



South Carolina Autism Society

Together We Can Solve The Puzzle

Spaces Still Available for Carol Gray's June 16-17 Workshop

Carol Gray, the creator of Social Stories, will hold a two-day workshop on Wednesday and Thursday, June 16 and 17, at the Columbia Conference Center off Fernandina Road. The workshop will be sponsored by SCAS.

"Improving the Social Equation in Autism Spectrum Disorders: Social Stories, Friendship and Bullying," will be helpful to teachers, parents, or anyone else who works with or lives with someone with an autism spectrum disorder (ASD).

Ms. Gray initiated the use of Social Stories in 1991. Written for a particular child or adult,

a Social Story describes a situation, concept or social skill that presents difficulties for the individual. The story explains the situation and suggests an appropriate response.

The charge for the two days is \$135. To register, call the S.C. Autism Society at 750-6988 or 800-438-4790, ext. 100, or you may register on line at www.scautism.org.

In addition to learning how to write Social Stories, participants will learn strategies to foster social interactions in the classroom, identify solutions to bullying and teasing,
cont. on p. 9 — see Carol Gray

John West Was a Friend to Those with Autism

The death in March of former Governor John West stirred memories for many in South Carolina's autism "family," but perhaps most of all for the Rev. William Bishop and his wife, Ann.

For it was Bill who met with Governor West one spring day in 1972 to tell him about his son, Paul, who was 11 years old and diagnosed with autism.

Seeking help for Paul, the Bishops already had been to the Department of Mental Retardation (DMR). But the staff there said they needed to take Paul to the Department of Mental Health. So the Bishops had taken Paul to the Department of Mental Health, only to be told it was DMR that needed to help him.

"We were caught in the crack between two agencies," Bill recalled recently.

A member of Bill's congregation, Senator

LaNue Floyd, asked Bill if he could help. Bill told Sen. Floyd he wanted a meeting with the Governor. The senator arranged the appointment soon afterward.

It was in that meeting that autism services began in South Carolina.

"You see, in the early days no one wanted to accept the responsibility for autism," Bill explained. "But Governor West was very cordial, caring, compassionate. I always say that going to his office was a lot like going to see God."

What happened is almost hard to believe today. After listening to Bill tell his story, Governor West picked up his phone and, making one call after another, called the directors of three state agencies.

"He called the Director of Mental Health and said, 'A man is in my office who has a son
cont. on p. 9 — see Governor West

From the Desk of the President

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Dear Friends:

I sometimes hear from families that the South Carolina Autism Society spends most of its time on children's issues and very little time on issues affecting adults. This isn't true.

It certainly *is* true that when it comes to autism spectrum disorders (ASDs), it tends to be the young children who are getting most of the attention now. Some of this is inevitable for many reasons, one being the fact that these are the years when families first seek information and support. Another is that diagnoses of ASDs are steadily rising in young children. Yet another is that the news media tend to focus on young children who are given this diagnosis, as opposed to the adults who were diagnosed years ago.

But as more and more children with ASDs are becoming adults, we are seeing and responding to significant concerns affecting teenagers, young adults and, yes, middle-aged and older adults on the "spectrum." SCAS is making a concerted effort to raise awareness in our state about issues affecting adults with autism spectrum disorders. In fact, some of our most steadfast supporters have continued to work closely with us as their children have grown from youngsters into adults.

In recent years we have had conference keynote speakers address challenges faced by adults on the spectrum. Last year Teresa Grossi focused on the transition teenagers and young adults make from the school years into employment. This year's conference, to be held October 15 and 16 (with a pre-conference workshop on the 14th) in Columbia, will feature Jerry Newport, an adult on the autism spectrum who has been featured on 60 Minutes. A movie is being produced about Jerry called "Mozart and the Whale," starring Josh Hartnett. Jerry will speak on Saturday, Oct. 16 about his experiences with relationships.

Another program we have that benefits adults is the Consumer Review Panel, which was formed six years ago. Panel members make visits to the homes and work sites managed by the Autism Division. These visits have led to improvements in the programs for some of these individuals.

I also spend a great deal of my time as an advocate in meetings that examine policies and regulations affecting adults living with autism. Just recently, I provided input on the renewed MR/DD Waiver.

