Welcome to another edition of the ASM’s newsletter. In response to the developing questions and conversation about the proposed changes to diagnostic criteria related to autism diagnoses in the forthcoming DSM-V, we have provided several resources for your use. First, our own board vice president, Dr. Matthew Siegel, Medical Director of the Developmental Disorders Program of Spring Harbor Hospital offers some concise information in response to frequently occurring questions. Next, is a link to a chart available on our own website which allows for viewing of the current diagnostic criteria (for autistic disorder, Asperger’s, PDD-NOS) and the proposed criteria for Autism Spectrum Disorders. Finally, there are three links to additional information including a statement from a member of the American Psychiatric Association (APA) Neurodevelopmental Disorders Workgroup discussing the committee’s reasons for integrating Asperger’s into a spectrum diagnosis. We also have included a statement from the Autism Society (ASA) national office addressing considerations for the implication of any changes to diagnostic criteria.

On a different note, we invite you to begin thinking about upcoming Autism Awareness Month in April. Information packets and ribbons will be available for free from our office in the next few weeks. Please consider spreading awareness by making use of these materials - and remember to wear your ribbon. Associated events include an April 11 Portland Pirates game and the annual ASM walk on April 29, now to be held in four locations (Biddeford, Bangor, Farmington, and Presque Isle) throughout the state. In addition to the enclosed announcements, check out the Events Calendar on our website for event additions and updates. We hope that you find all of the information useful.

Dr. Matt Siegel

As many of you know, the criteria for diagnosis of autism spectrum disorders are being revised for the new edition of the Diagnostic and Statistical Manual (DSM) which is due to be published mid 2013. The proposed revisions have been in the news lately, and have caused concern for some ASM members.

The proposed revisions were released January 26, 2011. There have been no announced changes to those criteria, which can be reviewed and compared to the currently used criteria at: www.dsm5.org. The recent spate of news stories occurred because several studies were just published that attempted to evaluate how the proposed revisions would change the population of individuals identified as having an ASD.

The studies showed that the new criteria may exclude some individuals with high functioning autism whose symptoms are more mild in appearance, as the criteria were revised based upon research aimed at making the diagnosis more accurate. The studies also identified, though, that with a couple of small...
Maine Autism Connections
A publication of the Autism Society of Maine

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Visit us online at: asmonline.org

Annual Walk for Autism - 10th Anniversary!
April 29, 2012
11:00 Registration
12:00 Walk for Autism Begins at all Locations:
University of New England, Biddeford
University College of Bangor, Bangor
Farrington Fairgrounds, Farmington
University of Presque Isle, Presque Isle

Please join the Autism Society of Maine for its 10th Anniversary Autism Walk event held in four locations this year! Each Walk is under 2 miles, and there will be t-shirts for those who raise $50.00 or more.

Every year brings new ideas that will make the Walk even better. This year we have added a new location in Presque Isle, we hope this location will be more accessible to the folks in the Northern part of Maine.

You can register your team/individual online at www.firstgiving.com/ASMMaine. Here you will be able to make your team/individual page and share your page with friends to help raise donations. If you prefer to register the day of the event, please come to the registration table and sign in.

The Month of April is nationally recognized as Autism Awareness Month and April 2nd is World Autism Day, an opportunity for ASM to raise awareness and educate people about autism. It is also an opportunity to raise funds to support families, individuals, families and providers across the state. Autism Awareness Packets will be available that include an autism awareness poster, informational flyers, ribbons and autism brochures. These would be appropriate for a bulletin board at your school, workplace library or store. We ask that you send in a picture of your bulletin board for the online photo gallery that can be seen on ASM’s website: www.asmonline.org/gallery.asp

Teachers are also taking this opportunity to educate their students about autism and promoting understanding and inclusion for their fellow classmates. We are happy to help in any way that we can, by providing autism information, books & dVd’s or by offering an autism presentation.

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For your convenience, we plan to make the lines for registration more smoothly. All teams should have a Captain (designated contact person) who can come to the registration table and sign in their team and pass in donations that their team has raised. This will alleviate having all team members in the sign in/registration line.

See online walk page to print out: brochure, vendor registration (Bangor & Farmington), poster & pledge sheet.

Please contact ASM if you are interested in volunteering at the Walk event and help with the many different tasks such as traffic control (directing cars where to park), set up, take down, balloons, popcorn machine, face painting, etc. 1-800-273-5200 or info@asmonline.org

Walk will happen rain or shine!
Camp Summit

This year marks the 10th Anniversary of Camp Summit. The camp is based in the Farmington area. ASM has collaborated with University of Maine Farmington since the beginning and utilize the college students as the children's one on ones. The students take this as a summer course through UMF. The camp Director is Dr. Susan Anzivino and the UMF course is through Dr. Joel King.

