

## **SCIENCE IN AUTISM TREATMENT**

Vol. 10 No. 3

Newsletter of the Association for Science in Autism Treatment

Summer 2013

# ASAT Celebrates its 15<sup>th</sup> Anniversary David Celiberti, PhD, BCBA-D, Executive Director

The Association for Science in Autism Treatment (ASAT) is celebrating its 15<sup>th</sup> anniversary! I am proud to have been part of ASAT for the last nine years. Since 1998, we have worked diligently to keep science at the forefront of the conversation about autism treatment, and have developed and maintained a comprehensive website and a quarterly newsletter. Our website and newsletter serve as primary sources of science-based information against a backdrop of information overload, pseudoscience, and inaccuracies that distract consumers from making the best possible treatment choices for their children. ASAT provides these and other resources with no charge whatsoever to anyone.

Autism treatment is a multi-million dollar industry with 400+ "treatments." For the majority, science is overlooked and pseudoscience is marketed using heart wrenching testimonials, surveys, and anecdotes providing outrageous claims about outcomes. Poke around the internet and you will quickly see that parents are promised the moon. Aggressive marketing of these so-called "therapies" and "cures" make them appear quite compelling. Some marketing campaigns can be absolutely overwhelming and serve to drown out accurate information for parents who are desperate to help their children, and for providers eager to help individuals realize their fullest potential. All of us at ASAT are committed to improving the education, treatment, and care of people with autism, and believe that we do no favors to individuals with autism and their families by ignoring quackery and not countering baseless claims. In addition, we believe that it is critical to provide tools to consumers and professionals so that they make informed treatment decisions and become savvy decision-makers who hold all treatment accountable

for claims made.

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Our mission is as follows:

We promote safe, effective, science-based treatments for people with autism by disseminating accurate, timely, and scientifically sound information; advocating for the use of scientific methods to guide treatment; and combating unsubstantiated, inaccurate and false information about autism and its treatment.

ASAT is a not-for-profit organization run by a volunteer board of professionals and family members of children and adolescents with autism (see page 24), as well as myself, as a part time, Executive Director. Almost half of the members of our Board of Directors have served for over five years. This level of longevity and commitment is what enables ASAT to remain a strong voice for science and accountability.

I would be remiss if I did not mention our Professional Advisory Board (see page 11), many of whom are actively involved with ASAT. Dr. Bobby Newman manages our NYC Marathon team and has been instrumental in helping us develop science-based lending libraries. Dr. Sharon Reeve coordinates the efforts of her graduate students at Caldwell College who author the research synopses. Dr. Catherine Maurice, ASAT founder, has remained a staunch supporter and sage advisor whose input remains highly appreciated and respected. Finally, we have scores of volunteers who serve in a wide array of capacities such as Coordinators, Externs, Media

## Letter From the Editor continued...

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Watch writers, and fundraisers. Many of these individuals, and their respective roles, are listed on page 12.

Since ASAT was established in 1998, it has been our goal to work toward adopting higher standards of accountability for the care, education, and treatment of all individuals with autism; essentially to raise the bar. It remains our goal to assure that the family of every person with autism has access to information that will help their loved one receive the best intervention that science can provide, delivered with competence, clarity, and compassion.

ASAT was the first autism organization to wholeheartedly embrace an empirical, science-based approach to any statements made about the causes and proposed treatments for autism. This commitment has led many to question if we were biased to supporting and promoting Applied Behavior Analysis (ABA). On a surface level, there may indeed appear to be such a bias; however, it is the underpinnings of this discipline that inform our advocacy. These include, but are not limited to:

- Reliance on and respect for published research;
- The use of single subject research design in documenting outcomes and assessing functional relationships between independent and dependent variables;
- An appreciation of the social validity of goals, methods, and outcomes;
- The transparency and potential for replication that results from explicit treatment descriptions;
- Objective definitions of treatment targets:
- Collection of inter-rater reliability data to ensure that measurement is accurate;
- Ongoing, objective data collection; and
- Data-based decision making.

In 1999, the first issue of *Science in Autism Treatment (SIAT)*, ASAT's quarterly newsletter, was published in order to make information accessible to consumers of autism treatment. The original newsletter was published for three years. In 2001, ASAT's website (<a href="www.asatonline.org">www.asatonline.org</a>) was launched to increase the reach of our information-sharing, including suggested reading lists, links, and key articles on autism and its treatments.

The last few years have been particularly important for ASAT. We are now comprised of six committees, each with their own distinct, yet complementary, purpose and goals. In the Summer of 2009, we resumed publication of SIAT, which now has over 8000 subscribers. The newsletter is published free-of-charge, to ensure everyone has access to accurate, helpful information. In many respects, the new format of our newsletter was more comprehensive and multifaceted than the original publication. Currently, ASAT's e-newsletter features:

- Invited articles by leading advocates of science-based treatment;
- A Clinical Corner which responds to frequently asked questions about autism treatment;
- A Consumer Corner which recommends resources that can guide and inform treatment decisions;
- A Focus on Science column designed to empower families to make educated treatment decisions by highlighting elements of science-based interventions and warning signs of unsubstantiated treatment;
- Detailed summaries of specific treatments for autism;

## Science in Autism Treatment's Team

## Co-Editors

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From The Archives

Laurie Brophy, LCSW, BCBA

**Advertising** 

Alice Walkup, MS, BCBA

## Letter From the Editor continued...

(Continued from page 2)

- · Book reviews;
- Highlights of our Media Watch efforts and discussion of accurate and inaccurate portrayals of autism and its treatment by the media;
- Reviews of published research to help consumers and professionals understand and gain access to the science; and
- Interviews with those who advance science-based treatment and confront pseudoscience.

At this time, I want to take a moment to discuss a recent transition on the editorial team of *SIAT*. After serving as Co-Editor for four years, Dr. Josh Pritchard has stepped down from this role. I am pleased to share that he is remaining on the Board of Directors and we look forward to his ongoing contributions, particularly in the arena of public relations and dissemination. It goes without saying that our newsletter would never be where it is now without the significant efforts of Josh. He was incredibly generous with his time and talent (it was a very important partnership for me, given my comparatively more limited technical skills). During his four-year tenure, 16 issues were distributed to readers in over 90 countries. These issues were comprehensive and enabled us to generate considerable new content for our website. Given that Josh's shoes will be hard to fill, we made a few changes to the organizational structure of the Editorial team:

- Dr. Daniela Fazzio has assumed the role of Co-Editor, and I am pleased to report that this outstanding
  issue of Science in Autism Treatment is the first example of her excellent work. I look forward to collaborating with her;
- Leanne Tull will serve as our Managing Editor and help ensure that content flows efficiently and that we meet production deadlines;
- Dr. Nicole Pearson, our current Clinical Corner Coordinator, will serve as Copy Editor;
- Dr. Sabrina Freeman has assumed the role of Consumer Coordinator. We are very grateful to Kate Fiske who previously served in this capacity;
- Alice Walkup, a current ASAT Extern, will help us expand our newsletter and web advertising within her role as Advertising Coordinator;
- Laurie Brophy, a current ASAT Extern, will help us best integrate newsletter content in our existing website within her role as Content Coordinator; and
- Kerry Ann Conde, who is behind our Shout Outs section, will help us increase our subscriber base both here in the US and internationally.

Daniela and I are pleased to announce a new ongoing feature to our newsletter. In each issue, we will be interviewing at least one individual from outside the United States. In this issue you will find interviews with UK-based actress, author, and entrepreneur, Jane Asher, on page 4 and with Toronto-based advocate and fund raiser, Christina Danos, on page 26. In the Fall 2013 issue, we will feature an interview with Pooja Panesar, Founder and Director of Kaizora Consultants in Nairobi, Kenya.

We have also continued to expand and upgrade our website to develop user-friendly resources and make it more accessible and relevant. In fact, we are amidst a major overhaul and have recently hired a Los Angelesbased web designer to oversee that effort. ASAT is currently developing specialized sections catering to distinct groups including the media, pediatricians, and parents of newly-diagnosed children (soon to be accessible on our home page). We have developed systems to engage ten Externs and over 50 volunteers productively within our organizational structure. Learn more about this by reading the article on page 20.

ASAT remains one of the foremost voices for this important mission: the dissemination of science-based information about autism and its treatments, and the promotion of greater access to credible, effective, and safe treatments. This is a time of rapidly accelerating scientific research on autism treatments (not only ABA but also other treatment modalities), and we are dedicated to providing up-to-date information to ASAT readers.

15 years and still going strong! Can you help us continue our important work? We are celebrating this significant milestone by launching a campaign designed to increase the visibility of ASAT and to increase support for our mission and initiatives. The next few pages detail 15 ways to support ASAT's work. I trust that a few of these will resonate with you! We will be asking for your involvement and participation throughout August and September, so stay tuned for regular posts about our campaign on our <a href="Facebook">Facebook</a> page.

# An Interview with Jane Asher, Actress, Advocate, and Entrepreneur By David Celiberti, PhD, BCBA-D

I recently had the wonderful opportunity to interview Jane Asher. Aside from her busy life as an actress and entrepreneur. Jane Asher is an actress, author and businesswoman. She has been working professionally in film, theatre and radio since she was 5 years old, and has run her own business, Jane Asher Cakes, based in Chelsea, London, since 1990, selling bespoke celebration cakes and a wide range of home baking equipment.

