2012 SANDS AT A GLANCE…….

This has been a big year for SANDS, we donated $750.00 worth of reference books about Down syndrome to the Pima County Library, approved 27 Give it Back! Grants to individuals and their families with Down syndrome for a variety of things that enhanced their lives for the better. Financially and physically supported 7 conferences and work shops on topics ranging from Inclusion to IEP’s. Many of the SANDS Board of Directors attended resource fairs, conferences and workshops both in state and nationally on subjects ranging from Self-Advocacy and transitioning to adulthood to applications for iPads to name a few. SANDS has been compiling information for a reference library on local and national resources for individuals and families/caregivers of individuals with Down syndrome, we have a great start. There is information on adventures, financial assistance, apps for electronic devices and much more. If we don’t have it we will find it. SANDS assisted six local support groups with guidance and financial assistance.

And of course our biggest event was our Tucson Buddy Walk, we made over $24,000. It was a great success again this year and we want to thank Jodi Bess and Frank Rendon for all the hard work they did to make it such a success.

(HealthDay News) -- A drug commonly used to treat patients with Alzheimer's disease does not appear to be effective for people older than 40 years who have Down syndrome and Alzheimer's, according to a new study. Although previous animal studies of the Alzheimer's drug, Memantine, showed promising results in mice with Down syndrome, this new study of people with Down syndrome aged 40 and older revealed the opposite, the researchers reported in the Jan. 9 online edition of The Lancet.

Memantine was given to 88 people with Down syndrome for one year, while another 85 patients received a placebo (the "control" group). Some of the participants had Alzheimer's and some didn't.

The investigators found that the brain function of the people in both groups declined equally. Serious adverse effects were experienced by 11 percent of the group that took the medication. Meanwhile, 7 percent of the placebo group had similar adverse events. Five people from the medication group died because of these events, compared to four in the control group.

"Memantine is not an effective treatment in this group of patients. We believe that this robust finding will have implications for clinical practice and research strategy in the future. Specifically, therapies that are beneficial for people with Alzheimer's disease are not necessarily effective for the treatment of cognitive impairment or dementia in the context of Down syndrome," the study's author, Clive Ballard, a professor at the Wolfson Centre for Age-Related Diseases at King's College London, said in a journal news release.

Because nearly 40 percent of people with Down syndrome over 60 years of age are diagnosed with dementia, the study authors pointed out that more research is needed to determine the best way to treat dementia in these individuals. "Further investment is urgently needed to develop treatments that are effective in this important group of people," the study's co-author, Anne Corbett, research manager at Alzheimer's Society (U.K.), stated in the news release.

More information The U.S. National Institute of Neurological Disorders and Stroke provides more information on Alzheimer's disease.
Here is an easy way to show your support for SANDS and all our programs, when shopping at amazon.com use the link on the SANDS web page http://www.sandsaz.org/support-sands/ It doesn’t cost you anything BUT SANDS will get a small percentage of the total sale. YIPPEE!!!

Have you ever heard of Treadmill Training?

Physical Therapists are now using treadmills to help children with Down syndrome learn to walk. Studies show treadmill training can help babies walk sooner, and with a more effective gait. Learning to walk on a treadmill allows for a longer stride length, with greater hip flexion, and Down syndrome children begin walking up to three months earlier than they would have without training. Talk to your child’s Physical Therapist, to develop ways to motivate your child to learn to walk on the treadmill.

Technology is a great distraction! To keep them engaged in the activity, try playing his or her favorite movie on a TV or laptop in front of the treadmill, or playing a favorite song. Some children have responded to a ball being rolled down the treadmill belt, encouraging the child to kick at the end of a stride. Many clinics use pediatric treadmills, but it is possible to use an full size treadmill.

