



Letter From David Celiberti, PhD, BCBA-D ASAT Executive Director

Happy New Year!

On behalf of ASAT, I hope 2014 brings you good things. I also hope that this year will bring to all a deeper appreciation for the relevance of science in both grounding and guiding autism treatment, greater expectations of accountability from *all* treatment providers, more accuracy within media portrayals, and heightened awareness of the pitfalls, costs, and distractions of pseudoscience for there are, sadly, quite many.

As you may recall, my Co-Editor, Dr. Daniela Fazio, shared many of our 2013 accomplishments in the Fall issue of *Science in Autism Treatment* (SIAT). As we welcome in the new year, we are anticipating an even more productive 2014.

Therefore, it is with great pride and optimism that I outline an array of goals and initiatives for 2014:

- Increase our *Science in Autism Treatment* subscriber base from 10,000 to 12,000 with

This Issue Dedicated to:

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Thank you for your continuous support of science in the treatment of autism!

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representation from 95 countries.

- Launch a new website this coming spring.
- Develop customized webpages for parents with a newly-diagnosed child, media professionals, and medical professionals.

- Increase our Facebook fans to 9,500, Twitter followers to 1,200, and increase ASAT's presence on quality autism community blog sites.

- Increase our presence within the medical community, particularly among pediatricians and family practice doctors, by making information on ASAT and science-based treatment readily available to them.

- Increase grant request submissions to support our important work.

- Increase ASAT's presence at state, regional,

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Letter From the Executive Director continued...*(Continued from page 1)*

and international conferences.

- Provide information regarding ASAT and its resources to faculty in special education, psychology, and speech-language pathology programs nationwide, as well as abroad.
- Expand coverage of genetics, epidemiology, assessment, and biologically-based treatment issues in SIAT.
- More extensively tap into the wealth of experience and expertise of our Advisory Board members.
- Recruit new writers and increase number of Media Watch responses to accurate and inaccurate portrayals of autism treatment, with heightened focus on international and lifespan issues.
- Hold bimonthly conference calls to advance an aggressive and comprehensive 2014 strategic plan and conduct our annual board meeting in Newark, NJ in October to finalize this plan.
- Host the 4th annual Rock'n 4 Autism Awareness benefit concert on May 3rd in Hoboken, NJ.



Dr. Celiberti and his son trying to scare away pseudoscience

I hope that you share our excitement in these goals and share our belief that ASAT's commitment to promoting science-based research plays a valuable role in the autism community. We cannot carry out our important work without the support of generous sponsors and donors. In fact, the ongoing success of ASAT is predicated on such support. We are particularly grateful to the sponsorship from Little Star Center, Inc., which has been a tremendous friend to ASAT over the last few years and has generously renewed their sponsorship at the Partner level! For that, we are dedicating this issue of the newsletter to them, an exemplary organization. In the pages of this issue, you will have the opportunity to learn more about their important work. Please find a program description on page 4 and an interview on page 6.

If you are affiliated with an organization, which shares ASAT's commitment to science in the treatment of autism, please consider becoming a 2014 *Real Science Real Hope Sponsor* (http://asatonline.org/about_asat/professional-sponsors). We are pleased to report that 45 organizations participated last year. Please see page 37 for more information about our sponsorship effort.

Also, please see page 35 for our 2013 Donor Wall. As we move into 2014, we also welcome the support of additional individual donors. If you recognize the need for accurate information about autism treatment, believe in the relevance of science, and want to support our efforts to change the conversation about autism treatment, please donate online through *Fundly* (<https://fundly.com/association-for-science-in-autism-treatment>). Any amount, be it big or small, will be deeply appreciated and used wisely to advance our initiatives. If you were kind enough to donate last year and you were inadvertently omitted from our donor wall, please let us know.

I wish you and yours a happy and healthy new year.

Warmly,

David



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Little Star Center
would like to thank
its distinguished
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(L to R): Dr. Dennis Reid, Dr. Dorothea Lerman,
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Mission:

The mission of Little Star Center, Inc. is to provide a structured, child-friendly facility where children with autism receive individualized therapeutic intervention. Based on the fundamental principles of applied behavior analysis (ABA), Little Star provides an atmosphere where children, therapists, and families can interact, support each other and receive ongoing training so that each child can reach his or her full potential at home and in a variety of settings outside of therapy.

History:

Started in Carmel, Indiana, Little Star Center is a non-profit organization founded in 2002 to serve the needs of children and families affected by autism. A pioneer in the state of Indiana, our state-of-the-art facility offers an environment where children receive individual intervention based on the fundamental principles of *Applied Behavior Analysis* (ABA) and Verbal Behavior. Families are provided the support they need to face the challenges of autism and become integral partners in their child's success.

Little Star Center's commitment to science-based treatment was evident from the very beginning. Steele and Amy Gudal faced many challenges with their daughter, Gentry, who was diagnosed with autism in 2001. They had done everything they were told to do – First Steps, private speech, and occupational therapy, the school district's developmental pre-school program, but still found that Gentry struggled and made limited progress. After much research, the Gudals found the treatment their daughter needed – *Applied Behavior Analysis*. ABA was (and still is) the only treatment for autism endorsed by the American Surgeon General and considered to be the best researched treatment by the American Academy of Pediatrics. However, the closest treatment facility was five states away – there were none in Indiana. Undaunted, the Gudals founded Little Star Center for their Gentry and for other families who needed the same intensive, medically necessary treatment for their children. The Gudals created a center model so unique that families from Florida, Ohio, Sri Lanka, Massachusetts and California have come to obtain services at Little Star.

Tragically, in the spring of 2006, Steele Gudal was killed in a small plane crash. Jim DeVoe, Steele's father-in-law (and Amy's dad), was also killed. The contributions these two men made to all Hoosier families affected by autism will never be forgotten and remain a significant inspiration for those committed to continuing their important work.

Little Star Center opened its second location in Lafayette, Indiana in March of 2011. Today, Little Star has over 100 employees working toward the success of its clients and is continuing to grow to meet the needs of even more children. Through this growth, however, Little Star has kept its core mission as its top priority. Little Star Center provides year round therapeutic intervention and various other programs for children with autism based on the science of ABA.

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Since its inception, Little Star has become a shining example of a grass-roots effort. Each year Little Star serves more children and families and offers support to the Indiana autism community. Little Star Center celebrated its 11th anniversary in September, 2013 as well as hit the million-dollar mark in services that were provided to families at no charge.

In August of 2011, Little Star Center was named the 2011 Excellence in Direct Care award winner by the Autism Society of Indiana. Little Star is the first and only center to win this title. LSC is currently in the process of opening a center in Bloomington, Indiana, expected to open in 2014.

LSC Programs:

LSC is comprised of three distinct programs each targeting a specific age range. The Early Learner Program (ELP) serves individuals <5, LSC age 5-12, Middle Star Center (MSC) ages >12.

- ☆ Full day, part day or braided school/center/home programs (i.e., components remain distinct)
- ☆ 12 month program
- ☆ Center, Community and Home-Based, tailored to meet the needs of each learner
- ☆ 1:1 intensive therapy provided by trained ABA therapists
- ☆ Group-based instruction
- ☆ Baseline assessment of skills
- ☆ Individualized programming developed and monitored by a BCBA
- ☆ Fully staffed training department to develop and maintain skills for both BCBAs and ABA therapists
- ☆ Natural environment, incidental teaching, and discrete trial instruction
- ☆ Verbal behavior
- ☆ Social skills
- ☆ Assessment and deceleration of problem behavior
- ☆ Parent training
- ☆ Transition services
- ☆ Collaboration with speech language pathologists, occupational therapists and school personnel
- ☆ Ongoing performance management for all staff



An Interview with Mary Rosswurm, Bill Bower and Michele Trivedi of the Little Star Center

By David Celiberti, ASAT Executive Director

As part of this issue's dedication to the Little Star Center, I had the opportunity to interview some of the leaders of this program of excellence: Mary Rosswurm (Executive Director), Bill Bower (Board President), and Michele Trivedi (Board Member and parent).

Mary, on behalf of ASAT's board we would like to thank Little Star for many years of support as one of our highest level sponsors. I was hoping you could share a bit about your background with our readers. Can you tell us about your career path, and what got you into the field of autism treatment, and specifically, behavior analysis?

