



SCIENCE IN AUTISM TREATMENT

Vol. 8 No. 1

Newsletter of the Association for Science in Autism Treatment

Winter 2011

Table of Contents

Interview with Cyndy Hayes.....	1
Message from David.....	1
SIAT Team	1
ASAT Advisory Board	2
Rock'n For Autism Awareness	5
Summary of Conference at Molloy College	6
Clinical Corner: My son bolts!	7
Mortality Review of Drowning in Autism.....	8
Letter from Josh	9
ASAT Committee Members	9
Tribute to Stephen Luce.....	10
Consumer Corner: Showcasing APBA.....	12
Consumer Corner: Showcasing Rethink Autism ..	13
Top 10 Questions Journalists Should Ask.....	14
ASAT Donor Wall.....	14
ASAT Board of Directors.....	15
Media Watch Update.....	15
Research Review: Parent Training Program	16
Research Review: Review of Weighted Vests	17
Research Review: Hyperbaric Treatment.....	17
Review of Weighted Vest and SIT	18
Visit from the AVON lady	20
ASAT's Facebook update	21
ASAT Advertising Policy	22
ASAT Sponsorship	23
ASAT Mission Statement.....	25

ASAT Welcomes Dr. Cyndy Hayes as Its Newest Board Member with an Interview by David Celiberti, Ph.D., BCBA-D

I am pleased to have this opportunity to interview you, the newest member of ASAT's Board of Directors. As you know from my letter, as we look to this new year, we are in the process of assessing and improving upon the extent to which ASAT's efforts support consumers living with or serving adults with autism, an often neglected segment of the autism community. I know you will be instrumental in helping us in this endeavor, and look forward to working with you in the years ahead. Prior to

responding to questions specific to your own journey in autism, I was hoping you could share a bit about your professional background.

Very early in my career, and after completing my Masters Degree in Psychology, it was my intention to pursue a private clinical practice. So

I initially started working in private industry in order to provide financial support for my continued studies and to pursue my passion for clinical work. Ironically, when I entered the private sector, I found that I enjoyed working with

(Continued on page 2)



Message from ASAT President, David Cellberti, Ph.D., BCBA-D

Happy New Year! I hope this newsletter finds you all well and that your 2011 is off to a great start! I was very proud to share many of our 2010 accomplishments in the Fall issue of Science in Autism Treatment (SIAT). In this issue of the newsletter, we have outlined an array of goals and initiatives for 2011.

- Increase number of Science in Autism Treatment subscribers to 10,000 by December 2011. We happily reached our 2010 goal of 6000 subscribers!
- Continue to generate new content for www.asatonline.org and update the

(Continued on page 24)

Science in Autism Treatment (SIAT) Team

Co-Editors

David Celiberti, Ph.D., BCBA-D
Joshua K. Pritchard, M.S., BCBA

Science Corner

Daniel W. Mruzek, Ph.D., BCBA-D

Editorial Consultant

Elizabeth Dyer, M.A. CCC-SLP

Research Reviews

Sharon Reeve, Ph.D., BCBA-D
Kathleen Moran, M.A.

Clinical Corner

Lori Bechner, M.A., BCBA

Consumer Corner

Kate Fiske, Ph.D., BCBA-D

Media Watch

Barbara Jamison, B.A.

Treatment Summaries

Tristram Smith, Ph.D.

Events

Denise Grosberg, M.A.

Interview with ASAT Board Member, Cyndy Hayes continued...

(Continued from page 1)

organizations to bring about important changes. At that point, I altered my educational direction, and completed my MBA and Doctorate in Business. After stints in sales and marketing, I began to work, first internally, and for the last ten years, as a consultant in the area of organizational development. I enjoy working at the senior level within organizations, as this allows me to design and facilitate leadership team development, strategic visioning, transformational change and organizational diagnostics initiatives.

That sounds like an incredible and exciting career path. So many autism organizations fail, or are unable to realize their fullest potential, due either to a lack of focus or to goals that are unreachable. We would like to learn more about the first chapter of your personal journey with a child with autism. Your son, Brandon, was diagnosed 18 years ago. What was that experience like for your family?

I have three beautiful children; my youngest son, Brandon, was diagnosed at the age of two. Initially, I thought he was the most clever of my three very clever children. Then, I began to see his skills slip away. There is no question that the diagnosis of autism affects the parents and family in a very deep and profound way. And clearly the impact and the reaction to the diagnosis show up in different ways for everyone. I distinctly remember thinking to myself within days of Brandon's diagnosis, that feeling angry and sorry for myself and asking, "Why me?" was not going to help anyone – certainly not my son.

So I hopped on a plane and headed out to UCLA to see Ivar Lovaas, and then up to New Jersey to visit some of its outstanding educational

programs, including Princeton Child Development Institute, The Alpine Learning Group, Eden Services and the Douglass Developmental Disabilities Center. I read everything I could get my hands on. And for me, decisions regarding the most appropriate intervention for my son had to be driven by data. I needed to understand which programs could demonstrate evidence-based outcomes. And I believed – and still believe – that the only intervention that met my criteria, and that was most appropriate for my son, was based on applied behavior analysis.

I organized a handful of families to schedule Dr. Lovaas to come to Florida (where we lived at the time) to train parents and instructors. Brandon began a 40-hour –a- week home program at age two, and has had the opportunity to work with many very talented ABA professionals over the last 18 years.

How has your professional background shaped your experiences as an advocate for your son and other young people with autism?

Soon after Brandon's diagnosis, I founded several organizations. The first of my endeavors was Reaching Potentials, a non-profit organization focused on early intervention, and parent and staff training. I am proud to say that this organization, thanks to the leadership of Pam Gorski, continues to provide great value to the field. I also founded Global Communities of Support, which provides support and services for teens and adults with autism. GCoS is currently partnering with Ryder University to create community programs for young adults with autism, and is also working with Allies Incorporated to establish additional residential options for adults with autism.

Most recently my focus has been on trying to construct a more abundant approach to collaboration within the autism community. My

initial design and participation in Advancing Futures for Adults with Autism (www.afaa-us.org) was, in part, a way to demonstrate the power of that approach. Working together, 14 of the leading autism organizations started a meaningful national dialogue

(Continued on page 3)

ASAT Advisory Board

F. J. Barrera, Ph.D., BCBA
 Stephen Barrett, M.D.
 Martha Bridge Denckla, M.D.
 Curtis Deutsch, Ph.D.
 William V. Dube, Ph.D.
 Deborah Fein, Ph.D.
 Eric Fombonne, M.D.
 Richard Foff, Ph.D., BCBA
 Gina Green, Ph.D., BCBA
 William Heward, Ed.D., BCBA
 Ronald Kallen, M.D.
 Alan Leslie, Ph.D.
 Bennett Leventhal, M.D.
 Johnny L. Matson, Ph.D.
 Joyce E. Mauk, M.D.
 Catherine Maurice, Ph.D.
 Bobby Newman, Ph.D., BCBA
 John Pomeroy, M.D.
 Stephen Porges, Ph.D.
 Sharon Reeve, Ph.D., BCBA
 Joyce Rosenfeld, M.D., FACEP
 Arthur Toga, Ph.D.
 Paul Touchette, Ph.D.
 Roberto Tuchman, M.D.
 Paul Yellin, M.D.

"I distinctly remember saying to myself within days of Brandon's diagnosis, that feeling angry and sorry for myself and asking, "Why me?" was not going to help anyone – certainly not my son."

Interview with ASAT Board Member , Cyndy Hayes continued...

about adults with autism. We conducted a think tank that included the leading experts in the field, a National Town Hall that brought 1,200 voices of various stakeholder groups together across 16 cities, and finally convened in Washington D.C. to deliver a National Agenda for Adults with Autism. And my latest initiative, Aging with Autism (www.agingwithautism.org), is focused on creating a community of practice, and on addressing the challenges and needs of individuals with classic autism.

There is no question that my professional skills continue to inform my advocacy work. I think the ability to take the “long view” is critical in creating any sustainable and meaningful change. That, along with thinking strategically about vision and mission, is critical. And finally, once that work is done, the ability to implement a disciplined action plan that really makes a difference in people’s lives is easier. I learned early on that advocating for my son gave me the opportunity, in fact, to advocate for the larger community. The opportunity to support all of the other “Brandons” has brought me great joy. I continue to learn from the parents and professionals in the field and to be impressed by their commitment and passion for this important work.

Eighteen years ago you witnessed a rapidly changing landscape of services at the early intervention level. As Brandon grew older, you have found yourself in uncharted terrain once again. What is your perspective on the state of adult services today? In your view, what needs to change and how can that change come about?

Well, I started working on adult services in 2001 when Brandon was eleven. But I really started thinking about adult services when he was a younger child. Concerns about his future and the question of what happens to him when I am no longer able to care for him, is what kept me up at night.

The reality is that the planning process for your child’s future should start early. The challenge for families caring for an individual with autism is that the work is so hard that making it through each day takes all of your energy. In fact for many, it takes more energy than is available, and so the impact on families is devastating.

The other big hurdle in creating effective programs and services for adults is that it is a lot easier to raise money and interest to support a cute two-year old that is the picture of hope and potential than an adult whose very behavior often makes people uncomfortable. So, when I think about the work of creating quality programs and services for adults with autism, it does take me back to my original efforts to create effective early intervention programs.

The current state of services for adults is a significant concern. There are a handful of programs across the country that are quite good. The need for services is so great, with long waiting lists in every state in the country. The increase in prevalence of autism has created a tremendous demand for services that could be compared to the impact of baby boomers moving through the general population.

There are definitely some pockets of excellence that exist. There are talented parents and other professionals that are passionately focused on creating programs and services that will provide the opportunity for full and meaningful lives for adults with autism. There is a strong group of advocates who believe that with the right level of support, adults with autism, regardless of the severity of their cognitive or behavioral involvement, can participate as fully functioning, competent members of society. And I truly believe that once we see that vision clearly, we will be able to make it a reality. My hope is that AFAA has opened the conversation. We now must continue our research, pilot new and innovative models and replicate those programs that demonstrate best practices and positive outcomes.

Tell us more about your newest organization.

In 2008, Brandon, who was then 18 years old, began exhibiting self-injurious behavior that resulted in several hospitalizations and ultimately 18 months in a state developmental center. He became so seriously ill that we almost lost him. I began to meet with agencies, organizations and elected officials both at a state and national level. I discovered that there were few services available to serve individuals with classic autism – those most severely involved, often with complex and challenging behaviors. Sadly, it still took a year and half to get my

(Continued on page 4)

Interview with a new Parent Board Member continued...

son into an appropriate placement in the community.

The reality that I couldn't escape was that if I had so much difficulty in finding services for my son, many families who were less prepared to navigate the system would be left completely without hope. Many individuals with autism would fall through the cracks. It was at this point I dedicated myself to creating a system of supports for families in crisis.