Once your child learns to walk, he or she may need the help of a shoe insert, or SMO (supramalleolar orthosis). These devices provide support and corrective forces to the foot and ankle, helping with gait and balance, when worn in tie-up shoes (tennis shoes are recommended). They are designed to treat flat foot in children with low muscle tone. Studies have shown that young children with Down syndrome showed immediate and longer-term (after 7 weeks of use) improvement in postural stability with the use of flexible SMOs.

For more information, check out www.surestep.net and www.dafo.com. You will need a prescription from a Physical or Occupational Therapist, or Orthotic Specialist. If your insurance does not cover SMOs, check with local hospitals and therapy centers for loaners or “recycled” (gently used) options. Keep in mind, your child will need Physical Therapy assessments throughout life.

SANDS has a need for additional Board of Directors (BOD). We are expanding and need more help, ideas and new enthusiasm. If interested visit our web site http://www.sandsaz.org/board-activity/ and read the BOD’s manual and download an application, you do not need to have Down syndrome or have a family member with Down syndrome to be a board member. Just a caring interest in our Down syndrome community here in Southern Arizona.

You too can make a difference!

If you are not interested in a BOD position, what about being on a committee? SANDS has many different opportunities to choose from including the best one of all Chair (s) for our annual Tucson Buddy Walk in 2013, this position gets the full support of the SANDS BOD.

What a fun and rewarding way to give back to our community!
It is time to take memory training seriously

Sue Buckley

It has been known for a long while that children with Down syndrome have a specific impairment in verbal short term memory. Research now indicates that memory training activities may be effective. For more than 25 years we have known that children and adults with Down syndrome have a specific impairments in working memory. Within the working memory system, they have particular difficulty with the verbal short-term memory part of the system. They have more difficulty remembering verbal information than visuo-spatial information in short-term memory tests.[1]

Given that verbal short-term memory skills – the ability to hold spoken words in short-term storage – is linked to spoken language development and to progress in reading and math’s [sic] in childhood, a number of researchers have been interested in exploring ways to improve verbal short-term memory through training activities with mixed results.

However, memory training may be about to become more popular as recent work with both children with Down syndrome and non-disabled children has shown positive effects. Francis Conners and colleagues recently reported small but positive gains from a parent supported training program.[2] Twenty children with Down syndrome aged 6-14 years took part in the study and 16 completed the training schedules therefore the findings are reported for these 16 children.

Parents were trained to carry out the intervention programs with their children. Parents were given training at the start of the study and supported by weekly telephone calls during the training periods. The verbal memory training was delivered entirely in an auditory/verbal mode – the children had to listen to digits spoken and then to say them, with the number of digits in the lists to be recalled increasing as children succeeded at a list length (e.g. 2 digits, then 3 digits, then 4 and 5 for some children). There were no visual materials used to support their learning as in some previous training studies.[1,4] This was an ambitious project as the tasks were really quite challenging but the aim was to really focus on trying to improve listening memory directly.

In order to be sure that any gain on the verbal training program was specific to the training, an alternative intervention using visual activities was used for comparison. The children were put into 2 groups and one group began with verbal memory training, the other with visual activities. The training sessions for each intervention took place for 10 minutes, 5 times each week for 3 months. Progress was audio-taped and tapes plus score sheets mailed to the research team weekly. After 3 months, the groups changed to the other activity and after another 3 months went back to the first activity program for a further 3 months.

Firstly, the results show that parents were able to implement the memory training at home and record progress. This is an important finding as the verbal memory training task was not easy for the children and they had to do it 5 times each week. The parents were supported on an ongoing basis but the study does demonstrate that parents can be actively involved in intervention research in this way. Secondly, the memory training did lead to a small but significant increase in digit span for the group – with some children making substantial progress and others less. There was also evidence that the use of phonological (speech based codes) in memory increased as a result of training and this could have important effects for improving the children's ability to learn the sound patterns of new words.