Well, I started out in speech therapy, but was really getting dissatisfied with many of the trends I was witnessing. It had changed and become, at least for me, churn and burn. Get them in, 50 minutes, 10 minutes of paperwork and then see you next week. When I went to school we wanted to see kids three times a week for maybe 20 to 30 minutes, but now it was see a client for 50 minutes once a week. I wasn't seeing the progress and I think, looking back, I was really motivated by their success. I had the opportunity to spend some time in the office of the clinic that I was working at and found that I was really enjoying some of the more administrative and support duties. Then the stars aligned (pun intended) and I had the opportunity to interview for a position with a struggling Applied Behavior Analysis (ABA) center. That was in 2004. I was able see first-hand how behavior fit in with everything – it just made sense to me and here I am, 10 years later! As I became more involved with the business side of the center, I went back to school and earned an MBA in 2006.

What an interesting career path, Mary. Tell us a little about the Little Star Center (my turn with the pun) and how the program has evolved.

When I started at Little Star, there were only four families left, as the center had gone through a split and most of the families and clinical staff

left to form a new center. The founder of the center was very hurt by the whole episode and pretty much wanted to close Little Star down, but



Mary Rosswurm, Executive Director

the remaining families wanted to keep going. The founder turned Little Star over to the parents and it became a parent run co-op until 2008, when that model just didn't work anymore for such a growing organization. At that time, the parent co-op dissolved and the center's Board of Directors took over control again. We have 75 learners now across three centers in Carmel's two locations, and Lafayette as well as a new center opening in Bloomington in the spring.

Bill and Michele, you have been on the Board at Little Star for a number of years. What makes you want to volunteer your time to this organization?

Bill: I am very proud that Little Star has grown from a small single facility that operated as a cooperative among parents trying to find therapeutic solutions for their children with autism to a three center (soon to be four) operation that provides a full spectrum of services from early

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Little Star Center Interview continued...

(Continued from page 6)

childhood to adolescence and entry into adulthood. All of this has been done as a not-for-profit, which has allowed us to provide free or reduced cost services to families in need. In fact, over the last 18 months Little Star has given over \$250,000 in free or reduced services to families in need!

Michele: When my daughter was diagnosed with autism in 2000, there were only two choices to access ABA therapy in Indiana - use one of the two Lovaas Institute consultants that lived in the state, or fly a consultant in from the coasts. For parents to have a resource like Little Star at a time when their life is turned upside down is so important. As a not-for-profit, the extra, non-billable services families receive in terms of securing health insurance, navigating waivers, finding support groups, and having a knowledgeable team to walk the journey with you is invaluable. I am proud to be a small part of what Little Star does to help parents and their children with autism. The community service that Little Star provides through its engaged and generous staff is another reason why I am so willing to volunteer for Little Star. From free community education programs, to training future nurses and ABA providers at no charge, to supporting local autism advocacy groups, to leadership in the local ABA provider groups, Little Star touches many lives well beyond the families that walk through our doors every day.

Bill and Michele, that is incredible! OK, all three of you, what is your vision for the future of Little Star Center?

Mary: I see Little Star continuing to grow, but in the slow, planful fashion that has guided its evolution to date.

It's really hard to maintain quality when you grow too fast. Also, as my son, who has autism, has gotten older, he's 23 now; I have become more and more aware of the lack of adult services available. Our "little stars" are growing up and there's not a lot out there for them. That is an area we are looking at further.



Michele Trivedi, Board Member and Parent

Bill: We feel strongly that we have the best centers in Indiana for ABA services. I would like for us to continue to grow and be able to help more families, all while effectively navigating the ever-changing medical and insurance environments.

Michele: I see a bright future for Little Star! We will continue with controlled growth in underserved communities to increase access to quality ABA services outside of the "wealthy" counties where ABA providers tend to set up shop. We will continue to advocate for proper health insurance coverage for autism in all health plans - state- and federally-regulated, as well as Medicaid. We will continue to be valued partners for our advocacy organizations locally and nationally. We will



Bill Bower, Board President

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Little Star Center Interview continued...*(Continued from page 7)*

also continue our efforts to advance the profession of Behavior Analysis, and to advance research.

Bill, you knew the founder of Little Star Center, whom Mary shared had died in a plane crash in 2006. What do you think he would think of Little Star today?

Bill: When Steele Gudal's widow asked me to take his board seat at Little Star, I knew it was important to grow the organization and its mission to be part of Steele's legacy. We have been lucky to have a very strong Executive Director, and great clinical staff that have allowed us to expand Little Star to have a positive impact on many families in Indiana. I know that Steele would be very proud of what Little Star has become.

Michele: I agree! Steele would indeed be very proud of what Little Star has become and where it is going. The quality of therapy provided at Little Star is top notch because of the dedication that our Executive Director and our clinical staff have to providing preeminent child-first care. At the same time, we are growing with a careful mind to never compromise that quality - Steele would love that! We are helping to ensure that families from all walks of life can afford ABA. Steele experienced first-hand not being



Steele's Room—Assessments

able to find an ABA provider for his children in Indiana, and he experienced first-hand not having health insurance coverage for ABA - paying thousands out of pocket to help his girls. Steele would be proud that Little Star has given over \$1 million in uncompensated care to families in need, and that we are serving families in every income bracket.

Michele, anything else you would like to add?

Little Star has been such a blessing for our family, I am happy to "pay it forward" by volunteering my time on the Board to continue Steele's vision! Little Star is like a second family to us, and our daughter is so happy to be there every day and has progressed so much. Our family would love to see a day where each family living with autism feels like they have such a wonderful support system!

Mary, I would also like to ask you about your perceptions of services at the state level as autism services vary widely across the United States. What is it like in Indiana? What changes have you observed in the last few years?

Well, there are a lot of services in Indiana, but not all BCBAs (or providers) are created equal! Unfortunately, a lot of people have begun to provide services because they can

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Cubicles

Little Star Center Interview continued...

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bill insurance companies for reimbursement. Many parents don't know what to look for, so they go for the flashy building or the provider who will promise them the results that they are hoping for.

However, there are some really good service providers in the state that are offering high quality services and really making a difference in the lives of a lot of kids. That is why I'm so excited about what ASAT does - it makes educating parents and doctors about quality ABA services that much easier!

Mary, how did you find out about ASAT?

I was at an ABAI conference in 2008, maybe, and I saw Mary Jane Weiss. I am a huge fan of her book, *Applied Behavior Analysis and Autism: An Introduction*, so I went up and introduced myself as a super fan. She was doing a panel discussion with you, and we were introduced. That was how I first became aware of ASAT, but I just can't remember the rest of the details - it's hard for me to remember my pre-ASAT existence...it just feels like it's always been around for me to refer to!

As my job entails working with parents of newly diagnosed children, I am always working on guiding them to evidence based treatments as opposed to the new, flavor of the month. I give the

ASAT info flyer to e v e r y family that comes through Little Star. Even if they don't choose Little Star as their service provider, I want them to know about the resources available and help them become a savvy consumer.

I also truly enjoy the ASAT newsletter and look forward to reading it each quarter! Running a not-for-profit, I understand that these things cost money and the thought of ASAT not being available...well, that is a bad thought - so I really felt like I should take on a supportive role - both financially and by spreading the word about what ASAT does.

Mary, has ASAT been helpful to you and Little Star in your treatment of autism?

Yes, absolutely! I come in contact with parents, doctors, teachers, college interns, and the news media, just to name a few, and I am asked for my opinion a lot - I appreciate having ASAT as a resource and saying, "Hey, don't just take my word for it..."

Let's face it, I'm selling Little Star services and I am biased about ABA...I like to have a back-up plan that pulls me out of the equation and can support what I'm saying. If somebody asks me about horse therapy, it's not just Mary saying: "Horse therapy, while fun, is not an effective, evidenced based treatment." I often say, "Well, let's

go see what the autism experts at ASAT think about this therapy." So it's like a second opinion from really, really, really smart people!

Mary, as a parent, why do you think pseudoscientific treatment flourishes in autism?

Well, there are a couple reasons. In 2010, my son went into the emergency room with a sore neck, a really bad head-



ELP Halloween

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Little Star Center Interview continued...

