South Carolina Autism Society
Together we can solve the puzzle

UPDATE

SOUTH CAROLINA AUTISM SOCIETY

Volume 29 Issue One Winter 2001

State Budget Crisis Means Big Cuts at DDSN; Be Counted March 7 at Disability Advocacy Day

If there ever was a year for families of children and adults with disabilities to speak up at the State House, this is it.

The Governor's state budget calls for 15 percent cuts to all departments except K-12 education. This means the Department of Disabilities and Special Needs (DDSN), which includes the Autism Division, will lose up to $65 million next fiscal year unless funds are restored to the Governor's budget.

In turn, $65 million in cuts means reductions or even elimination of local disability board funded services such as respite, summer programs and intervention programs. Officials say some residential and day programs for adults with disabilities would be closed.

DDSN may be the most severely affected department because every dollar in state funds is matched by two more in Medicaid funds. (The $65 million includes Medicaid money.)

What can you do? Speak up! Contact your senator and representative now, or call the S.C. Autism Society to see if your representative is on the House Ways and Means Committee, which will set the budget that goes to the House early this spring. Better yet, join other concerned families at Disability Advocacy Day the morning of Wednesday, March 7, at the State House. SCAS is a cosponsor of the event, which is more important this year than ever before.

Turn to page 13 for important details about Disability Advocacy Day. See page 3 for SCAS Executive Director's message about the budget cuts.

The larger the turnout this year, the louder families will speak up for individuals with autism in our state. Let your legislators know which services your loved one receives and what those services mean to your family. It can be very effective to have your child with autism with you at the State House.

Registration by Feb. 15 is strongly recommended. Fill out the form mailed in the Advocacy Day packet or register on line at www.scautism.org. If you need a form, call SCAS at 800-438-4790 or 803-794-2300.

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A Message from New President

January is always a time for looking forward, and this, the real beginning of the new millenium is no exception. Along with looking forward, though, it's helpful to do a little looking back.

The year 2000 was a busy one. Several staff joined the Parent-School Partnership program, which gives us the power to help that many more parents with the IEP process. We hope to add more staff in 2001so there will be someone trained and available nearby in all parts of the state.

Palmetto Housing Options was launched in 2000. This new program will eventually help provide opportunities for housing for our adults with autism. In 2001 SCAS will be doing research to insure that we have the latest and best ideas.

Last year the Autism and Informed Response Program trained close to 1,000 of our law enforcement and other emergency personnel about the possible reactions to stressful situations of those with autism. The program will continue its training of police and other emergency professionals across the state this year and in the future.

The Consumer Review Panel visited several of the professionally run homes for our adults with autism, and is planning to make their second visits in 2001.

One note of interest this year, among many, is a workshop sponsored by one of our partner advocacy organizations, PRO-Parents. Professor Wright will come to Columbia to discuss the legal rights of those with disabilities May 4-5. Contact the SCAS office if you want to go.

The challenge this year will be the state budget. Cuts already announced will impact funding for SCDDSN. That, of course, could affect the services provided for our loved ones, perhaps in a big way. We urge each of you reading this newsletter to ask your state legislators to consider very carefully the impact of any cuts they feel they have to make. Write them, call them, or contact them in any way you can. They need to know how they will be affecting our lives. The SCAS office has the information you need to feel confident about what you want to say.

I recently saw the movie, "Finding Forrester." If you've seen it you will know what I mean when I say I was stirred by its illustration of so many of the values that we hold dear here in South Carolina. I don't want to give away the plot for those of you who haven't seen it yet, but both of the main characters, Jamal Wallace and William Forrester, had lost a part of their family. The fact that they were able to find the support and help of a different kind of family was truly heartwarming. The courage they showed was a good example for all of us. After I came home from watching it, I was struck by the similarities there were to our SCAS family, especially to our ones with autism. The challenges are great. The courage needed to meet the challenges is sometimes breath-taking. But it can be done. In fact it IS done every day. By continuing to work together as we do I know that we will keep meeting those challenges.

Sincerely,

Becky Shippy

From the Desk of the Director . . .

In the past the South Carolina Autism Society has been instrumental in providing advocacy at the state level. I have always been assured that many families would respond if I sent out a request to make phone calls or send letters to state legislators. This response by families has made us quite successful at achieving our legislative agenda each year.