We are talking about the most vulnerable on the autism spectrum, and we know so little about them. We have few programs and services that are designed to meet their unique needs. I feel strongly that we must shine a light on these individuals, challenge our assumptions and begin to create new and innovative programs that are about seeing the potential that lives within each one of them. So it was with these individuals and their families in mind that I founded Aging with Autism (www.agingwithautism.org).

The other focus of Aging with Autism is to create an online community of support. AWA website is a manifestation of the abundance mentality that I mentioned earlier. The website features other autism organizations that are doing important work in the field. Visitors to the site can review the purpose and visions of these other organizations, but they can also donate to these other organizations on the Aging with Autism website if their missions resonate with them.

We look forward to seeing how the future unfolds for Aging with Autism and applaud your efforts to better meet the needs of adults with autism and those who are more classically or significantly impacted by autism. If you could do anything different raising and advocating for your son what would be it?

Well, there is no question that I have been sprinting in a marathon. And certainly intellectually, that doesn't make sense. But I'm quite sure that if I had it to do over again, I'd probably do it the same way. Not that there is a right or wrong way to react to this challenge, but for me it would have to be about being fully engaged.

"I feel strongly that we must shine a light on these individuals, challenge our assumptions and begin to create new and innovative programs that are about seeing the potential that lives within each one of them."

With that said, in retrospect, rather than compartmentalize my career, my advocacy and my life, I think it would have made sense for me to find a way to combine the three more effectively. And of course, as a parent, you want to have as much quality time as possible with your children. And there is no question that advocacy takes time. I have thought a lot about the commitment I have made to advocacy. Should I have focused in a more singular way on the needs of my son?

And this is the way I process that choice. I believe that my advocacy has benefited my son by bringing new resources to his life. It has benefited my work with him and my own personal growth through connecting with other powerful and passionate parent and professional advocates. And of course, to get a letter from a parent that has benefited in some way from your work is priceless.

Any advice for parents of newly-diagnosed children?

Yes, I do have a few suggestions:

Become an autism expert. Learn as much as you can.

Be a discriminating consumer of products, programs and services. Examine outcomes – require and make sure you understand the data.

Understand and challenge any assumptions about your child that limits him or her. You are the expert on and voice of your child. Build an effective team of professionals for your child, but you drive the process.

Work with other families; they have similar needs and can be a great source of information and support. Together you can do more.

And even though this is a huge challenge and it often feels like you have to take it one day at a time, find those moments when you have just a little bit of reserve energy. Use this time to take the long view.

Autism is a lifelong disability. Lifelong planning is critical to providing quality lifelong support. This means seeking legal and financial advice. It also means creating a vision for what your child's life can look like at its best and creating a plan to make that a reality.

And finally take a deep breath; take lots of deep breaths. Take care of yourself and if you have a partner in this journey, take care of each other. You can do this!

Rock'n 4 Autism Awareness Event Review by Ruth Donlin M.S.

This past July 31st, ASAT decided to have its first benefit rock concert, Rock'n 4 Autism Awareness. The notion of this event began with a dinner amongst a few friends, my brother Barry Donlin included. Barry is a contractor and owns Donlin Construction in Lancaster, PA. Tracy Horning is a longtime friend and an Event Planner for Heritage Hills. Barry was inquiring when his band, Eye Wish Eye, could play at the Pennsylvania Renaissance Faire, which is known for hosting great talent and supporting wonderful non-profit groups. After talking about some dates and possibilities, Barry suggested we put together an autism benefit rock concert. He is a humanitarian who had just recently played drums in a band for a benefit concert for Haiti. Tracy is a party planner, supporter of the local music scene, and strong believer in ASAT's mission. She has always worked to help the underserved and collaborates with Peaceful Warriors, a group that encourages individuals to give back to their local communities through service, fundraisers and events. Jessy Hamel, who works for the PA Renaissance Faire, was also at this dinner. She suggested they host the first ASAT concert, as this would be the first benefit they hosted to benefit those affected by autism. What made this family-friendly outdoor event particularly special was the promotion of autism awareness and education about best practices. ASAT board members, some of whom were also parents of children with autism, were available at our information table. They answered questions and handed out bags filled with valuable resources and articles including information about scientifically-supported interventions. Dissemination of quality information took place all while enjoying great

music, food, drink, games, and prizes.

The event drew a great crowd, many of whom are followers of the five well-known bands who volunteered their time and played live. They were: Steven Courtney, Mark DeRose Duo, Josh Albright, Chuck Gibson, and Eye Wish Eye. The music was amazing. Thanks Guys!!!

Planning an event like this clearly takes a lot of time and investment, so ASAT was fortunate to have Barry and Tracy working around the clock to have nearly all performers, musicians, clowns, and jugglers donate their time and energy. I followed up with Barry and Tracy to see what motivated them to help ASAT and what they felt was most memorable about the event.

Tracy felt it was wonderful to be "working with great people to support a very worthy cause while combining my love of charity, event planning and music." Barry had some familiarity with autism but states this was his chance to personally give back to families and children with autism. He went on to say, "I respect ASAT's mission. I wouldn't want to be lied to, misinformed, or misled about effective treatments if I had a child with autism."

What stood out as most memorable about the event to Tracy was "the few moments when I simply stopped everything to just look at what was going on around me. Stealing a quiet moment to see the smiles on the children's faces, watch the volunteers interacting with and educating the public, and hearing the bands play as the soundtrack to this beautiful picture."

There were numerous high points of the day, but Barry strongly felt that, "The most memorable and most impressionable had to be the videos." Barry played a key role in

developing video footage to create two powerful videos about young children with autism and how applied behavior analysis has positively made a difference in these family's lives. Barry went on to say, "There was information about autism all around, whether it was literature, people or musicians telling others about it, but it was the video that captivated the message. The second standout moment would be seeing just how many people would volunteer their time for this cause."

Seeing other people become involved in an ASAT project, even when they are not directly affected by autism, was inspiring to me. We had numerous dear friends from New York come and join us that day, along with some board members and their children. Reflecting back on the day, Tracy said she learned the following: "I learned how autism touches lives on many different levels. The strength and love of families touched by autism is beyond comparison and never ending. To work side by side with these families supporting the cause and helping to raise money was a true honor." Barry felt grateful and reiterated that he learned too much to say briefly, but he now knows that, "1 out of every 110 children are on the spectrum, there are a thousand ineffective treatments, there are many misconceptions about autism and its causes, and implementing effective behavior strategies takes strong commitment and dedication."

Rock'n 4 Autism Awareness gained the support of Loxley's, an excellent restaurant in Lancaster, PA, that agreed to list ASAT as one of the charity choices for diners when paying their bill to support R4AA. Loxley's raised \$2,423 for ASAT! This fortuitous experience, fostered by

(Continued on page 6)

NJ Area Subscribers.....Mark your calendars for 4/9/2011. 3:00-7:00 pm! The success and excitement of this Lancaster concert inspired us to organize a Rock'n 4 Autism Awareness benefit concert in Hoboken, New Jersey! We are joining HOPES, CAP, Inc in hosting Hoboken's very own Fuzzy Lemons with a special appearance by NY Jets Player Mike DeVito!!!

Rock'n 4 Autism Awareness Event Review continued...

Science in Autism Treatment

Volume 8, Winter 2011

Tracy, helped ASAT start its Dine InDeed fundraising program (found on Facebook as Dine InDeed Hoboken). Overall, the R4AA concert raised approximately \$5,750.

We are thankful to the many local businesses, organizations, and families whose generous sponsorships/donations, time, and energy made this event possible, including: Loxley's Restaurant, Rethink Autism, Heritage Hills Golf Resort, The Irish Cottage, National Fire & Safety Solutions, Apollo Electric, C.M. Richey Electric, Cissy and the Man (Juggler and clown entertainers) based in Lancaster County, Hartman Team Photography, and Laura Duran & Associates, LLC. We are also most grateful to the Pennsylvania Renaissance Faire for donating the location for the event, advertising, support & staff. This event would not have been possible without the hard work, boundless energy and dedication of our entire R4AA committee.

Watching a community come together across three states (PA, NY, NJ) was a memorable and gratifying experience. Helping to educate and empower families to make choices based on empirically supported methods drives us every day to continue this important and inspiring work. If you are a SIAT subscriber and know a business that may be interested in supporting ASAT, we welcome the opportunity to talk with you further. Please do not hesitate to contact Ruth Donlin, ASAT Event Coordinator at asatevents@aol.com to discuss this or to answer any questions you may have.

As you read on the prior page, we are already planning our next rock concert in Hoboken, New Jersey, this time for the kids! Visit the R4AA Facebook page at www.facebook.com/R4AA.Hoboken. Special thanks to Candice Stern for designing the promotional materials for this NJ event. Check out her work at: www.candicestern.com

Autism Intervention: Making Better Choices through Science - A Conference at Molloy College by Nicole Sugrue, ELIJA Foundation

On Friday, October 15th, ELIJA held a collaborative conference with Molloy College and The Association for Science in Autism Treatment (ASAT) in Farmingdale, New York. Keynote speaker, Dr. Catherine Maurice, founding member of ASAT and author of *Let Me Hear Your Voice*, addressed an audience of over 100 attendees including professionals, students and parents. The program included a full day of scientific presentations by Dr. Robert LaRue, Dr. David Celiberti, Dr. Daniel W. Mruzek, a panel moderated by Ruth Donlin, MS, and an overview of ASAT resources by parent and ASAT Board Member, Marianne Clancy. Attendees left with a step-by-step approach to understanding what it means for an intervention to be science-based, as well as which of the current available treatments enjoy existing scientific support. The topics were geared to highlight that science and scientific methods are not only relevant to discussions of autism treatment but should serve as the foundation upon which treatments should be chosen, implemented, and evaluated.

I would like to extend a special thank you to Maggie Blair, Adjunct Professor at Molloy College and Dr. David Celiberti, President of ASAT, for working so closely with us to make this conference a success. A portion of the proceeds from this conference benefited ASAT (a non profit 501 c 3 organization).

Indiana -
more than corn!

The Cream of the Crop
- providing ABA services
since 2002


little star center

www.littlestarcenter.org

LittleStarOrg  FOLLOW US ON TWITTER  Find us on Facebook

Clinical Corner: My son has bolted out of the house on a few occasions. Aside from street traffic, I am also concerned about my neighbor’s pool. What steps can I take? Answered by: Kate E. Cerlino Britton, M.S.Ed., M.A., BCBA (Principal/Assistant Director, Alpine Learning Group

Many parents of children with autism express concern about safety. The social and language deficits central to autism may put children at heightened risk for experiencing potentially dangerous situations. In this issue, Kate Cerino Britton provides specific suggestions for proactive measures to keep children safe who have a tendency to engage in bolting. She also lists several possible resources that we hope will be helpful for families who have safety concerns for their children with autism.
Lori Bechner, M.A., BCBA
SIAT Clinical Corner Coordinator

You are not alone. In fact, according to an online survey conducted by the National Autism Association, 92 percent of the parents indicated their child with autism was at risk of wandering away from his or her home or care provider. An additional concern is that when wandering, many children with autism are unable to take steps to ensure their safety such as identifying who in the community is safe vs. unsafe, asking for assistance, or stating important information such as their phone number. I hope the following guidelines can help you in preventing potentially harmful situations.