She has also written more than a dozen books, including three best-selling novels. Jane's work in the charity sector is well respected. She is President of Parkinson's UK, President of the National Autistic Society and President of Arthritis Care, Vice President of Autistica, Ambassador for the Prince's Trust, Friend for Life, Terrence Higgins Trust. She is a Patron of many other voluntary organizations.

Can you share with our readers how you were first introduced to autism?

I first became involved with autism when I went to a children's tea party in 1985. Children representing various charities had been invited, and I remember the room being full of the noise and excited laughter that one would expect. One table, though, was oddly different. At first I couldn't think quite why it stood out from the other three - the children had no obvious disability and looked quite 'normal' - but after a few seconds of watching I could clearly see that not only were the

children unusually quiet, but that there was no interaction between them: no shouting or joking – no squabbling or arguing. They didn't even look at each other – indeed they seemed completely unaware of each others' presence. The difference from the behaviour of the other children was so marked that I asked one of their helpers where they were from (This 'carer' was Lorna Wing, whom, as I'm



sure you know, was one of the great pioneers in the autism world and first described the 'triad of impairments'. So I had my first lesson from the top!). The children were, of course, autistic, and that was when my association – and, in some ways, fascination – with autism began.

Your work within the autism community has grown substantially since that initial encounter. What has led up to your heightened level of involvement?

Soon after that day, I was asked by the National Autistic Society (NAS) to open a new playgroup they were going to run in a room at their head office for some local children with autism, and I was only too happy to do so. While I was there I learned even more about the condition, and spent quite some time with the children.

Clearly, although autism can be extremely distressing, even devastating, for those affected and their families, it also entails a way of seeing and interacting with the world that is extremely interesting and makes one consider just what we neurotypicals take for granted and consider "normal." I have huge sympathy with the view of much of the Asperger community that the autistic way of looking at things is just as, or in some ways more than, valid as that of the rest of us. The way neurotypicals talk nonsense in 'social communication' for instance (whether it's talking about the weather or casually lying without thinking twice). I found myself becoming more and more intrigued and interested - and, gradually, more knowledgeable and engaged.

Eventually I found I could be useful to the NAS by not only visiting schools and residential units and hopefully gaining a little publicity and spreading awareness, but also by speaking about autism to people who might know nothing about it or who could provide us with valuable

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## Interview with Jane Asher continued...

(Continued from page 4)

funding. Once drawn into the world of autism, few of us ever leave it!

You are very knowledgeable about the fact that there are so many unsubstantiated treatments for autism, many of which are dangerous. Most lay people have no idea that this is a huge challenge for the autism community as a whole, particularly for parents of newly-diagnosed children who are looking for clear answers and expert guidance. What is the experience like for parents of newly-diagnosed children in the UK?

You are so right about the many unsubstantiated 'treatments' even 'cures' - that are suggested for autism (as, indeed, they are for so many other conditions). It's so hard for any parent or caregiver to have their child diagnosed with an incurable condition that it's unsurprising that many turn to alternative or complementary therapies. There are large numbers of these therapies which can be divided into several rough categories; from manipulation of various parts of the body to the channelling of 'energy fields,' from the removal of mercury from the body to changes in diet. Few of these therapies are supported by any clinical research, but you can easily see how a desperate parent might leap at the idea of some 'miracle cure' highlighted in one of the tabloids something that sadly happens only too often. Some of these interventions are positively

harmful; but with autism being such an individual and variable condition it can be very difficult to construct standardised, double -blind clinical trials.

In the UK, particularly in the current economic climate, it can be hard enough - still - to access a diagnosis of autism, and even harder to access the correct educational and social support that is the statutory right of every child with a disability. You can well understand why people turn to unconventional theories and implausible interventions. As a doctor's daughter, naturally I fear for those who make such uninformed choices and only wish that everyone had access to someone with genuine understanding and knowledge of this condition and its possible interventions. It's vital that a fully informed choice is made. Parents and medical practitioners should be aware of the extent to which a particular intervention has been shown to be safe and effective in peer-reviewed scientific studies. So much is anecdotal (even the very popular gluten-free diet has not yet been shown to be effective in scientific studies, and



Jane with one of the children at the National Autistic Society's Sybil Elgar School.

it may even be that such restricted diets are potentially harmful).

At the NAS we work very hard in lobbying government and local authorities to do more for those with autism (the Autism Act was a recent triumph in at least putting the case for adults with autism clearly on the agenda), but there is a long way to go. Not enough doctors, psychologists, nurses or educationalists understand the complexities surrounding autism, let alone know just what it may take to offer the best possible hope of an improvement in symptoms and a maximisation of the potential of the individual. Every person with autism will show the effects of their condition differently and there will never be one solution that will work for all.

Here in the United States, families are bombarded by information on the internet much of which is grossly inaccurate. Where can UK families turn for accurate information?

In the UK there is excellent information available nowadays, firstly via the National Autistic Society (particularly on our website, www.autism.org.uk), which is easily accessible and puts across a balanced view of just what the parents of newlydiagnosed children should be trying to access in order to help give their child the best possible outcome (also for newly diagnosed adults of course). There is also the other organisation that I support, Research Autism.

www.researchautism.net, that

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## Interview with Jane Asher continued...

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specifically researches interventions in autism and gives balanced and scientifically-based information on just what appears to help, and - maybe more importantly - what has no basis for claiming to do so. So the information is there, but naturally again, as with cancers, degenerative diseases and other serious conditions, you will never stop people from searching for an answer; especially for that elusive 'cure'; and we can all become irrational when confronted with something so potentially devastating and for which there is no easy or obvious way forward.

As an actress, there must be so many different organizations lining up to ask for your help. We are so grateful that you have chosen to use your celebrity status to support the development and testing of science-based treatments. The concept that science is crucial in terms of treatment for people with autism is much more complex than simply supporting any organization that helps children with autism swim with dolphins or access some other specific treatment. Do you have a background in science? How did you become so involved in this particular issue (advocating for science-based treatment)?

That's an interesting question! I suspect it is largely due to the influence of my father, Dr Richard Asher, a consultant endocrinologist who was renowned for his rational and well-informed approach to the complex field of medicine (and for his witty and inspirational lecturing and writing: his ex-students include Oliver Sacks and the British doctor/theatre director Jonathan Miller). I've grown up fascinated and enthralled by science, and get very

depressed when its wonders are ignored and pushed aside by pseudo-science or fantasy. For many years I was a patron of another organisation of which I was very proud - SIMR, which campaigned for public understanding of the need for animal research. This organization was started by a young man with Friedrich's Ataxia, who was deeply frustrated by the actions of the antivivisectionists. He sadly died a few years ago after many years of excruciating pain and other problems. So I guess the subject of promoting the understanding of science is a subject generally very close to my heart.

Due to your knowledge in this area, do you have a *vision* about how we need to go about educating professionals, paraprofessionals and laypersons about the importance of following the science before subjecting a person with autism to a treatment?

No specific vision I fear... it's all part of the major problem that I've touched on in the previous paragraph. How do we combat the rather fascinating, but ultimately extremely damaging, instinct and tendency of the human species to believe in things for which there is absolutely no evidence- whether it be the supernatural, rituals, luck, magic or other paranormal areas, or 'miracle cures' and their like rather than trusting science and modern medicine? And, as I mentioned before, it's particularly difficult to target the strong instinct of a parent to try almost anything, no matter how expensive and/or unproven, in the desperate search for something to help their child. We all know how easy it is to make completely erroneous deductions from what appears to be clear evidence, and I'm sure if I had had



Jane with Dr. Lorna Wing

a child with autism who had been speaking and behaving in a neurotypical way up to the time of an MMR jab and who had soon thereafter developed autism, it would have been only too easy to have come to a totally misguided conclusion. We just need more people spreading the word about the only approaches to autism that appear to make a difference, and even that is not really researched enough to give unequivocal results. As with so many important causes, money comes into this, and also the teaching of science in schools, which has not been as good as it should be in the UK for some years. For anyone keen to learn more, I highly recommend an Open University course that I took a couple of years ago - 'Autism in the 21st Century' - which is a beautifully constructed, scientifically-based module that really brought my information up to date.

Finally, do you have any advice for parents of newly-diagnosed children?

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## Interview with Jane Asher continued...

Naturally it can be very distressing for any parents to have their child diagnosed with autism, but I think it's really important to see that as the first achievement in making the best possible life for him or her. Without a diagnosis it's impossible to access whatever support and education may be the best way forward. It's important, too, to understand exactly what the diagnosis means - the word autism now covers such a very broad spectrum of conditions. It's vital to know exactly which one the child has and whereabouts on the range of ability the condition falls. Early intervention can make a real difference and if parents are not automatically put in touch with them, then it's a good first step to contact the local social and educational services - they'll be the key contacts for providing what may

be needed. But I'm not going to say it's easy - even if the best possible school is found, for example, it can be a legal and emotional nightmare getting the funding put in place to access it. And this is why it can be so tempting to try an unsubstantiated intervention that may be easily available, but I'd definitely recommend that before trying anything, a call is made to the NAS helpline. They can put parents in touch with the right person to help them. There's also a very helpful leaflet on the website 'After Diagnosis' to download. For sure I'd say don't try anything that hasn't been recommended by a medical professional before checking for certain that it will do no harm and that it won't interfere with accessing something that can really make a difference. Above all, with the knowledge that we now possess, I

think it's worth saying that, although children with autism will grow up to be adults with autism, there is much to be done to ensure that they can live lives of dignity and fulfilment. Families in the UK can contact the National Autistic Society Helpline: 0808 800 4104 (Monday-Friday 10am – 4pm).