This legislative session is shaping up to be one where your input is greatly needed. Governor Hodges has proposed a 15-percent cut in all state agency budgets, except for K-12 education. This budget cut includes the Department of Disabilities and Special Needs (DDSN). If the Governor's proposal were to be accepted, DDSN would lose up to $65 million. A loss of this size would clearly affect services.

The House will start to work on the budget this month and the Senate will begin in March. The final budget won't be approved until late May or early June, so there's time for you to speak up. Let your representatives know how you feel about the DDSN cuts. Several things to note when talking to your legislators:

(1) Medicaid matches most of the state money received by DDSN. Thus a cut of $1 results in a loss of an additional $2 in Medicaid.

(2) DDSN currently has a waiting list of 1607 people for residential services, and 866 people are waiting for day, employment and family support services. Cuts will increase the lists.

(3) Tell them your story. Let your legislators know how you use DDSN services and the importance of them to you and your family.

Handwritten letters are best, followed by personal visits and phone calls. (But if all you can manage is a phone call, be sure to do that.) Try to set up an appointment. Let them know your opinion about the proposed cuts. Enlist others to do the same.

The other thing I ask you to do this year is to attend the Disability Advocacy Day on March 7. (See pages 1 and 13.) Send the message that those concerned about disability issues are a large and active group. I encourage everyone to attend this important event.

I'll continue to send out updates. Further, I will use the South Carolina Autism Forum to send out action alerts. If you are not yet a member of the forum, please sign up through our web page, www.scautism.org or sign up at scautismforum at egroups.com.

Craig Stoxen
Executive Director

The *Update* is published four times 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 229 Parson Street 1-A (Suite 326), West Columbia, SC 29169. Call us at 803-794-2300 or 800-438-4790; fax us at 803-794-2303; or reach us electronically at scas@scautism.org or www.scautism.org.

Future and Special Needs Planning for Individuals with a Disability

by Barton Y. Stevens
Chartered Lifetime Assistance Planner

PART THREE

Editor's Note: In Parts One and Two, Bart addressed the need for planning. Part Three below shows a ten-step procedure for beginning and completing the plan. Part Four will appear in the spring edition of the Update.

You can prepare a life plan for the relative with disabilities without feeling overwhelmed. I recommend that you follow the 10 life planning steps outlined below. Following the steps will help you to focus on the lifestyle and care needs of the individual. Work on one step at a time and for no more than two hours each evening. You will have time to review each step and think about what you want, without feeling overwhelmed. A professional special needs planner can help you through the entire process or work with you on a limited consulting basis.

STEP 1 – THINK THROUGH THE LIFE PLAN

Decide what you want for the future regarding residential needs, employment, education, social activities, general lifestyle and any other needs.

STEP 2 – PREPARE INFORMATION AND LIFESTYLE DIRECTIVES

Put your hopes, desires, instructions, and goals for your loved one in a written "letter of intent." Include information about care providers and assistance, physicians, dentists, medications and their monitoring, functioning levels, activities enjoyed, daily living skills, diet, and rights and values. Video tape interactions with the person at home, work or school. Use video to show him or her communicating with others and receiving any assistance required for daily activities.

STEP 3 – DECIDE ON SUPERVISION

Guardianship and conservatorship are legal appointments requiring court ordered mandates. Individuals or institutions manage the estates of people who are judged incapable of caring for their own affairs. (Note that "incapable" is not necessarily the same as "incompetent.") Guardians and conservators are also responsible for the care of and decisions made on behalf of people who are unable to care for themselves.

Legal guardianship may not be appropriate for the individual who can perform most daily living tasks and who is gainfully employed and living independently to some degree. Legal counsel, care providers, and physicians should be consulted for guidance. An alternative to guardianship is a "Durable Legal and Medical Power of Attorney." This requires that the person with special needs be able to understand and sign a legal document. It provides others with the authority to make legal and medical decisions on behalf of the person, if and when he or she is unable.

STEP 4 – DETERMINE THE COST

List and total current and anticipated monthly expenses. Then decide on a reasonable return on investments, and estimate how much will be needed to support the person's lifestyle. Include government entitlements and the effects of inflation.

STEP 5 – IDENTIFY RESOURCES TO FUND PLAN

Resources include government benefits, family assistance, inheritance, savings, life insurance, pensions, real estate and investments. Most families do not have assets immediately available to fund the Trust, but can designate assets through their will and beneficiary designations.