The first step I recommend is to secure your home and yard area so that your child is less likely to wander away. Sometimes standard locks are not enough as many children quickly learn how to operate standard locks on doors, windows and gates. Install locks on doors and gates in the yard that your child cannot open. In addition, if your home has an alarm system, keep it set to go off whenever a door or window has been opened. If your home does not have an alarm, install an alarm system that signals when a door or window is opened. There are a variety of systems available, including high-tech and low-tech options. You may consider contacting a medical or educational provider, who can help identify resources to help obtain funding for such systems/equipment. Here are some suggested websites:

- www.addalock.com
- www.childsafetystore.com
- www.protectmefirst.com

Another option is to monitor your child around the house by using a video monitoring system or a baby monitor that has video monitoring capability, such as:

- www.x10.com
- www.childsafetystore.com

If you have a pool or there is a pool nearby, ensure there is a locked fence surrounding the pool. You can also purchase a pool alarm for yours and/or your neighbor’s pools (e.g., www.poolguard.com). If your child goes into pools unsupervised, you can also use the Turtle

(www.safetyturtle.com), which is a wristband that locks securely around your child’s wrist and sounds an alarm if it becomes immersed in water.

It is also critical to inform your police and fire departments that an individual with autism resides in your home. You can do this by calling your local non-emergency telephone number and ask personnel to note in the 911 database that someone with autism lives at your address. If there is ever an emergency, the emergency responders will know in advance that they need to respond accordingly. I also recommend giving local police and fire departments a picture of your child with your contact information on the back which can be helpful in identifying your child if s/he is ever brought to the station by someone else. Another suggestion would be to register with the National Child Identification Program (www.childidprogram.com). The program provides a kit that includes information on everything law enforcement would need in case of an emergency. You can also consider completing the Autism Elopement form found by clicking [here](#)

Another tip is to make sure your trusted neighbors are aware of your situation. Give them a picture along with some helpful information about your child (e.g., s/he is unable to speak, s/he responds to simple commands, s/he likes to swim so please keep your pool gate locked) and about autism in general. Also include your cell phone and home phone numbers, and ask them to call immediately in the event they ever see your child wandering away from the house or walking the street unaccompanied by an adult.

Also, assess your child’s current level of communication. For example, can s/he answer social questions and be understood by novel listeners? Strangers will be most likely to ask your child, “What’s your name?” So it is important that your child can be understood by listeners who don’t know your child. If your child will not be understood or can’t relay enough information, you could use medical identification jewelry, such as a bracelet (e.g., www.medicalert.org).

Once your home is secure, vacations may still seem unrealistic. However, there are some steps you can take to allow your family to safely stay in a hotel or space other than the safe haven you have created. When planning for a vacation, really think about your vacation destination and determine the potential risk(s) for your child with autism. Specifically, if your child has a history

Suggested Products:
www.protectmefirst.com
www.projectlifesaver.com
www.Caretrack.com
www.ion-kids.com
www.protectmefirst.com
www.uLocate.com

(Continued on page 8)

Clinical Corner continued...

of wandering (especially towards pools or other swimming areas) you may want to ask for a room furthest from the pool area or without an ocean view—or maybe even choose a location that does not have a pool. When checking into the location, inform the hotel staff about your child and advise them that s/he will require supervision at all times and if they see him/her unsupervised to call you immediately. Also, consider using portable door alarms for hotel rooms, a child-locator systems and/or a global positioning system (GPS). You can find low-tech tracking devices and high-tech devices online. Please see some suggested products on the previous page.

Lastly, it's essential to proactively teach your child skills that will increase his/her safety. Work with your child's school or treatment program to include the important safety goals in your child's individualized education plan (IEP) such as:

- * answering questions to provide personal information
- * responding to name
- * holding hands

- * requesting permission to leave the house
- * waiting appropriately
- * using a cell phone
- * crossing the street safely (if appropriate given age and level of functioning)
- * seeking assistance when lost
- * tolerating identification jewelry
- * identifying outdoor boundaries (i.e., not leaving the front lawn)
- * learning clear rules about outdoor play (getting a parent if a stranger approaches, asking for help if ball goes into street)
- * swimming more proficiently
- * learning clear rules about pool use (with time out as a possible consequence)

Check out www.awaare.org for sample letters to submit to your case manager and attach to your child's IEP.

Finally, it cannot be overstated that children with autism require very close supervision when in harm's way. We hope you find these proactive and teaching suggestions helpful in minimizing your son's risk.

Review of Mortality in Autism Drowning by Scott Myers, M.D.

Several studies have shown that, although many individuals with autism live long and healthy lives, there is an increased risk of death (mortality) associated with autism¹⁻⁵. A standardized mortality ratio (SMR) is the ratio of the observed number of deaths to the expected number of deaths, so any value greater than 1.0 means that the observed death rate exceeds expectations.

Studies in the USA (California), Denmark, and Sweden have found SMRs associated with autism to range from 1.9 to 5.6¹⁻⁵. This means that individuals with autism have a somewhat higher risk of death than other individuals do. However, to put this number in perspective, it is important to note that the mortality rate in the general population is quite low. For example, in 2008, the mortality rate for all children under 5 years old was 8 per 1,000. The SMRs for autism indicate that the risk for children with autism is roughly between 16 and 60 per 1000—still very low but enough of a risk that families and providers should take extra precautions to ensure safety. The elevated death rate associated with autism is largely accounted for by the subset of individuals who also have moderate, severe, or profound intellectual disability (mental retardation) and epilepsy.

The risk of accidental death by drowning was elevated in people with autism in California, where 5% (11/202) of all of the deaths of individuals with autism between 1983 and 1997 were caused by drowning¹. This is substantially higher than the combined rate of 0.4% when the Swedish and Danish studies are combined, perhaps due to increased access to pools and other bodies of water in California.

Although death rates for almost all causes were higher for individuals with moderate, severe, or profound intellectual disability, drowning and other accidental deaths were found to occur at a higher rate than expected even in those without epilepsy or severe intellectual disability. In the California study, the SMR for drowning in individuals with autism who had mild or no intellectual disability was 3.9, and the SMR for those with autism and moderate, severe, or profound intellectual disability was 13.7¹.

Information about mortality that includes specific causes of death is important because it may influence treatment strategies, including prevention. These statistics remind us that children and adults with autism are at risk for accidental death, especially by drowning, and that strategies to increase water safety in people with autism may save lives.

References:

1. Shavelle, R.M., Strauss D.J., & Pickett J. (2001). Causes of death in autism. *Journal of Autism and Developmental Disorders*, 31, 569-576.
2. Pickett J.A., Paculdo D.R., Shavelle R.M., & Strauss D.J. (2006). 1998-2002 update on "Causes of death in autism." *Journal of Autism and Developmental Disorders*, 36, 287-288.
3. Isager, T, Mouridsen, S.E., & Rich B. (1998) Mortality and causes of death in pervasive developmental disorders. *Autism*, 3, 7-16.
4. Mouridsen, S.E., Bronnum-Hansen H., Rich, B., & Isager T. (2008). Mortality and causes of death in autism spectrum disorders. *Autism*, 12, 403-414.
5. Gillberg, C., Billstedt E., Sundh, V., & Gillberg, I.C. (2010). Mortality in autism: A prospective longitudinal community-based study. *Journal of Autism and Developmental Disorders*, 40, 352.

Letter from Josh Pritchard, M.S., BCBA

We did it! With your help, we have surpassed the 6000 subscriber mark! Think for a moment — that is 6000 people that now have access to as much information as we can pack into our quarterly newsletter. If that helps even 1 child reach better treatment options due to an informed consumer, then our reward is great. All of our work has been worth it. Having rested on those laurels long enough, I'm ready to issue our next challenge—10K. No, I'm not talking about some charity run — I am talking about our new goal for 2011. 10,000 subscribers by the 1st issue in 2012. Can we do it? I think so, but we will need your help.

Normally, I am in some other country when I write my letter, and include some facts or backstory about the country. But this year, I'm sitting at home and my letter will have an American flavor. Rather than talking about founding fathers, I want to borrow from the current political arena. Instead of a historic picture of some mythical battle or a dangerous and exotic animal taking a bite of me, I want to share a bumper-sticker I saw a few days ago that wraps up my feeling of our subscriber drive this year!



When I'm in some other country writing my letters, I often state how they might really benefit from some science-based autism treatment. To some readers, it may even seem as if I think the problem of proliferation of wacky autism treatment is a thing of the past here in the United States. Unfortunately, the international flavor of my past letters has been less of an indication of the health of science-based treatment at home and more of my context at the time of writing.



In fact, I'm not sure that the countries that I have visited are in any better or worse shape than my home country.

It seems that every time that a treatment with no scientific basis fades away, two or three others pop up to claim they have the answer, even though they are unwilling to test it.

I'm heartened by the media's shift in focus away from controversial distractions (they make great news, but awful health care decisions), and hope that we will continue to see funding flow into the scientific examination of autism. In fact, it is my hope that ASAT will soon have a much bigger job trying to disseminate all the new scientific findings that allow for better treatment of autism. That is something I would happily volunteer more time to do.

However, sometimes we need more than just volunteers' time. I want to reiterate David's point that in this new year, we would deeply appreciate it if you consider supporting us in our efforts to help make sure that science is used in decision making to protect and help those who are most vulnerable. This can be a small donation, or even putting us in touch with a business that might wish to sponsor ASAT.

Thanks for such a great 2010. I can't wait to see what is in store for 2011!

ASAT Committee Members

In addition to our Advisory Board, a number of individuals lend their time and talents to support ASAT's mission and initiatives. As you can see, we have individuals who support each aspect of our organization. If you want to assist, please email us at info@asatonline.org

ASAT Public Relations

- Suzanne Clark, MEd
- Denise Grosberg, M.A.
- Jennifer Hieminga, M.Ed., BCBA
- Lewis Mazzone, M.A.
- Audrey Meissner, M.Ed., BCBA
- Sage Rose, Ph.D.
- Nancy Philips, B.A.
- Jessica Ziiski-Pineno, MSED

ASAT Finance Committee

- Denise Grosberg, M.A.
- Jessie Martin, B.A.
- Denielle Nicastro
- Paul E. J. Pangburn, B.S. CFP
- Jacqueline Weber, M.Ed., BCBA

ASAT's Science in Autism Treatment

- Lori Bechner, M.A., BCBA
- Lynn Faerber, B.A.
- Kate Fiske, Ph.D., BCBA-D
- Denise Grosberg, M.A.
- Natalie Homa, B.A.
- Germaine Ibrahim, M.Ed.
- Emily Meyer, M.A.
- Renita Paranjape, M.Ed., BCBA
- Tabitha Ramminger, B.S., BCaBA
- Allyson Ross, B.S.
- Sage Rose, Ph.D.