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ache and vomiting...and we left two weeks later after he had brain surgery to remove a tumor. But that experience was vastly different from his autism diagnosis experience. For the tumor, the doctors laid it all out for us – surgery, chemo and perhaps radiation. Follow up MRIs twice a year for 10 years. They gave me the plan. When my son was diagnosed with autism, it was like, “Well, maybe call the school and good luck to you. Oh, and get some speech therapy and occupational therapy.” The plan was left up to me. That right there, I think, is the difference. The people diagnosing do not have a plan to give parents so then they hit the Internet.

From here, we get the *shot-gun blast approach*, which is: try everything all at once. It often seems that the kid who is getting some good ABA at the same time he is on a gluten-free diet, will have parents who say, “Boy, is that diet a miracle!” But more problematic, I think, is the *no stone left unturned approach*...there is always something new out there and as a parent, you would never want the one thing that you did not try to be the one thing that made a difference. This is why it is so important that diagnosticians give parents of newly diagnosed children a plan with realistic timeframes and outcome expectations. With the brain tumor, I never thought that I should seek alternative treatments, but this is just not the case for autism.

I think another issue is that we live in America. I want it fast and I want it easy. Intense therapy takes a long time and it is expensive. Parents are looking for a quick fix (aren't we all!). Really, think about it, I can have 40 pounds of fat sucked out of me and buy a better nose. I can make my brown eyes blue with contacts and be a blonde within a matter of hours. We don't like

to wait – for anything- and autism treatment is no different. We know that diet and exercise is really the best way to lose weight for long-term results, but so often we'll try the diet pill. So, I guess my point is that the best way is not necessarily the easiest way.

Mary, you raise so many valid points that characterize the challenges facing so many of our families. What suggestions do you offer parents of newly diagnosed children?

Grieve. It's OK...be sad, be mad, join a support group, but then pull yourself up by your boot straps and move forward. I know that this is not what they had planned, but this is the hand that life dealt them and they have to make the best of it. I swear that it gets easier. Find some other parents that know what you are going through and surround yourself by supportive people. Autism is a marathon, not a sprint, so drink your Gatorade!

Mary, what advice do you have for new professionals in the field?

Of course, to sign up for the ASAT newsletter, and that they need to know what they don't know; it's okay, we don't expect them to know everything! Be open to continually learn, don't over promise to parents and if the day comes that you don't enjoy what you do, find something that you do.

Thank you all for a great interview and for your support of ASAT! I want to share with our readers that I had the opportunity to visit Little Star Center in 2012 and was very impressed with the program, facilities, and staff. It was a privilege to showcase information about Little Star Center in this issue of our newsletter. Keep up the great work!



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Clinical Corner

Conducting Preference Assessments with Individuals with Autism

Maximizing motivation is an essential component of effective teaching and behavior reduction; therefore, preference assessments can help identify those items and activities that will be most motivating for individuals with autism. In this issue of Clinical Corner, Niall Toner shares why preference assessments are so important and provides an excellent overview of the various types of preference assessments that can be conducted with individuals at home and/or school.

Nicole Pearson, Psy.D., BCBA -D, Clinical Corner Coordinator

I am a special education teacher working with students with autism. At times I find it difficult to figure out what motivates my students and what they're interested in. Can you make some suggestions about the best way to do this?

Answered by Niall Toner, MA, BCBA

New York State Institute for Basic Research in Developmental Disabilities

This is an excellent question and one that highlights a challenge often experienced not only by teachers, but also by family members of individuals with autism. We know that the interests and preferences of individuals with and without autism vary significantly over time. Also, we know that effective teaching of skills and behavior change are predicated upon the timely use of powerful reinforcement (i.e., positive consequences of skilled behavior that motivate and strengthen that behavior). As discussed below, identifying an individual's preferences is a critical first step in teaching new skills because these preferences often lead to the identification of powerful reinforcers; but *how* we do this can be easier said than done, especially when the learner has a limited communication repertoire or very individualized interests. The best way to identify preferences is through ongoing preference assessments.

The value of preference assessments

Since many individuals with autism may have difficulty identifying and communicating their preferences directly, we must consider alterna-

tive methods of obtaining this information. At the onset, it is important to keep in mind that what may be rewarding or reinforcing for one individual may not be for another. For example, one child may enjoy bubble play, crackers or a particular cause-and-effect toy while a classmate may find one or more of these uninteresting or even unpleasant. Furthermore, an individual's preferences change across time. For example, an individual may have demonstrated little use for music at age 11, but she may demonstrate a keen interest in music at age 13.

Preference assessments provide a systematic, data-based approach to evaluating a host of potential interests (e.g., food, toys, activities) for an individual. Although preference assessments do require time and effort up front, their use can decrease the time and energy, required to change behavior in the long run. Research indicates that when caregivers use a *presumed* preference that, in fact, is not the learner's actual preference, valuable time, energy and resources are lost (Cooper, Heron, & Heward, 2006).

Types of Preference Assessments

Preference assessment can be conducted in three distinct ways: (1) **Interviews and Formal Surveys**; (2) **Direct observation**; and (3) **Systematic assessment**.

Interviews are a straightforward technique that can be used to gather information quickly. They involve obtaining information from the individual's parents, siblings, friends, and teachers (and

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Clinical Corner Continued...

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from the individual, if communicative) by asking both open-ended and comparison questions. Examples of open-ended questions include: “What does he like to do?” “What are his favorite foods?” and “Where does he like to go when he has free time?” Comparison questions might include: “Which does he like better, cookies or crackers?” and “What would he rather do, go for a walk or eat chips?” Resultant information is then compiled in a list and identified items and activities can be piloted out as possible reinforcers.

Formal surveys can also be used to guide these discussions. One widely used survey is the *Reinforcement Assessment for Individuals with Severe Disabilities* (RAISD; Fisher, Piazza, Bowman, & Amari, 1996). This interview-based survey gathers information about potential reinforcers across a variety of domains (e.g., leisure, food, sounds, smells, and ranks them in order of preference. It should be noted that, although simple and time-efficient, using interviews alone can result in incomplete or inaccurate information. In fact, some studies have shown that, for the same individual, staff interviews did not reveal the same information as using a survey (Parsons & Reid, 1990; Winsor, Piche, & Locke, 1994).

Direct observation involves giving the individual free access to items and/or activities that he or she may like (presumed preferences) and recording the amount of time the individual engages with them. The more time spent with an item or activity, the stronger the presumed preference. In addition, positive affect while engaged with these items and activities could be noted (e.g., smiling, laughing). During these observations, no demands or restrictions are placed on the individual, and the items are never removed. These direct observations can be conducted in an environment enriched with many of the person’s preferred items or in a naturalistic environment such as the person’s classroom or home. Data are rec-



orded over multiple days, and the total time spent on each object or activity will reveal the presumed strongest preferences. Direct observation usually results in more accurate information than interviews, but also requires more time and effort.

Systematic assessment involves presenting objects and activities to the individual in a pre-planned order to reveal a hierarchy or ranking of preferences. This method requires the most effort, but it is the most accurate. There are many different preference assessments methods, all of which fall into one of the following formats: single item, paired items, and multiple items (Cooper, Heron, & Heward, 2006). Single item preference assessment (also known as “successive choice”)

is the quickest, easiest method. Objects and activities are presented one at a time and each item is presented several times in a random order. After each presentation, data are recorded on duration of engagement with each object or activity.

Paired method or “forced-choice” (Fisher et al., 1992) involves the simultaneous presentation of two items or activities at the same time. All items are paired systematically with every other item in a random order. For each pair of items, the individual is asked to choose one. Since all objects and activities have to be paired together, this method takes significantly longer than the single item method but will rank in order the strongest to weakest preferences. Researchers found that the paired method was more accurate than the single item method (Pace, Ivancic, Edwards, Iwata & Page, 1985; Paclawskyj & Vollmer, 1995).

The multiple-choice method is an extension of the paired method (DeLeon & Iwata, 1996). Instead of having two items to choose from, there are three or more choices presented at the same time. There are two variations to this method: *with* and *without* replacement. In the multiple

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Clinical Corner Continued...

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choice *with* replacement method, when an object is selected, all other objects are replaced in the next trial. For example, if the individual is given a choice of cookies, crackers, and chips, and he chooses cookies, the cookies will be available for the next trial but the crackers and chips are replaced with new items. In the *without* replacement method, the cookies would not be replaced and the choice would only be between the crackers and chips. No new items would be available.