On behalf of the Association for Science in Autism Treatment, I want to thank you, Ms. Asher, for taking time from your very busy schedule to participate in this interview. The autism community in the UK is very fortunate to benefit from your time and talent, particularly given your strong adherence to the notion that science matters and that research should guide decision-making. We certainly hope our paths cross again!

## From the Archives (Summer 2012 Issue):

## Top 10 Questions Journalists Should Ask Before Writing the Next Autism Story

- **#1** Are there any published research articles in peer-reviewed journals documenting the efficacy of the intervention method featured in my article or I am just finding hopeful testimonials? If not, why not, and how should I pitch my article given the absence of supporting research? If so, are the studies well designed?
- **#2** Who am I interviewing for this story and what are his/her qualifications? What does (s)he stand to gain by this interview? Is (s)he making claims of efficacy or effectiveness that are not supported by scientific data?
- #3 Is there any evidence of harm associated with this intervention? What are the risks?
- #4 How much does the intervention cost? Is the cost reasonable? How is it paid?
- **#5** What kind of training and supervision do treatment providers need to have before implementing the intervention? If none or little, have I explored the ethics involved and asked if there is adequate consumer protection?
- #6 What position statements from respected professional organizations support or do not support this?
- **#7** Are already science-based interventions (such as applied behavior analysis) recommended by these organizations?
- #8 Have I consulted with an unbiased entity for their input?
- **#9** As described or discussed in this article, "Does the intervention encourage false hope or suggest unrealistic benefits for a family coping with a pervasive developmental disability?"
- **#10** Have I provided readers with related resources and references that are objective, science-based, and minimize the risk of coercion or manipulation?

## Research Reviews

In this newsletter, we have two very interesting article summaries. The first article summarized research conducted by ASAT's own Vice President Dr. Florence D. DiGennaro Reed and her colleague on an evaluation of therapeutic horseback riding. The second review summarized research conducted by Tanaka and colleagues on the effectiveness of computer-based intervention in establishing facial recognition skills. We hope you enjoy these summaries and find them informative!

Sharon A. Reeve, Ph.D., BCBA-D

Research Corner Coordinator

# An Experimental Analysis of the Effects of Therapeutic Horseback Riding on the Behavior of Children with Autism.

Jenkins, S. R., & DiGennaro Reed, F. D. (2013). An experimental analysis of the effects of therapeutic horseback riding on the behavior of children with autism. Research in Autism Spectrum Disorders, 7, 721-740. doi: 10.1016/j.rasd.2013.02.008

Reviewed by: ToniAnne Giunta, M.A., BCBA, Caldwell College

## Why review this topic?

Therapeutic horseback riding (THR), which involves teaching horsemanship skills (e.g., holding a horse's reins, controlling the horse with voice commands, using basic riding skills), has been reported to relieve symptoms in a variety of domains, including socialization, self-regulation behaviors, expressive language, and motor skills. Existing studies, however, have had significant limitations. For example, investigators have relied solely on parent ratings, instead of including other types of measures such as direct observations of children's behavior. Also, THR has implemented in conjunction with other interventions (e.g., programmed reinforcement), making it difficult to determine the effects of THR by itself. The present study selected behaviors similar to those analyzed in previous studies, but used more direct observations and a sound experimental design.

## What did the researchers do?

Seven children with autism, ages 6-14 years, participated in the study over nine weeks. Four

participants were assigned to a treatment group that included a non-treatment baseline phase followed by weekly 60-min THR therapy sessions, and three participants were assigned to a waitlist control group in which no treatment was given. In the treatment group, treatment started at differing times for each participant, allowing for an experimental test of whether the introduction of treatment rather than the passage of time was associated with any behavior changes made by the participants. The following behaviors were observed during academic, art, game, and snack centers at an after-school program and in participant homes: (a) happy versus unhappy affect, (b) spontaneous initiations, (c) responses to initiations, (d) off-task behavior, (e) compliance, and (f) problem behavior. For participants in the treatment group, the above behaviors were also measured during THR sessions, in addition to vocal/gestural commands to direct the horse and their posture. For all participants, pre- and posttests on standardized assessments (The Child Behavior Checklist, CBCL/6-18; Teacher Rating Form, TRF) were also supplemented for comparison.

#### What did the researchers find?

Participants in the treatment group showed minimal to no differences in all the behaviors measured during the center-based activities and home visits (affect, spontaneous and responses to initiations, off-task behavior, compliance, problem behavior) when comparing the baseline phase to THR treatment phase. Furthermore, their behavior levels throughout the study were comparable to the participants in the control group, who did not receive THR treatment at all. During the THR sessions, the researchers

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## Research Review Continued...

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detected some improvement in all participants for overall posture improved for all participants. However, responses to initiations and rate of vocal/gestural commands to the horse remained unchanged, spontaneous initiations either remained unchanged or decreased, and compliance either remained unchanged or improved. For three of the four participants, problem behaviors were low during THR sessions. Two of the four participants in the treatment group, as well as all three participants in the control group, showed improvements in their CBCL scores from pre- to post-tests. Three of four participants in the treatment group and one of three in the control group showed some improvement in TRF scores.

## What are the strengths and limitations of the study?

The study examined an already-established treatment program (THR) yet failed to replicate the previous studies' positive effects, likely because of the direct and repeated measurement used (as opposed to subjective self-reports used previously). Limiting factors to this study included a shorter amount of exposure to THR than in previous studies, lessons that somewhat differed from previous studies, and minimal loss of data from a few sessions.

#### What do the results mean?

THR did not produce clinically significant effects or meaningful improvements in any of the measured behaviors in both the center-based and home activities, contrary to previous research and testimonials. Children who received THR showed improvements on the CBCL and TRF, but so did children in a waitlist control group. Therefore, it cannot be concluded that THR was responsible for the changes noted in the participants on these measures. Although it may be possible to find an appropriate use of THR in future studies (e.g. attending a THR session after earning tokens during academic programming), therapeutic horseback riding is not recommended as a treatment for addressing symptoms of ASD.

## Using Computerized Games to Teach Face Recognition Skills to Children with Autism Spectrum Disorder: the Let's Face It! Program.

Tanaka, J.W., Wolf, J.M., Klaiman, C., Koenig, K., Cockburn, J., Herlihy, L., Brown, C., Stahl, S., Kaiser, M.D., & Schultz, R.T. (2010). Using computerized games to teach face recognition skills to children with autism spectrum disorder: the Let's Face It! program. Journal of Child Psychology and Psychiatry, 51 (8), 944-952.

Reviewed By: Jaime Mulcahy, Rutgers University

### Why study this topic?

Prior research indicates that children with autism spectrum disorders have selective impairments in attending to and recognizing faces as compared to typically developing peers. Some research has suggested that these impairments may be at the root of the social dysfunction associated with ASD. Despite this finding, little research has been published to show whether facial recognition in individuals with autism can be improved through direct training.

#### What did the researchers do?

The researchers in this study evaluated the effectiveness of the *Let's Face It! (LFI!)* computer program in enhancing the facial recognition skills of children with autism. The *LFI!* program consists of seven interactive computer games that address the following face processing deficits associated with autism: inattention to the eyes, impaired recognition of identity, and failure to perceive faces holistically. The games employed engaging graphics and music as well as high-score tables to increase the children's

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## Research Review Continued...

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motivation to use the program.

Participants in this study included 79 children, adolescents, and young adults with autism spectrum disorders. Before beginning the study, participants' facial recognition skills were assessed using the LFI! Skills Battery, a computerbased battery that assesses perception of facial identity across various tasks. Participants were then randomly assigned to either an active treatment group or a waitlist control group (with randomization stratified by mental age and diagnosis). Individuals in the active control group received the LFI! computer game to take home and were instructed to play the games for a minimum of 100 minutes per week. Play within that time was self-paced and not directly monitored by the parents or caregivers. However, families of the participants were provided with a set of plastic token reinforcers to use to increase motivation to comply with the intervention. Compliance was monitored by the researchers through weekly log files generated by the LFI! software. Participants continued with the program until total intervention time reached 20 hours (over a two- to four-month period). Individuals assigned to the waitlist control group underwent treatment as usual for a comparable period of time. Upon completion of the intervention period, the LFI! skills battery was re-administered to both the treatment and control groups.

#### What did the researchers find?

Compared to the waitlist control group,

participants in the active treatment group showed significant improvement in analytic and holistic face processing skills. Specifically, recognition of eye and face features was enhanced, with the greatest improvements shown in analytic recognition when the face parts were tested in isolation. However, participants in the active treatment group did not show significant gains relative to the control group in the following areas: detecting featural and configural face changes, identifying faces across changes in expression and orientation, and recognizing faces over a short retention.

## What were the strengths and limitations of the study? What do the results mean?

The results indicate that improvements in facial recognition abilities of children with autism can be achieved through computer-based intervention. This is the first time that such results have been shown through a large-scale clinical trial. The use of a computer-based intervention has the benefits of being inexpensive, easy to implement in home or school settings, and not requiring direct supervision of the participants. The fact that participants in this study did not improve in certain areas of facial recognition, some of which are important in social settings, suggests that some improvements may need to be made to the Let's Face It! program, or that a longer length of treatment may be necessary for improved results. However, this study provides a first step toward developing a more comprehensive program to improve the facial recognition and processing skills of individuals with autism.