The camp is based on socialization for the children and they experience what others kids experience at summer camp. The camp is tailored towards the needs of an individual on the spectrum. Camp Summit is free and there are only 12 spots open in each age range. There is an extensive application form to fill out. The camp committee reviews each application and has to match the child’s needs with a college student who can meet that need. Not all applicants are guaranteed a spot in the camp program. Applications will be ready by April 1, 2012. Call the office to receive an application.

Please join us at St. Joseph’s College in Standish on July 20 - 22

We know change is hard for our children, but we feel it is time for us to change to a location that can offer more for families. St. Joseph’s has an indoor pool, rock climbing wall, gym, two lounge areas and perhaps the best part are the dorm rooms. They are comfortable and have double the space for families. Each floor has 4 pods, and each pod has 5 to 6 dorm rooms with four bathrooms. You will have more privacy and security. There is even an elevator in the building, and you will be able to park your car right outside the dorm. Everything is in walking distance. The cafeteria has awesome food (ASM staff stayed for lunch when we visited), and they will even be able to accommodate any family member who is on GFDF diet. We have not changed the price so you can expect to pay the same as last year.

There are a few changes for the weekend. First, we will offer respite on Friday night, but it will be limited to the gym area only. The pool will be open on Friday & Saturday night for any families who want to enjoy this activity together. We will also be able to have lunch on Sunday before you leave – you will have to be out of your room, but you can stay and enjoy lunch. For those who like to enjoy the beach, Sebago Lake is just behind the St. Joseph’s College. They even have a small rocky beach to enjoy the water. Sebago Lake State Park is a 20 minute ride from St. Joseph’s college.

Registration for the Family Retreat Weekend will be available on April 1st.
Autism Information Specialist Program

The Autism Society of Maine (ASM) completed its 2012 Autism Information Specialist (AIS) training in March. Six people have been added to the program: Ashleigh Barker, Amanda Kenneson, Catherine Larsen, Michelle Small, Beth Whitehouse, and Ryan Whitehouse.

Autism Information Specialists contract with ASM for individual assignments. These assignments vary from talking with families as a support person to attending educational (IEP) or vocational (PCP) planning meetings to giving public presentations. They provide valuable resource information to individuals, families, service providers, employers, schools, and agencies across the State. They promote and encourage understanding, empathy, and compassion for individuals with Autism Spectrum Disorder (ASD).

On December 21st, Autism Society of Maine Board Vice President, Matthew Siegel, M.D. published a study entitled “Specialized Psychiatry Units for Children with Autism and Developmental Disorders: A United States Survey,” in the Journal of Autism and Developmental Disorders. The study is the first to identify the rapid growth of hospital units initiated due to the growing and needy population of children identified with autism in the U.S. over the past decade.

The study revealed an average length of stay of 42 days, a population composed of 66% children with autism, and a universal employment of multi-disciplinary teams with more than a hint of concern in her voice she asked, “Why didn’t you drink them? I wanted you to stay hydrated in this heat.” I couldn’t understand why she was making such a fuss over the water bottles felt more like 100lb bricks strapped to my back, but like a trooper it didn’t deter me from wandering around for hours in the scorching heat with them neatly tucked inside my pack. New Orleans is known for its Mardi Gras beads and bling. Each display stored never ending racks filled with a vast selection of shiny colorful beads. They weren’t stores to me; they were shrines to bling-bling. I had discovered the autistic mecca where those of us autistic followers of shiny colorful objects must make pilgrimage to at least once in their life. Like a kid in a candy store I was so completely mesmerized by all the “eye candy” that I didn’t even feel the heat of the blazing sun that afternoon.

Despite the growth in programs, only 137 beds nationwide were identified, and these were heavily concentrated in the Northeast, with no hospital resources available west of Denver, Colorado.

Dr. Siegel commented “This is the first study to attempt to describe the U.S. system of care for children with autism who need psychiatric hospitalization.” “Specialized hospital units are being initiated due to the growing and needy autism population – a population with a high prevalence of co-morbid mental illness and use of psychiatric services.”

The study identified 9 specialized hospital units in the United States, five of which had opened in the last 10 years.

A United States Survey of Specialized Psychiatry Units

Currently we have Autism Information Specialists in the following locations:

- Bangor
- Fairfield
- Oxford
- Brewer
- Farmingdale
- Portland
- Bridgton
- Georgetown
- Presque Isle
- Brunswick
- Lincoln
- Sidney
- Dexter
- Naples
- South Portland
- East Millinocket
- New Sharon
- Vassalboro
- Edmunds
- Northport
- Wiscasset

Our goal is to have an Autism Information Specialist in every county in the State. If you are interested in becoming a part of this program and want to know more about it, please call Darlene Lepoff at 1-800-273-5200.