SCAS has been very active in seeking funding for programs to benefit adults with autism and other disabilities. Many of our efforts at the State House focus on maintaining and expanding funding for residential services, job coaching and day treatment programs.

These are only a few of the issues concerning adults living with autism, and SCAS is involved in others as well. But for us to be the most effective advocates possible, we need to know what issues you and your family are facing. It is always more effective to use real examples when we advocate for more and better programs.

Please feel free to contact me with your experiences. You can always call me at 803-750-6988 or e-mail me at craig@scautism.org.

Another way you can share any concerns you may have is by attending one of the regional meetings I will hold with families beginning in August. It also will be a good way to network with other families. You will hear more about the meetings this summer.

Meanwhile, I hope to see you at the Carol Gray workshop on Wednesday, June 16 and Thursday, June 17 at the new Columbia Conference Center in northwest Columbia. Carol is an excellent presenter, and her method is easy to use and to individualize.



Craig C. Stoxen
President and CEO

Supporters raise nearly \$23,000 for SCAS

Supporters raised nearly \$23,000 for the South Carolina Autism Society in April for Autism Awareness Month.

The money was raised through activities including bowling and golf, a motorcycle run, a silent auction and a memorial benefit.

Event sponsors and other contributors are listed on pages 4 and 5, as well as page 8.

“We would like to thank everyone who sponsored, contributed and volunteered to make these events a success,” said SCAS President and CEO Craig Stoxen.

The golf tournament held at Indian Wells Golf Course raised \$13,790, and the bowling tournament in Northeast Columbia, \$3,542, Craig reported.

The second “Rick Fest,” held at Bimini’s Oyster Bar and Seafood Café in Myrtle Beach at the end of March, honored the memory of Rick Duff. Rick was an owner of

The restaurant and a friend to Sommer Bauerle, daughter of SCAS President Cheryl Bauerle. The event raised \$3,745 for SCAS.

Motorcyclists in the Aiken area again rode to Columbia on a sunny Saturday, presenting SCAS with \$600 in donations collected at the Aiken Motorcycle Shop, as well as before and after the ride.

The S.C. Association of School Resource Officers and the S.C. Association of Crime Prevention Officers presented SCAS with the proceeds from their silent auction held during the groups’ joint conference this year. The proceeds totaled \$1,064 and were an indirect result of training SCAS has provided to school resource officers over the past year.

“Not only do these events raise funds for SCAS, but they really do help to increase awareness about autism all over the state. If you have an idea for a fundraiser in your area, please give us a call,” Craig added.

CDC, Academy of Pediatrics Put ASDs at 1 in 166

The Centers for Disease Control and the American Academy of Pediatrics have put the rate of autism spectrum disorders at 1 in 166 children.

The rate is included in a bulletin issued in January for medical professionals. The bulletin is called “Autism ALARM,” with ALARM used as the following acronym: Autism is prevalent - Listen to parents - Act early - Refer - Monitor.

One out of every 6 children are diagnosed with a developmental disorder and/or behavioral problem, according to the bulletin, which states prominently, “Developmental disorders have subtle signs and may be easily missed.”

There are numerous suggestions in the bulletin for practitioners. To see the complete bulletin online or to obtain more information, go to: www.medicalhomeinfo.org.

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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June 2004

Autism Awareness Month Special Appreciation

FUN IN THE SUN GOLF TOURNAMENT

April 24, Indian Wells Golf Course, Garden City

Platinum

Pfizer

Diamond

William & Nicole
McLain

Gold

Showa Denko
Carbon, Inc.