ASATonline.org

- Bridget Butler
- Kerry Ann Conde, M.S., BCBA
- Amanda Wadsworth, M.S., Ed.

Media Watch

- Chris Benavides, Ph.D.
- Geoff Debery, M.A., BCBA
- Regina Claypool-Frey, B.S.
- Hannah Hoch, Ph.D., BCBA -D
- Sharon Reeve, Ph.D., BCBA-D
- Anya Silver, MA, BCBA

Pediatrician Awareness

- Denise Grosberg, M.A.
- Zachary Houston, M.S., BCBA
- Elisabeth Kinney, M.S., BCBA

Dr. Stephen C. Luce Tribute Series

Late last year another leader in the field of autism treatment passed away. It is with great sadness that we report the death of Dr. Stephen Luce. We invited a few colleagues to share their thoughts about Steve and the impact that he had on the autism community. **David Celiberti, Ph.D., BCBA-D**

Tribute to Dr. Stephen C. Luce by Eric V. Larsson, Ph.D., L.P., BCBA-D, Kathleen Dyer, CCC-SLP, Ph.D., BCBA-D, and Patricia Egan, Ph.D., BCBA-D

Stephen C. Luce, Ph.D. passed away after a long battle with cancer. He is survived by his wife, Claire, and three sparkling daughters, Megan, Kirsten, and Emily. He lived in successful remission for many years, during which he continued to enjoy life to its fullest. Aside from being an accomplished researcher, clinical leader, and editor of respected journals, Steve inspired those around him with his acumen, intense personal style, and *joie de vivre*.

Most recently, Steve was the Vice-President for Clinical Programs, Training and Research of Melmark, where he was responsible for all clinical programming for over 200 individuals of all ages with developmental disabilities, autism, and acquired neurological impairments in Pennsylvania, Massachusetts, and Maryland. At the same time, he was Clinical Professor of Psychology at the Philadelphia College of Osteopathic Medicine.

Steve was a graduate of Marietta College in Ohio. He went on to achieve his Masters from the Division of Exceptional Children at the University of Georgia. He then began

teaching children with special needs in Colorado before going on to study under R. Vance Hall at the Juniper Gardens Children's Project at the University of Kansas. There he received his doctorate in 1979 in Developmental and Child Psychology from KU.

He acquired an international reputation at The May Institute in Chatham, Massachusetts. From 1978 until 1990, he and Pete Christian transformed a sleepy

lightness and sense of humor and play transformed the most difficult assignment into an enthusiastic and joyous endeavor with his team of colleagues. It was emotionally grueling work, but it didn't feel hard at all – though I don't think it would have felt that way without Steve there."

Pat Egan writes, "Steve was so positive and full of energy that he made the job a lot of fun for us – he was the definitive reinforcer. He not

“His enduring contributions are the many, many behavior analysts, all around the world today, whose work was reinforced by his leadership, and who continue to strive for the highest possible outcomes for their every client.”

residential “camp” for children with autism (one of the first dedicated autism programs in the world) into a cutting-edge residential treatment program. The work was hard and grueling, and Steve settled for nothing less than the best. This was in the primary era of applied behavior analysis, and its newness could be felt in every respect. The original staff members were openly hostile to behavioral principles, to the great harm of the children served. As a result, every behavioral system had to be built out of nothing. Due to his great dedication, the team was able to innovate and design the entire system, from direct clinical treatment to staff training to organizational management, to reach the highest levels of success. Steve himself could often be found working late into the night on the campus, effectively intervening with severe behavioral challenges and inspiring intense loyalty in his behavioral converts. He very clearly understood and intentionally used the power of accurate, differential reinforcement with his own staff.

Kathy Dyer writes, “Steve

talked me into taking an overnight supervisor position at the May for two years, he had me believing it was a great opportunity. Funny, though – in the end, it actually turned out to be.”

Amongst his many innovative applications of behavioral principles and systems, including task-analyzed training systems, behavior management techniques, teaching family homes, and language skill development, Steve envisioned and implemented the concept of transitional programming – that the purpose of the residential treatment was not long-term care, but actually to train the children and their home environments to be able to transition them back from the institution to their homes and local schools. Based upon this foundation, he developed a full continuum of services for persons with autism.

While the clinical innovation and management would be enough to consume most professionals, Steve also took this work to its next level and implemented comprehensive research and training programs, resulting in the granting of numerous

(Continued on page 11)



Tribute to Dr. Stephen C. Luce continued...

(Continued from page 10)

Masters degrees and Ph.D.s to May staff, and the publication of numerous research studies. As a result of this effort, over Steve’s tenure, the size of the May Institute grew from 38 children served to 52, with an impressive success rate of successfully transitioning 50% of the children back to their communities, while reducing the length of treatment from four to 2.9 years.

Steve held numerous faculty and clinical consultation appointments at universities and clinics around the world. He served as an expert case evaluator for the U.S. Department of Justice. He was often called upon to provide expert testimony on behalf of children with autism. After the May Institute, Steve held the position of Associate Director of Behavioral Services for post-acute rehabilitation of head injuries at New Medico Associates in Boston and New Hampshire.

He then took the position of Vice President of Program Operations at Bancroft in New Jersey. There, amongst his many responsibilities in serving over 500 persons with developmental disabilities, autism, and head trauma, he initiated one of the first systematic replications of the Lovaas Young Autism Project. This work spun off into one of the main branches of the Lovaas Institute, and is still sustained to this day by Scott Wright and other staff who Steve mentored. One of Steve’s most popular books came out of that effort (Behavioral Intervention for Young Children with Autism, edited with Drs. Catherine Maurice and Gina Green).

Before his final position, Steve served as the Executive Director of the Sonia Shankman Orthogenic School and Clinical Professor of Psychiatry at the University of Chicago. This was the actual director position once held by the infamous Bruno Bettelheim. In this role, he was able to provide crucial internal data and information for the making of the PBS investigative film “Refrigerator Mothers,” which documented the debunking of Bettelheim’s destructive psychoanalytic theories. One of Steve’s fondest memories was of being able to take Bernard Rimland and Ivar Lovaas into that inner sanctum and give final confirmation to their analysis of Bettelheim’s misrepresentations.

So often in Steve’s era, there was a sense of oppression of behavior analysis. Not only would we have to work hard to develop funding for unproven models in a skeptical environment, but the new staff and consumers themselves would approach the work with a chip on their shoulder – needing convincing that the behavioral innovations were the way to go. Further, the intense needs of the children and adults also brought high risks to clinical missteps. In this highly adversarial environment, Steve’s natural competitiveness gave us the energy to persevere. And yet I, and everyone who responded to news of his passing, had the same reminiscence – his lightness and sense of fun infused it all with a sense of enormous enthusiasm and invigoration and positive spirit. His enduring contributions are the many, many behavior analysts, all around the world today, whose work was reinforced by his leadership, and who continue to strive for the highest possible outcomes for their every client.

Tribute to Dr. Stephen C. Luce by Jamie Pagliaro, Rethink Autism

I learned of Steve Luce through a book, *Behavioral Intervention for Young Children with Autism* (Edited by Maurice, Green & Luce, 1996), which was given to me by the first family I worked for in a home-based ABA program. As a college student without much knowledge of ABA or autism, I could hardly appreciate the value of a manual that helped newly-diagnosed families navigate the treatment process in a time when there was limited funding available, there were few programs for children with autism, and no credentialing of Behavior Analysts.

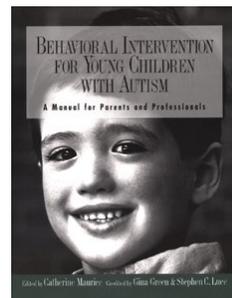
So imagine my surprise (and nervousness!) when years later I was presenting data at a weekly staff meeting at Melmark, when I walked a tall man who introduced himself as “Dr. Steve Luce.” He was there to observe, and - I later learned - for a job interview.

As I wrapped up my data presentation, Steve raised his hand. Worried that I misspoke or misinterpreted something, I was relieved to hear him ask a few insightful follow-up questions that prompted me to take a closer look at the data I had just presented. That day began a professional mentorship and later a friendship for which I will always be grateful.

Steve was a remarkable person in his ability to mentor and support others throughout his career. He inspired so many young professionals in the field to stay motivated, go back to school, and focus on creating better options for individuals with disabilities. He also modeled how to make the “science” more accessible, and emphasized the importance of dissemination. I learned from Steve how to promote ABA in a way that was more palatable to others, thus

increasing the acceptance of a scientific approach to changing behavior.

Even throughout his battle with cancer, Steve remained upbeat and optimistic. Whenever I asked about his health, he had a way of quickly turning the conversation back to what I was up to and sharing his advice. As I reflect on our relationship, I realize the most important thing Steve ever taught me was the value of using the principles of reinforcement to shape the behavior of the individuals we serve as well as those around us. Steve sometimes called it “sprinkling a little fairy dust,” and those who experienced it know just how magically effective it was! He will be missed!



Effective Support for Practitioners: The Association of Professional Behavior Analysts by Gina Green, Ph.D., BCBA-D, Executive Director, APBA

The practice of applied behavior analysis is at a crucial juncture. If you are an ABA practitioner or practitioner-in-training, an employer of ABA practitioners, a consumer of ABA services, a trainer of ABA practitioners, or an advocate for ABA services, laws and regulations that could have a big effect on your life are probably being adopted or considered as you read this. Some of those policies will determine who will be allowed to call themselves behavior analysts and to practice ABA. Many will affect funding for ABA services, now and far into the future.

Various individuals and groups are expending tremendous efforts to influence those who write and vote on policies governing the practice of ABA. Many of them have far greater numbers, resources, and experience with regulatory processes than do most behavior analysts at this point in time. *That's why ABA practitioners and consumers need a professional organization that is focused exclusively on the practice of ABA and has the knowledge and experience to help protect their interests in the complex arena of public policy.*

APBA is that organization. The founding and current Directors of APBA have strong repertoires in research, practice, practitioner training, advocating for public policies, leading behavior analysis organizations, and setting up systems to support the practice of ABA (such as professional credentialing and peer review programs). Our Autism Spectrum Disorders Task Force provides the Board with expert advice and resources on research and practice in ASD, and we are establishing a multidisciplinary Advisory Board to help guide decision-making.