STEP 6 – PREPARE LEGAL DOCUMENTS

Choose a qualified attorney to prepare the necessary documents, which may include: wills, trusts, guardianship, conservatorship, and power of attorney.

STEP 7 – CONSIDER CREATING A "SPECIAL NEEDS TRUST"

The "Special Needs Trust" holds assets for the benefit of persons with special needs, and uses the income to provide for their supplemental needs. When drafted properly, assets are not in the person's name, which prevents the jeopardizing of government entitlements such as cash and health care benefits. The trust can also avail the repayment of health care provided by the government. Trustees are appointed to manage the trust, with successor trustees named as well.

STEP 8 – PUT ALL DOCUMENTS IN A BINDER

Place all pertinent information in a binder and let those who will take over the care and supervision of the individual know where to find it. Copies of legal documents should be placed in the binder. Original documents should be kept in a safe fireproof location.

STEP 9 – HOLD A MEETING

Give copies of relevant documents and instructions to family and care providers. Review everyone's responsibilities and make sure they understand and agree to them.

STEP 10 – REVIEW THE PLAN

As the person with special needs grows and changes, his or her needs will also change. This is why the plan should be reviewed annually. If necessary, make changes in the "Letter of Intent" and consult with an attorney if legal documents need to be modified.

Once families commit to preparing a plan for their loved one, it can be completed in a very short time using this process. What greater gift to give a person with a disability than the continuing love and guidance of his or her parents through a comprehensive plan that takes effect when Mom and Dad no longer can care for their child.

Three CARE Centers Now Open in S.C.

by Carol Wade
SCDDSN Autism Division

To diagnose, assess and plan services for people with autism, the South Carolina Department of Disabilities and Special Needs (SCDDSN) now has three Carolina Autism Resource and Evaluation (CARE) Centers across the state.

The Charleston center was the first to open in 1998 in collaboration with the Medical University of S.C. Working with the USC School of Medicine, SCDDSN opened the second CARE Center in Columbia in 2000. The newest center opened later last year in Greenville in collaboration with the Greenville Hospital System.

As understanding of autism has grown, the issues involved in the diagnosis of autism have become increasingly complex. Many children with autism have accompanying problems, such as developmental delay, certain genetic conditions, and seizure disorders. Children are being identified at younger and younger ages, which further complicates the task of determining if a child has slow development or a pervasive developmental delay. While some cases of autism can be identified by behavioral observation alone, others require the involvement of a team of professionals from a variety of backgrounds.

Through the CARE Centers a psychologist, early education specialist and speech therapist with specific experience and training in autism work as a team to assess each child's needs and skills and provide a diagnosis. Professionals such as a developmental pediatrician, occupational therapist, psychiatrist, neurologist or geneticist may also participate when there are complex issues such as medical, sensory and auditory problems. If the child is determined to have autism the team also recommends a plan of services and teaching strategies designed to address specific strengths, difficulties, and learning styles.

There is no cost to the family for evaluation by the core team of a psychologist, early education specialist and speech pathologist. Medicaid covers fees for more extensive services for the Medicaid eligible. Private insurance or Medicare may also pay a portion of the fee.

The CARE Centers help families to develop a home-based teaching plan for the family member with autism. Parents may share the plan with teachers and other service providers. The early education specialist shows the family what to teach and how, as well as the order in which skills should be taught. The specialist also demonstrates the planned teaching activities and coaches family members in using them. The family returns to the Center on a regular schedule for an agreed-upon number of sessions to review progress and set new goals.

CARE Centers are located in Greenville, Columbia and Charleston, and operate in affiliation with the three Developmental Evaluation Centers across the state. For more information about the CARE Centers or to obtain a referral, contact your regional Autism Division office, or the Autism Division central office at 803-898-9609.

In the Coming Months

February

10th - Housing meeting for families of adults with disabilities. Presenters from Palmetto Housing Options, Methodist housing programs in N.C. Saturday, Feb. 10, 2 p.m., Grace Methodist Church near Irmo. Call SCAS for more information.

11th - Serena Weider, Ph.D., to speak on "floor time" intervention, Charleston Convention Cntr., Sunday, 8:30 a.m.-noon. $40 per person ($65 for two). Must register in advance, 803-252-5646 or 800-445-8629.

