South Carolina Autism Society
Together we can solve the puzzle

UPDATE

SOUTH CAROLINA AUTISM SOCIETY
Volume 29 Issue Four Fall 2001

Autism Society Has Big Mission; Support It Today with New Choice of Member Options

Do you believe in someone with autism?

Then you believe in the South Carolina Autism Society – and its mission.

The Society's mission is big: To enable all children and adults in South Carolina who have autism spectrum disorders (ASDs) to reach their maximum potential.

How can we meet such a big mission? *With support from you – and others like you.*

Because we just can't improve the lives of people with autism spectrum disorders without ongoing support. Your support allows us to continue what we've begun … find new ways to help … better serve the families who speak for loved ones … come closer to solving the many puzzles of ASD.

If you believe in someone who has an autism spectrum disorder, then you believe in the Autism Society's mission. Please become a member today. And ask your family, friends and coworkers if they, too, would like to support our mission.

We have three new levels of membership you can choose from. Also, the minimum rate has been reduced to make membership affordable for more families across our state. We hope this will add to the Society's diversity.

Current members can renew at the lower rate or "step up" to the next level. You may want to note that joining at the higher levels means that more money goes directly to programs here in South Carolina (not to the national parent organization). The tokens of appreciation you will receive will increase at higher levels. But your biggest satisfaction will be the knowledge that you are helping the Autism Society to continue its mission.

Help us to help someone you believe in. Turn to page 10 and choose the membership option that's right for you. Thank you.

250 Hear Temple Grandin

Keynote speaker Temple Grandin drew just over 250 people to the SCAS 2001 Conference in October. Dr. Grandin is an author, faculty member, designer of livestock systems and autism consultant. She has autism.

Another big draw was the keynote speaker on the previous day, Susan DuRant, who directs the Office of Exceptional Children for the S.C. Department of Education. She has an adult daughter with autism.

About 125 people, mostly teachers, attended Joe Reichle's pre-conference workshop on functional communication.

A third of those who attended the conference filled out evaluations. Half the respondents rated it as excellent; 30 percent rated it as very good; 4 percent rated it as average. No one rated it as poor, and 16 percent did not assign a general rating to the event.

From the Desk of the Director

At our annual meeting at the 2001 conference, the South Carolina Autism Society's members voted to accept the new bylaws as presented by the Board of Directors. These changes were made to bring the Society into a more modern and "best practices" mode of operation.

The major change will expand our focus. Previously our governing documents stated that SCAS's purpose was to "advocate continuously to service-providing agencies for appropriate lifelong services that will enable every person with autism to reach maximum potential."

This was changed so that SCAS's purpose now is to "advocate continuously to service-providing agencies for appropriate lifelong services that will enable **all** persons with **autism spectrum disorders** to reach their maximum potential."

This change may appear to be just a matter of semantics, but it widens the spectrum of who we serve. Prior to October 13, the Society's stated purpose was to advocate for those with autism only. Now this focus has expanded to meet the needs of all families who have loved ones with autism spectrum disorders (ASDs). This would include autism, high functioning autism, Asperger's and any other pervasive development disorders.

The other change was restructuring to fit a corporate model. The Board President is now the Board Chair. Her primary task has shifted from chief executive officer to chief volunteer officer. The duties of the executive director have been clarified and include the duties of the president and chief executive officer. This change allows the board to focus its attention on governance, and the executive director to focus on the day-to-day operations of the office and programs. The shift to a corporate model will make SCAS more attractive to prospective funders, and it is the direction that the Autism Society of America is moving toward.

In addition to these changes, you will note that we have diversified our membership levels. Our goal remains the same, to meet the needs of families in South Carolina. Offering a
Basic membership at a lower rate will allow more families to participate in the Society. Our hope is that current members will remain at the same level and that some who are able to will become Supporting Members or even Benefactors.

SCAS needs your support to continue to provide family support and advocacy on behalf of all adults and children with ASDs. Increasing our membership helps to increase our clout with lawmakers, auti-TD 9pLe,--
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Urgent Alert: DDSN to See More Budget Cuts

The Department of Disabilities and Special Needs (DDSN) will have to cut services as the result of a 4-percent budget cut to all state agencies announced by the State Bud-get and Control Board October 30.

This cut is not the same as the reduction of about the same amount that came at the beginning of the current fiscal year. DDSN was able to "absorb" that reduction with administrative changes, such as consolidating positions and reorganizing the department. As a result, services were not reduced or eliminated. But, that is not the case with the 4-percent cut that was announced last month.

