (travel mugs, t-shirts, etc.)
- Exclusive limited edition member coffee mug (Family level receives two mugs)

BENEFACTOR:
Individual $75 Family $100

- Basic and Supporting benefits ***plus***
- Exclusive "Solving the Puzzle" ribbon lapel pin (Family level receives two pins)
- Personal invitation to special events

FULL-TIME STUDENT:
Individual $10

- Basic benefits

Carol Gray Workshop Will Be in N.W. Columbia

Carol Gray, who developed the "social stories" method of helping individuals with autism to manage problem situations, will present a two-day workshop next June 16-17 at the Columbia Conference Center in the St. Andrews area.

Ms. Gray's program will be called, "Improving the Social Equation in ASDs: Social Stories, Friendship and Bullying." Cost and other details will be available soon from SCAS, the sponsor of the workshop.

Her work in designing custom scenarios for individual children and adults to follow has been used by professionals and families for many years. Recently she has applied her methods to helping students to learn how to respond to bullies.

ASD 'Superconference' Set for North Charleston

Starfish Press will hold a two-day autism spectrum disorder "superconference" at the Sheraton North Charleston on Feb. 27-28.

The "Making a Difference" superconference will feature Teresa Grossi, Cathy Pratt, Carol Gray, Diane Twachtman-Cullen, Jennifer Twachtman-Reilly, and Liane Holliday Willey.

Information on the Charleston conference is available at www.ASDconferences.com or by calling 1-877-STARFISH (1-877-782-7347).

Mark Your Calendars: March 3 Is Disability Advocacy Day

Wednesday, March 3 will be Disability Advocacy Day at the State House in Columbia. Join hundreds of South Carolinians with lifelong disabilities, their family members and their service providers to see the General Assembly at work and personally urge lawmakers to support essential services for children and adults with developmental disabilities. Watch your mailbox for more information from SCAS about this important annual event.

Rett Syndrome

cont. from p. 4

nonspecific X-linked mental retardation who have a mutation in the MeCP2 gene.

As you can see, even when we have the ability to test for a gene mutation, things may not be as simple as we would wish. We may or may not be able to predict the severity of Rett Syndrome on the basis of a specific mutation in the MeCP2 gene. One additional comment is necessary. Research studies may identify a MeCP2 mutation in a girl or a boy. However, research labs are not certified clinical laboratories. Clinical laboratories operate under stringent guidelines for testing and only clinical laboratories can complete a definitive clinical diagnostic test. Thus, if a MeCP2 mutation is suspected in a research study, a clinical laboratory must provide the clinical diagnostic test.

We have come a long way. We have one clinical diagnostic test for a disorder which may be confused with autism. Hopefully, we will soon do the same for autism.

The USC-Duke Collaborative study would like to thank all of our participants in our research study. We are excited because we have been awarded a supplement from NIH to help establish a national resource – an autism cell line bank. We look forward to working with our current families to make this possible. Also, we continue to look for families with an individual or individuals with Autistic Disorder or Asperger Disorder to participate in our research. (telephone 803-898-2343). In our next newsletter, we will report on some of our exciting findings. Thanks again. Together we can make a difference.

I Am

by Nathan Howard

Editor's note: Nathan is a ninth-grade student in Ms. Tanner's English class at Greer High School.

I am different, but the same
I wonder what it would be like to be like everyone else
I hear quiet
I see a skinny person in the mirror
I want to go to college
I am different but the same

I pretend I am playing in an orchestra
I feel all kinds of feelings
I touch the sky
I worry that I might make bad grades
I cry … wait, I don't cry at all
I am different, but the same

I understand that I cannot be like everybody else because I am different
I say that people who are smart, dumb, fat, thin, short, tall,
Deaf, blind, mute, or lame are not any less a person, just different
I dream that I will be the best I can be
I try to be like everyone else but I see that I don't need to be
Like everyone else because I am me
I hope one day I will be the best I can be
I am different, but the same

August-October Donors

Practical Energy Solutions
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Jessica Yoder by Barbara Yoder and Selena Yoder
Ryan Holbert by M/M Alex Holbert
Ryan Marquis by M/M Bret Marquis
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In Memory Of

Frances Nesbitt by M/M Louise Nesbitt, Dora Brogdon's S.S. Class, Wilson Hall, M/M Clark Willingham, Ms. Frances Britton

Renewing Members

Gloria Jean Sloan
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M/M Ken Boggs
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Darryl Frick
Ruth Abramson
Denise Long
M/M Jeff Mense
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Margaret Moore

Please support your local United Way.