March

13th - Training by Autism Division of SCDDSN: Parent Training (Piedmont Region*)

20-22 - Autism Division training: Basic Treatment Strategies (Beaufort, Coastal Region*)

21-23 - Autism Division training: Basic Treatment Strategies (Pee Dee Region*)

24th - Autism Division training: Parent Training (Midlands Region*)

* To register, call your regional office of the Autism Division. Midlands: 803-935-5090 Coastal: 843-852-4120 PeeDee: 843-664-2720 Piedmont: 864-594-4907

April

April is Autism Awareness Month. Look for more details soon!

7th - 2nd Annual Motorcycle Run to SCAS office sponsored by ABATE. To ride, call T. Wayne Johnson at 803-648-5752.

27th - Autism Awareness Rally in Washington, D.C. (If a minimum number of people go, we can charter bus at reduced rate.) See p. 16 for details.

May

12th - Third Annual SCAS Golf Tournament at Quail Creek Country Club near Myrtle Beach. See p. 16.

4th, 5th - Peter Wright, special education lawyer and author of *Wrightslaw* guide, to conduct all-day workshops in Columbia. Friday for professionals; Saturday, parents. SCAS, PRO-Parents to cosponsor. Call SCAS for more info.

2001 Meetings of the SCAS Board of Directors

January 27 * April 28 * July 28 * October 27

Research Review: Rett Syndrome, Medications

by Ruth K. Abramson, Ph.D., FACMG

The year 2001 is an exciting time for those of us who dedicate our work to finding the causes of autism. Why? Because 2001 brings us into an era when we will finally identify both the genetic and environmental factors that underlie the expression of this disorder.

We will have to wait a bit longer before we can review the first of the new millennium's research involving autism. So let's take a look at some of the research from the very end of the millennium that just ended.

The discovery that Rett Syndrome is caused by a mutation in the MECP2 gene was a major advance last year. Rett's, which initially may resemble autism, is diagnosed primarily in girls. The MECP2 gene is found on the X chromosome. Since the gene has been identified, we have learned a lot about Rett's. Boys with a mutation in the Rett's gene usually die before or at birth. Males have one defective copy of the gene; they have no good copy because they have only one X chromosome. Mothers may carry the gene, but it becomes preferentially inactivated and only the good copy of the gene on the other X chromosome is expressed. Therefore, they don't have full signs of Rett Syndrome.

We have also learned that there may be more than one mutation within the MECP2 gene, and that the position of the mutation within the MECP2 gene affects the severity of the disease and what symptoms are present. Recently, Orrico, Lam, Galli, et al. (2000) published a paper, *"MECP2 mutation in male patients with non-specific X-linked mental retardation,"* in the FEBS Letters 481: 285-8. This research describes a family where there was a novel mutation in the MECP2 gene (A140V). This mutation was found in a mother with mild mental retardation. The same mutation was found in her daughter, who was affected, but was also found in her four adult sons who had severe mental retardation. This paper indicates that MECP2 mutations are not necessarily lethal in males and that this mutation results in non-specific X-linked mental retardation in males. The Rett Syndrome research thus shows us that different mutations in one gene cause different symptoms and that a parent can have a gene mutation, but not show full signs, or sometimes any signs, of the disorder. Current theory about genetic causes of autism support the hypothesis that more than one gene is involved in the final expression of the disorder. Lessons we can learn from Rett's are that a gene mutation may not always be expressed the same in males and females, and that different mutations in one gene may cause different disease associated symptoms in families.

Bryan King (2000) has published an article, *"Pharmcological Treatment of Mood Disturbances, Aggression, and Self-Injury in Persons with Pervasive Developmental Disorders,"* in the Journal of Autism and Developmental Disorders 30:439-445. Although the title describes Pervasive Developmental Disorders, the article is about individuals with autistic disorders. In the article, the authors note that aggression, self-injury and mood disturbances are relatively common in autistic disorders, but are not core features of autistic disorders. They stress that these problems can occur for a variety of reasons and these need to be

carefully assessed before beginning pharmacologic intervention. No single drug or class of medication works for all individuals, but within the past decade a series of medications have shown promise. King describes the different classes of drugs used to treat mood disturbances, aggression and self-injury. The drugs affect brain neurotransmitters. They may act on one or more of the following neurotransmitter systems within the brain: the dopaminergic, serotoninergic, adrenergic, opiodergic and glutamatergic. King lists all of the medications for which research is available within each system, describes the number of studies, how many people were involved and whether studies were controlled or open. An open study is one where a medication is given and the results charted. It does not include a control population or a placebo medication to see if the results for the drug are better than the results with no drug at all. Otherwise stated, problems such as mood disturbance, aggression and self-injury may improve or change with time on their own. An open study cannot discriminate whether the outcome is due to the drug or a change which might have occurred anyway.