A few final recommendations

When conducting preference assessments, consider testing leisure items/activities and food assessments separately because food tends to motivate individuals more than toys and other leisure items (Bojak & Carr, 1999; DeLeon, Iwata, & Roscoe, 1997). Also, be sure to assess preferences early and often. Preference assessments should be conducted prior to starting any new intervention or behavior change program. And remember that preferences change over time and require continuous exploration. Therefore, assessments should be updated monthly or whenever an individual appears tired of or bored with the preferred items. Keep in mind too, that the identification of one type of preference may provide ideas for other potential reinforcers. For example, if an individual loves a certain type of crunchy cereal, he/she may like other cereals or crunchy snacks. Or if an individual enjoys coloring with crayons, consider exploring whether he/she may enjoy coloring with markers or using finger paints.

Finally, when selecting a preference assessment method, a practitioner or parent should consider the individual's communication level, the amount of time available for the assessment, and the types of preferred items that will be available. Taken together, these preference assessment methods can provide the valuable information necessary to help motivate and promote behavior change in individuals with autism.

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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 through: the dissemination of accurate, timely, and scientifically-sound information; advocacy for the use of scientific methods to guide treatment; and the countering of unsubstantiated, inaccurate and false information about autism and its treatment." With this in mind, ASAT is striving to reach 12,000 subscribers by the end of the year. We are currently at 10,058 subscribers. Help us reach 12,000 subscribers by clicking on the following link: <http://asatonline.org/newsletters/signup>. You can also "like" ASAT's Facebook page at <https://www.facebook.com/ASATonline?fref=ts>.

If you are a supervisor or administrator, please consider passing along a [sign-up sheet \(http://www.asatonline.org/pdf/subscribeme.pdf\)](http://www.asatonline.org/pdf/subscribeme.pdf) to help us recruit new subscribers. After these are completed, they can be emailed to newsletter@asatonline.org or mailed to ASAT PO Box 3250 Hoboken, New Jersey 07030.

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...

- **Outpatient Behavioral Services at the Virginia Institute of Autism** for distributing ASAT flyers in all their family packets, intern trainings, and workshops
- **Trumpet Behavioral Health** for sharing information about ASAT and its mission on their Facebook page
- **NYSABA** for sharing ASAT news on their Facebook page
- **Rethink First** for posting ASAT's recent auction to all of their Facebook fans
- **SARRC** for letting their Facebook community know about ASAT and encouraging them to sign up for our newsletter
- **Achieve Beyond** for soliciting ASAT Newsletter sign ups at a recent staff training event
- **Eden II** for soliciting ASAT Newsletter sign ups at a recent staff development event and through Facebook and email
- **Challenge Early Intervention Center** for soliciting newsletter sign ups at a recent workshop
- **The Autism Science Foundation** for providing a link to the ASAT newsletter on their website
- **Thivierge & Rothberg, PC** for including a link to ASAT on their list of resources
- All of **ASAT's 2013 NYC Marathon Runners** and their support of ASAT
- **Hofstra University** for sharing information about ASAT at their disability awareness film festival
- **Little Star Center** (especially Tim and Taylor - see photo on the right) for sharing *SIAT* on their table at the WMU Job Fair on Friday, January 24, 2014.
- **Kristine Saccone** from the **Connecticut Center for Child Development** for posting a link to *SIAT* their Facebook page as well as sending it in an email to all of their families, staff, and conference attendees

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



Weight to Go Kettlebells 4 Autism!

By Mary Kay Jones, MSN, CRNP



Christina Danos

Christina Danos created Kettlebells 4 Autism in February 2013. The goal of this initiative was to employ Kettlebell training and sport as a platform to raise awareness about autism, and more specifically, the delivery of evidence-based practices to individuals with an Autism Spectrum Disorder. One of the ways that the organization raises funds is through the online sale of Kettlebells 4 Autism merchandise. Visit the [website \(http://kettlebells4autism.com\)](http://kettlebells4autism.com) and you'll find an assortment of fun t-shirts with much more merchandise coming soon including hoodies and gym bags, as well as apparel for babies and toddlers.

Kettlebells 4 Autism's founder, Christina Danos, is an advocate from Toronto, Canada, whose interest in autism began shortly after her cousin started Intensive Behavior Intervention (IBI). Christina was greatly influenced by this experience and subsequently applied for a position as an Instructor Therapist in 2003. Since then she has worked as an Instructor Therapist, then Senior Therapist in a publicly funded IBI program. In the first photo, you will see her in action as she disseminates research about the benefits of exercise for individuals with autism with other professionals. It is also important to share that she is a kettlebell sport competitor as well.

Currently, Kettlebells 4 Autism raises funds for the Geneva Centre in Toronto, Canada and the Association for Science in Autism Treatment (ASAT). We are pleased to share that their incredible fundraising efforts have resulted in more than \$1000 in contributions for ASAT to date. These funds have been invaluable in helping ASAT develop new resources for parents and disseminate our free newsletter to readers internationally.

We are also excited to be one of the beneficiaries of the next Kettlebells 4 Autism fundraising event. The first annual "90-second swings for autism" invited participants to dedicate 90 seconds of kettlebell swings to autism, and encouraged every participant to recruit sponsors to pledge a donation of a monetary amount per rep. For example, a sponsor commits to \$0.50 per rep, the participant completes 50 reps, and then the sponsor donates \$25. This year, participants can choose between a kettlebell workout, CrossFit workout, or body weight/equipment free workout, and each involves a minimum of one 90-second interval, devoted to autism awareness and fundraising for this year's beneficiaries. Final workout details and the event date will be posted shortly so be sure visit them on Facebook to learn more: www.facebook.com/Kettlebells4Autism.



Saukyn Luque, Christina Danos, Cynthia Roulston, Rachenne Regozo, and Nicole Powankumar

(Continued on page 17)

Kettlebells continued...

(Continued from page 16)

We are very grateful to Christina Danos, Kettlebells 4 Autism, and the kettlebell community worldwide for its support. We look forward to hearing how the 2014 event goes, and will share details in an upcoming issue of Science in Autism Treatment.



Erica Sweden and Alex Lorenzo



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 merchandise sales, and the 90 Seconds of Swings fundraising event in 2014, will be donated to the Association for Science in Autism Treatment, and the Geneva Centre for Autism, in Toronto.

[Shop online at www.kettlebells4autism.com](http://www.kettlebells4autism.com)

Consumer Corner

It's crucial to be a savvy consumer when it comes to one of the *most* important decisions you will make for your loved one with autism – choosing an ABA treatment provider for your child. Those of us who have already walked in your shoes know that *all* treatment providers are not the same. To the uninitiated, these professionals all look marvelous. From the slick websites, to the large numbers of associations of which these professionals are members, it is becoming increasingly difficult to differentiate between mediocre and outstanding treatment providers. Furthermore, publication of research in high quality journals is not synonymous with clinical expertise.

Fortunately, in this issue of Consumer Corner, we present a summary of consumer guidelines created by the **Autism Special Interest Group (SIG)** of the Association of Behavior Analysis International to help you make an informed choice when searching for ABA professionals to design, run and maintain your child's program. It is important to remember that your child's future depends on highly quality consulting. Good luck!

Sabrina Freeman, Ph.D., Consumer Corner Coordinator

Qualifications of Practitioners/Consultants who Practice in the field of Applied Behavior Analysis (ABA)

1. Certification:

Treatment professionals must all have advanced degrees, e.g., a Master's Degree or a Doctorate in a relevant field of study, and be certified either by the Behavior Analyst Certification Board (BACB), or a board that has equal or higher level requirements than the BACB. To look up your consultant, visit: www.bacb.com and click on "Find A Certificant." If the potential consultant is not on this list, ask where he/she became credentialed, and trained so that you can verify licensure and experience to determine whether it is equal to/or surpasses the standards of the BACB. If this individual responds to your inquiry in a defensive manner, then you may consider looking elsewhere as you are well within your right to seek clarification about certification status.