In its first couple of years, APBA has worked diligently to see that Board Certified Behavior Analysts (BCBAs) and Board Certified Assistant Behavior Analysts (BCaBAs) are recognized as professionals in their own right so they can practice and be paid for their services. To date, we have assisted with legislation to require private health insurance plans to pay for ABA intervention for autism spectrum disorders in more than 20 U.S. states. In most of the states that have adopted such laws, BCBAs (and in some cases, BCaBAs under supervision) are, or will be, receiving reimbursement for treating ASD. We have also worked

Association of



Professional
Behavior Analysts

Kate Fiske, Ph.D., BCBA-D, SIAT *Consumer Corner* Coordinator David Celiberti here again. Kate Fiske will be resuming her role as SIAT *Consumer Corner* Coordinator in the Spring Issue. In this installment of *Consumer Corner*, we are showcasing brief overviews of the Association of Professional Behavior Analysts and Rethink Autism's Tip of the Week.

with behavior analysts, consumers, state officials, and legislators in 10 states on other types of laws and regulations allowing BACB certificants to practice and be paid.

Membership in APBA is open to professional behavior analysts and others who are interested in the practice of ABA. Dues are very reasonable, and there are several categories of membership:

- **Board Certified Behavior Analysts and Board Certified Behavior Analysts – Doctoral**
- **Board Certified Assistant Behavior Analysts**
- **Advanced Professional Members** (those with doctoral degrees in any field, not certified by the Behavior Analyst Certification Board)
- **Master's Professional Members** (those with master's degrees in any field, not certified by the BACB)
- **Bachelor's Professional Members** (those with bachelor's degrees in any field, not certified by the BACB)
- **Consumers** (recipients of ABA services or family members of recipients, not certified by the BACB)
- **Students** enrolled full-time in a university degree program that offers a BACB-approved course sequence, a degree in applied behavior analysis, or a specialization in applied behavior analysis

Benefits of membership include:

- Effective, experienced help with advocating for public policies to support behavior analysis, starting and building behavior analysis associations, and practicing behavior analysis.
- A subscription to the monthly electronic newsletter, the *APBA Reporter*, which is chock full of timely, practical information on the latest developments in public policies, applied research findings, sources of funding for ABA services, and regular "Practitioner's Notebook" and "Ethics Challenge" columns.
- For most U.S. members, the opportunity to purchase professional liability and health insurance at competitive rates.
- Access to resources on the APBA website, including back issues of the *Reporter*, results of

(Continued on page 13)

Effective Support for Practitioners continued...

surveys on important practice matters, bibliographies of applied research, resources for behavior analysts who are, or want to become, health insurance providers, resources on professional credentialing, practice guidelines, and more.

- Discounts on registration, workshop, and CEU fees at the exciting **first annual APBA convention, March 31 – April 2, 2011 at the Marriott Copley Place in the fabulous**

Back Bay area of Boston. The convention will be unique, with a program of invited presentations and networking events customized to the needs and interests of professional practitioners, program and agency directors, university faculty, students, consumers, and advocates. Among the featured presentations will be keynote addresses by Gregory Hanley (Western New England College), Raymond Ro-

manczyk (SUNY Binghamton), and Lorri Unumb (Autism Speaks). A special all-day workshop on March 31, sponsored by Autism Speaks, will focus on health insurance coverage of ABA treatment for autism spectrum disorders. Details are available at www.abaphome.net, and updates will appear frequently on our website, in the *APBA Reporter*, and on our Facebook page.

Looking for a science-based conference? Please see the many conference offerings for 2011 at: <http://www.asatonline.org/conference/conference.htm>

Rethink Autism: Tip of the Week by Elizabeth Neumann, BCaBA, ASAT Volunteer

Rethink Autism's Tip of the Week is a free, weekly e-newsletter containing excerpts of their Applied Behavior Analysis-based training videos and lessons that pertain to a particular topic of importance. Past topics have addressed timely concerns such as helping a learner participate more fully in Halloween activities or preparing for winter, as well as specific skills ranging from foundational (Preparing for Fine Motor Skills) to complex (Advancing Conversation Skills). These video clips highlight the importance of detailed task analyses and thorough preparation for new events and activities. Such

analyses and preparation often separate effective instruction efforts from those that yield poorer acquisition of skills. Although most of the video messages are brief in nature, these tips offer food for thought and instructional techniques relevant to both parents and professionals. For instance, the recent tip about preparing for winter may remind even the most seasoned clinician to assess the adequacy of indoor recreation skills and perhaps aim to address this repertoire more extensively if warranted.

Those new to autism may hear phrases such as "social skills" without really grasping what they entail and the improvement they can bring to a learner's daily life. Seeing the target behaviors in action and the distinct steps involved in teaching their component

skills may be of great benefit.

The inclusion of topics that may not be readily thought of (such as Teaching to Wait Appropriately or Helping Your Child Stay Physically Fit) should help viewers to consider the many functional areas that can improve learners' quality of life.



To see the archive of Tip of the Week videos, visit: www.rethinkautism.com/AboutAutism/WeeklyTip.aspx

By signing up for the Tip of the Week, you will receive these tips automatically. You will also

receive invitations to Rethink Autism's Expert Access Webinar Series. In these free interactive sessions, noted experts in the fields of autism education and research share their advice and respond to participants' questions in ways that are practical and easy to understand. Past webinars have included *Managing Problem Behavior at Home* with Dr. Bridget Taylor, and Dr. Peter Gerhardt on *Adolescents and Adults with Autism*. To view full-length archives of the Expert Access Webinar Series, visit www.rethinkautism.com/Community/webinars/default.aspx

You can access these free resources by registering for the Tip of the Week in the bottom right corner of the homepage at www.rethinkautism.com.

Top 10 Questions a Journalist Should Ask

BEFORE They Write the Next Autism Story

Science in Autism Treatment

Volume 8, Winter 2011

- #1 Are there any published research articles in peer-reviewed journals documenting the efficacy of the intervention method? If not, why not? If so, are the studies well designed?
- #2 Whom am I interviewing for this story and what are his/her qualifications? Is he/she making claims of efficacy/effectiveness that are not supported by scientific data? What does he or she stand to gain by this interview?
- #3 Is there any evidence of harm imposed by this intervention? What are the risks?
- #4 How much does the intervention cost? Are these costs reasonable? How is it paid?
- #5 What kinds of training and supervision do treatment agents need to have before implementing the intervention? If none or very little, have I explored the ethics surrounding this and if there is adequate consumer protection?
- #6 What position statements have respected professional organizations generated that support or do not support this intervention method? Are there science-based interventions (such as applied behavior analysis) which are recommended by these organizations?
- #7 Have I consulted with an unbiased entity (such as the Association for Science in Autism Treatment at info@asatonline.org) for their input?
- #8 Who may benefit financially from my article?
- #9 How might I benefit from this article?
- #10 Have I taken necessary steps to avoid putting caregivers and treatment recipients at risk?

In addition to our entire board of directors, we acknowledge the following 2010 donors. Without their support, our important work could not be carried out.

ASAT Donor Wall

Champion \$2000 and above		Contributing \$1 - \$99	
Leah and Alain LeBec Foundation, Inc. Loxley's		Kevin Augustine	Jonathan Kimball
		Kenneth & Linda Bekman	Elisabeth Kinney
		Kelly Hunter Black	Katherine R. Lambert, <i>In Honor of Peggy Halliday</i>
		Lisa Brownfield	Debbie Lancette, <i>In Honor of Sarah Jack</i>
		David Burke	Debra Berry Malmberg
		Eddy Byam	Kelly Ann McDonough
		Douglas Celiberti, <i>In Memory of Ann Celiberti</i>	John & Marlene McElwee
		Shelby P. Conneely, <i>In Honor of Suyash Tiwari</i>	Ellen Murphy
		David Diosi	Trudy Murray
		Deborah Fein	Patricia Myers, <i>In Memory of Pete Pennington</i>
		Jon Fried	Noreen Norcini
		Michael Gann	Anthony Oland
		Normand Giroux	Renita Paranjape
		Barry Goldman	Lora Perry
		Leonard Green	Lori Scheur
		Mikhail Gubin	Casey Smith, <i>In Honor of Suzanne Smith</i>
		Bethany Halliday	Erik Solberg
		Megan Halliday	Sara White
		Joel & Sandra Hornstein, <i>In Memory of Inez Hornstein</i>	Kirsten Wirth
		Julie DiRico Hyman, <i>In Honor of Harry Hyman</i>	Marissa Gynn-Ricafort <i>Washington at Ridgewood School Staff</i>
		Robert Ross	
Sustaining \$100 - \$1000			
Antoine Andary	William Heward		
Stephen Anderson	Rene Hiebert		
Megan Atthowe	Susan Hyman		
Francisco J. Barrera	Louis Irwin		
Miriam Beveridge	Richard Malott		
Jill Belchic-Schwartz	Patricia McDonnell-Megahey		
Bruce Boyer	Paul & Elizabeth McDonnell		
Warren & Judith Carter	Stephen Porges		
Cathy Curcio	Sharon Reeve		
Lola Gershfeld	Tom & Carol Sloan		
Anthony Davids	Carl Sundberg		
("Gourmet Specialties, LLC")	Rusdy B. Udisusetyo		
Gina Green	Saralyn Walker		
James Guerin			

If you were a 2010 donor and we inadvertently left you off this list, please accept our apologies and e-mail us at donate@asatonline.org

ASAT

Providing Accurate, Science-Based Information - Promoting Access to Effective Treatment

ASAT Board of Directors

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

Mary McDonald, Ph.D., BCBA-D
Vice President

Barbara Wells
Treasurer

Florence DiGennaro, Ph.D., BCBA-D
Secretary

- Preeti Chojar, M.C.A.
- Marianne Clancy
- Kathryn Dobel, JD
- Ruth Donlin, M.S.
- Elizabeth Dyer, MA, CCC-SLP
- Joseph Forgione, M.B.A.
- Sara Jane Gershfeld, M.A.
- Peggy Halliday, M.Ed., BCBA
- Cyndy Hayes, MS, MBA, DBA
- Barbara Jamison, B.A.
- Robert H. LaRue Jr., Ph.D., BCBA-D
- Scott Myers, M.D., F.A.A.P.
- Daniel W. Mruzek, Ph.D., BCBA-D
- Joshua K. Pritchard, M.S., BCBA
- Tristram Smith, Ph.D.
- Bridget Taylor, Psy.D., BCBA-D

ASAT
P.O. Box 188
Crosswicks, NJ 08515-0188

E-mail: info@asatonline.org
Website: www.asatonline.org
Facebook: www.facebook.com/Asatonline

Media Watch Update by Barbara Jamison, ASAT Board Member and MW Lead

The media is often one of the first points of contact that the public consumers have with autism treatment. Unfortunately, it has not always been a great resource to get the best treatment. In fact, the media are often motivated by news stories that are likely to be sensational. Science is rarely sensational, it tends to move too slowly and tediously for the media. While this is good for those receiving the treatment, it does not help those who are trying to find out about treatment options.