However, worse may be yet to come. On top of the 4-percent reduction, it is projected that state agencies will see *an additional cut* for next fiscal year that will average 10 percent.

If this projection holds, it means that some departments would see cuts of less than 10 percent, while others could see even greater cuts. The exact amount will be decided by the state legislature and governor before the next fiscal year, which begins July 1, 2002.

Advocates are urged to act now to minimize these anticipated cuts. Contact your state senator and representative now and throughout the next legislative session, which begins in January 2002. They need to hear your story, specifically how the loss of services from DDSN will affect your loved one — and the rest of your family.

Please make it a point to meet your representatives if you haven't already. A face-to-face meeting is the best way to begin. Then keep in touch on a frequent basis. And be sure to thank them for their time and their past support of DDSN.

Family members and self-advocates were able to make a real difference just before the current fiscal year began. You heeded a call to action and played a clear role in paring down what could have been a much bigger reduction for DDSN. However, you may need to put forth an even greater effort this year. Today is not too soon to begin.

(Note: If you're not sure who your state senator or representative is, or which senate or house district you live in, call your county Voter Registration office.)

The *Update*

The *Update* is published four times a a year by the South Carolina Autism Society, a nonprofit chapter of the Autism Society of America. 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 to readers simply to keep them informed about options. SCAS maintains offices 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 reach us electronically at scas@scautism.org or www.scautism.

Holiday Gift Idea

If there's someone on your holiday gift list but you can't think of a thing to get them, how about a contribution to SCAS in their name? Call the society office for more details.

SCAS Staff (with new phone extensions)

Call us at our new Columbia number, 750-6988, or toll-free at 800-438-4790.

President and CEO Craig C. Stoxen (106)
Administrative Assistant Vickie Stowe (100)
Program Admin. Assist. Sheila Raulerson (109)
Bookkeeper/PHO Coord. Mary Bennett* (105)
Development Director Johanna Nwanagu (104)
Program Svcs. Director Wanda Gamaché (101)
Training Coord. Carol Niederhauser* (102)
Info. and Referral Spec. Lynn Ragsdale (108)
Parent Mentor, Coastal Dandrea Woolridge* (304)
Parent Mentor, Horry Sarah Pascarella* (305)
Parent Mentor, Midlands Kim McHugh* (103)
Parent Mentor, Midlands Melanie Marquis* (303)
Parent Mentor, Pee Dee Lissa Waring* (302)
Parent Mentor, Piedmont A.J. Cheshire* (301)

** parent of child with an autism spectrum disorder*

Palmetto Housing Options Forming a Nonprofit Trust

by Mary Bennett
SCAS Palmetto Housing Options Coordinator

Palmetto Housing Options (PHO) has begun to form a nonprofit organization to expand housing options for adults with disabilities in South Carolina.

PHO already has been incorporated within the state of South Carolina, and has begun the process for obtaining federal tax-exempt, or 501(c)(3), status for a housing trust. Tax-exempt status will allow contributors to deduct contributions to the trust on their income tax forms. Just as important, it will allow the organization to compete for foundation grants and other funding.

The Partnership of Disability Organizations, which received a grant from the S.C. Developmental Disabilities Council for PHO, decided to form a nonprofit organization after looking over results of two surveys. SCAS, which administers PHO, is a Partnership member.

The first survey was a nationwide search for information about housing programs outside South Carolina. The second was the more recent survey of 6,000 individuals who receive, or are eligible to receive, services from the S.C. Department of Disabilities and Special Needs.

The return rate for the South Carolina survey was 5 percent, which is considered excellent for a survey that requires respondents to answer questions and return it at their own expense. Most respondents made it clear that they want more choice and control in housing. Thirteen percent of the respondents have autism.

Other recent activities of Palmetto Housing Options included housing fairs in Conway and Irmo, both which were well received. Also, a presentation was given to a group of parents of adults with disabilities who live in the Midlands area. The group is seeking housing alternatives for their children.

For more information or to receive an application for housing, call Palmetto Housing Options at 803-750-6988, ext. 109, or toll-free at 800-438-4790.

Book Addresses Important Role of the Paraprofessional

by Anjeanette (A.J.) Cheshire
SCAS Parent Mentor, Piedmont Region

Schools are putting paraprofessionals to work in rapidly increasing numbers. Originally, paraprofessionals helped teachers with tasks that were not instructional in nature. Now that there is a commitment to educating students with disabilities, their function has shifted to direct instruction, giving them a significant and important role.

Paraprofessionals are known by many different labels, including one-to-one, aide, one-to-one aide, shadow, follow-along, and teaching assistant. But whatever their title, they provide unique support that is integral to the education of students with disabilities.