2. Extensive Hands-On Supervised Training:

Consultants are required to have extensive hands-on training treating children with autism in which they have worked at least one full year (1000 clock hours or 500 hours if taking an intensive practicum) under the supervision of a credentialed BCBA Certificant. In addition, they need to prove competency in many areas that cover the design and implementation of both *individualized* ABA interventions, and *compre-*

hensive ABA treatment programs. The partial list below was created by the *Autism Special Interest Group (SIG)* below. Your consultant should be competent in **all** the following areas:

a) Design and implement **individualized ABA Interventions**

- community living skills
- functional communication skills (vocal and non-vocal)
- "learning to learn" skills (e.g., looking, listening, following instructions, imitating)
- motor skills
- personal safety skills
- play and leisure skills
- pre-academic and academic skills
- reduction of behaviors that jeopardize health and safety and impede successful functioning (e.g., stereotypic, obsessive, ritualistic, aggressive, self-injurious, disruptive, and other behaviors often described as "challenging").
- school readiness skills
- self-care skills
- self-management skills
- social interaction skills
- vocational

b) Design and implement both **comprehensive ABA intervention**

programs (using multiple ABA procedures to ad-

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Consumer Corner continued...

(Continued from page 18)

dress multiple intervention targets) and **focused interventions** (using one or more ABA procedures to address a small number of intervention targets).

c) Delivering ABA interventions directly to at least 8 individuals with autism who present with a range of repertoires, levels of functioning, and ages.

d) Implementing the full range of scientifically validated behavior analytic procedures, including but not limited to:

- reinforcement (including differential reinforcement)
- extinction
- discrete-trial procedures
- modeling (including video modeling)
- incidental teaching and other “naturalistic” methods
- activity-embedded intervention
- task analysis
- chaining
- activity schedules
- scripts and script fading
- prompting and prompt-fading
- errorless training
- error correction
- motivating operations

- stimulus control
- preference assessments
- choice
- augmentative and alternative communication training procedures.

3. Continuing Education:

Not only do behavioral consultants need to be trained as above, in order to maintain their certification, practitioners must also pursue continuing education in a variety of areas that may include, but are not limited to, Applied Behavior Analysis.

Red Flag

These practitioners should not be working collaboratively with professionals who implement an eclectic mix of interventions that are untested, discredited or experimental in nature. If the consultant you use endorses an eclectic approach, understand that this practice is inconsistent with the BACB Guidelines for Responsible Conduct for Behavior Analysis. This red flag is a particularly helpful way to be forewarned about a consultant who is not a good choice to design and maintain your child’s program!

For more information on the exhaustive list of competencies, read the latest ABAI Autism Special Interest Group Consumer Guidelines at:

<http://asatonline.org/pdf/sig.pdf>

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Interview with Dr. Joyce Elizabeth Mauk

By David Celiberti, Executive Director

I had the opportunity to interview Dr. Joyce Elizabeth Mauk, a longstanding member of our Professional Advisory Board. Dr. Mauk serves as President/CEO/Medical Director of the Child Study Center. She graduated from the University of Rochester School of Medicine in 1982. She has served as Director of the Behavioral Rehabilitation Service at Children's Seashore House in Philadelphia, Pennsylvania, which is a hospital serving children with developmental disabilities and chronic illnesses. Dr. Mauk is a neurodevelopmental pediatrician who has done extensive research on autism spectrum disorders, psychopharmacology and behavioral disorders. She is currently a member of Cook Children's Physician Network, along with many other professional and scientific societies.

Tell us about your career trajectory, and how you got involved in the care and treatment of children with autism.

In the 1980s, as a Pediatrics Resident, I was drawn to children with neurologic disorders. For a while, I considered going into child neurology, but decided on a fellowship in developmental disabilities. I have always felt that, of the organs, the brain is the most interesting and the brain in action and in development was most fascinating to me. As a Neurodevelopmental Pediatrician at Children's Seashore House and Children's Hospital of Philadelphia, I was the Medical Director of a service line focused on children with developmental disabilities and behavior disorders. Needless to say, many of those children had a diagnosis of autism. At the Agency I direct in Fort Worth, about 40% of our patients have a diagnosis of autism. Since my early heavily clinical days, my role has changed.

Can you tell us more about that shift. What is a typical day like for you now?

I now spend more time in an administrative and mentoring capacity. I balance clinical, administrative, fund-raising, and several other key roles all focused on improving the lives of children with disabilities. Sometimes that entails working with complex budgets and insurance issues, sometimes by educating my lay board, mentoring clinicians, and seeing patients. Fortunately, each day is a little different.

You have been a valuable member of our Professional Advisory Board for many years. How did you get first involved in ASAT?

I was made aware of ASAT by my colleagues in the Behavior Analysis field, and enjoyed receiving the

newsletters. Dr. Sigrid Glenn from the University of North Texas nominated me to join the Advisory Board during ASAT's first few years.

As you know, there has been a proliferation of so called "treatments" for autism. What pseudoscientific treatment trends concern you the most and why?

I continue to be concerned about the low level of health and scientific literacy in the general population. As a Neurodevelopmental Pediatrician, I often need to counsel families about unscientific and even dangerous treatments. Two types of treatments are most concerning to me for different reasons. Sensory Integration Therapy- generally performed by an Occupational Therapist. My major concerns about this form of treatment are the expenditures in cost and time, given that there is no scientific evidence of efficacy. Since it is performed by an accepted type of licensed therapist, it has grown and prospered to the point of being considered standard of care. In addition, it also appears to be continued for years because clear outcome measures are not established for each case. Physicians are not always knowledgeable to challenge the ongoing therapy and thus continue to authorize it. The costs to society for this treatment, which is often covered by insurance and Medicaid yet is unproven, is astronomical. Furthermore, time spent with this form of therapy is time not being spent engaged in scientifically validated treatment. "Biomedical treatments" are concerning due to potentially dangerous side effects as well as cost. Some marketing of questionable treatments include statements that the treatment is good for arthritis, heart disease, cancer, lung

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problems, and autism- or some other combinations of disorders with no common pathophysiologic process. Some physicians who claim to specialize in autism have no training in developmental disorders or psychopharmacology. For example, families should be very cautious about an ENT (ears, nose, and throat) or allergist who claims to be an autism expert. Again, I am also concerned about lost opportunity to pursue effective treatments. Psychopharmacology of behavior disorders has improved greatly and medications may play a significant role in maximizing outcome. Legitimate biomedical vs. unproven treatments are difficult for the lay person to differentiate. Unconventional, unproven medications, and “natural” treatments often have side effects and may prevent families from seeking appropriate care.

In light of plethora or treatments for autism, most of which lack scientific merit. What advice do you have for parents of newly diagnosed children?

I tell them to visit the ASAT website and also Quackwatch before starting new therapies. I tell them that helping their child will be hard work and that there is no magic involved. Also that a diagnosis of does not mean that challenging behavior should be tolerated. It is true that communication deficits may predispose a child to use nonverbal ways to communicate, but aggression or disruptive behavior should never be acceptable. I am amazed at what sometimes is accepted as an inevitable consequence of a disability- with the whole family dancing around the child’s problem behavior and the behavior become more entrenched over time

What do you see as the most promising area of biomedical research?

I think a greater understanding of the genetics of autism is very promising. Current microarray technology has increased the number of children with known genetic causes- hopefully in the next ten years the clinical outcome of children with varying genetic causes will be clearer. This may help lead to improved ability to predict outcome or treatment response.

Tell us about the research you have conducted, involving children with autism.

In the past I have been involved in a research project to try and differentiate subtypes of self-injury in patients with autism and then prescribe tailored



Dr. Mauk Photo by Jill Johnson

treatments. This approach combined a functional analysis of behavior with observations on the rate, topography and associated behaviors of the self-injury. The take home message was that the majority of the self-injury was operant or learned. Of the patients whose self-injury was not operant or was mixed (had no clear antecedents or consequences, was self-maintained) some associated features such as crying, agitation, and aggression were predictive of response to medication classes (e.g., antipsychotics, SSRI's, beta blockers, and naltrexone).

Do you think the changes to the DSM-5 autism diagnostic criteria will change the diagnostic profile of the patients you treat?

For me, as an experienced clinician, the changes are largely academic. From a functional standpoint my patients need help of various intensities no matter what their disorder is called. From a practitioner in the field’s point of view autism has been over identified in the last few years so there is apt to be some correction in numbers. There is also some evidence of diagnostic substitution- individuals with cognitive disability being labeled with autism, for example. An individualized approach to treatment that incorporate behavioral excesses, deficits, and the family’s needs should transcend diagnosis.

I want to thank you, Dr. Mauk, for taking time from your busy schedule to participate in this interview. Furthermore, on behalf of the Association for Science in Autism Treatment, I would like you to know that your service on our Professional Advisory Board is much appreciated!