Below are just a sample of the most recent Media Watch responses to both accurate and inaccurate portrayals of autism intervention in the media (Click dates to read full replies):

- **ASAT Responds to Atlanta Journal-Constitution’s “Tech Hopes to Develop Early Warning Tool and Treatments for Autism”** ([September 30, 2010](#))
High-tech early detection using smart video cameras may be around the corner, according to researchers at Georgia Tech. ASAT applauds these efforts and underscores the importance of early, empirically-based intervention as well in a letter to the Atlanta-Journal.
- **ASAT Responds to Canadian CBC’s “N.B. Can Be a Leader in Autism Services”** ([October 23, 2010](#))
Parents, in an effort to help their children with autism, sometimes go to desperate measures. Although writer Bob LaMendola, acknowledges that the drug Lupron is not condoned by the medical establishment for autism treatment, he refers to ABA as a “painstaking treatment.” ASAT President David Celiberti calls LaMendola to task and encourages him to do his homework before writing his next article on autism.
- **ASAT Responds to Chicago Tribune’s “FDA Cracks Down on Autism Treatment”** ([October 26, 2010](#))
The truth about chelation therapy: It can result in kidney damage, dehydration and even death, according to a recent report by the FDA. ASAT responds to the Chicago Tribune story, "FDA Cracks Down on Autism Treatment."
- **ASAT Responds to Stamford Advocate’s “Phony Autism Specialist Sentenced to Three Years in Prison”** ([October 29, 2010](#))
The fleecing of the autism population: Stacy Lore faked her credentials to appear as a certified behavior analyst, and was paid over \$155,000 by families and the Norwalk, NY school district. She will serve jail time, but how can parents effectively vet autism providers for their children?
- **ASAT Responds to Scientific American’s “Desperate for an Autism Cure”** ([December 04, 2010](#))
How does it happen that a medical professional - someone trained to look for randomized trials in science-based studies - succumbs to the alluring siren of unproven treatments for his son with autism? Read ASAT's response to Scientific American's "Desperate for an Autism Cure."

We wholeheartedly welcome you to join our efforts. You could be involved by alerting us of articles or media pieces that may warrant our attention or you could assist us with tracking information more formally by setting up an alert system to identify important articles as they come out. If you would like more specific information about how to participate in Media Watch, you can reach us at MediaWatch@asatonline.org. We hope to hear from you!



Research Review: Pilot Study of a Parent Training Program for your Children with Autism.

Solomon, R., Necheles, J., Ferch, C., & Bruckman, D. (2007). Pilot study of a parent training program for young children with autism: The PLAY project home consultation program. *Autism, 11*, 205-224.

Reviewed by Kathleen Moran, M.A., Caldwell College

Why research this topic?

Research has shown that children with autism benefit from comprehensive and intensive therapies. Comprehensive therapies target multiple areas of development (e.g., language, sensory, social, educational). Intensive therapies consist of one-on-one teaching, early treatment, and a planned approach. Both therapies include a focus on language and social behavior. However, one concern is the expense required to provide these therapies. This current investigation evaluated a cost efficient, alternative treatment based on the developmental, individualized, and relationship oriented (DIR) model. The project was called the PLAY Project Home Consulting Program. This program was designed to provide intensive, cost effective, structured treatment to help improve language, increase socialization, and decrease repetitive behaviors. The PLAY program employed a play-based treatment approach using parents to deliver treatment.

What did the researcher do?

Sixty-eight families participated in the study. Parents were taught to provide intensive, one-on-one services to their children at home from three consultants, trained in DIR and the PLAY project. Parents were provided with a manual, a one-day workshop, and consultant training and visits. A 7-step sequence was used to train parents to implement play-based treatment with their children. In addition, monthly visits were provided for a twelve month period to provide feedback to parents. A rating scale was used to measure changes in the caregiver's behavior and the child's functional development, before and after treatment. The FEAS rating (The Functional Emotional Assessment Scale), is a clinical rating scale that was applied to evaluate videotaped interactions between children with autism and their caregivers

These articles evaluate the effectiveness of three interventions often used with individuals with autism. The intervention in the first article is based on the developmental, individualized, and relationship oriented (DIR) model which focuses on multiple areas of development and is often implemented by parents. The second reviews the effectiveness of hyperbaric oxygen therapy (HBOT) where oxygen is delivered in a pressurized chamber to increase oxygen absorption in bodily tissue. The third study is on sensory integration therapy in which the participant receives sensory stimulation with the goal of improving attention and cognitive functioning, while decreasing disruptive or repetitive behaviors

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

What did the researchers find?

Based on FEAS scores, 45.5 percent of children made good to very good functional developmental progress over the study period. Children who had the fewest hours of interaction with parents received lower scores. In the end parents were very satisfied with the program

What are the strengths and limitations of the study?

The PLAY Project took the DIR theory and created a manual, training, and assessment method for a family based intervention. An advantage is that the project was community based and cost effective. A potential limitation was that a rating scale was used to evaluate the children's interactions rather than a direct measurement. The study also did not have a control group. A control group helps ensure that progress was due to the intervention and not something else.

What do the results mean?

A parent's involvement may be more important than the actual training. The DIR model supports parents as the primary play partners and offers a naturalistic play based interaction that engages the child. The results of this study, however, need to be interpreted cautiously due to the absence of a control group and additional research is still needed in this area to determine if this intervention is effective.

ASAT's Guiding Values

ASAT is **committed to science** as the most **objective**, time-tested and reliable approach to discerning between safe, effective autism treatments and those that are harmful or ineffective. ASAT supports **all scientifically-sound research** on the prevention, treatment and cure of autism, as well as all treatments for autism that are shown to be effective through solid scientific research, **regardless of discipline or domain.**

Research Review: Review of use and of the efficacy of Weighted Vests

Stephenson, J., & Carter, M. (2009). The Use of Weighted Vests with Children with Autism Spectrum Disorders and Other Disabilities. *Journal of Autism and Developmental Disorders*, 39, 105-114. Reviewed by Kathleen Moran, M.A., Caldwell College

Why research this topic?

Sensory integration therapy involves providing controlled sensory stimulation through activities such as brushing or rubbing the body, deep pressure and compression of joints, and scooter boards. Along with such activities, interventions often include “sensory diets”, that are activities and environmental adjustments intended to complement the individual’s sensory needs. An intervention that is often part of a sensory diet is wearing weighted vests, which are approximately 10% of the person’s body weight evenly distributed across the whole vest. It has been proposed that vests provide deep pressure that has a calming and organizing effect on the central nervous system. Although many children with autism receive sensory integration therapy and sensory diets, little research is available on whether or not interventions

such as weighted vests have any effect on behavior.

What did the researchers do?

Researchers reviewed seven different studies that focused on weighted vests, involving a total of 20 students having a diagnosis of autism or another developmental disability and ranging from 2 to 11 years old. For each study, students wore weighted vests while actively involved in an activity. Sessions lasted 5, 10, 15, 30, and 120 minutes with a total of 11-25 sessions per child. The amount of weight ranged with each study approximately between 5-10% of individuals’ body mass.

What did the researchers find?

In four studies, weighted vests were found ineffective, with no significant effect on behavior. One study had mixed results and two studies were described by their authors as having positive effects.

However, the researchers in the present review did not detect these effects when they inspected the data, and they noted that the studies had a number of limitations such as not monitoring what children did while they wore vests. The researchers also noted that wearing a heavy weighted vest may pose a risk of injury. The study review makes clear that wearing weighted vests has not been shown to have positive effects.

What are the strengths and limitations of the study?

This review provides important evidence that weighted vests do not appear to be effective and may not be safe. The review is limited by the paucity of studies on weighted vests but indicates that weighted vests are not a recommended treatment at this time.

Research Review: Double-blind controlled trial of hyperbaric treatment for children with autism

Rossignol, D.A., Rossignol, L.W., Smith, S., Schneider, C., Logerquist, S., Usman, A., Neubrandner, J., Madren, E.M., Hintz, G., Grushkin, B., & Mumper, E. A. (2009). Hyperbaric treatment for children with autism: A multicenter, randomized, double-blind, controlled trial. *BMC Pediatrics*, 9, 21. Reviewed by Kathleen Moran, M.A., Caldwell College

Why research this topic?

In recent years, hyperbaric oxygen therapy (HBOT) has become a popular but controversial intervention for children with autism. HBOT involves the individual inhaling up to 100% oxygen at a pressure greater than one atmosphere (atm) in a pressurized chamber. The goal is to repair injured tissue in the body. It is unclear, however, whether children with autism actually have abnormal amounts of injured tissue. HBOT also has the potential for side-effects such as seizures and damage to the ear drum.

What did the researcher do?

The researchers evaluated HBOT in a sample of 55 children with autism. Twenty-nine children were randomly assigned to receive the real hyperbaric treatment at 1.3 atm and 24% oxygen for one hour for 40 sessions over 4 weeks. Another group with 26 children spent the same amount of time in a hyperbaric chamber, but did not receive HBOT. Only the technician administering the treatment was informed whether or not a child was receiving HBOT. Children were assessed for changes in overall functioning, speech/communication, play, and stereotypical behavior.

What did the researcher find?

Children who received HBOT showed improvements in overall functioning, language, social interaction, eye contact, and sensory/cognitive awareness compared to children in the slightly pressurized room. The most improvements were seen in

children over the age of 5 and who had lower initial autism severity. The treatment was described as safe and well tolerated by all the children, with few side effects. Side effects included skin rash, increase in urinary frequency, abdominal distension, and diarrhea.

What are the strengths and limitations of the study?

The strengths of the study included a group that received the treatment to a group that did not. Limitations are that many of the outcome measures have not been shown to be valid measures of change and that there was no test of whether children actually absorbed the oxygen administered during HBOT sessions. In addition, because parents entered the hyperbaric chamber with their child, they may have been aware of whether they were getting HBOT or not, even though they were not told directly. Another limitation is that the authors did not measure outcomes after treatment ended to determine whether effects lasted or whether ongoing treatment would be needed.

What do the results mean?

The study compared the effects of children receiving hyperbaric treatment and those not receiving treatment. Although there was a positive improvement in children who received treatment, the results need to be interpreted very cautiously because of the limitations in the study design. Much more research is needed to evaluate long-term outcomes and determine if this treatment is supported with valid research. HBOT should still be regarded as an unproven therapy with potential risks.