## Treatment Summary: Rapid Prompting Method (RPM)

**Description**: In the Rapid Prompting Method (RPM), practitioners attempt to compensate for the assumed sensory overload and apraxia in children with ASD by continually speaking and requesting responses so that the children stay attentive. They may attach writing implements to children's wrists and prompt the children to type out messages.

Examples: Rapid Prompting Method, Soma, Alphabet Therapy

**Research Summary**: There have been no scientific studies of rapid prompting for individuals with autism spectrum disorders.

**Recommendations**: Researchers may wish to conduct studies with strong scientific designs to evaluate rapid prompting method. Professionals should present rapid prompting method as untested and encourage families who are considering this intervention to evaluate it carefully.

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	\$800 per issue	\$400 perissue	\$400 perissue	\$480 perissue	\$480 per issue	\$640 per issue
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# ASAT Coordinators, Externs, and Committee Members

In addition to our Advisory Board a number of Coordinator, Externs, and other Volunteers lend their time and talents to support ASAT's mission and initiatives. These are our helping hands.

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Website Newsletter Content Science in Autism Treatment Kerry Ann Conde, MS, BCBA Caroline Simard-Nicolas, MS, BCBA Amanda Wadsworth, MSEd, BCBA





## Coming up in the Fall 2013 Issue of Science in Autism Treatment!

- Research Summaries, including one on <u>environmental enrichment as a treatment for autism</u>;
- Clinical Corner installment on <u>autism genetics and recurrence risk in families;</u>
- Book Review of <u>Behavioral Foundations of Effective Autism Treatment</u> (Mayville and Mullick, 2010), by David Celiberti;
- Book Review of <u>Do You Believe in Magic? The Sense and Nonsense of Alternative Medicine,</u> (Offit, 2013), by Dr. Lori Ernsperger;
- Interview with Dr. Joyce Mauk, ASAT Advisory Board Member;
- Interview with <u>international service provider, Pooja Panesar</u>, from Nairobi, Kenya. And so much more! Subscribe today at <u>www.asatonline.org/signup</u>



## 15 Ways to Celebrate ASAT's 15th Anniversary:

Bid, bid, bid (and encourage others to do the same)! The Association for Science in Autism Treatment ASAT is hosting an online auction through *Bidding for Good* to celebrate our 15<sup>th</sup> = anniversary. We have over two-dozen great items for sports fans, entertainment enthusiasts, as well as those seeking professional resources and training opportunities related to autism treatment. Some of our great silent ღ auction items include autographed albums by Bruce Springsteen and the Rolling Stones, a Marc Jacobs handbag, sports memorabilia signed by the very best, and registration to the upcoming Autism New Jersey conference in signed by the very best, and registration to the

Atlantic City to name a few!

https://www.biddingforgoo
AuctionHome.action?auctio

If you are interested, there is https://www.biddingforgood.com/auction/ AuctionHome.action?auctionId=199297297

If you are interested, there is still time to donate an item for the online auction. Please email dceliberti@asatonline.org

#### #2

"Like" ASAT on Facebook and encourage others to do the same so we can surpass our 7,000 fan goal for 2013 (https:// www.facebook.com/ASATonline). See updates from ASAT, Media Watch announcements, and information about upcoming conferences. We welcome your active participation and encourage you to post comments and share content with your own friends on Facebook.

## #3

Follow ASAT on Twitter <a href="https://twitter.com/">https://twitter.com/</a> asatonline and retweet our posts. We have 843 followers. Help us surpass our 2013 goal of 1,000 followers.

### #4

Purchase a t-shirt at "Kettlebells 4 Autism" online store (http://kettlebells4autism.com/ shop/). A portion of their proceeds will be donated to Association for #Science in #Autism Treatment. You can read more about this effort on page 26.

## #5

Support ASAT by purchasing quick, delicious drinks, snacks, spices, soups, and more from Tastefully Simple (www.ts4asat.com) and 15% of your sales go to ASAT! Don't forget to 'like" the Facebook page for this fundraiser and 'share' to spread the word!!

www.facebook.com/TastefullySimpleASAT

#### #6

Email ASAT's newsletter link to 15 friends and colleagues and encourage them to sign up for our free, informative quarterly newsletter (http://www.asatonline.org/newsletters/ signup). If you do, our 2013 goal of 10,000 subscribers will be quickly realized. Since the summer of 2009, we have published 16 issues of our newsletter, Science in Autism Treatment, which now has over 8,000 subscribers.

## #7

Support Team ASAT in the 2013 NYC marathon on November 3! The Association for #Science in #Autism Treatment is participating in the marathon. You can donate money on behalf of the individual runners of Team ASAT (http://www.crowdrise.com/ ASATnyc2013)

#### #8

Help celebrate our 15<sup>th</sup> anniversary by volunteering for the Association for #Science in #Autism Treatment. ASAT's success rests on the volunteer service of family members, professionals, and community members. Do you have a special talent or a little time to offer our organization? If you are interested, please visit http://asatonline.org/about asat/

## 15 Ways to Celebrate ASAT's 15th Anniversary Continued ...

## volunteer.html

## #9

Display ASAT donation jars at a wide array of business establishments to help educate consumers and to raise money to support our mission. We encourage you to place a donation jar in your place of business! ASAT will provide the materials needed (donation jars, an ASAT information insert card for the jar, business cards, and signage) for any participating business. Contact <a href="mailto:asatevents@aol.com">asatevents@aol.com</a> for arrangements. You can read newsletter articles about participating businesses at <a href="mailto:http://">http://</a>

asatonline.org/about asat/ raising.html fund-In honor of our 15th anniversary, please encourage 15 friends to donate \$15 to the Association for Science **Autism Treatment** (through http://fundly.com/ asatonline). These funds will support a wide array of initiatives including the development and distribution of materials to educate medical professionals about evidence-based treatment.

#### #11

Help us identify new newsletter subscribers at your place of business. Please download a sign up sheet at <a href="http://asatonline.org/pdf/subscribeme.pdf">http://asatonline.org/pdf/subscribeme.pdf</a>. You can scan completed sheets and email to <a href="mailto:newsletter@asatonline.org">newsletter@asatonline.org</a> or mail to ASAT PO Box 3250 Hoboken, NJ 07030

#### #12

Show your support for ASAT <u>and</u> enjoy the benefits of being a sponsor, including recognition and online or newsletter advertisements! We have two types of sponsorship options each with several levels: professional (<a href="http://asatonline.org/about\_asat/professional-sponsors#learn">http://asatonline.org/about\_asat/professional-sponsors#learn</a>) or community (<a href="http://asatonline.org/about\_asat/community-sponsors">http://asatonline.org/about\_asat/community-sponsors</a>). Please also encourage your supervisor or provider to do the same.

## #13

Help ASAT celebrate its 15<sup>th</sup> anniversary by proudly displaying our brochures or other promotional materials in your workplace or other venues, such as coffee shops and bookstores. Doing so will spread the word about ASAT and the importance of science in the treatment of autism. If you are interested, please contact <a href="mailto:dceliberti@asatonline.org">dceliberti@asatonline.org</a>.

### #14

Be a proud supporter of our mission by distributing ASAT's flyer or brochure to medical providers and educators in your community. If you are interested, please contact <u>dceliberti@asatonline.org</u>.

#### #15

You can help spread ASAT's message of the importance of science in the treatment of autism! At your next professional event, include a slide about ASAT at the end of your presentation or distribute sign-up sheets for our free quarterly newsletter. If you are interested, please email us at info@asatonline.org.

## Team ASAT is Going the Distance!



ASAT is looking forward to participating in the NYC marathon because this year the NYC marathon will have more meaning than ever before. This will be the first post-Sandy NYC marathon and the first since the Boston terror attack. On November 3, 2013, Team ASAT will proudly be at the NYC Marathon, ready to run.

The first New York City Marathon in 1970 was a relatively small event with a course contained within Central Park, and only 55 runners crossed the finish line. In 1976 Fred Lebow revised the race to course through all five boroughs from Staten Island through Brooklyn, Queens, and the Bronx to Manhattan.

This prominent event is now one of the world's greatest marathons, pursued by more than 100,000 applicants annually. As stated on their website <a href="www.nycmarathon.org">www.nycmarathon.org</a>, "The race attracts many world-class professional athletes, not only for the more than \$600,000 in prize money, but also for the chance to excel in the media capital of the world before two million cheering spectators and 315 million worldwide television viewers. As any one of the more than 700,000 past participants will attest, crossing the finish line in Central Park is one of the great thrills of a lifetime.

This great event will be Team ASAT's first NYC marathon. ASAT's mission is to disseminate information regarding evidence-based treatments for the Autism Spectrum Disorders. ASAT is committed to helping parents, providers, and other consumers understand the difference between sensational claims of how to help or cure autism versus science-based research that guides effective intervention.



**Bobby Newman** 

ASAT is looking forward to the NYC Marathon and hopes you will consider supporting Team ASAT, by checking out our runners' Crowdrise links, where individual donations can be made. Team ASAT is made up of Bobby Newman, Randy Horowitz, Sheila Jodlowski, Alex and Jamie Schneider, and ASAT board member

Barbara Wells Reimann. We are very excited to share a bit of background about our runners:

Bobby Newman serves as Team ASAT's captain and has been working in the field of Applied Behavior Analysis for over 25 years. His books are popular introductions to ABA and the Autism Spectrum Disorders. This is Bobby's tenth marathon and second NYC, following in the footsteps of his marathoner father, Leo Newman.