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With your help, we are reaching out to more and more people every day, united in their commitment to accountability, respect, and science in autism treatment. Individuals with autism deserve nothing less! Join us on [Facebook](#) to stay connected and get immediate content updates. <https://www.facebook.com/ASATonline>.



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Research Review

This newsletter highlights a study recently conducted by Houghton and his colleagues on the Son-Rise Program. Although the Son-Rise Program was developed in the 1970s, this is the first experimental study to date to evaluate its effectiveness. We hope you find this summary informative.

Sharon A. Reeve, Ph.D., BCBA-D, SIAT Research Corner Coordinator

Promoting Child-Initiated Social Communication in Children with Autism: Son-Rise Program Intervention Effects

Houghton, K., Schuchard, J., Lewis, C., & Thompson, C.K. (2013). Promoting child-initiated social-communication in children with autism: Son-rise program intervention effects. *Journal of Communication Disorders*, 46, 495-506.

Reviewed by: Kathleen Moran, Caldwell College

Why research this topic?

A major focus in the treatment of autism is to increase social interactions such as, initiating play or communication. Developmental approaches, which posit that children learn through back-and-forth exchanges with responsive adults, are popular interventions for social interaction deficits. The “Floortime” (i.e., Greenspan) model is the best known of these approaches. Another method, known as the Son-Rise Program (SRP), attempts to improve spontaneous, child-initiated interactions. This treatment includes an adult engaging in parallel play until the child initiates interaction and then praising and “joining” the child. Although SRP was developed in the 1970s, this is the first experimental study to date to evaluate its effectiveness.

What did the researchers do?

Twelve children with autism participated. Participants were separated into two groups;

one received treatment and the other did not. Data were collected on each child’s social and communicative behavior, including the number of head orientations, gestures, and “verbalizations” towards the adult to initiate interaction, as well as the duration of social interaction. Initially, each child participated in a baseline phase in which the experimenter made no attempt to interact. If a child initiated an interaction, the experimenter responded but did not provide any praise or prompt further interactions. Following baseline, one group received 40 hours of SRP intervention over a 5-day period. During intervention, the experimenter engaged in parallel play until the child initiated an interaction. Once the child initiated by using a communicative act such as a head orientation, gesture, or verbalization, the examiner responded immediately by providing praise, joined the child, and prompted for more interaction. After the intervention phase, each child returned to the baseline phase.

What did the researchers find?

During baseline there was no difference between the groups. At follow-up, the children who received treatment showed an increase in the number and length of spontaneous initiations of interactions. Verbal behavior also increased, but not significantly. In contrast, children who did not receive treatment showed little change.

What are the strengths and limitations of the study? What do the results mean?

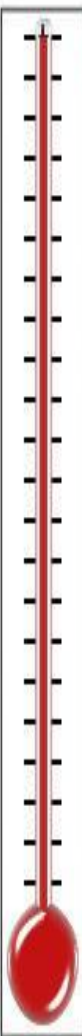
This study was the first to use data to assess the effectiveness of the SRP intervention. Although

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Research Review Continued...

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results suggest that the SRP intervention increased social interaction behaviors and possibly verbalizations, no conclusions about SRP can be drawn because of major limitations in the study design. First, children were not randomly assigned to treatment and no-treatment groups. Second, it was difficult to determine how participants were selected from the pool of families that went to the SRP training. Third, there was no test of whether gains generalized to other settings or maintained over time. Fourth, the investigators did not examine whether SRP therapists administered this intervention as intended. To begin providing credible data on effectiveness, future studies should address these methodological limitations and replicate the findings with additional children.



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4th Annual Rock'n 4 Autism Awareness Concert and Festival is Right Around the Corner!

David Celiberti, Executive Director



It's that time again! We are getting ready for the [4th Annual Rock'n 4 Autism Awareness Concert and Festival](#) on Saturday, May 3, 2014 from 2:00-6:00 pm in Hoboken, New Jersey. This community-based event is co-hosted by the Association for Science in Autism Treatment (ASAT) and Hoboken-based [HOPES CAP, Inc.](#)

Last April, the concert featured Hoboken's very own [Fuzzy Lemons](#), a popular and family-friendly rock band who wowed the crowd with their infectious songs and charismatic stage presence.

It is always heart-

warming to see scores of children dancing up a storm... and a few Moms and Dads as well!

Over 100 businesses donated money, merchandise and services, and 70+ volunteers came out to make the 2013 concert a wonderful experience. In addition to ASAT and HOPES representatives, volunteers came from Target, State Farm, Enterprise Rental Car, Hoboken Grace Church, Party with Purpose, as well as the community at large. This momentous support helped us raise almost \$25,000! It was such a tremendous success... so we've decided to do it all over again!

We are pleased to share that Hoboken Mayor, Dawn Zimmer, will welcome the audience at the out-



Cindy Vero at the Concert Welcoming Our Dancers



The One and Only Fuzzy Lemons

set of the festivities. Also, this year, the Fuzzy Lemons will be back again to dazzle and entertain. Be ready to enjoy two great sets as well as our guest MC once again, [Cindy Vero](http://www.ktu.com/onair/cindy-vero-21577/) www.ktu.com/onair/cindy-vero-21577/ from W-KTU (FM 103.5). No doubt Cindy will bring her upbeat style and energy, and help us make this event an even greater success! In addition to all the indoor and outdoor fun, attendees will also get the chance to talk with a number of knowledgeable parents and professionals from ASAT, and the [Hoboken Special Needs Parent Group](http://www.hobokensnpg.org/) <http://www.hobokensnpg.org/>, who will

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Rock'n 4 Autism Continued...

(Continued from page 26)

be providing information and take-away materials about awareness, education, and best practices in the field of autism.



Kids enjoying the concert

To date, over \$2,500 in sponsorships have been raised and donations for our silent auction are starting to come in each week.

For more details about the Rock'n 4 Autism Awareness Concert and Festival, please visit our Facebook page at: www.facebook.com/R4AA.Hoboken.

If you would like to volunteer to help with this event or donate an item for our silent auction, please email me at: dceliberti@asatonline.org. Please see the box below for more information about how to donate. If you live in the area, please come out and join us. Tickets can be purchased at: www.tinyurl.com/r4aa2014tickets.

We look forward to seeing you there! Make a difference and have some fun doing it!

Calling All Supporters: Donate Items for Our Silent Auction

This is ASAT's second year launching an online auction through Bidding for Good,. This means that our bidding can be opened up to anyone! We created a list that details donations that may serve as successful silent auctions bid items. Much of this is based on data collected by Bidding for Good. Data include hundreds of live online auctions that have identified bid items that drew the greatest number of bidders, and the greatest revenues. Check out the list below:

- 1. Travel packages and hotel stays;
- 2. Unique experiences such as, aerial adventures, lunch with a celebrity, and personal tours of fascinating places;
- 3. Sports memorabilia;
- 4. TV and movie memorabilia;
- 5. Collectibles; and
- 6. Gift certificates (restaurants, stores, businesses in which merchandise can be offered online).

If you are in a position to donate an item for our auction, please let us know dceliberti@asatonline.org.

International Interview:

With Nicole Rogerson, founding Director and CEO of Autism Awareness Australia

By David Celiberti, Ph.D., BCBA-D

I recently had the opportunity to interview Nicole Rogerson, founding Director and CEO of Autism Awareness Australia, a national not-for-profit organization. She is one of Australia's leading advocates for the awareness and understanding of Autism Spectrum Disorder, and is a staunch supporter of science-based autism treatment. Nicole is frequently asked to speak about autism with appearances on various Australian programs such as 60 Minutes, the 7.30 Report, the Today Show, A Current Affair, Today Tonight and Australian Story, as well as in the Australian Women's Weekly. When her son Jack was diagnosed with autism in 1999, Nicole left a career in marketing and public rela-

Nicole, by way of background, can you tell our readers a bit about your family?

My husband and I have two sons, Jack (18 yrs) and Tom (13 yrs), and we live in Sydney. Jack is on the autism spectrum. I'm afraid we experienced that all-too-common story of fumbling our way through our child's diagnosis. Jack was our first-born child and we simply didn't see the delay (or didn't want to). He didn't always look when you called his name ('because he is an independent person'), he didn't talk ('because his father and mother never stop, so he can't get a word in edgewise'), and wasn't interested in toys ('probably too gifted to be bothered playing



Sydney Opera House lit up blue for autism

with them'). He was our first child, we didn't have any friends with children and I considered myself way too cool to join a mothers group; so the fact that he wasn't developing like other children was news to me. "He is fine" we would say to anyone who asked about his speech delay. Is it possible to love a child so much, that you can be so blind to what was increasingly clear to those paying even a minute's notice?