Putting a Dead Horse in a Weighted Vest: Another Review of Sensory Integration Training by Thomas Zane, Ph.D., BCBA-D Institute for Behavioral Studies at The Van Loan School of Graduate and Professional Studies, Endicott College

Sensory Integration Therapy (SIT) and similar sensory-based interventions have long been common but controversial treatments for autism (Green, Pituch, Itchon, Choi, O'Reilly, & Sigafoos, 2006; Interactive Autism Network, 2008). Scientific reviewers contend that these treatments remain unproven (Arendt, MacLean, & Baumeister, 1988; Daems, 1994; Hoehn & Baumeister, 1994; Miller, 2003; Parham, et al., 2007; Smith, Mruzek, & Mazingo, 2005), yet interest in using these interventions continues to grow (Schaaf & Davies, 2010), with occupational and physical therapists serving as primary advocates. Given their continuing popularity, the purpose of this article is to comment on the most recent review of the evidence to appear in the *American Journal of Occupational Therapy (AJOT)*, a major repository of research on SIT and similar sensory-based treatment approaches.

In this review, Case-Smith and Arbesman (2008) examined different types of occupational therapy interventions, including "Sensory Integration and Sensory-Based Interventions," involving strategies such as Auditory Integration Training (AIT), brushing, and massaging. The authors categorized the quality of each study using the following rubric: Level I research involved randomized-controlled trials, systematic reviews, and meta-analyses; Level II research involved clinical trials that were not randomized (such as static groups); Level III research involved simple A-B or before-after designs, which, along with Level II research, can never prove cause and effect (e.g., Fraenkel & Wallen,

2009).

Case-Smith and Arbesman found only 8 studies that qualified for Level I research, of which only one pertained to SIT (others focused on auditory integration techniques and massage). This study was a systematic review of prior research on the effects of sensorimotor interventions, including (but not limited to) SIT. They found studies reporting positive effects of SIT on "modulation" (i.e., controlling arousal, decreasing sensitivity to stimuli) and participating in social interactions. However, they described these studies as having scientifically weak designs (categorized as Levels II and IV), which did not prove a causal relationship between an intervention and behavior changes. Accordingly, they concluded that evidence of the effectiveness for SIT for improving modulation and social interaction is

"At this time there is simply no proof that SIT and similar interventions can promote improvement in behavioral or social functioning of persons with autism."

"inconclusive at this time" (p. 418).

Case-Smith and Arbesman expressed the view that there was more compelling evidence for the beneficial effects of SIT and similar approaches on inappropriate behaviors, hyperactivity, self-stimulatory behaviors, attention, and focus. They concluded that SIT (including, at least in this instance, interventions such as therapeutic touch) was related to improvements in these areas. As corroboration, they cited only two Level I studies. Field et al. (1997) used experimental and control groups to test the effect of touch therapy on

off-task behavior, touch aversion, and social withdrawal, as measured by classroom observations, teacher ratings, and a test of social communication. Participants in the experimental group received touch therapy that involved a 25-step protocol (e.g., stroking the leg, brushing the cheek, etc.). Participants in the control group sat on the lap of a volunteer student and played a game. The researchers reported that, at the end of the study, the experimental group outperformed the control group on all three outcome measures and concluded that touch therapy was causally related to improvement in the experimental participants.

However, Case-Smith and Arbesman cautioned that the study was very short-term (four weeks), that the rate of interobserver agreement in scoring the behavior observations was poor (lower than the commonly accepted 80% level) and that the accuracy of implementation of the 25-step touch procedure was not assessed. This is a crucial omission, since

the procedure was quite complicated. Last, the authors admitted that the results were confounded by the possibility of increased attention to the participants by the researchers who conducted the procedures. For these reasons, it is questionable whether improvement was necessarily due to the touching therapy.

Escalona, Field, Singer-Strunck, Cullen, and Hartshorn (2001) conducted the other study that, according to Case-Smith and Ardesman, offered Level I evidence of SIT effectiveness. Escalona et al. (2001) compared an experimental group

(Continued on page 19)

Dead Horse in Weighted Vest continued...

that received nightly massages from their parents before bed to a control group whose parents read to their children nightly before bed. The dependent measures were parent ratings of activity level and sleep, as well as behavior observations at school of positive response to touch, on-task behavior, stereotypical behavior and social relatedness. Although the experimental participants improved on these measures more than the control participants, the study is fraught with problems. For example, the dependent variables had no established reliability; thus, there could have been measurement error. Parents completed the sleep diaries, which is a potential problem, given the subjective nature of the information and that the parents knew what condition their children were in, potentially skewing their recordings as well.

Overall, the most recent review published in AJOT (conducted by occupational therapists who are proponents of SIT), find inconclusive results on SIT and other sensory-based interventions. The continued belief by some caregivers and parents that SIT is an effective treatment (e.g., Miller, Coll, & Schoen, 2007) brings to mind the old adage that “one is entitled to one’s own opinion, but not to one’s own facts.” The fact is that the evidence about effectiveness of SIT and similar interventions remains inconsistent at best. Furthermore, the interventions that seem most common in treating persons with autism, such as weighted vests, brushing, swinging and joint compression, have few, if any, well controlled research indicating their effectiveness. At this time there is simply no proof that SIT and similar interventions can promote improvement in behavioral or social functioning of persons with autism.

References

- Arendt, R., MacLean, W. E., Jr., & Baumeister, A. (1988). Critique of sensory integration therapy and its application in mental retardation. *American Journal of Mental Deficiency, 92*, 401-411.
- Baranek, G. T. (2002). Efficacy of sensory and motor interventions for children with autism. *Journal of Autism and Developmental Disorders, 32*, 397-422.
- Case-Smith, J., & Arbesman, M. (2008). Evidence-based review of interventions for autism used in or of relevance to Occupational therapy. *American Journal of Occupational Therapy, 62*(4), 416-428.
- Daems, J. (Ed.). (1994). *Reviews of research in sensory integration*. Torrance, CA: Sensory Integration International.
- Escalona, A., Field, T., Singer-Strunck, R., Cullen, C., & Harts-horn, K. (2001). Brief report: Improvements in the behavior of children with autism following massage therapy. *Journal of Autism and Developmental Disorders, 31*(5), 513-516.
- Field, T., Lasko, D., Mundy, P., & Henteleff, T. (1997). Brief report: Autistic children’s attentiveness and responsivity improve after touch therapy. *Journal of Autism and Developmental Disorders, 27*(3), 333-338.
- Fraenkel, J. R., & Wallen, N. E. (2009). *How to design and evaluate research in education. Seventh edition*. New York: McGraw-Hill.
- Green, V. A., Pituch, K. A., Itchon, J., Choi, A., O’Reilly M., & Sigafos, J. (2006). Internet survey of treatments used by parents of children with autism. *Research in Developmental Disabilities, 27*, 70-84.
- Hoehn, T. P., & Baumeister, A. A. (1994). A critique of the application of sensory integration therapy to children with learning disabilities. *Journal of Learning Disabilities, 27*, 338-350.
- Interactive Autism Network (2008). Retrieved November 29, 2010 at http://www.iancommunity.org/cs/ian_treatment_reports/occupational_therapy.
- Miller, L. J., Coll, J. R., & Schoen, S. A. (2007). A randomized controlled pilot study of the effectiveness of occupational therapy for children with sensory modulation disorder. *The American Journal of Occupational Therapy, 61* (2), 228-238.
- Miller, L.J. (2003). Empirical evidence related to therapies for sensory processing impairments. *Communique, 31*, 34-37.
- Parham, L. D., Cohn, E. S., Spitzer, S., Koomar, J. A., Miller, L. J., Burke, J. P., Brett-Green, B., Mailoux, Z., May-Benson, T. A., Roley, S. S., Schaaf, R. C., Schoen, S. A., & Summers, C. A. (2007). Fidelity in sensory integration intervention research. *The American Journal of Occupational Therapy, 61*(2), 216-226.
- Schaaf, R. C., & Davie, P. L. (2010). Evolution of the sensory integration frame of reference. *The American Journal of Occupational Therapy, 64*(3), 363-367.
- Smith, T., Mruzek, D. W., & Mzingo, D. (2005). Sensory integrative therapy. In J. Jacobson, R. Foxx, and J. Mulick (Eds.), *Controversial Therapies for Developmental Disabilities: Fad, Fashion, and Science in Professional Practice*. Pergamon Press.

It's Not Your Mom's AVON Anymore



I remember when the AVON lady used to come to my house and my mom was always buying something. I also recall mom's AVON stuff to be "old stuff." So when Donna Broniak from AVON wrote to ASAT stating that AVON has a beauty fundraising program that could benefit ASAT, I replied uncertain about how well the AVON products would sell.



Well, I must admit, it's definitely not the AVON I remember. First of all, the prices are excellent considering what beauty products cost (I would know...I use everything from Dior, MAC and high end hair products as well). I was still doubtful. How can such inexpensive products be so good, right???

Secondly, I had no idea that AVON had so many great new products. For example, this past June, Allure magazine published their Reader's Choice Awards and four of the Breakthrough Products of the year were from AVON! These winning products were also featured in Allure's special "Best of Beauty" issue in October 2010.



Thirdly, now you can easily shop via the Internet by browsing through AVON's

The winning AVON products:

- Best Facial Moisturizer – A NEW Ultimate Age Defying Day Cream SPF 25
- Best Anti-Aging Product – A NEW Ultimate Age Defying Day Cream SPF 25
- Best Eyeliner - Glimmersticks Eye Liner in Blackest Black
- Best New Fragrance - In Bloom by Reese Witherspoon

eBrochure, with new sales and

products all the time. You can also pay with a credit card or the ease of PayPal. When I went in search of what to buy, I discovered that AVON products are reviewed and rated, making it easier for me to decide what I wanted to try. I'm addicted to trying new lip glosses because so many of them are sticky, and you can *never* have too many! I'm accustomed to paying \$15 and up for a lip gloss. AVON's Glazewear Lip Gloss has earned rave reviews and typically costs \$6, but they are currently on sale for \$2.99 each. Well, I just received my five new glosses in the mail (very quick delivery), and I was very pleasantly surprised. The lip gloss has great pigment, applies easily, and is not sticky. I also invested in the Glimmersticks Eye Liner in Blackest Black. No wonder it is award winning. This eye liner glides on effortlessly and makes me want to buy more colors. Well, here is a great opportunity for you to order great products *AND* simultaneously donate to ASAT without spending any additional monies.

You can support ASAT while shopping for AVON products through our AVON Fundraising Program that designates a portion of purchases to ASAT when you use the link below.

CLICK HERE www.beautyfundraising.com/bfrfscr.html?id=790025 to register as a supporter of Association for Science in Autism Treatment.

MAJOR CREDIT CARDS AND PAYPAL ARE ACCEPTED!

Once you register, you will end up at the following link, which lets you know you have found your way!

<http://dbroniak.AVONrepresentative.com/>

Check out AVON and help support ASAT.



Join our [Facebook Fan Page](#)! Please invite your Facebook friends to join as well.