Working memory delays are also seen in children within the non-disabled population in regular classrooms, and Sue Gathercole and colleagues have carried out a number of studies with these children in recent years. They have also been investigating the effectiveness of memory training and report positive results of using computer training programmes with children with ADHD and with children with poor working memory. This team have used Robomemo, produced by CogMed[6], and children work on this daily. The author and colleagues have had positive results in a small pilot study using the Mastering Memory software[7,8] with children with Down syndrome of primary school age.

Clearly there is a need for further research into memory training which evaluates different approaches to training and also follows up post-intervention to see if benefits of training last. In our previous work, we found an interaction between classroom settings, reading progress over time and lasting gains from memory training games. Specifically, the children in mainstream classrooms who were in daily reading instruction gained from memory training and continued to improve their short-term memory skills over time, while those in special education classrooms showed equally good gains at the end of the memory training period but these gains disappeared over the next 18 months.[9]

Further research into both home based and classroom based memory training could lead to gains in memory, speech and language and literacy for children with Down syndrome. The fact that progress in these areas is inter-related requires more training studies to take account of all these skills at the outset and following training studies should also take account of the educational settings and educational experiences of children taking part in training.
To the wonderful families of SANDS and their support community,

I want to wish you all a very Happy New Year! As I reflect on the past year in 2012, SANDS is proud of its involvement with our community. For example, our successful 11th Annual Tucson Buddy Walk, our financial support and facilitation of the Inclusion Workshop Series, our donation of books to the Pima County Library system, pool party co-sponsorship, World Down syndrome day at Peter Piper Pizza and numerous workshops, fundraisers and conferences to support the Down syndrome community.

The mission of SANDS is “To improve and enrich the lives of individuals with Down syndrome and to promote public awareness.” We are able to fulfill a part of that mission through our “Give it Back!” Program. The program is a sponsorship and reimbursement program for individuals with Down syndrome and their families. Over the past two years we have given over $21,000 to the Southern Arizona Community through of this program. All of those funds go directly to families to use as they see fit with a few guidelines. Go to our redesigned website at http://www.sandsaz.org/give-it-back/ for more details. Families have been able to pay for eyeglasses, school supplies, learning aids, sports programs, therapies, conferences, etc. Each board member is very proud of this program and strives to ensure that we are able to fund it each year.

Consider your purpose for 2013. There are many families who are in need of help, be it big or small. Will you consider paying it forward by coming out and joining our board? We need dedicated and hardworking individuals to come out and support our mission in the community. Be sure to contact us right away so that we can put your talents to use.

Again, I wish you and your families a healthy and safe New Year!

Sincerely,

Steve Freeman, President
Southern Arizona Network for Down Syndrome
SANDS “Give It Back! Program” for Individuals and the Community

The Give it Back! Program provides a medium by which SANDS can return funds we raise directly to individuals with Down syndrome and their families. This is an extremely important part of our mission, both to enrich the lives of those with Down syndrome, and to fulfill the needs of the community in which we live. In addition to helping families financially, a desirable benefit of the program is to inspire families to explore new and/or alternative options that may not otherwise be considered.

The Give it Back! Program provides three different options for individuals with Down syndrome and their families:

1) Individuals with Down syndrome or Family Member Training Sponsorship  
2) Reimbursement/Pre-payment option  
3) Community Sponsorships  

For more details on the program & application form visit our website http://www.sandsaz.org/give-it-back/ or 520-47SANDS

Examples of some of the items SANDS has sponsored: Individual sponsorship—Attendance at the Down Syndrome Congress Conference in Boston, San Antonio and Washington DC, AYSO soccer, special heavy duty stroller, iPads, computers, therapies.