Our next training will be in the winter of 2013.

Amanda Kenneson

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dazzling beads around my neck. My equilibrium was a touch off, no doubt the result of the mechanical bull ride. I noticed large crowds gathered under the balconies waving their arms at the people above who were dangling strings of beads over their heads. Once I realized that they were throwing the beads into the crowd I made my way into the pack. Free beads, who could resist! Much to my surprise (I am usually not that uninhibited) I hooted and hollered with the best of them, lunging in mid air to be the one catching the necklaces thrown my way. No easy feat when your balance is off! The scene was very reminiscent of Sea World where we the seals were clapping, doing tricks, and begging for the fish dangling in front of our noses by the handlers which in this case were the party goers on the balcony. When it was all said and done, I ended up back at the hotel with a 5 gallon pail’s worth of Mardi Gras beads.

Knowing the next day was going to be busy with sightseeing I decided to pack as soon as I got back to the hotel so I could move into a new hotel the following night. Since I fly with a military camouflaged rucksack as opposed to carryon luggage, whatever didn’t fit in the rucksack had to be left behind. That was a challenge with 4 cans of specialty coffee, tons of souvenirs, and of course my bucket’s worth of beads. I crammed and I shoved and filled every nook and cranny until every last item was stuffed away. The pack now weighed close to 50 lbs. We would drop it off at the next hotel I was staying at in the morning before sightseeing so that I didn’t have to schlep it on my back while with Sister.

It was dark when I had to check in to the new hotel and my room was in another building across the parking lot. Sister who drove me there wanted to walk me to my room to ensure I got there safely. The hotel offered to take my pack to my room, but I had an unbreakable rule that no one carries my stuff but me. It took 2 valet parking attendants to manhandle the bulky, massive rucksack onto my back; it was that heavy. It truly was a challenge to stay upright, but I was determined I could do it. I managed (despite the concerns of management) to exit the lobby and lumber across the parking lot as graceful as a drunken sailor. I was so busy bragging to Sister about my upper body strength and agility; I failed to notice the recessed manhole cover in front of us. One foot avoided this depression but the other foot didn’t and down I went.

What a humiliating way to end an otherwise perfect day! I insisted I could right myself with the pack still strapped to my back but it took all my strength just to avoid dipping over. It only took seconds of struggling before I ended up flat on my back staring up at the stars. Not wanting to admit defeat I desperately flailed my arms and legs hoping for traction to no avail. Like a turtle flipped over on its back, I too with my green camo shell lay there helpless. The shoulder straps snugly pressed into my collarbone acted like the best padded restraint any mental hospital could afford, keeping me completely and helplessly immobilized and pinned to the pavement. Completely embarrassed and unable to function at all, I could do was watch as Sister struggled to unbuckle the jammed straps that dug into my shoulders. We got it done and somehow by some miracle I made it on the plane and home without jettisoning any treasures but boy the Big Easy wasn’t all that easy for me this time around.

Free Movie Event

Sponsored by the Rotary of Lewiston-Auburn
April 14, 2012
Saturday at 10 am (arrive by 9:30 to get checked in and snacks)

Dr. Seuss’ The Lorax
Flagship Cinemas
730 Center Street
Auburn, ME 04210

The Lewiston-Auburn Rotary Club is sponsoring a movie event in support of families whose children with autism live in the Lewiston/Auburn area. The movie will be closed to the general public and will start at 10:00 am. This will be a sensory free environment, the lights will be kept on low, sound will be lowered and there will be no previews. Each child will receive a popcorn and drink.

Reserved seating is required – call the Autism Society at 1-800-273-5200.

2012 Ride for Autism

Save the Date - Sixth Annual
Ride For Autism
September 15, 2012

Ride will start at the Kennebunkport Conservation Trust Building in Kennebunkport, ME
www.firstgiving.com/ASMMaine/rideforautism
or call 1-800-273-5200

Mandate - Autism Insurance Coverage

Effective January 1, 2011, state-regulated health plans are required to provide coverage of the diagnosis and treatment of autism spectrum disorders for individuals age 5 and younger.

Coverage of treatments will be provided when prescribed, provided, or ordered for an individual diagnosed with autism by a licensed physician or a licensed psychologist who determines the care to be medically necessary.

Coverage includes:

- Habilitative or rehabilitative care - including applied behavior analysis or other professional or counseling services necessary to develop, maintain and restore the functioning of an individual to the extent possible
- Psychiatric care
- Psychological care
- Therapeutic care - meaning services provided by certified speech, occupational, or physical therapist

Coverage for Applied Behavior Analysis (ABA) is subject to an annual maximum of $36,000, but there will be no limits on the number of visits to an ABA provider.