Silver

DePuy - Peter Irussi
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Autism Awareness Month Special Appreciation

ROLLING FOR AUTISM AWARENESS

April 17, Royal Z Lanes, Columbia

Platinum

Sam's Club Foundation

Bronze

Eau Claire
Rotary Club

Gold

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Silver

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Other Bowling Sponsors / Donors / Volunteers

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Royal Z Lanes

The Bowling Review

Ryan's Steakhouse

Charleston Ghost Walk

Sticky Fingers

D's Northeast

Most Money Raised

Cole Hughes (\$405)

Shoney's

Red Lobster

Kroger

Olive Garden

Piggly Wiggly

Merrill Lynch

RICK FEST 2004

March 27, Bimini's, Myrtle Beach

Saul Shavitz * Karen Todd * Staff at Bimini's Oyster Bar

Stacey Hollar * Horry County Autism Family Support Group

and all other Volunteers, Contributors and Bidders

SCHOOL RESOURCE/CRIME PREVENTION

OFFICERS' SILENT AUCTION

April 7, Myrtle Beach

Renea Lowder * Lt. Vickie Fyvie * Lt. William Gonzalez * Jody Lynch

and all other officers / family members who provided items or purchased them

AIKEN-COLUMBIA MOTORCYCLE RUN

April 3

Richard Reeves * Aiken Motorcycle Shop * T. Wayne Johnson

and all other Contributors and riders

IMFAR: 600+ Autism Researchers Meet

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 USC-Duke University team that is researching the genetics of autism spectrum disorders.

We have just returned from the exciting International Meeting for Autism Research (May 7-8) in Sacramento, California near the MIND Institute. Over 600 autism researchers attended from all over the world, including our groups and the MUSC group. It was an exciting opportunity to share ideas and look to shape new directions for treatment interventions and for finding genes to help us identify the many roads to a cure. The Duke/University of South Carolina Research team made 13 presentations representing research completed over this past year. In the next newsletter we will share some of our findings.

For this newsletter, I would like to report on two presentations highlighting the importance of joint attention. M. Siller and M. Sigman of UCLA reported on "Joint Attention Behaviors in Children with Autism: Stability and Change During the Preschool Years." The ability to coordinate attention with others using objects or events (joint attention) is thought to be critical for the social and language development of young children. One characteristic of children with autism is that they have a deficit in joint attention not found in matched controls. Siller and Sigman looked at the stability and change of specific joint attention behaviors in 33 children with autism (average age, 47 months), who were evaluated yearly over a three-year period. Four specific attention behaviors from the Early Social Communication Scale (ESCS) were evaluated annually. These four measures of joint attention were (1) looking up while manipulating a toy (JA-Looks); (2) alternating gaze between an interesting event and another person's face (JA-Alternates); (3) pointing to or showing objects to other people; and (4) following others' pointing gestures. Over the three-year period, the frequency of three of the four joint attention behaviors increased significantly. The only joint attention behavior that did not increase in frequency was JA-Alternates. Children's improvements in JA-Looks were independent of children's growth in language skills.

This was supported by H. Schmidt, C. Lord and S. Risi, from the University of Michigan, who presented "Correlates and Predictors of Peer Interaction in Autistic Spectrum Disorder." A group of 82 children were assessed at ages 2 and 9. Current IQ showed a strong relationship to level of peer interaction and current class placement was also related. Early level of joint attention (measured by the Autism Diagnostic Observation Schedule) was the strongest predictor of later peer interaction. Thus, these reports suggest that measures of joint attention may be a way to evaluate developmental growth and positive intervention outcomes.

We want to thank families who have participated in our continuing research study of autism and Asperger's disorder and invite new families to join in our effort to work towards a cure. If you have a child with one of these disorders and would like to participate, please call Sarah Ravan or Alicia Hall at 803-898-2343.

I would like to introduce three new people who will be joining us in South Carolina as a part of a new NIH funded initiative. Katherine Warner is a project coordinator, and Heather Smith and Chamarlyn Fairley are psychologists. We look forward to a productive year! Together we can make a difference.

Film Being Made About Next Keynote Speaker

The Saturday keynote speaker at SCAS's fall 2004 conference is the subject of a feature length movie, "Mozart and the Whale," that is now being filmed and stars Josh Hartnett.

Hartnett plays Gerald Newport, an adult with autism, who will speak at the S.C. Autism Society's "Perspectives in Autism" conference on Oct.16. The movie is based on Newport and his wife, Mary Newport, although the names of the characters in the movie will be different.

According to the Autism Society of America, the screenwriter for the movie "Rainman" was the mastermind behind "Mozart and the Whale."

Hartnett has appeared in "Pearl Harbor" and "Black Hawk Down."

For more information about Newport and the 2004 SCAS conference, see the calendar below. Also, watch your mail for the conference brochure later this summer.