Randy Horowitz is the Associate Executive Director at Eden II Programs.



Randy Horowitz

(Continued on page 17)

## Team ASAT is Going the Distance! Continued...

Ms. Horowitz has a Master of Science in Education from Queens College and Certificate of School Administration from the College of New Rochelle. She is an adjunct lecturer at Queens College and has presented at local, national and international conferences on topics relating to educating students with autism.

Sheila Jodlowski has been working with children with autistic spectrum disorders for more than 15 years. She received her doctorate in Behavior Analysis from Teachers College Columbia University. She provides academic and behavior management consulting services for families in Westchester, Putnam, Dutchess, Orange and Columbia counties. You can support Sheila on her Crowdrise page <a href="http://www.crowdrise.com/ASATnyc2013/fundraiser/sheilajodlowski">http://www.crowdrise.com/ASATnyc2013/fundraiser/sheilajodlowski</a> and contribute to her goal!

Alex and Jamie Schneider are 23 year old identical twins. Each is profoundly autistic with limited communication skills or understanding of safety in the community. However, both are accomplished runners and love to run! Both young men have completed five marathons to date, including two Boston Marathons, two Hamptons Marathons, and one Marine Corp Marathon. The New York City Marathon will be their sixth; and for the first time they will be running to raise funds for ASAT. Alex in particular has an incredible gift of speed when he races; he just recently completed the 2013 Boston Marathon in 3 hours and 23 minutes. Alex and Jamie are not able to run alone. They will be running with guides whose sole responsibilities are to set the pace, help the boys navigate the course and hydrate when needed. If not for the altruism of the running guides, the Schneider twins would not be able to compete in these races. To support them, visit <a href="http://www.crowdrise.com/">http://www.crowdrise.com/</a> ASATnyc2013/fundraiser/alexandjamieschneider To read more about the Schneider twins, please visit www.autismrunners.com.



Barbara Wells Reimann



Sheila Jodlowski



Barbara Wells Reimann has been an integral member ASAT's Board of Directors since 2006 and currently

serves as the Treasurer. She is a mother Alex and Jamie Schneider of an adult son with autism and dedicated her life to promoting evidence-based interventions for individuals with autism. Help Barbara reach her goal by donating on her Crowdrise page at <a href="http://www.crowdrise.com/ASATnyc2013/fundraiser/barbarawells1">http://www.crowdrise.com/ASATnyc2013/fundraiser/barbarawells1</a>.

Please consider joining us on November 3<sup>rd</sup> to help cheer on and support Team ASAT!

## **Pennies DO Make Dollars:**

## Demonstrated by Maine Dairy Queen Owners Each and Every Day David Celiberti, Ph.D., BCBA-D

On behalf of the Board of Directors of ASAT, I would like to take this moment to express our heartfelt gratitude to Larry and Kathy Hannon, owners of Dairy Queen stores in three locations in Maine: in the Bangor Mall, in Old Town, and in Freeport. The Hannons recently made a \$1,500 donation to ASAT and through the generous support and patronage of Dairy Queen customers over the last 4 years, have raised almost \$10,000 from donation jars placed on their counters and at their drivethru window!

This story would be incomplete without a bit of background. Seven years ago, the Hannon's daughter was diagnosed with autism. The evaluating psychologist informed the Hannons that her prognosis was quite poor, and that she may not learn to talk. Fortunately, their daughter was already enrolled in an inclusive preschool with a team of people, well versed in Applied Behavior Analysis, incorporating a broad spectrum of effective teaching techniques, intensive one-on-one instruction, related



ASAT donation jar

services by providers committed to collaboration, reverse mainstreaming to provide meaningful and structured opportunities for skills to generalize within interactions with typically developing peers, and carefully planned and delivered shadowing in the classroom. Almost immediately, the Hannons observed that their daughter was acquiring important skills and was responding very favorably to treatment. Fast forward 7 years and she has blossomed into a fun-loving, inquisitive young lady with a beautiful singing voice and honor roll grades. She has just completed fourth grade and participates in a general education classroom and curriculum for most of the day with fading supports.

Discovering ASAT through their internet research, the Hannons were comforted to know that they were on track and that the decisions they made for their daughter were not only scientifically sound, but demonstrated best practice. Back in 2009, Larry was quoted as saying, "I'm a realist- I believe in facts -but sometimes parents don't know if the information they find online is fact or fiction. This is why ASAT is such an important organization for the autism community." Today, Larry elaborates, "The only appropriate education is an effective one — one based in science. It is so sad that many families will get stuck in their pursuit of miracle cures."

As the years pile on, Larry and Kathy's commitment to giving back to ASAT has been unwavering. Every April for Autism Awareness month, the Hannons set up tables displaying an array of information

about autism and best practices. Furthermore, they have shared hundreds of business cards and fliers showcasing ASAT's resources, such as our newsletter and website. Stay tuned for further updates from this wonderfully supportive and dedicated team from Maine. For those of you in Maine or traveling to Maine, please stop by the Bangor Mall, Old Town, or Freeport Dairy Queen and let Kathy and Larry Hannon know that you join us in our heartfelt appreciation of all they do to support families, to raise awareness, and to help every person with autism have a greater chance of accessing science-based treatment. And while you are there, buy yourself a Blizzard!



Austism Awareness Month display table

## **2nd Annual Conference**

# Big Thank You to Our Partners

On Friday, June 7th, the Association for Science in Autism Treatment, in conjunction with Achieve



Beyond, held its second annual Autism conference. This all day conference took place in Flushing, NY and was attended by over 80 parents and professionals. We were able to offer 4.5 BACB Type II CEUs to behavior analysts.

This educational event featured several vendors, networking opportunities, and presentations by ASAT board members, including keynote speaker Daniel W. Mruzek, PhD, BCBA-D., Mary E. McDonald PhD., BCBA-D and Ruth Donlin, MS. Presentations included a range of treatment related topics, including:

## Scientist-Practitioners in the Classroom: Using Data to Guide Our Students' Progress:

Daniel W. Mruzek, PhD., BCBA-D

In an age when educators and school-based therapists increasingly feel the pinch of growing demands, decreased resources, and busier school days, Dr. Mruzek discussed how to use the methods of science to promote progress for learners with autism. He brought together examples of "real world" educational conundrums and offered science-based solutions. Most importantly, he reviewed key principles of the scientific method and how they can be used to aid decision-making, measure outcomes and plan next steps in the promotion of our students' independence and quality of life.

## Increasing Flexibility in Students with Autism Spectrum Disorders:

Mary E. McDonald, PhD., BCBA-D

Dr. McDonald provided an overview of behavioral and cognitive flexibility and the importance of focusing on these areas with students with ASD, who often adhere to fixed routines, rote repetitive responding, or appear to have limited repertoires of responses. This workshop focused on research in cognitive and behavioral flexibility and provided specific practical strategies for improving behavioral and cognitive flexibility in individuals with ASD.

## Using Research to Increase Intervention Outcomes for Visual Learners

Ruth Donlin, MS

Ms. Donlin described how individuals with autism struggle to infer meaning and context in social interactions and in nonverbal communication. The neurological functioning of the brain and the ability to understand and build social and emotional awareness were discussed. This presentation highlighted research regarding what individuals with autism tend to focus upon in social and emotional situations, as well as the corresponding treatment implications.

Achieve Beyond provides pediatric therapy and educational services to children, students, and families throughout the United States including the greater Los Angeles, California (CA) area, northern Virginia (VA) / Maryland / DC area, the greater Dallas, Texas (TX) area and New York (NY). These services include: Speech Language Therapy, Occupational Therapy, Physical Therapy, Special Education, Autism Services, Behavior Consultation, and Counseling. For more information, please visit <a href="https://www.achievebeyondusa.com">www.achievebeyondusa.com</a>.

## Do You Believe in Science-Based Autism Treatment? So Do We. How About a Volunteer Opportunity with ASAT? Lauren Schnell, M.Ed., BCBA, ASAT Externship Coordinator

The great work that ASAT does in promoting science-based treatment for individuals with autism could not happen without our volunteers. Currently, ASAT has over 40 volunteers and externs who work tirelessly to fulfill their commitment to evidence-based autism treatment. Volunteers have the opportunity for professional growth and networking through collaboration with an array of knowledgeable, seasoned professionals who aim to promote the advancement of science-based treatments for autism.

There are many important roles that volunteers play within the organization. Some of these activities include, but are not limited to:

- Helping to promote our website, www.asatonline.org;
- Helping to promote our newsletter, Science in Autism Treatment;
- Writing journal article synopses and other content related to autism treatment:

"I am honored to be involved with an organization that is committed to helping families and professionals draw the line between unsubstantiated treatment options and behavior analytic interventions, grounded in the best available scientific evidence. Working alongside knowledgeable board members has provided me with many valuable research, writing, and social media opportunities. Thank you ASAT!" ~ Leanne Tull (Toronto, Canada)

- Monitoring and/or responding to misinformation from the media and promoting accurate information through our Media Watch efforts;
- Reviewing website content and monitoring website navigation;
- Helping to compile and update links and resources for visitors to our website;
- Creating databases; and
- Participating in and assisting with fundraising activities.