The South Carolina Autism Society is a participant in many United Way organizations across the state.

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

United Way contributors who designate SCAS are listed as donors in the *Update* when this information is provided by the individual United Way organizations.

Thank you from SCAS and the United Way.

New Members

Maria Atkinson
Barbara Rosenbaum
M/M Johnny Nexsen
Paula Watson
Dawn Stephens
Donna Fowler
Anthony Fields
Christian Martin
Robin McLaughlin
Linda Snipes
David Haynes
Sandra Johnson
Julie Wellons
Karen Wright
Rebecca Lyon
Sandra Hutchinson
Lois Dicks
Gary Evans
Kathryn Burns
Susan Tanner
Melissa Peach
Patricia Douglas
Erin Beers
Judy McCoy
Betty Padgett
Ginger Sowell
Donna Gardner
Arlene Lathan
Terri Deal
Missy Collins
Holly Myers
M/M Rafiel Iniguez
Tim Conroy
M/M Joe Walker
Jodi Cholewicki
Dottie Couch
Julie Shoemaker
Ron Williams
Bruce Mills
Tara Gregori
Sylvia Vandroff
Delilah Green-Bonnert
Delores Davis
Tim Brooks
Jackie Waldron
Patricia Sheldon
Deloris White
Kelvin Lewis
Dustin Beatty
Carey Hopkins

SCAS Announces the Bravo Awards

The S.C. Autism Society's Parent-School Partnership is proud to announce the Bravo Awards. The awards will be given quarterly during the school year to deserving individuals who serve students with autism spectrum disorders in our schools.

Parent mentors from SCAS will nominate these very important professionals based on their observations of them as they interact with students who have ASDs. Although our parent mentors have children of their own in special education, they will nominate school professionals who work with any children with these disorders. This is just one of the things that will distinguish the Bravo awards from the S.C. Autism Society's annual awards. Another difference is that the new awards will be given more than once a year.

Bravo Award winners will be chosen for their love and dedication to students with ASDs. Each winner will receive a certificate from SCAS and recognition in the *Update* newsletter. SCAS will also send a letter about the award to the superintendent of the particular professional's school district, as well as to his or her immediate supervisor.

The S.C. Autism Society is proud to say "Bravo!" to the following individuals, who are the first to receive the new award.

Michelle Tharp, Teacher
Forestbrook Elementary School, Horry County S.D.
By Sarah Pascarella, Parent mentor
Ms. Tharp teaches a first-through-third grade self-contained class and has several students with autism in her room. She is a master at individualization and obviously loves teaching and her students.

Amy West, Teacher
Sevier Middle School, Greenville S.D.
By Anjeanette Cheshire, Parent Mentor
Ms. West teaches a self-contained middle school class. Her smoothly run classroom is evidence of her impressive management skills, as is her dedication to transitioning students to the adult world by making sure they are prepared.

Ms. Cindy Clark, Coordinator of Programs for Children with Disabilities
Orangeburg School District 5
By Dandrea Woolridge, Parent Mentor
Ms. Clark is a very understanding, patient and calming person who always looks for the best education possible for the children that she serves.

Ms. Janice Moore, Teacher
Cheraw High School, Chesterfield County S.D.
By Lissa Waring, Parent Mentor
Ms. Moore is a first-time teacher to a student with autism. She is loving, firm and open to suggestions. She has taken the initiative to ask for training in autism.

Mrs. Linda Snipes, ABA Therapist
North Elementary School, Lancaster County S.D.
By Tammy Ruiz, Parent Mentor
Mrs. Snipes has been working with students with autism for many years. She has enjoyed working with students with autism so much that she requested further training and became a district ABA Therapist.