What's Coming Up

- July 7-10 35th National Conference on Autism Spectrum Disorders, July 16-17, Autism Society of America, Seattle, Wash.; asareg@tmiexpos.com or 440-446-9483, ext. 10 (9 a.m. to 4:30 p.m. Eastern Time)
- July 16-17 Educating Children with Autism and Aspergers, cosponsored by Emory Autism Center and Piedmont College North, \$75 for both days; Alison McKay or Sheila Wagner, 404-727-8350
- August 16 Come Dance with Me ... Opening the World of Conversation for Children with High Functioning Autism/Asperger Syndrome, sponsored by the Horry County Autism Program, University of N.C.- Greensboro, \$115, www.languageinks.us
- August 20 Come Dance with Me ... Opening the World of Conversation for Children with High Functioning Autism/Asperger Syndrome, sponsored by the Horry County Autism Program, Myrtle Beach Middle School, \$115; www.languageinks.us
- Oct. 15-16 Perspectives in Autism, S.C. Autism Society's Annual Meeting and Conference, cosponsored by SCDDSN Autism Division and S.C. Department of Education; Friday keynote speaker, Linda Hodgdon, M.Ed., Director of the Cornerstone Communication Center and author of *Visual Strategies for Improved Communication* and *Solving Behaviors in Autism*; Saturday keynote, Gerald Newport, author, *Your life is Not a Label* and *Autism-Asperger's and Sexuality*; pre-conference workshop Oct. 14, "No Child Left Behind: Analysis and Implications for Special Education," with Mitchell Yell, Ph.D. and Erik Drasgow, Ph.D. Watch your mail for more information; or call 750-6988 or 800-438-4790, ext. 100 for more details (registration will be possible online later this summer at www.scautism.org)

The Autism Division training calendar and brochure is now on the S.C. Department of Disabilities and Special Needs website at <http://www.state.sc.us/ddsn/>. Just click on the Autism Division and then "Training 04-05."

February - April Donors

Patricia Fayson	Stuart Shields
Colleen McLennon-Freeman	Renea Lowder
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M/M Douglas Elliott	Wayne Yates
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M/M William Galardi	Valerie Bellini
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In Honor of

Mildred Lilley by Dr. & Mrs. Charles Banov

Bowling Pledges In Honor of

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Ethan Reid by M/M Jonathan Reid, M/M Paul Addy, M/M Foster McLeod

Lindsay Frick by Stephen Woodrow

More Autism Awareness Month Sponsors/Donors/Volunteers can be found on pages 4-5.

February - April New Members

Benefactor

Molly Piscitello
Karen Owens-Blanding
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M/M Mark Williams
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Basic

Patricia Fayson
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Basic

M/M Danny Rabb
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Adrienne Reed
Walter Jenner
Dave Williams
Beth Hedges
Sue Irick
David Rothholz

Renewing Members

Supporting

Maria Delgado
Judy Johnson

Basic Renewal

M/M Jonathan Reid

In Memory of

Rick Duff by Charlotte Mejia, Kimberly Hardwick, Iliia Prieto-Hinckley, Mandy Sorg, Timothy Kepley, Christopher Gordon, Paul Grimshaw, Roy Patterson

Darlene McJenkins by M/M Joseph Park

Iris Shirley by Don Shirley

Laura Smith by Edward Gregg

Jimmie Amick by M/M Joseph Park

Mrs. H. Madden by Dr. & Mrs. Charles Banov



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 for giving from SCAS and the United Way.

Governor West

cont. from p. 1

who is autistic and I want you to meet with him and help him.’ Then he called the Director of Mental Retardation, and then he made a call to Dr. Owens Corder, the Director of the Department of Education.

“He told all three of them, ‘I want you to meet with him and find a way to help his son, Paul.’ And then he said to me, ‘This will be the first time agencies have met together for common cause.’”

About the same time, another parent of an autistic child, Nancy Banov, had been seeking help from Senator James Waddell, chair of the Senate Finance Committee. Sen. Waddell attended the meeting with Bill and the three department heads.