Nothing can prepare you for the day you sit in a doctor's office and they first use the word *autism*. It is the stake through your heart, the words that, once said, are now your new truth. No going back. He has autism. Here are the tissues,

tions in order to pursue better support, services and representation for families affected by autism. Since establishing Autism Awareness Australia in 2007, Nicole has spearheaded numerous national education awareness and fundraising campaigns to do just that. The most prominent of these is *Light It Up Blue*, a campaign where Sydney's Opera House and other

iconic landmarks are lit up blue for World Autism Awareness Day. Nicole has led many other campaigns and events, which have inspired, touched, and educated Australians; including production of a short film on autism, '*What are you doing?*', for school children; and three television community service announcements.

good luck.

Jack was 3.5 when he was diagnosed in 1999. Any doctor with a degree out of a cereal box could have diagnosed him at two, but our *laissez-faire* attitude and state of denial kept autism out of our lives for that little bit longer. Putting it off, I learned, doesn't make it go away. When Jack was diagnosed I had no clue what to do next. The paediatrician's appallingly limited advice wasn't exactly a step-by-step guide in how to help this child! I was on my own. Google was in its infancy, but there was still a good array of so called "therapies," miracle cures and heart-

(Continued on page 29)

International Interview Continued...

(Continued from page 28)

wrenching stories to keep you reading.

I didn't have to wade through the options long before I came across the one that seemed to be recommended by all of the sensible grownups around the world. Applied Behaviour Analysis (ABA) made sense to me right from the start. It wasn't rocket science - just start teaching him the things he can't do by breaking them down into small, teachable steps and then 'reinforce' the behaviour. Then repeat.

I read the books (thank goodness for Catherine Maurice), bought the manuals, educated myself on how to do this; and then went looking for people to help me. This is where our luck started to change. I met Elizabeth Watson, who, along with Michelle Furminger, would run Jack's ABA program for the next 10 years. ABA would teach Jack

how to talk, how to read, how to behave, how to be social, how to live with us, here in the real world. Autism was never to be an excuse in our family. The goal was always, and still is, to take away all of the problems autism brought to our door. Jack was going to live with us, not with autism. I was resolute on that point. I won't bore you with the story [insert amazing autism story / blow by blow] of Jack's early intervention and school years. You would have read it all before. I can simply say that ABA gave me my boy back - so I fell in love with it and there I have stayed.

If you're ever lucky enough to meet my Jack, you'll meet a well-mannered, polite, funny, empathetic young man who delights everyone he meets. His teachers at school are his unofficial cheer squad. I am just so proud to be his Mum.

Aside from Autism Awareness Australia, I understand you are also the Co-Founder of the Lizard Children's Centre, Australia's leading early intervention centre for children with autism and developmental delays. Tell us about your roles within these two organizations.

I am the Director of the Lizard Centre and CEO of Autism Awareness Australia. ABA programs were scarce in the late 1990s/early 2000s in Australia and there were very few professionals well organized enough to increase ABA's profile and reach. I was passionate about

more children having access to the kind of quality early intervention my son had, so in 2003 I joined with Elizabeth Watson (Speech Pathologist who had run Jack's program) and started the Lizard Centre. We wanted to increase the profile and reach of ABA and hopefully set up a career path for people wanting to work in the field. So our little company started, and then continued to grow and we are now Australia's largest private early intervention clinic.

I have now been lucky enough to witness hundreds of children learn and develop through their ABA programs and it still never ceases to amaze me. The very humane nature of what ABA does, the inherent kindness in teaching a child a skill they weren't learning on their own, and surrounding them with reinforcement - what's not to love about that? ABA is a 'Yes we can' kind of therapy - I was hooked from the beginning.

In 2007, I was inspired listening to Catherine Maurice speak at the Association for Behavior Analysis International's First Annual Autism Conference in Boston. She perfectly articulated the frustration I felt with families languishing in a sea of misinformation, pseudoscience and this so-called 'democracy of therapies.' I was determined to go home and do my best to better educate families, and indeed the rest of Australia, about autism. So that year, I began Autism Awareness Aus-

(Continued on page 30)



Jack

International Interview Continued...*(Continued from page 29)*

tralia, which is now the nation's leading not-for-profit autism education and advocacy organization. We have rolled out some pretty great projects since then, but lighting the Sydney Opera House blue each year for World Autism Awareness Day, has been a highlight.

What is autism treatment like in Australia? Can you share details about any national legislation that has influenced the delivery of services?

There has been great improvement in this area in the last 6 years, but we still have a ways to go. Despite publishing [Best Practice Guidelines in 2006](#), which rated ABA highly and recommended a minimum of 20 hours a week of early intervention, the Federal Government refused to fund it. They did however fund children to have \$6000 worth of early intervention per year for 2 years until the age of 7. Sadly, this saw the amazing growth in children receiving 1 – 2 hours per week of therapy, mainly with a speech therapist or OT. Not that either of these are harmful per se, but on their own, without the back up of intensive behavioural treatment, we know that makes them as good as useless. Sadly, 'Evidence Based' is a term thrown around in Australia as easily as low-fat – the devil is always in the details.

In 2012, after further work, the Federal Government released the Good Practice Guidelines

(sadly, this is not a joke), which watered down the recommendation regarding intensity (15 hours/week now recommended). They did however put in a rating system for therapies that saw ABA come out on top and indeed some therapies come off the [approved list](#) (Sensory Integration Therapy).

It is not all bad though. ABA has gone from being considered a version of child abuse in the late 1990s to now being recognized as the therapy with the most evidence-supporting efficacy. Sadly, as there are limited funds for it, it is still being accessed only by families who can: a) afford it, or b) beg, borrow and steal to make it happen. ABA still takes hits from 'specialists' who recognise it is considered best practice, but say that other less-intensive therapies work just as well. Parents are voting with their feet and they understand intensity is what is needed.

Australia is just about to implement a National Disability Insurance Scheme (NDIS), which will bring universal disability care to all Australians. The scheme is in its infancy, but reading the overview of the legislation and its commitment to providing individuals with early intervention, which is supported by actual evidence, it might mean funding will become available for families, which ultimately should see more children being able to access ABA for their early intervention.

What resources do parents turn**to in order to learn about autism treatment? Do these resources recognize best practices based on scientific evidence?**

Sadly parents are still under-supported at this time. The government set up a network of 'Autism Advisors' in each state which were charged with meeting parents just after they had received their diagnosis, give them some information and then process the paperwork for them to access the limited early intervention funding. Sadly, they were also prevented from being able to give advice (*I hear you, autism advisors who can't give direct advice*). So, parents still turn to Google – with all its wonder and pitfalls. One government-made website that does quite a good job is the Raising Children Network, which has a [guide](#) to therapies for families.

Still, there is a strong undercurrent of 'let families find the therapy that works best for their child' and 'people must have choice.' All true, but we must also protect families from the (some time well meaning) charlatans who dwell in this industry, and give them the tools to make sound decisions for their children.

Have the professionals in your country organized to advocate for evidence-based autism treatment? What about the parents? If yes, are they organized or is everyone fighting on their*(Continued on page 31)*

International Interview Continued...

(Continued from page 30)

own? If not, why do you think they are not?

To be honest, I think this is where Autism Awareness Australia has come into its own. Backed by some pretty smart parents, we have run campaigns such as '1 in 100 need it funded' in this last Federal Election, and we are, when possible, walking the halls of our national parliament trying to make change in autism policy in Australia. Sadly, we are sometimes held back by the health bureaucrats who still run some generic special educational style programs, whose careers have been made on the 'low intensity' services we are so desperate to make a thing of the past. Just last year, I organised a group of leading ABA service providers, academics and State-based interest groups to come together to form the National Organisation for Applied Behaviour Analysis. It is our goal to make sure all of the leading people working in ABA in Australia are working together to promote and raise awareness of ABA within all areas of the Australian community. We also wanted to educate people on what good quality ABA actually involves. Unfortunately, we have some less-than-reputable service providers running low intensity ABA programs (is there such a thing?) to better accommodate the funding families have access to. I am staunchly opposed to service providers retro-fitting their ABA programs

to accommodate available funding. Sadly, the ABA field is not immune to charlatans either.