Cassy Paschal, Teacher
Irmo Middle School, Lexington-Richland District 5
By Melanie Marquis, Parent-School Partnership Coordinator
Ms. Paschal took over the autism classroom at the beginning of this school year. She is well organized, as her classroom will show the minute that you enter. The students and staff all know what is expected of them, which makes the classroom run very smoothly. She has a very good understanding of behaviors relating to autism and continues to receive training in many areas relating to the disorder.

DDSN Approves Contracts for Seven Providers

The Department of Disabilities and Special Needs has awarded new contracts for services to seven providers, including the S.C. Autism Society for service coordination (see page one). All of the contractors plan to serve individuals with autism.

Carolina Autism Supported Living Services of Charleston was approved as a housing provider, as well as day habilitation and pre-vocational services, for clients age 6 years and older in Charleston County.

The Chesterfield County Board of Disabilities was approved for an array of services in five to 13 counties, depending on the particular services. The services include housing, individual rehabilitation supports, supported employment, day habilitation, prevocational services, facility-based rehabilitation supports and respite care for all ages.

Lutheran Family Services, based in Columbia, won approval for housing, day habilitation, prevocational services and facility-based rehabilitation supports for clients age 22 and up across the state.

South Carolina Mentor, also based in Columbia, was approved for housing, also statewide.

United Cerebral Palsy of S.C. Residential Services, based in Atlanta, won approval to serve ages six years and up for housing, day habilitation, prevocational services and rehabilitation supports in all counties.

United Cerebral Palsy of N.C., based in Raleigh, was approved for supported employment, in-home respite care, and individual rehabilitation supports in all counties.

Dec. 30 will be the next deadline for submitting proposals to DDSN.

Further information may be obtained from the individual providers.

SCAS Programs

- **Information and Referral:** Information for parents and professionals about autism spectrum disorders and available services.
- **Advocacy:** Advocacy on many levels, from individual to systems change.
- **Autism and Informed Response:** Training for emergency responders (law enforcement, EMS, firefighters) on autism and risk factors.
- **Awareness Training for Dept. of Social Services Caseworkers:** Training on autism and other developmental disabilities, their effects on families, and what professionals can do to help. Funded by the S.C. Developmental Disabilities Council (DDC).
- **People with Disabilities and 9-1-1 Assistance — Bringing the Two Together:** Funded by the S.C. Developmental Disabilities Council, this project is designed to increase awareness about the availability of informed response across the state, so as to better protect citizens who are at higher than normal risk in emergencies.
- **Parent-School Partnership:** Assists families and schools by building relationships between the two. Goal is the best education possible for children with autism spectrum disorders.

Mission Statement
South Carolina Autism Society

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

SCAS is a chapter of the Autism Society of America.

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S.C. Autism Society Staff

Reach us at 803-750-6988 or 800-438-4790. Extensions are listed below. Our fax number is 803-750-8121. Our website is www.scautism.org. E-mail us at scas@scautism.org.

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** parent of child with an autism spectrum disorder*

Gift Idea: A Donation in Someone's Honor

Looking for a gift for your child's teacher, therapist or another helpful professional this holiday season?

Or a family member who has supported you and your child over the past year?

You might consider either paying for a membership to SCAS for that person, or making a donation in his or her name.

Either way, you can honor that person *and* help SCAS at the same time. SCAS will send a card to donors before the holidays to let them know about your gift, as long as your donation is received by Dec. 18.

Give SCAS a call at 800-438-4790 or 750-6988 in Columbia to arrange for your gift. The fax number is 750-8121. You may contribute by check or charge it on your VISA, Mastercard or Discovery card.

Here's Another: 'Brie' Bears Support SCAS Too

The S.C. Autism Society still has a supply of "Brie" remembrance bears, named for a 10-year-old girl with autism, for the price of $10 each.

A percentage of the proceeds will help to fund SCAS programs.

The bears are available now, and were very well received at the SCAS conference in October. They would make a great holiday gift for a teacher or therapist.

The plush yellow bean bag bears are eight inches tall. They have the colorful autism puzzle piece tie embroidered on them, as well as a ribbon around their necks.

SCAS would like to hear from you if you have a fundraising idea for the bears. Call 800-438-4790 or 750-6988, ext. 104, with your fundraising idea.

South Carolina Autism Society
Together We Can Solve The Puzzle

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