All requests for funding from SANDS must be accompanied by an individual or community GIB! Form

To obtain a GIB! form visit our web site http://www.sandsaz.org/give-it-back/  
e-mail info@sandsaz.org or call 1-520-47SANDS (7-2637)

Only the GIB Committee has the authority to approve funds. Allow 6 to 8 weeks for processing

Below is a quick overview of SANDS finances for 2012, a more detailed accounting of SANDS finances is available on the SANDS website

www.sandsaz.org

Income:
Buddy Walk $36,259.45  
Other $7,959.16  
TOTAL $44,218.61

Expenses:
Give It Back Applications $7,076.25  
Approved 27 individuals (Items included iPads, laptops, therapies, swim lessons, eye glasses and reference books)  
Buddy Walk $12,532.42  
Down Syndrome Connection $1,555.33  
Santa Cruz Parent Love Connection $1,790.00  
Other organizations $2612.03  
Books Donated to Pima County Library $702.43  
Operational Expenses $14,391.59

To include rental of venues, printing for workshops, insurance, bank fees, website, newsletter, storage rental reference and table fees  
TOTAL $40,660.05

SANDS is partnering With Albertson’s to raise funds for SANDS.
To be part of this fund raising project, just contact me to get a free key ring tag. Then, every time you shop at Albertsons have your tag scanned. As a result SANDS, will get a percentage of the total sale. The more you shop the more we earn.

Best regards, Cindy 495-9343
41st Annual Convention  
National Down Syndrome Congress 2013

Each year, thousands of people from across the globe attend the National Down Syndrome Congress Annual Convention. For most, it’s to hear the latest information from world-renowned experts. For others, it’s a great vacation. But, for nearly all, there’s the one-of-a-kind NDSC family reunion feeling that permeates the convention weekend.

**This is a fun and educational event for all ages and the sessions fill up fast, so register now!**

If funding is an issue there are several options available: SANDS Give it Back! Individual Grant [http://www.sandsaz.org/give-it-back/](http://www.sandsaz.org/give-it-back/) and the Pilot Parents Leap Grant [http://www.pilotparents.org/ppsaw/ProgramsandServices/Leap.aspx](http://www.pilotparents.org/ppsaw/ProgramsandServices/Leap.aspx) Start your applications now as they can take from 30 to 60 days for approval.

*We hope to see you July 19-21, 2013 for the 41st Annual NDSC Convention in Denver, Colorado.*

Call for Speakers
The deadline for speaker proposals was January 4th. The Convention Committee will begin the selection process. If you have any questions please contact Coleen@NDSCcenter.org.

2013 Hotel Reservations
Hotel Reservation for the Hyatt Regency Denver at the Colorado Convention Center will open early March along with Convention registration. Please visit the Hotel & Travel section for more information.

NDSC Convention from your Couch
To commemorate our 40th Annual Convention and for the first time in Convention history, NDSC live streamed 17 workshops and sessions from Washington, D.C. To share the experience of “the world’s largest family reunion” anywhere, and learn the latest developments and advancements from the Down syndrome community’s leading voices these sessions were recorded and are available through the convention site. A summary of these recorded sessions can be viewed at [Recorded Sessions](http://convention.ndsccenter.org/wp-content/uploads/2012/08/CH-RecordedSessions.pdf)

**To access or register for the 2012 Convention’s Recorded Sessions**
[https://register.ndsccenter.org/Userlogin.aspx](https://register.ndsccenter.org/Userlogin.aspx)

Registration and access to the Convention’s Recorded Session is available until June 1, 2013. To register simply go to [http://convention.ndsccenter.org](http://convention.ndsccenter.org) open an account if you don’t have one and choose the live streaming/recorded session option

2013 41st National Down Syndrome Congress Annual Convention Schedule

- July 19-21, 2013
- Colorado Convention Center Denver, CO
- Convention Registration will open March 2013.
- Convention Hotel Block at the Hyatt Regency Denver will open March 2013.
- Exhibitor Registration will open March 2013.

Volunteer registration will open March 2013.