Also about the same time, the South Carolina Society for Autistic Children (now the S.C. Autism Society) was formed. The Banovs, Bishops and several other families formed the chapter. Using national rates, it was believed there were approximately 1,000 people with autism in South Carolina at that time. (Today the number is estimated at 16,000 to 25,000.)

“Governor John West mandated that we begin to work together for the purpose of helping children with autism in South Carolina,” Bill explained.

“The result was that in 1972, at Governor West’s request, \$25,000 was appropriated from the legislature to fund a study to determine the need for services to persons with autism in South Carolina.”

It was the Department of Mental Health, through Dr. Raymond Ackerman, that took the lead role in establishing services for children with autism.

Dr. Corder of the Department of Education was a key player as well, and in 1972 the first program for children with autism started on the grounds of North Charleston Elementary School under Andy Mance. Paul entered the program a few years later after his family moved to Charleston.

“The average person today takes it for granted that all of this has always been. But it was by the determination of people like the Governor, the legislature and professionals who did what was necessary to get things started,” Bill continued.

“You can never take it for granted. And the quality of life can be greatly improved yet if we continue to work together with high expectations and demands. So thank you, Governor West.”

Born in 1922, John West served as Governor of South Carolina from 1971 to 1975.

Carol Gray

cont. from p. 1

and learn how to teach a child with an ASD to effectively respond to a bullying attempt.

Bullying has become an increasingly common concern for parents and teachers of students with autism spectrum disorders.

“We are hearing more and more from parents who are concerned their child may be the victim of bullying, whether this is in the school cafeteria, the playground or, for that matter, at a park, in a recreation program, or in their neighborhood,” Craig Stoxen, SCAS president and CEO said.

“This is why we requested this particular workshop of Carol Gray’s. She has become a leading expert and advocate in this area.

“Just like her Social Stories method, her methods to address bullying are hands-on and very practical,” Craig said.

Registration will be taken at the door as long as seats remain.

Lunch will be included. The Columbia Conference Center is off Fernandina Road (the frontage road to the east of Interstate 26) between the Piney Grove and St. Andrew’s road exchanges on I-26 northwest of Columbia.

Carol Gray is the author of *The New Social Story Book*; *What’s Next? Educating Students for Success in the Community*; *Taming the Recess Jungle*; and *Comic Strip Conversations: Colorful, Illustrated Interactions with Students with Autism and Related Disorders*.

Examples of situations her New Social Story Book addresses are substitute teachers, eating in a restaurant, manners for the dinner table, and how to sit still during prayer. Possibilities for Social Stories are virtually limitless.

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

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.
- **Service Coordination for DDSN clients with autism:** New SCAS program for children or adults who have been certified as eligible by the S.C. Dept. of Disabilities and Special Needs.
- **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.

2004 Board of Directors

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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

21 Winners of Autism Awareness Events

Rolling For Autism Awareness Winners

Male High Score

Charles Reese - 198

Harold Reed - 198

Female High Score

Andea Alford - 160

Youth Male High Score

Alex Alford Jr. - 129

Youth Female High Score

Gina Bellini - 139

Golf Tournament Winners

1st Place

Jaime Harris, Captain

John McKeown

Mike Carter, Sr.

Mike Carter, Jr.

2nd Place

Dick Ward, Captain

Todd Ward

Buddy Williams

Drew Kelly

3rd Place

John Isemah, Captain

Don King

Ryan Brancenburg

Ken Speilvolgel

Closest to Pin

Dick Button (17)

Eric Pope (14)

Jaime Harris (6)

Rob Pascarella (8)

Golfer Alert! Details Out Soon about Fall Tournament

If you're a golfer and you couldn't make it to the Fun in Sun Golf Tournament in Garden City in April, you will have another chance to play next fall — and all for the benefit of the S.C. Autism Society, too.

The second annual Fun in the Fall tournament is scheduled for Saturday, Nov. 13. It will be held in the greater Columbia area.

The exact location and other details will be included in the Fall *Update*.

SCAS members and friends are encouraged to help find sponsors for the event. Please ask friends, family, neighbors or a member of your church whether they or their employer would be interested in sponsoring the event. Call 750-6988, ext. 104 for more details.

South Carolina Autism Society

Together We Can Solve The Puzzle

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Columbia, SC 29210

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2004