Dopamine antagonists show efficacy in reducing aggression and self-injury. Controlled studies of newer medications have been completed only for Risperdone, although other medications in this class appear to work also. Some problems associated with these medications are that there is dose-related sedation (the mechanism of action is nonselective), and many symptoms (not just aggression) improve with time.

Serotonergic involvement in aggression is supported by animal studies where aggression is modified by serotonergic drugs. Controlled studies with Clomipramine, Fluvoxamine (Luvox) and Buspirone specifically address aggressive behavior. Again, there is a problem with symptom heterogeneity. It is not clear whether the medications act because there is an underlying mood or anxiety disorder, such as depression or obsessive compulsive disorder which is treated by the medication or whether drugs like the serotonin reuptake inhibitors exert primary antiagressive effects in persons with autism.

Some of the drugs discussed where controlled trials have done, such as naltrexone (opiodergic), clonidine (adrenergic), and lamotrigine (glutamatergic) all show improvement in aggression in some, but not all individuals.

Dr. King concludes that we have come a long way in the treatment of mood disorder, aggression and self-injury in autism. The underlying factors which result in the expression of these behaviors may be environmental or genetic or both, i.e. are heterogeneous. Until we can identify those specific factors, pharmacologic treatment for autism will continue to involve trial and error to achieve optimum results.

The South Carolina group (Harry Wright, Michael Cuccaro, Sarah Ravan, Karen Decena, and I) of the Duke/USC Autism Research Study want to extend the best to all you in the New Year. We would like to thank you for your continued support of our work. We extend an invitation to families who have not participated in this research to identify causes of autism to join the study. We hope that this will be a year of discovery for autism. Together we can work to make it happen!

Medications Can Help Children with Autism

by Lissa Waring
Parent Mentor, Pee Dee Region

Our children with autism exhibit many challenging behaviors which may be improved with the use of medication. Pacing, the inability to sit still for more than a few minutes at a time, anxiety during a new situation, and sleep disturbances at night are just a few behaviors that can be helped with regular medication.

While medication can improve the lives of our children, often parents are reluctant to explore this possibility. For the first two or three years after my son was diagnosed he was manageable. His outbursts of temper were not too bad and during his "night parties" between 2 and 4 a.m. he would remain in his room even though he was wide awake. All this changed the summer he turned six. In a outburst of anger he hit a car windshield with his head, cracking the windshield (but not hurting himself, thankfully) and I knew the time had come to explore medications. Like many parents I was rather apprehensive about this, telling my husband, "I won't have him walking around like a zombie." Our regular pediatrician knew she could not help us but she put us in touch with a pediatric neurologist at Duke who has been wonderful these past five years.

We have tried many different medicines starting with Ritalin which did help Andrew to sit still in school and attend to his teachers. Now he takes three different medicines during the day and one at night for sleep and his behavior continues to improve. He is able to control his impulses better, can focus on verbal instructions better and is easier to discipline (for the most part!). I would not have thought that an 11-year-old could take four different medicines a day and not be in a drug induced stupor but that is exactly what has happened. Because of these medications his life and ours have improved dramatically. Without these medications he would not get as much out of life as he does now and he would be a miserable fellow for sure. Medicines alone are not a total, magic cure for behaviors associated with autism but rather a helpful aid to any behavior therapy for some children.

If parents choose to explore medications, they must seek a qualified professional to guide them. A regular pediatrician may not be familiar with the various medications needed to help these children but could refer parents to a specialist who could help them. Parents also have a responsibility to ask questions and research a drug's side effects and interactions. All drugs have side effects but if the benefits (i.e. desired behavior) far outweigh the side effects, why not try the medication? Getting the child to consume a medicine is another challenge. Sometimes a med can be mixed in water, milk, juice or disguised in chocolate syrup. My son takes his medicines with one or two m&m's and it took much trial error to figure this out!! Pharmacists are often helpful in this area.