To learn more please see our <u>Volunteer Announcement</u>. If you are interested in becoming a volunteer, please submit the <u>ASAT Volunteer Application</u>. It is important that volunteers communicate their specific interests so that their service to ASAT can be a mutually satisfying experience.

If you are interested in a more extensive and structured experience, please consider a 150 hour Externship with ASAT. We accept Externs with a wide arrange of backgrounds from high school

through advanced graduate training. Externship activities revolve around the following:

- Writing for our quarterly newsletter or for our website (e,g., Clinical Corner);
- Proofreading content of our quarterly newsletter;
- Learning how to critically evaluate published re-

(Continued on page 21)

"The Externship has been a valuable professional experience that has helped me to develop a variety of professional skills while also contributing in a meaningful way to the dissemination of quality information on science-based autism treatment. " ~ Elizabeth Callahan (Hoboken, New Jersey)

## Do You Believe in Science-Based Autism Treatment? Continued...

(Continued from page 20)

#### search:

- Learning about grant writing and participating in all aspects of the process starting with grant research and selection, and culminating in actual submission;
- Learning how to evaluate and critique media representations of autism treatment;
- Learning about fundraising conceptualization, development, and execution both at the community and national levels:
- Actively participating in social media and learning about its use to convey information to the autism community;
- Learning about autism services in other parts of the world and engaging in efforts to promote dissemination and awareness of science-based treatments:
- Working alongside Board Members in an array of writing, editing and fundraising activities; and
- Participating in monthly Extern conference calls to share ideas, update on externship activities, and dis-

"Working with ASAT has been a great experience. I've had the opportunity to use my strengths and build upon them by writing in the newsletter, learning about the grant application process, and collaborating with other team members. Most of all, my experience has enhanced my skepticism and ability to look for the facts." ~ Alice Walkup (Los Angeles, California)



## **Consumer Corner: The DSM-5**

The long awaited and highly anticipated Diagnostic and Statistical Manual of Mental Disorders (DSM-5) has arrived. However, the shift in diagnostic criteria for Autism Spectrum Disorders (ASDs) has certainly evoked some questions and confusion among parents, professionals, and educators. In this issue of Consumer Corner, Leanne Tull will attempt to address the various issues that have arisen due to the DSM -5. Readers will find a link to a more extensive article on the subject at the end of this piece.

Sabrina Freeman, PhD
Consumer Corner Coordinator

## Why was the ASD diagnostic criteria revised?

By: Leanne Tull, M.ADS, BCBA

The DSM-IV-TR describes Pervasive Developmental Disorder (PDD) as the diagnostic umbrella, with five subtypes: 1) Autistic Disorder; 2) Asperger's Disorder; 3) Rett's Disorder; 4) Childhood Disintegrative Disorder; and 5) PDD-NOS ("Not-Otherwise-Specified"). The aim of the DSM-5 is to improve diagnostic criteria that are not

precise, such as combining subgroups of ASD and reducing diagnoses currently called "Not Otherwise Specified". The DSM-5 reduces the well-known triad of impairments to a dyad:

Impairment of social interaction and communication (now regarded as one combined domain); and restricted repetitive and stereotyped patterns of behavior (Wing, Gould, & Gillberg, 2011).

Despite a reduction in underlying impairments, the latest diagnostic criteria expand to include four symptom domains. To diagnose ASD, all of the four criteria must be met. Current research shows that DSM-5 diagnostic criteria may, when compared to earlier DSM editions, alleviate or reduce over-diagnosis and misdiagnosis (Lord, Petkova, Hus, Gan, Lu, Martin, et al., 2012; McPartland, Reichow, & Volkmar, 2012), but it may also deny individuals with "sub-threshold disability" (i.e., individuals previously diagnosed with Asperger's Disorder) access to services.

## Where is the Asperger's Disorder diagnosis?

The "disappearance" of Asperger's Disorder has created a lot of confusion. DSM-IV-TR differences in communication and social deficits across Asperger's Disorder and autism were not clearly delineated. As a result, in the DSM-5 the disorder was removed as a possible diagnosis. Currently, we do not know whether Asperger's Disorder is genetically identical to, or distinct from, autism. To many parents, professionals, and educators, Asperger's Disorder describes a population of individuals who may respond to a different set of interventions than those with typical autism (e.g., cognitive behavioral intervention).

Many individuals and families affected by Asperger's Disorder fear losing a diagnosis could also result in a loss of benefits and services. Fortunately, a well-established DSM-IV diagnosis of Autistic Disorder, Asperger's Disorder, or PDD-NOS will likely be given the diagnosis of ASD. In addition, researchers anticipate that individuals who previously met diagnostic criteria for Asperger's Disorder may be moved into the new category of 'Social (pragmatic) Communication Disorder' (SCD) (Lai, Lombardo, Chakrabarti, & Baron-Cohen, 2013). Optimistic consumers hope there will be just as many services available for individuals diagnosed with SCD as there are for its well-recognized cousin, autism.

#### How will changes affect ASD prevalence rates?

With an estimated prevalence of 1 in 88 children, ASD is one of the most common neurodevelopmental disorders; however, the changes in DSM-5 diagnostic criteria may address a criticism of prior DSM

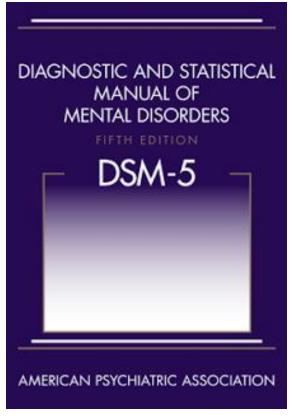
(Continued on page 23)

## The DSM-5 continued...

(Continued from page 22)

editions that have been associated with increased prevalence rates (McPartland et al., 2012). Researchers predict that the prevalence of ASD diagnoses will dramatically decrease with the introduction of the proposed DSM -5 criteria (Worley and Matson, 2012; Matson, Hattier, & Williams, 2012). Although the definition of autism, as a neurodevelopmental disorder, has certainly evolved, a large change in prevalence rates from the DSM-IV-TR to the DSM-5 should not be unexpected.

Despite these changes to the DSM-5 diagnostic criteria, at least one critical point remains the same: early detection of autism and timely, high-quality, science-based intervention is key to promoting optimal independence for individuals with ASD. The Center for Disease Control and Prevention provides a list of possible "red flags" for autism at <a href="http://www.cdc.gov/ncbddd/autism/signs.html">http://www.cdc.gov/ncbddd/autism/signs.html</a>. Parents and caretakers who have concerns about the social or communicative development of their child can review these "red flags" with their child's health care provider as part of their determination of whether or not additional testing is warranted.



For a more detailed analysis of the recent changes to the DSM, please <u>click</u> (<u>http://asatonline.org/resources/articles/dsm.htm</u>) to read the full length article on this topic.

#### References:

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## Shout Outs, Accolades, and Appreciations!

By Kerry Ann Conde, MS, BCBA

ASAT's mission is to promote safe, effective, science-based treatments for people with autism by disseminating accurate, timely, and scientifically sound information; advocating for the use of scientific methods to guide treatment; and combating unsubstantiated, inaccurate and false information about autism and its treatment. With this in mind, ASAT is striving to reach 10,000 subscribers by the end of the year. We are currently at 8,024 subscribers. Help us reach 10,000 subscribers by clicking on the following link: <a href="http://asatonline.org/newsletters/signup">http://asatonline.org/newsletters/signup</a>. You can also

ASATonline.

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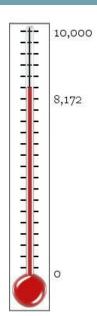
If you are a supervisor or administrator, please consider passing along a sign-up sheet to help us recruit new subscribers. We have an individual version and group version. After these are completed, they can be emailed to <a href="mailto:newslet-ter@asatonline.org">newslet-ter@asatonline.org</a> or mailed to ASAT PO Box 3250 Hoboken, New Jersey 07030.

"like" ASAT's Facebook page at <a href="https://www.facebook.com/">https://www.facebook.com/</a>

ASAT would also like to recognize those individuals and organizations who strive to support our mission. Specifically, we would like to thank and send a "shout out" to...

- ☆ Dr. Linda LeBlanc for forwarding the ASAT newsletter, SIAT, to all staff at Trumpet Behavioral Health
- ☆ Little Star Center in Indiana for providing a link to ASAT on their website and for providing ASAT fliers to the families they serve
- ☆ Rethink Autism for posting about ASAT on their Facebook page

If you would like to share information about any initiatives you have undertaken to support ASAT, please write us at <u>publicity@asatonline.org</u>.



# Toward 10,000 subscribers worldwide!

Help us reach our goal! Share the newsletter with friends, family and colleagues, and support dissemination of evidence-based autism treatment.

## **Central Basketball League: Scoring Points for Autism!**By Ruth Donlin, MS

**CBL** 

The Central Basketball League (CBL) is a professional minor basketball league that has chosen to support ASAT's mission and commitment to the autism community.

The CBL consists of 5 franchises within the league, hailing from 5 different states, playing a total of 12 games each. The CBL's first spring 2013 season came to a

close on June 23<sup>rd</sup>. Congratulations, St. Louis Hawks, for winning the League Championship!



St. Louis Hawks, League Champions!

is made up of professionals who have been involved in various sports related positions over the years. ASAT is grateful to John Guy, the Operations Director, and the Central Basketball League for promoting science-based treatments for autism . John has been instrumental in collaborating with ASAT to broaden autism awareness and begin lo-

cal and regional initiatives to promote science -based treatment.