Paraprofessionals are individuals who provide direct instruction and support to students with disabilities under the supervision of a certified teacher. They facilitate learning, which is a role unique to them. This role requires that paraprofessionals develop skills and receive training designed specifically for paraprofessionals. But, they normally receive little or no training, and what training they do receive is often inadequate and provided on a one-time basis only.

Training for paraprofessionals should be comprehensive and continuous. IDEA 97 and IDEA Final Regulations 99 identify the significance of appropriate training for support staff and require states to have a comprehensive system of personnel development that ensures an adequate supply of qualified special education, regular education, and related services personnel [34 C.F.R. 300.135]. Most states have inadequate personnel training programs; however, information and resources are becoming more available.

A wonderful resource for paraprofessionals is "How to be a Para *Pro*" by Diane Twachtman-Cullen, Ph.D. Dr. Twachtman-Cullen has worked as a consultant for children and youths with various developmental disorders, but in particular, pervasive developmental disorders such as autism and Asperger Syndrome. Some of the information in the manual is general and is applicable to all paraprofessionals working with students with disabilities. However, "How to be a Para *Pro*" specifically focuses on the disability of autism and related disorders.

Dr. Twachtman-Cullen does an outstanding job of presenting concise and useful information about autism and the job of the paraprofessional.

Part One, Autism Spectrum Disorders "101": A Short Course, is very thorough in presenting information about what the autism spectrum disorders (ASDs) are. The explanations and details will provide greater understanding of autism to paraprofessionals and professionals. Part Two, The "Art and Science" of Being a Para *Pro*, provides helpful techniques and strategies to use when working with students with ASDs. The worksheets, checklists, and aids will be effective tools for paraprofessionals.

"How to be a Para *Pro*" is available from Starfish Press, www.starfishpress.com. I highly recommend this manual as an information and training guide.

Planning Essential for First Generation of People with Disabilities Expected to Outlive Their Parents

Planning for the financial security of someone with a developmental disability like autism can be a complex and overwhelming process. To lead families through this process, Bart Stevens, founder of Life Planning Services, has developed a Special Needs Planning Kit, a step-by-step system that enables families to prepare a plan for the future care, supervision, financial security and quality of life for their loved one with a disability.

Bart has been a presenter for two years at SCAS annual conferences and has presented workshops in our state. His kit provides a way for parents or other family members to create a special needs trust for their loved one. Special needs trusts allow caregivers to provide for the future security of a son, daughter or other relative without jeopardizing the government benefits available to them.

These benefits include Supplemental Security Income (SSI) and Medicaid for many individuals, and sometimes Social Security Survivors Benefits (SSA) or Social Security Disability Income (SSDI). When a person's resources exceed $2,000 they will not be eligible for SSI, and in most cases, Medicaid. If assets are received in the individual's name in excess of $2000, they will not only lose their SSI and Medicaid benefits, but may have to repay Medicaid for services provided. Information on these benefits is included in the Special Needs Planning Kit.

Also included is a method for preparing a simple will (a way to locate a local attorney, needed to complete the process, is offered); forms for a "letter of intent" (a directive that provides detailed instructions for the future care, supervision and quality of life of the individual); information on government benefits, and more. A computer disk containing forms for planning is included. According to Bart, typical costs for this planning can easily exceed $1500, whereas his kit costs $240. For more information, call 1-888-447-2525.

The news media are beginning to focus attention on the growing numbers of individuals with disabilities who are expected to outlive their parents. Not only is the number of children born with disabilities increasing, but adults with disabilities are living longer. Increased life expectancy is due to several factors, such as improved medical care and inclusion in society.

Nationwide, 480,000 adult children with disabilities live with caregivers 60 years or over, according to the Chicago Tribune earlier this year. This number is expected to double in the next 30 years.

While financial security is of great concern, so is ensuring that future caregivers will understand the quality of life needs of these individuals. This is the purpose of the letter of intent, an accepted way method to address these needs. To develop the letter, family members consider the person's daily activities, medical care, dietary needs and preferences, values, treasured memories, needs for encouragement, personal desires, and whatever else the family and/or individual feels is important.

The 2000 census indicates that there are over 13 million Americans who have a developmental disability. This means that approximately 5 percent of the U.S. population is affected. This number is growing at a rate of 3 percent each year. The census further indicates that 33 million Americans have a severe disability and 54 million have some type of disability.

In addition to the new kit, Bart provides free educational seminars, free initial consultations, private planning services, and group planning workshops.