With your help, we are reaching out to more and more people every day united in their commitment to science in autism treatment. Individuals with autism deserve nothing less! Posts on our fan page include:

- Information about upcoming issues of our newsletter, [Science in Autism Treatment](#)
- Media Watch announcements and alerts
- Open letters from ASAT about issues of importance
- Information about upcoming ASAT conferences and events
- Other ASAT news and highlights

We now have over 2646 fans on ASAT's Facebook!
 But are you one of them?
 If not, become one now; click on the logo to the right
 or visit www.facebook.com/ASATonline



Find us on Facebook



www.asatonline.org



ASAT Real Science, Real Hope
ASSOCIATION FOR SCIENCE IN AUTISM TREATMENT

Over 10 Years of
 Education
 Advocacy
 Information

To support ASAT's mission and make a significant difference in the lives of children with autism and their families, please complete this form and remit it to:

The Association for Science in Autism Treatment
 P.O. Box 188 Crosswicks, NJ 08515-0188

Amount of my Gift: \$25 \$50 \$100 \$250 \$500 \$1000 _____
 (Please make check payable to ASAT)

Name _____ Phone (____) _____

Address _____

Email _____

Yes, I give permission to publically acknowledge my donation by including the following information on ASAT printed material or website.

- Donor Name
- In Honor of / In Memory Of _____
circle one

No, I prefer that my donation is not listed in ASAT material.

ASAT offers a Free Newsletter
 Science in Autism Treatment

- I have already subscribed at www.asatonline.org/signup
- Please add me as a subscriber

/donor card/newsletter/

ASAT Advertising Policy and Protocols

The Association for Science in Autism Treatment (ASAT) accepts advertising for the ASAT.org website, newsletter and other ASAT publications to offset its operational expenses. Products or services accepted for advertisement by ASAT will be consistent with our mission to disseminate accurate, scientifically-sound information about autism and its treatment and to improve access to effective, science-based treatments for all people with autism, regardless of age, severity of condition, income or place of residence.

All advertisers must sign the ASAT Advertising Application. ASAT maintains the right to refuse any proposed advertisement that is incompatible with its mission, as determined through a case-by-case review by the ASAT Board of Directors, prior to placement of advertisement in ASAT publications.

In order to be considered for acceptance by the ASAT Board of Directors, the proposed advertisement must **NOT**:

- make unsubstantiated health or treatment claims
- suggest endorsement by ASAT
- contain religious or political content
- contain pop-ups, floating ads or surveys
- collect personal information from an individual visiting www.ASAT.org
- use cookies, applets or other such files that transmit or otherwise collect personally identifiable information.

For each possible ASAT advertiser, an authorized person will be required to sign off that his/her organization is in 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 treatments that have been shown to be safe and effective in scientifically rigorous, peer-reviewed research studies.
3. Service providers should take steps necessary to help consumers differentiate between scientifically-validated treatments and treatments that lack 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.

Advertisement on www.asatonline.org, newsletter or other publication does not imply endorsement by ASAT of the advertised company, service or product. All advertisements will be clearly labeled as an advertisement. ASAT reserves the right to decline any advertising request if the content of ad contains reference to treatments that are not established. ASAT may also decline requests if the website or mission statement contains content not consistent with the tenets above.

This policy is intended to provide general guidance and is not inclusive or exhaustive. ASAT may change this policy at any time, at its discretion, by posting a revised policy to the ASAT.org website.

For questions about advertising, contact newsletter@asatonline.org.

Disclaimer- ASAT has no formal relationship with any of its advertisers. Furthermore, their stated endorsement of the above tenets is not verified or monitored by ASAT. Although ASAT expects that all advertising organizations will act in accordance with the above statements, ASAT does not assume responsibility for ensuring that advertisers engage in behavior that is consistently congruent with the statements above.

Rates

Sponsor and non-sponsor rates are listed below. For more information about becoming a sponsor, please see http://asatonline.org/about_asat/sponsors.htm#learn.

As you can see below, we are offering additional percentage discounts in addition to a free ad for our 2010 Alliance and Patron sponsors.

Formatting of Newsletter Ads

Please create ad that conforms to dimension ratios specified below.

All ads will need to be sent in TIFF or JPG format.

To allow for highest quality, do not compress ads.

Larger ads are allowed, as long as they are in the appropriate ratio (i.e., – a 9:7 ratio for a full-page ad) – sending larger files may allow for better ad quality.

Please ensure that your ad does not make unsubstantiated health or treatment claims, suggest endorsement by ASAT, or contain religious or political content.

2011 Advertising Rates	Non Sponsors	Champions \$2000/yr	Benefactor \$1000/yr	Alliance \$500/yr	Patron \$200/yr
	See Rates below	One Free Half page and then 50% discount	One Free Quarter page and then 40% discount	30% discount	20% discount
Full Page 9" X 7"	\$800/Issue	\$400/Issue	\$480/Issue	\$560/Issue	\$640/Issue
Half Page 4.5" X 7" [9"X 3.5"]	\$500/Issue	\$250/Issue	\$300/Issue	\$350/Issue	\$400/Issue
Quarter Page 2" X 7" [5"x 3"]	\$300/Issue	\$150/Issue	\$180/Issue	\$210/Issue	\$240/Issue

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 would be empowered with skills in identifying and choosing the most effective, scientifically-validated interventions for their child.

.....when the media would educate and not confuse parents by providing accurate information and asking the right questions.

.....when all providers would be guided by science when selecting and implementing their interventions.

What it means to be a sponsor.....

ASAT's 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 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 2011 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.

The tasks of educating the public about scientifically-validated intervention and countering pseudoscience are daunting ones, and ASAT appreciates the support of all of its sponsors.

If you are interested in becoming a 2011 sponsor, please visit the sponsor page on our website at www.asatonline.org/about_asat/sponsors.htm#learn.

Thank you for your consideration!

2010 Sponsors in Real Science, Real Hope Sponsorship Initiative

BENEFACTOR \$1,000

- [Different Roads to Learning](#)
- [Rethink Autism](#)
- [Accelerated Educational Software](#)
- [Pyramid Educational Consultants, Inc.](#)

ALLIANCE \$500

- [Association for Behavior Analysis International](#)
- [Autism New Jersey](#)
- [Eden II Programs](#)
- [Melmark](#)
- [New England Center for Children](#)
- [Organization for Research and Learning \(O.R.L.\)](#)
- [Quality Services for the Autism Community \(QSAC\)](#)
- [Quest Autism Program](#)
- [Virginia Institute of Autism](#)

PATRON \$200

- [Alpine Learning Group](#)
- [Asperger Syndrome and High Functioning Autism Association](#)
- [Autism Science Foundation](#)
- [Beacon Services](#)
- [Behavioral Intervention Association](#)
- [Brooklyn Autism Center](#)
- [Child Study Center of Fort Worth](#)
- [Connecticut Center for Child Development](#)
- [Evergreen Center](#)
- [Institute for Educational Achievement](#)
- [Institute for Educational Planning](#)
- [Lizard Children's Learning Center](#)
- [NY Center for Autism- Charter School](#)
- [Providence Service Corporation](#)
- [Room to Grow](#)
- [SKF Books](#)
- [Somerset Hills Learning Institute](#)
- [Wellspring Healthcare Services](#)

ASAT Needs Your Help in 2011

We know that many of our readers are concerned about the plethora of treatments that lack scientific support - and the burden this then places on families and service providers who are struggling to make decisions about treatment.

Help us make a difference!

Become a 2011 Sponsor !

IMPORTANT DISCLAIMER: ASAT has no formal relationship with any of the sponsor organizations. Furthermore, their stated endorsement of the above tenets is not verified or monitored by ASAT. Although ASAT expects that all sponsoring organizations will act in accordance with the above statements, ASAT does not assume responsibility for ensuring that sponsoring organizations engage in behavior that is consistently congruent with the statements above.

Message from ASAT President David Cellberti, Ph.D., BCBA-D continued

treatment summaries on www.asatonline.org for biomedical, behavioral and non-behavioral treatments.

- Identify ways in which ASAT's initiatives can better address interventions for adults with autism and their caregivers.
- Expand "Topical Articles" to include coverage of research regarding genetics, epidemiology, and assessment.
- Develop consumer-friendly website features such as a webpage for parents who are new to autism treatment.
- Assess the needs of pediatricians and related medical providers to determine appropriate goals and strategies. Direct involvement of medical professionals will be solicited to accomplish this goal.
- Increase awareness by sharing information about ASAT during presentations at various state, regional, and national conferences.
- Increase distribution of ASAT's printed materials at state, regional, and national conferences.
- Participate in the ABAI Program Exposition in Denver, CO and in other venues throughout the year.
- Continue to forge collaborative relationships with other similarly-minded organizations who are committed to science.
- Aim for biweekly Media Watch responses to accurate and inaccurate portrayals of autism treatment.
- Offer media education for journalists through the development of a media page on website.
- Develop a media award for those who accurately portray autism interventions.
- Pursue grant writing as a mechanism to fund specific ASAT initiatives.

Please indulge me in ending this letter with a heartfelt appeal. We can not carry out our important work without your financial support. The ongoing success of ASAT is predicated on the financial support of generous donors.

In contrast to most other disorders, parents of children with autism have to work hard to find effective interventions supported by scientific research. This is against a backdrop of often irresponsible journalism and an internet replete with misinformation and marketing ploys. At ASAT, we truly believe that parents deserve access to a community that values science over profit, expects accountability from all treatment providers, and gravitates towards methods already proven to be effective.

If you support our mission, believe in the promotion of science, and recognize the need for accurate information about autism treatment, and we hope you do, please complete the donor panel on page 21 or donate online through Pay Pal found on the lower left corner of our [home](#) page. Any amount would be deeply appreciated.

In addition, if you are affiliated with an organization that shares ASAT's commitment to science in the treatment of autism, please consider becoming a 2011 Real Science Real Hope Sponsor. We are pleased to report that 31 organizations participated last year. Please see page 23 for more information.

I wish you all a happy and healthy new year.

Best,
David



Autism Treatment: Buyer Beware!



Today a parent of a child with autism is continually bombarded with “THE” treatment that will cure all that ails them. If the promised cure does not follow, they suggest they need to try the treatment longer, at higher doses, or in combination with some other therapy. They often don’t provide metrics of performance against which they can be held accountable. Without these, the consumer is left holding the bag.



In times like these, we hope that ASAT serves its mission by creating resources to produce savvy consumers of these services armed with the information needed to navigate a buyer-beware market like this.



The antidote to all of these supposed “cures” is knowledge, and that is most often derived and verified through scientific examination and objective assessment of outcomes. Therefore, science and the dissemination of accurate reports of it are at the heart of ASAT’s mission.



Please share any new scientific evidence with us that we may have missed at info@astaonline.org.

ASAT Mission Statement

Our mission is to educate parents, professionals, and consumers by disseminating accurate, scientifically-sound information about autism and its treatment and by combating inaccurate or unsubstantiated information. In doing so, we promote the use of effective, science-based treatments for all people with autism, regardless of age, severity of condition, income or place of residence.