John developed a personal interest in autism intervention after learning that one of his adopted grandchildren, Seth, who is now an eight-year-old, has autism. The reason John chose to collaborate with ASAT is because of



John's grandson, Seth Oliver

ASAT's scientific approach to the disorder. John

stated, "We have a lot of noise in the autism community that is based on theory and not fact, and ASAT is based on scientific evidence. As a family, we tried numerous interventions. We even had a doctor tells us Seth could outgrow his autism. There are a lot of professionals out there who subscribe to wacky theories which creates roadblocks for families." Seth is now in a behaviorally-

based program that promotes greater mainstreaming opportunities. John felt strongly about partnering with an autism charity and wanted CBL to be a platform for educating the community.

CBL's efforts have been noteworthy, including making educational fliers about autism available to their basketball crowds and publicizing ASAT's mission to provide information to those affected by autism. In addition, we are thankful to CBL for raising over \$100 for ASAT on their very first promotional night!



Hornets Take Down Storm!

The CBL teams, Bowling Green Hornets, Dayton Air Strikers, Middle Tennessee Storm, River City Panthers, and St. Louis Hawks will commence their second season this fall.

Learn more about the teams, schedules, and stats at the CBL website: <a href="http://">http://</a>

www.centralbasketballleague.com/ or on Facebook at https://www.facebook.com/ CentralBasketballLeague

## Interview with Christina Danos, Founder of Kettlebells 4 Autism By Alice M Walkup, MS, BCBA

Here at ASAT we are always excited to collaborate with organizations and businesses who share our commitment to evidence-based autism treatment. One such organization is Kettlebells 4 Autism, a Canadian-based effort dedicated to raising autism awareness through fitness. I had the opportunity to interview Christina Danos, an entrepreneur and advocate from Toronto, Canada who founded Kettlebells 4 Autism (KB4A) with the intention of using kettlebell training and sport as a platform to raise awareness and funds for autism.

Please tell us a little about how you became involved in autism treatment.

I became involved shortly after a cousin began Intensive Behavior Intervention (IBI therapy). After observing one of his sessions I was hooked! An Instructor Therapist position became available shortly thereafter, so I applied, and was hired. That was in 2003 and since then I've worked as an Instructor Therapist, then Senior Therapist in a publicly funded IBI program, and recently as a Behavior Consultant with a new initiative in Ontario, providing ABA-based services to individuals with an Autism Spectrum Disorder (ASD) diagnosis. I'm also pursuing a Master of Science degree in ABA.

## Can you describe what kettlebells are for our readers who are not familiar with this particular fitness program?

A kettlebell looks like a cannonball with a handle. Its history can be traced to Ancient Greece and 18th Century Russia, where its use evolved from a rudimentary weight to a functional strength and conditioning training tool. Kettlebells are cast iron, and differ from a dumbbell or barbell in that the shape lends to the bulk of the weight being located in the centre of the kettlebell, and the handle allows the user to maintain neutral wrist position. Full body movement is required to pull the kettlebell via a "swing" motion with the aim of completing high repetitions at submaximal load, therefore targeting both musculosketal and cardiovascular training.

There is also kettlebell sport, or known by its Rus-



sian name, Girevoy Sport (GS). Athletes aim to complete as many repetitions as they can in a 10minute set, without setting down the kettlebell. There are three main events or disciplines: Jerk, Snatch, and Long Cycle, in addition to Biathlon, which is Jerk set followed by a Snatch set. For the Jerk and Long Cycle event, male athletes compete with two kettlebells, and one kettlebell for the Snatch event, With the Snatch event, competitors can switch hands once during the set. Women compete with one kettlebell for all events, and are permitted to switch hands once during the set. During a competition, each athlete completes their set before a judge who will determine if a repetition is counted or not counted, based on form/technique; for example, if the athlete's arm doesn't fully extend overhead but remains bent at the elbow, it's a "no count." The winner is determined by the most repetitions per body weight category, per kettlebell weight, and event.

# There are so many autism causes from which to choose. How did you choose ASAT and the Geneva Centre for Autism as your recipients?

I've known about ASAT for some time, and have used the website as a resource. I mentioned to a friend that I was looking for beneficiaries for the T-

(Continued on page 27)

## Interview with Christina Danos continued...

(Continued from page 26)

shirt campaign, and she mentioned ASAT. ASAT's mission is completely in line with the goals of KB4A, and I think it's an excellent resource for parents and professionals. Since I live in Toronto, I wanted to support a local initiative too which is how I became involved with The Geneva Centre for Autism. Their Monarch Café program is a vocational training program for adults with autism. They are working toward developing a "case study style" digitized manual and other support tools to help replicate the café in other areas of Canada with the goal to transitioning more adults with autism into long-term successful employment. Again, this initiative is in line with the goal of KB4A.

There are many sites that claim autism awareness is their passion. More specifically, why did you decide to emphasize the evidence-based practices?

As a professional working closely with families, I see how confusing and stressful it can be to navigate through the information available about interventions, and the vulnerable position caregivers are in when they are seeking what is best for their child. I also know that science-based interventions typically require more effort, from all involved in providing treatment, including caregivers. As professionals, this puts us in a difficult position, but we need to be open and understanding of parent's wishes, while remaining committed to providing high quality service, and while competing with other interventions that may require far less effort and possibly make broader claims for success. The equivalent exists in the fitness community, which is why so many "quick fix" and "low effort" gimmicks exist that ultimately aren't effective, continue to thrive. With KB4A, I chose to focus on supporting evidenced based treatment, because I want to bring more attention to practices that are likely to provide individuals with autism and their families the best possible outcome. I'd say that despite the many fundraising campaigns that currently exist for autism, there are only a few specifically aimed at supporting evidence-based practices. As such, there remains a need to increase awareness that emphasizes those prac-

tices that have a proven evidence base. Kettle-bells4Autism is dedicated to moving this awareness forward and will support four organizations per year with ASAT and Geneva Centre being the first two.

We are so grateful that you are committed to evidence-based autism treatment. Please tell us about your website and your products.

The website is a work in progress, and I'll take this opportunity to request assistance from any interested readers. We have a big event coming up in February 2014, our second annual Kettlebell Swings Event, with all funds donated to our beneficiaries. All of my time is donated, and I have had the support of some great friends when needed (Thank you, Shawn and Sara of Agatsu, Cynthia and Erika!). Last year this event raised over \$5000, and it looks like we'll have more than double the number of participants this year. I'm aiming for the website to be similar to Movember or Ride to Conquer Cancer, where donors can sponsor a participant, and all donations are tracked online. I'm in the process of updating the website to accommodate this event.



In terms of our products, the T-shirts are great! The designer, Joel Tellier, created an amazing logo, and I'm getting fantastic feedback. They are a cotton- polyester blend, the cost is \$30 plus shipping, and all proceeds raised through T-shirts sales will be divided and donated to ASAT and Geneva Centre for Autism. Funds raised from a comedy night fundraiser in Toronto, and

(Continued on page 28)

## Interview with Christina Danos continued...

the Kettlebells Swings Event in 2014 will also be donated to these two beneficiaries. Following the Kettlebell Swings Event, two new beneficiaries will be chosen.

We will certainly share more information about this event as the date approaches. I also understand that the T-shirts are being sold at several locations as well. You may not be aware but we have a few hundred subscribers who reside in the province.

Yes, I am happy to report that a number of gyms are selling the T-shirts for a limited time. These include: The Academy of Lions at 64 Ossington Avenue in Toronto, ON, SPEED Strength and Conditioning at 7551 Jane Street in Vaughan, Ontario, and Agatsu Academy at 202 Prom Ronald Montreal West in Montreal, Quebec. Readers should also check the website for an up-to-date list of locations carrying the T-shirts.

That is wonderful! What are you hoping to accomplish with this fundraiser?

I would like to raise a minimum of \$5,000 for each

beneficiary this year, then double the funds raised and number of beneficiaries the next year. In terms of raising awareness, I hope that those who buy the T-shirts or participate in the Kettlebells Swings event learn a little more about ASD, which can lead to compassion and support for those affected by autism.

Christina, we appreciate that you took the time to tell us more about your program and fundraiser. Physical fitness is important for everyone, and if you haven't found a routine that works for you, perhaps it can be found in kettlebells. Supporting Kettlebells 4 Autism helps support ASAT and spreads the word about science-based autism treatment. Getting involved is easy. Visit <a href="http://kettlebells4autism.com/">http://kettlebells4autism.com/</a> to find out about upcoming fundraising events and get a great looking Tshirt!. Check out the 2013 Kettlebell Swings Event here:

http://www.youtube.com/watch?v=kvyaaLi1WgY

Many thanks, Christina! We will certainly keep our readers apprised of your fantastic efforts!





#### Kettlebells 4 Autism

Kettlebell training and sport as a platform to raise awareness about autism, and to raise funds for not-for-profit organizations supporting autism research and treatment.

All funds raised from T-shirt sales in 2013 will be donated to the Association for Science in Autism Treatment, and the Geneva Centre of Autism (Monarch Café program) in Toronto.

Shop online at www.kettlebells4autism.com



## Clinical Corner: Integrating Occupational Therapy and ABA

"My child is enrolled in an ABA-based program where he also receives some OT services. How can occupational therapy benefit my child's ABA program?"