I understand you shared your story at the United Nations. Can you tell us about that experience?

Autism Awareness Australia has



Nicole Rogerson at the United Nations

achieved some pretty amazing things over the last few years, and I was invited in speak about them in 2011 at the United Nations in New York. I was invited back in 2013 to premiere a documentary film I made called 'What are you doing? A film about autism.' The film was made to better educate children in a mainstream setting about what autism is, so they can better understand their classmates who are on the spectrum. The film stars siblings and friends of children on the spectrum, who explain to their peers what autism is all about. I am pretty proud to say that last year, with the help of

the Federal Government, we distributed it to every elementary and secondary school across Australia. I believe in walking the walk of inclusion, not just talking the talk.

Any final thoughts?

Absolutely! I'd like to ask the professionals reading to remind themselves what fabulous humanitarians they are. I am constantly reminding my staff how brave and determined they are. You simply don't sit back assessing a problem and writing a report on it. That is merely stage one for you! You analyze, collect data, write procedures, implement them, re-assess, graph and chart progress. You don't talk the talk of intervention, you *run* the walk! You teach children skills which gives them independence. You give them freedom from their disability and you give parents their children back. In short, you're my heroes.

No fair Nicole! Parents like you, are my heroes. My colleagues and I choose autism, parents do not. Working with parents who roll up their sleeves to help their child is an incredible reinforcer to us. Seeing parents who dedicate their blood, sweat, and tears to helping other parents have a clearer path, is nothing short of inspirational.

Thank you for taking time to share your story with our readers.

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- ⇒ All families will be empowered with skills in identifying and choosing the most effective, scientifically-validated interventions for their child.
- ⇒ The media will educate and not confuse parents by providing accurate information and asking the right questions.
- ⇒ All providers will be guided by science when selecting and implementing interventions and use data to demonstrate effectiveness.

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ASAT's 2014 Sponsors have indicated their support of the following tenets:

1. 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.

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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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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 empirically –sound 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.



Barbara Jamison, BA, Media Watch Lead

- ASAT Responds to Toronto Star's "Groundbreaking adult autism survey reveals mountain of unmet needs" (July 25, 2013) What happens to individuals with autism when they reach adulthood? Star.com's Laurie Monsebraaten reports on a recent groundbreaking study. http://www.asatonline.org/media_watches/107
- ASAT Responds to CNN.com's "Jenny McCarthy and Fear-Based Parenting" (August 2, 2013) Misinformation and fad treatments gain even greater traction when endorsed by celebrities. http://www.asatonline.org/media_watches/108
- ASAT Responds to High Plains Journal's "Family uses agriculture as autism therapy tool" (October 23, 2013) Immersion in an agricultural setting may provide a wonderful opportunity to develop a variety of social and vocational skills, but ASAT cautions Writer Jennifer Latzke against terming this experience a "therapy tool." http://www.asatonline.org/media_watches/109
- ASAT Responds to AutismDailyNewscast.com's "Limitations apparent in applied behavior analysis research" (December 4, 2013) What three questions should families ask potential providers of autism treatment? http://www.asatonline.org/media_watches/110
- ASAT Responds to ScienceCodex.com's "Making sense of sensation" (December 7, 2013) A new study by Thomas Jefferson University seems to imply that a sensory integration approach may be more effective than behavior training...but is it? http://www.asatonline.org/media_watches/111
- ASAT Responds to Forbes.com's "Court rulings don't confirm autism-vaccine link" (December 13, 2013) commending journalist Emily Willingham for providing a clear and sound voice of reason in yet another attempt by a media outlet to draw a connection between vaccines and autism. http://www.asatonline.org/media_watches/112
- ASAT Responds to NYTimes.com's "Wandering is a major concern for parents of children with autism" (December 15, 2013) Stories of elopement or wandering catch at the heart of any parent, but are particularly concerning to families with a member on the autism spectrum. http://www.asatonline.org/media_watches/113
- ASAT Responds to DigitalJournal.com's "Journal of Communication Disorders Releases First Autism Study of the Son-Rise Program" (January 2, 2014) The very fact that this is the first study examining the benefit of a program that has been touted as an amazing and highly successful treatment for the past 35 years is alarming in and of itself. http://www.asatonline.org/media_watches/114
- ASAT Responds to TheGuardian.com's "Is it right to try to 'normalize' autism?" (January 8, 2014) Calling applied behavior analysis a "controversial U.S. teaching method," Guardian reporter Chloe Lambert sparks a Media Watch response that answers arguments posited by ABA detractors. http://www.asatonline.org/media_watches/116
- ASAT Responds to TheBlaze.com's "Parents set up hidden camera to monitor autistic son's therapy sessions – what they saw happening in real-time is gut-wrenching" (January 21, 2014) Sadly, therapist abuse happens...what practical steps can parents take to secure a qualified, competent person to work with their child? http://www.asatonline.org/media_watches/117

Write to us at mediawatch@asatonline.org

Team ASAT Crosses the Finish Line!

By Ruth Donlin, MS



The 43rd ING New York City Marathon held on November 3, 2013 was welcomed with great enthusiasm and worldwide spectator support as thousands of people gathered along the 26.2-mile course through all five boroughs. Fittingly, the race commemorated the heroes and victims of super storm Sandy and those who were affected by the Boston Marathon bombings.

Of the 50,266 marathon finishers, Team ASAT Captain Bobby Newman and four volunteer runners, Randy Horowitz, Sheila Jodlowski, and 23-year-old twins Alex and Jamie Schneider diagnosed with autism, are to be congratulated. They each dedicated extensive time and training to complete the run, and we are grateful and honored to be their chosen charity to support.

We would also like to thank all the individuals who donated to Team ASAT. These donations make it possible to continue providing a free quarterly newsletter, along with other valuable resources to families and consumers by disseminating information regarding evidence-based treatments for autism spectrum disorders. ASAT is committed to helping people understand the difference between sensational claims of how to help or cure autism versus science-based research that guides effective intervention. In addition to all the excitement gearing up for this international event, ASAT was thrilled when ABC's "Good Morning America" (http://www.youtube.com/watch?v=aIEHck_80os) was so inspired by the Schneider twins, that they interviewed the family, filmed the boys in training, and aired two exclusive video clips about them and their family the day of the marathon. Alex and Jamie have severe autism with limited communication skills and understanding of safety in the community. However, both are gifted athletes and love to run. This was their first time participating in the NYC Marathon as well as first time fundraising for ASAT. Alex beat his personal best, clocking in with a run time of 3:14.35! To read more about their captivating story, click here: <http://www.asatonline.org/pdf/fall2013.pdf>.



Alex and Jamie Schneider

The success of this event was made memorable by our team runners; we also would like to extend our thanks to the New York Road Runners and to the ABC staff and crew who provided wonderful media coverage and mentioned ASAT. Here is another [clip](http://www.youtube.com/watch?v=N5jLzg3bHol): <http://www.youtube.com/watch?v=N5jLzg3bHol>

As a result of this publicity, the Schneiders' inspirational story generated a tremendous response in social media, as well as a mention in dozens of publications including Runner's World and the Huffington Post.

If you have ever wanted to run in the NYC Marathon, there is an opportunity for you to run and contribute to our worthy charity. By joining Team ASAT, a fundraising page will be set up for you on-line through the NYC marathon and Crowdrise. Your friends and family can then sponsor you to help you meet your fundraising requirement.

If you are interested, please contact Ruth Donlin at: asatevents@asatonline.org.

There is STILL time to help support the twins' charity fundraising or to support Team ASAT by going to: <http://www.crowdrise.com/>

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ASAT's Newsletter, Science in Autism Treatment
Justin DiScafani, PhD
Caroline Simard-Nicolas, MS, BCBA
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Coming up in the Spring 2014 Issue of *Science in Autism Treatment!*
This issue will be dedicated to the Behavior Analysis Center for Autism
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- ☆ Program Description of BACA and Interview with Dr. Carl Sundberg
- ☆ Clinical Corner: Safety Skills (From the Archives)
- ☆ Consumer Corner: Review of resources to prevent bolting
- ☆ International Interview: Professor Mickey Keenan, University of Ulster, N. Ireland