Medication is an important issue to be considered in the management of individuals with autism, and for some it may greatly improve their quality of life.

New Memberships and Renewals
July - December 2000

Renewals

Ms. Vi Bazzani
Mr. and Mrs. Richi Glaser
Ms. Honoria Poon
Mr. and Mrs. William Faust
Ms. Barbara Hurtgen
Mr. and Mrs. William Gettys
Mr. and Mrs. Robert McCarty
Mr. Mitchell Yell
Dr. Jane Charles
Ms. Mary Pate
Mr. and Mrs. R. Carlisle Reames
Mr. and Mrs. Ken Boggs
Mr. and Mrs. C. Gene Arnette
Mr. and Mrs. L.S. Taylor

New Memberships

Ms. Laurie Priester
Ms. Hattie Payne
Mrs. Mary Bennett
Ms. Rebecca Mussman
Mr. and Mrs. Bob Derr
Mrs. Sarah Orlov
Mr. Roy Williams

Contributions and Donations
July - December 2000

Crossroads Middle School
Karl Smith
Mildred Sherlock
J.R. Mullis
Sally Elliot
Margie Freeman
Taylor Enterprises
Doris Collier

In lieu of Holiday Gifts - by William Floyd

IN MEMORY OF

Craig Yoder by Fred Fels, Laura Fels, Richard Boye and Carol Niederhauser

IN HONOR OF

Dr. William Hunter by First Presbyterian Church
Eric Park by Stephen Park
Audrey Horne by Henry Velte, C. Gene Arnette, Anne Dudek and Barbara Park

Mission Statement
South Carolina Autism Society

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

SPRING NEWSLETTER DEADLINE

To submit events for the calendar, support group updates or articles for the spring newsletter, please send information to SCAS no later than March 30.

Join SCAS on our website: www.scautism.org

South Carolina Autism Society Support Groups

ON-LINE SUPPORT GROUP
Sign up through SCAS website:
www.scautism.org

AIKEN
When: Quarterly
Time: 7 p.m.
Place: Aiken Regional Hospital
Contact: Amy Weeks - 803-642-0712

ANDERSON
When: 1st Tuesdays
Time: 6:30 p.m.
Place: Boulevard Baptist Church
Contact: Dixon Huiett - 864-225-3500

BARNWELL COUNTY
When: 3rd Monday
Place: Barnwell Elementary School
Contact: Faye Mitchell 803-259-1599

COASTAL REGION
When: 2nd Monday
Contact: Beverly McCarty - 843-763-6877

COLUMBIA
When: 3rd Monday
Place: Family Connection
Contact: Kim McHugh - 799-4223

FLORENCE
Contact: Laurie Gonce - 803-673-0475

GEORGETOWN
When: Following school board meeting
Contact: Glenda Owens - 803-546-4824

ORANGEBURG
Contact: Theresa Jameson - 803-536-4832

GEORGETOWN
When: Following school board meeting
Contact: Glenda Owens - 803-546-4824

HORRY
When: 4th Wednesday
Time: 7 p.m.
Place: Horry DSN, Hwy. 501
Contact: Sarah - 347-3010, ext. 225
Denise - 497-1410

KERSHAW
When: 3rd Thursday
Contact: Margo Cook - 803-438-8877

MANNING
When: Each Wednesday at 10 a.m.
Contact: Saundra Wallace - 435-4007

CSRA (NORTH AUGUSTA)
When: 4th Thursday
Contact: Lisa Bryant - 803-279-4242

SUMTER
When: 2nd Thursday
Contact: Shirley Ballard - 803-481-0342
Kids/Sibling Nights Out begin Feb. 22 (every 4th Thursday)

UPSTATE FAMILY NETWORK
When: 2nd Thursday at 7 p.m.
Contact: Kelly DeWitt - 864-241-9839

Important Information about Disability Advocacy Day

As pointed out in several other parts of this newsletter, parents and other concerned advocates of individuals with disabilities are strongly encouraged to participate in Disability Advocacy Day at the State House in downtown Columbia on Wednesday, March 7. Registration is strongly encouraged. (See details below.)

Activities will begin at 9 a.m. in the first floor lobby of the Blatt Building where an orientation will be held for all participants. At 9:30 a.m. the group will go to the State House for the opening of the formal House session at 10 a.m. Parents can seek out their House member before, during or after the session. When the group sits together in the gallery, our numbers will stand out. At 10:30 a.m. the group of advocates will move to the Senate side of the building for the session to begin there at 11 a.m. (The same procedures will be followed there.)