Answered by Amy McGinnis, MS, OTR, BCBA

Occupational therapy (OT) can be beneficial as a supplemental treatment to your child's ABA program. The goal of occupational therapy is to support an individual's health and participation in life through engagement in occupations or everyday tasks (AOTA, 2008). The occupational therapy process begins with an evaluation. The evaluation helps to determine whether your child has met developmental milestones in a wide variety of occupations. The occupational therapy evaluation can help your child's behavior analyst choose developmentally appropriate goals to be included in his ABA program. The OT evaluation may also be helpful in understanding why a child struggles with a particular task. For example, if your child struggles with writing, the evaluation can determine whether this difficulty stems from an inappropriate grasp, poor posture, muscle weakness, visual memory, or lack of eye-hand coordination. Pediatric occupational therapy typically addresses the following domains:

- Play
- · Activities of Daily Living
- Education
- Social Participation

Play is the primary occupation of childhood, and is often an area of need for children with autism. Occupational therapy can be effective in helping children learn new play skills (Stagnitti, O'Connor, & Sheppard, 2012). Many pediatric occupational therapists use a play-based approach to their sessions, exposing children to a variety of toys, games, and different ways to play. If your child engages in repetitive play behaviors or has limited interests, the occupational therapist may be helpful in finding other activities that share similar sensory properties of the toys your child already enjoys. Some of the sensory activities used in occupational therapy may function as reinforcers, which could be used in your child's ABA sessions as well (McGinnis, Blakely, Harvey, Hodges & Rickards, 2013). Occupational therapists typically include an assessment of activities of daily living (ADLs) as part of the evaluation. ADLs include those basic self-care tasks that an individual performs each day, such as eating, grooming, dressing, and using the bathroom. Occupational therapy can help to build the strength, coordination, and perception skills needed to perform these tasks. For example, if your child has oral motor defiMany children with autism receive occupational therapy services as part of their early intervention and educational programs. In this edition of Clinical Corner, Amy McGinnis provides an overview of the occupational therapy assessment process and shares how occupational therapy programs can complement a child's ABA-based programming to further skill development across a variety of areas.

**Nicole Pearson**, PsyD, BCBA-D Clinical Corner Coordinator

cits, occupational therapy can help your child learn the mouth movements necessary for chewing and drinking (Eckman, Williams, Riegel, & Paul, 2008; Gibbons, Williams, & Riegel, 2007). Occupational therapy can also help older children and adolescents learn more advanced ADLs, like independent bathing (Schillam, Beeman & Loshin, 1983). Occupational therapists are trained in identifying multiple ways to perform routine tasks, and can recommend an approach that will work best for your child and can be integrated into your routines at home (Kellegrew, 1998).

As individuals with autism age, occupational therapists can help teach skills that will lead to greater independence at home and in the community (McInerney & McInerney, 1992). These include preparing meals, managing money, shopping and using public transportation. Often these skills are more complex and may require an activity or task analysis that breaks the task down into simpler steps. With extensive training in developing task analyses, occupational therapists can share these analyses with your child's ABA team so that skills can be taught across settings. If tasks are still difficult, an occupational therapist may recommend adaptive equipment to make a task easier. Occupational therapy can also help your child participate more fully in his or her educational program. Occupational therapy can help young children acquire tasks such as coloring and cutting (Case-Smith, Heaphy, Marr, Galvin, Koch, Ellis, & Perez, 1998), as well as help older children acquire skills such as handwriting (Denton, Cope, & Moser, 2006). If your child has difficulty moving through the school setting or actively participating in movement activities, occupational therapy can help your child develop functional mo-

Social participation can be challenging for many individuals with autism. Occupational therapists may engage your child in activities that promote functional communication, sharing, taking turns, and following

(Continued on page 31)

## Clinical Corner continued...

(Continued from page 30)

rules. If your child requires a form of augmentative communication to interact with others, the occupational therapist may play a role in improving your child's dexterity or modifying signs. Occupational therapists can also help select an appropriate assistive technology device, and teach your child how to use their device (Shull, Deitz, Binningsley, Wendel & Kartin, 2004).

When children display atypical responses to sensory experiences that interfere with their daily routines, occupational therapy can play a role in overcoming these challenges. If your child tends to avoid certain sensory stimuli, such as noises, textures, or movement, your child's occupational therapist and behavior analyst can work together to develop a treatment plan to progressively and systematically teach your child to calmly tolerate these experiences. If your child seeks sensory experiences by engaging in inappropriate or unsafe behavior, the occupational therapist may help identify more appropriate alternative behaviors that provide a similar type of input. During your child's occupational therapy sessions, the occupational therapist will document your child's progress. Documentation of progress can vary across different types of settings, and across therapists. It may be helpful to request that the therapist record data on the amount of assistance your child needed to complete a task, how many times the child completed the task, or how long your child engaged in a particular task. These data can be plotted on a line graph, and analyzed to see how your child is progressing (Clark & Miller, 1996).

It is important to note that there are a variety of treatment approaches that can be used in pediatric occupational therapy. Some of these approaches are not scientifically based, and may not produce the desired effects. Given that your child is receiving ABA, you will want to find an occupational therapist who uses a behavioral approach to occupational therapy, and is open to collaborating with your child's behavior analyst. When your child's behavior analyst and occupational therapist work together to create goals, manage problem behavior, teach new skills, and analyze data, your child is more likely to reap the benefits of a comprehensive, evidence-based program.

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## Media Watch

Media Watch is a subcommittee of the Public Relations Committee whose primary initiatives are:

Educating the public about effective autism treatment through proactive contact with the media; Responding to inaccurate information or proposed treatments described by the media (as it relates to scientific findings about their effectiveness); And supporting accurate media depictions of empiricallysound interventions for individuals with autism spectrum disorders.

We seek to increase awareness of the scientific underpinnings surrounding autism treatment that can lead to real hope for those touched by this disorder.

We have been busy since we last ASAT Responds to Texas Observ- ASAT Responds to CNN.com's updated you on our Media Watch efforts in the Winter issue! Here are the articles that caught our attention and received our feedback.

ASAT Responds to WPMI Local 15 News "Local Family Using **Breakthrough Autism Treat**ment" (February 03, 2013) Could the Integrated Listening System be the next "breakthrough treatment" for autism?

http://asatonline.org/ media watches/99

ASAT Responds to The New York Times "Some With Autism Diagnosis Can Overcome Symptoms, Study Finds" (February 26, 2013)

A new study from the University of Conn. claims the hope of "recovery" for some children with autism.

http://asatonline.org/ media watches/100

ASAT Responds to Fox.com's "Study Looks at Worm Therapy to Treat Autism" (March 04, 2013) Worm therapy - is it viable? http://asatonline.org/ media watches/101

er's "Autism Inc.: The Discredited Science, Shady Treatments and **Rising Profits Behind Alternative** Autism Treatments" (March 27, 2013)

Journalist Alex Hannaford describes the journey of several duped parents - once amazed by the gamut of so-called "miracle cures" -- but now informed, and able to draw the line between quackery and science.

http://asatonline.org/ media watches/102



**ASAT Responds to** FoxPhilly.com's "Parents Of Autistic Children Worry What Life Will Bring When They're Adults" (April 01, 2013) The tsunami of young adults on the autism spectrum is a growing Read all posts online. If you have concern for parents and caregivers.

http://asatonline.org/ media watches/103

"CDC: Higher number of children with autism" (April 22, 2013) CDC's latest numbers for prevalence of autism spectrum disorder in children are disturbing: one in 50.

http://asatonline.org/ media watches/104

ASAT Responds to Triblive.com's "Pa. Autism Services Hope to make inroads in workplace" (April 25, 2013) Attention to post-graduation employment should be begun early, carried out extensively, and planned meaningfully.

http://asatonline.org/ media watches/105

ASAT Responds to Springfield News-Leader.com's "Parents can get help with autism issues" (May 31, 2013) Parents should be encouraged to be wary of "miracle cures" and treatments that are not based in scientific evidence.

http://asatonline.org/ media watches/106

any comments or would like to contribute, contact us at info@asatonline.org

## **SPONSORS IN REAL SCIENCE, REAL HOPE SPONSORSHIP INITIATIVE**

## Does Your Agency Share ASAT's Values?

ASAT believes that individuals with autism have the right to effective treatments that are scientifically-demonstrated to make meaningful, positive change in their lives.

We believe that it should not be so challenging for families to find accurate information about the efficacy of various autism interventions.

ASAT works toward a time... When all families will be empowered with skills in identifying and choosing the most effective, scientifically-validated interventions for their child.

When the media will educate and not confuse parents by providing accurate

information and asking the right questions.

When all providers will be guided by science when selecting and implementing interventions.

## What It Means to Be a Sponsor:

ASAT's sponsors have indicated their support of the following tenets:

- All treatments for individuals with autism should be guided by the best available scientific information.
- 2. Service providers have a responsibility to rely on science-based treatments.
- 3. Service providers should take steps necessary to help consumers differentiate

between scientifically validated treatments and treatments that lack scientific validation.

- 4.Consumers should be informed that any treatment lacking scientific support should be pursued with great caution.
- 5. Objective data should be used when making clinical decisions.

## Become a 2013 Sponsor Now!

These sponsorships not only provide financial support used specifically for our dissemination efforts, but also send a clear message that ASAT's vision is shared by others within the professional community.

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