Letting Go
By Shandra Umazar, Charlotte, NC

Almost 29 years ago, my husband and I sat with our daughter, Islah, in the conference room at a big long table. We were on one side and the genetic doctors were on the other. We sat quietly as the doctors told us all the things Islah would never do. What stuck out most in my mind was telling us that she would never be able to live alone. I remember how hard it was to fight back the tears. For some reason, I tried hard not to show any emotions one way or the other. I also remember as we left the office that Islah, only several months old, started babbling. Now 29 years later, I know she was saying, “I am going to prove you wrong.”

Today, Islah is a junior at University of North Carolina in Greensboro, and living in a furnished, three-bedroom off-campus apartment alongside other college students. Thanks to a program called Beyond Academics she learns independent living skills to help her live successfully in her community. Looking back, I realize this has been a process of dreaming big and learning to let go. I remember when Islah was learning to walk, she would slap my hand away — determined to take the first steps alone. In high school she wanted to come home from school and not sit at my job waiting for me to get off work. The bus driver assured me she would make sure Islah got in the house and locked the door. She would only be alone for a few hours until her dad got home.

Islah finished high school at 18 years old — just like her siblings — and wanted to go to college. She enrolled in the compensatory education program at Central Piedmont Community College, and attended until the opportunity arose to attend Beyond Academics. After high school, Islah also participated in a program called Partners in Policymaking. It is a great program that teaches self-advocates and young parents how to effectively advocate for themselves and their children. Islah learned that there are all kinds of disabilities. It was there she learned to be advocate for herself and accepted having Down syndrome (DS).

Islah taught us to have confidence in her and her ability to try — no matter how hard the task might be or whether she could complete it. I realized that my fears for Islah are no different from the fears I have for my other children; it just feels different because of her label. Teaching everyday skills and functional social skills in an inclusive environment is so important for our children with DS in taking steps to independence. Letting go is not easy. The unimaginable has become a reality. Islah now lives away from home and family, makes decisions and is responsible. With supports, she experiences college life, and hangs out with classmates in and out of class.

One weekend, Islah’s sister and I drove to Greensboro to have breakfast with her. While we were there, her friends came over to visit. How cool that is, we thought, remembering the hours she would spend in her room watching TV, or waiting to be taken to a program. It is important that parents and the community give our children the opportunity to grow, learn and become productive citizens in their communities.

Editor’s note: This article first appeared in the July 2012 issue of the DSA of Greater Charlotte newsletter with permission given to reprint in DSN Down Syndrome News, newsletter of the National Down Syndrome Congress 30 Mansell Court, Suite 108 Roswell, Georgia 30076 www.ndscenter.org.
SANDS Board of Directors
2013 Meeting Schedule
Second Monday each month except January
(annual retreat, closed meeting) October (TBA
in combination with Buddy Walk meeting) and
December (BOD on hiatus)
Meetings are open to the public
(except annual retreat)
6:00pm to 8pm
Fronimo’s Greek Café
3242 E Speedway Blvd
Food available for purchase

This newsletter is available at http://www.sandsaz.org/newsletter/
We also publish an electronic newsletter with updates between our official newsletter.
To be added contact sands at info@sandsaz.org Don’t forget to like us on
facebook.com/southernarizonanetworkfordownsindrome

Southern Arizona Network for Down Syndrome
Is asking you to make a tax deductible donation
SANDS a 501 (c)3 Non-Profit

Yes! I want to make a tax deductible donation to SANDS

__$5.00 ___$10.00 ___ $15.00 ___$20.00 ___$25.00 ___Other

A few examples of where your kind donations go: purchase reference materials pertaining to Down syndrome for libraries in Southern Arizona. Informational workshops, seminars and conferences. Fulfilling requests from individuals and their families through the Individual Give it Back! Program (IGIB) for items that will enhance their lives. Providing support and operating funds for local support groups through the Community Give it Back! Program (CGIB). Every donation helps.

Make your checks payable to “SANDS” Send to SANDS, PO Box 17011, Tucson, AZ 85731

Printed Name _____________________________________________ Phone #_______________________________
Address________________________________________________ City________________ State______ Zip Code___________