This is a great opportunity to be "counted" in a year of critical proposed cuts to the South Carolina Department of Disabilities and Special Needs (DDSN), of which the Autism Division is a part.

Come prepared to talk about what DDSN services mean to you and your family. It is an excellent idea to bring your loved one with autism with you.

If you plan to go, please register by Feb. 15 by filling out the form sent to newsletter readers in an information packet a few weeks ago. The reason registration is strongly encouraged is that it enables organizers to (1) prepare sufficient packets for those who attend; and (2) determine whether advocates from the same district can be grouped together for an even more impressive presence.

Contact SCAS if you need a registration form. Or check the SCAS website, www.scautism.org for all the information that was in the packet. The packet contains a map and shows where parking spots will be reserved. It also contains an advocate guide to visiting elected officials.

Disability Advocacy Day is cosponsored by the Partnership of Disability Organizations, which represents nonprofit organizations who in turn represent individuals with disabilities that qualify them for DDSN services. These organizations include SCAS, S.C. Brain Injury Alliance, SC Spinal Cord Injury Association, The Arc (mental retardation), and the Brain Injury Association of S.C.

If you haven't already, read message about the budget crisis on page 1, as well as the Executive Director and SCAS President's messages on pages 2 and 3.

Be sure to join us March 7 at the State House!

INROAD Wants 'Yes I Can' in More Lexington, Richland Schools

INROAD is working to expand its "Yes I Can" inclusion program into more middle and high

2001 SCAS Board of Directors

President
Rebecca Shippy
(adult son has autism)

Vice President
Amy Weeks
(son and daughter have autism)

Secretary
Ann Bishop
(adult son has autism)

Treasurer
Mitchell Yell, Ph.D.
USC Professor

Immediate Past President
Joyce Nielson
(son has autism)

Coastal East
Denise Chastain
(son has autism)

Coastal West
Denise Long
(son has autism)

Midlands East
Gaye Hartley
(daughter has autism)

Midlands West
(OPEN)

PeeDee East
Cheryl Bauerle
(daughter has autism)

PeeDee West
Shirley Ballard
(son has autism)

Piedmont East
Mary Pate
(son has autism)

Piedmont West
Denise Oxford
(daughter has autism)

2000 - 2003
At Large
Erik Drasgow, Ph.D.
USC Professor

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

2001 - 2004
At Large
Michael Fillipone
(son has autism)

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

1998 - 2001
At Large
Tim Daugherty, Ph.D.
Winthrop Professor

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

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

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

SCAS Staff

Executive Director Craig C. Stoxen

Administrative Assistant Vickie Stowe

Bookkeeper Mary Bennett*

Program Coordinator Carol Niederhauser*

Program Admin. Assistant Sheila Raulerson

Parent Liaison Jan Mandeville*

Parent Mentor, Coastal Dandrea Woolridge*

Parent Mentor, Horry Sarah Pascarella*

Parent Mentor, Midlands Kim McHugh*

Parent Mentor, Midlands Melanie Marquis*

Parent Mentor, Pee Dee Lissa Waring*

Parent Mentor, Piedmont Anjeanette Chesire*

* parent of child with autism

WANTED: **Families to go as group to Autism Awareness Rally Friday, April 27 in Washington, D.C.**

Autism Society staff working on bus and motel accommodations

Estimated Travel/Lodging Cost
$100 per person, double occupancy

Leave April 26
Return early a.m. April 28

Rally to feature Open Your Eyes photo display of people with autism. To stretch length of 15 football fields — yet represent just 10 percent of affected population

To submit photo or reserve bus seat, call SCAS at 803-794-2300 or 800-438-4790

S.C. Autism Society
3rd Annual Golf
Tournament

Saturday, May 12
8 a.m. Shotgun Start

Quail Creek Golf Club
(Near Coastal Carolina University between Conway and Myrtle Beach)

$50 per player or $200 per foursome
Fee includes cart and greens fees, awards and refreshments

For more information, call SCAS at 803-794-2300 or 800-438-4790

UPDATE winter 2001

South Carolina Autism Society

South Carolina Autism Society
229 Parson Street 1-A
West Columbia, SC 29169

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