Book Addresses Important Role of the Paraprofessional

by Anjeanette (A.J.) Cheshire
SCAS Parent Mentor, Piedmont Region

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Autism Division Offers Free Classes for Parents, Professionals

by Lynn Ragsdale
SCAS Information and Referral Specialist

I recently attended the Basic Treatment Strategies three-day course offered by the Autism Division of the S.C. Department of Disabilities and Special Needs. The class is free to parents and professionals and is just one of several standard classes offered throughout the year in the four DDSN regions. The regional offices also offer their own specialized training for parents.

The objectives of Basic Treatment Strategies are to:

1. Present information for "exposure only" (no tests or criterion checks in this class);
2. Provide the opportunity to observe, and maybe practice, skills and techniques helpful in the treatment of people with autism;
3. Provide information that could be the background for future consultation;
4. Provide ideas on strategies and techniques that the participants might be able to use in their work with people who have autism.

I believe this class would be beneficial to any parent, teacher, "shadow," or other person who works with a child or adult with autism. This course is varied enough to be helpful to those new to autism, or as a refresher course for those with more experience.

Janet Spearman and May Baird, Autism Division consultants for the Midlands Region, did a wonderful job of presenting the material in a clear and concise manner. The information was easy to understand and the strategies would be easy to implement.

Editor's Note: The Autism Division offers this class in all four DDSN regions, and will launch a "Focus on Adults" version in the Pee Dee Region in December. The other standard classes offered across the state are Introduction to Autism, Early Interventionist Training (an introductory class on autism geared to early interventionists), and Applied Treatment Strategies. For further information on the classes, call your regional office of the Autism Division. Numbers are listed below.

Regional Offices Develop Own Specialized Parent Training

The four regional offices of the DDSN Autism Division develop their own free classes for parents on topics of interest to their client families. The topics range from visual schedules to social skills to medications to starting an Applied Behavior Analysis (ABA) program—all depending on the region and the expressed (or perceived) needs of parents there.

There are other topics as well. The quickest way to learn what specialized training your regional office sponsors is to call them. Specialized classes are already scheduled for December and the first six months of 2002. For example, Coastal Region is offering a three-part "core" training as well as separate monthly classes on 10 topics beginning in January. Midlands Region will focus on social skills on Dec. 14 and self-help skills April 19.

Call the Midlands Division office at 803-935-5090; Coastal at 843-852-4120; Pee Dee at 843-664-2720; and Piedmont at 864-594-4907.

DD Awareness Training for DSS Being Developed

By Carol Niederhauser
SCAS Training Coordinator

Developmental Disability Awareness Training is the newest South Carolina Autism Society program to be funded by the S.C. Developmental Disabilities Council.

The purpose of the training is to increase awareness about developmental disabilities among employees at the S.C. Department of Social Services. DSS has agreed to make a five-hour elective class available to its employees on developmental disabilities. SCAS will develop and conduct the classes at the Children's Center in Columbia. The class will be conducted several times.

Over the next year information will be gathered for the curriculum and a short videotape to be shown during the classes. Information will be provided about the various developmental disabilities, as well as how having a child with a disability affects families.

In all likelihood a special focus will be placed on how symptoms of disabilities can be mistaken for signs of maltreatment and what DSS employees need to know when children with developmental disabilities are placed in foster homes. Training Coordinator Carol Niederhauser is speaking with DSS workers in different county offices to determine what kind of information they feel they need most.

Carol also is collecting information from families about interactions they have had with DSS, particularly if the information would help her in developing the curriculum and videotape. Please call Carol at SCAS, extension 102, if you have input or suggestions.

Are You in Touch with a Support Group?

There are at least 14 autism support groups that meet regularly across South Carolina. If you are looking for a support group, please call the South Carolina Autism Society at 800-438-4790 or in Columbia at 750-6988. Ask for Lynn Ragsdale at extension 108. She will direct you to the nearest group.

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.

WINTER NEWSLETTER DEADLINE

To submit events for the calendar, support group updates or articles for the winter newsletter, please send information to SCAS no later than Thursday January 31.

Let us hear from you!

South Carolina Autism Society

Together we can solve the puzzle

JOIN TODAY

South Carolina Autism Society
652 Bush River Road, Suite 203
Columbia, SC 29210
Office: (803) 750-6988 or (800) 438-4790 Fax: (803) 750-8121

To build a more diverse membership base, SCAS is announcing the following new membership options.

☐ New member ☐ Renewing member

Name _____

Address _____ County _____

City _____ State _____ Zip _____

Home Telephone _____ Work Telephone _____

E-Mail _____

Please indicate which best describes you:

☐ Parent ☐ Medical Professional ☐ Service Provider
☐ Family Member ☐ Educator ☐ Individual with Autism
☐ Other _____

BASIC: ☐ **Individual $30** ☐ **Family $45**

- Autism Society of America Membership and Newsletter
- State conference discount including invitation to VIP Members Reception
- Receive the *Update*, state chapter 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 $50** ☐ **Family $75**

- Basic benefits ***plus***
- 10% discount on all SCAS promotional items (travel mugs, t-shirts, etc.)

BENEFACTOR: ☐ **Individual $100** ☐ **Family $125**

- Exclusive limited edition member coffee mug (Family level receives two mugs)
- 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 $20**

Payment type: ☐ Check ☐ VISA ☐ MasterCard ☐ Discover

Credit Card #_____

Signature _____

Total: Membership Fee: $_____

*Donation: $_____

Amount Enclosed $_____

* All contributions are tax deductible in accordance with federal regulations. Receipts will be issued upon request.

2002 SCAS Board of Directors

President
Amy Weeks
Aiken, SC
(son and daughter have autism)

Vice President
Cheryl Bauerle
Myrtle Beach. SC
(daughter has autism)

Secretary
Ann Bishop
Leesville, SC
(adult son has autism)

Treasurer
Mitchell Yell, Ph.D.
West Columbia, SC
(USC Professor)

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Rebecca Shippy
Greer, SC
(adult son has autism)

Pee Dee West
Shirley Ballard
Sumter, SC
(son has autism)

Pee Dee East
Aixa Rodriguez-Mariana
Georgetown, SC
(son has autism)

Coastal East
Denise Chastain
Goose Creek, SC
(son has autism)

Coastal West
Denise Long
Williston, SC
(son has autism)

Midlands East
Ute Anderson
Columbia, SC
(son has autism)

Midlands West
Gaye Hartley
Leesville, SC
(son has autism)

Piedmont East
Mary Pate
Duncan, SC
(son has autism)

Piedmont West
Denise Oxford
Anderson, SC
(daughter has autism)

2000 - 2003
At Large
Erik Drasgow, Ph.D.
Columbia, SC
(USC Professor)

2000 - 2003
At Large
William Floyd III, Esq.
Lexington, SC
(son has autism)

2001 - 2004
At Large
Michael Fillipone
Mt. Pleasant, SC
(son has autism)

2001 - 2004
At Large
Maria Delgado
Seneca, SC
(son has autism)

1998 - 2001
At Large
Alex Holbert
Conway, SC
(nephew has autism)

1999 - 2003
At Large
Beverly McCarty
Charleston, SC
(twin sons have autism)

1999 - 2003
At Large
John Edwards
Charleston, SC
(adult son has autism)

1998 - 2001
At Large
Joyce Nielson
Summerville, SC
(*son has autism)*

South Carolina Autism Society
Together we can solve the puzzle

2002 Meetings of the SCAS Board of Directors

February 2 * May 4 * August 3 * November 2

Thank You for Helping Us with Furnishings, Reception and Open House

The S.C. Autism Society would like to thank Connecting Elements for donating desks, credenzas, cabinets and other furnishings for the society's new office on Bush River Road. Seven rooms were furnished, thanks to the generosity of the company, which is located in Columbia.

Several businesses helped to make our VIP Reception and Open House a success. Bojangles, Kroger, Publix, Walmart, Sam's Club, Party City and National Distributing Company contributed food, beverages and other items for the two events. The society greatly appreciates all of these generous contributions.

United Way

During this campaign season, please support your local United Way!

The Power of One

The South Carolina Autism Society has been a United Way partner since 1976.

United Way allocations and designations are an important source of funds for the society.

Hosts with the Most Sought for Fundraising … and Fun

Thinking about throwing a party this holiday season? Why not turn the event into a fundraising opportunity to benefit SCAS?

A full-course, sit-down extravaganza is not required, unless that's your style. It could be a wine and cheese reception or a casual pizza party. How about a Super Bowl fest after the start of the new year?

You select the guests, and SCAS designs and prints the invitations. We'll give you brochures and other information to hand out, and you provide the food and beverages. The society can send a speaker if you'd like. Guests are asked to make a tax deductible donation.

Interested? Then give Johanna Nwanagu a call at the society's office. If you have just the seed of an idea she'll help you to make it grow. Call Johanna at 750-6988 in Columbia or toll-free at 800-438-4790. Her extension is 104.

UPDATE fall 2001

South Carolina Autism Society

South Carolina Autism Society
652 Bush River Road Suite 203
Columbia, SC 29210

www.scautism.org

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Chapter of Autism Society of America

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