There will be no dollar or number of visit limitations on other covered treatments unrelated to ABA.

The law does not affect any obligation to provide services to an individual under an individualized family service plan, an individualized education program (IEP), or an individualized services plan.

Maine law does not apply to self-funded insurance plans as they are federally regulated by ERISA. Self-funded plans can self adopt coverage and many do. If you need help approaching your self-funded employer about adding coverage, please contact judith.ursitti@autismspeaks.org.

For additional information, please visit http://www.autismspeaks.org/mai or contact Judith Ursitti at judith.ursitti@autismspeaks.org.
There are many ways to give to the Autism Society of Maine. We rely on donations and fundraisers to help cover the cost of our programs and activities that bring awareness and community to individuals and families impacted by ASD. Here’s how you can help:

- **Donate to us during our second Autism Society of Maine Fall Annual Appeal.**

  General donations may also be made anytime of the year online using our secure donation forms (or you can download and print our PDF forms) at:
  

  • Donations through Network For Good may be made at:
    

  • Donations via Facebook, powered by the Network for Good, may be made at:
    
    [http://apps.facebook.com/causes/238491?m=3f1cca43](http://apps.facebook.com/causes/238491?m=3f1cca43)

  • Donations through United Way can be directed to the Autism Society of Maine. For more information, visit:
    

  - Host a fundraiser with proceeds going to ASM. Some of the past and current fundraisers have included: Avon, Pampered Chef parties, Mary Kay parties, bake sales at events, selling autism awareness items at conferences or craft events, selling Christmas wreaths, selling T-shirts. If any of these fundraisers interest you please call us for more information.

  For other ways to contribute, become a volunteer or become a member contact us at: [http://www.asmonline.org](http://www.asmonline.org)

**Ways to Give**

**Donations to the Autism Society of Maine are tax-deductible. Please consider us as you plan your year-end giving.**

Thank you for your generosity!

In Memoriam:
- **David Allen, Sr.**
  
  James, and Carol Bennett (Boftfald’s Furniture)

- Joseph Simos & Mary Ann Wood

- Andrea Lovelace

- Louis Stockas

- John Huse

- Joanne & Hersey Wilkins

- Alice & Cardena Bonvicin

- Mary & David Hinon

- Central Maine Orthopaedics in honor of Debra Allen’s grandfather

- Robert & Gloris Wright

- Keith & Della Fulton

- Joe & Melodie Plourde

- Richard & Carla Newcomb

- Pauline Parker

- Christopher LaVallee

- Portland Sand & Gravel, Inc.

- Ellen Burrell

- Anthony & Deanna Wilson

- Fraternal Order of Eagles No. 431

- Ann Horton

- Suzanne & John Culvin

- Suzanne Golder

- Cynthia Curry & Robert Jessup

- Joan & Gordon Smith

- James Hatch

- Valerie & J. Damon Carrier

- Florence Morris & Sharon Krasney

- Maine Auto Credit

*In Memory of Timothy Stickney by Susan & Brian Greenwood*

*In Memory of Timothy O’Donovan by UNUM Matching Gifts by Bonnie Wilson*

*In Memory of Michael O’Donovan by Bonnie Wilson*

*In Honor Of*:
- Jack & Judi French by Jean Marie Ivey
- Merry Christmas, Jack & Karen Fecteau by Emily Fitzgerald
- Isaiah Shaver by Ellen Shaver
- Mr. & Mrs. Richard Farrell, Teresa Port & Steve Lisbonsky, Mr. & Mrs. Vaillancourt, Ms. Carol Connolly, Colonel & Mrs. Michael Port, and Todd Ronningfeld by the Vaillancourt Family
- Derek Volk, Scarborough Leader’s “Great Person of the Year” by Lynn Goldfarb

Ride for Autism
- Marion’s Marina
- Mary Brown Tilton
- Frederik & Patricia Palmer
- David & Linda Pope

Donations:
- Regina Lachance by Portland Models & Talent
- UPS Foundation, Inc.
- Rotary Club of Boothbay Harbor for volunteerism by Joanne & Ken Mason
- Mary Gabriel
- Gregory & Norma St. Angelo
- John & Ann Bay
- Anonymous
- Rhonda Lavosie, Scentsy Rep
- MedTech Media
- Linda & Lawrence Grant
- Rising Tide Brewing Company
- New York Life Foundation
- Toddlie Inn, South Portland
- Laurel Portier
- Jennifer & Paul Pinette
- Barbara E. Warner
- Jack Dyer
- Steven & Margaret Shaver

Employee Pledges
- UPS, Scarborough/S. Portland
- Stacey Tobey
- Linda Aulet in recognition of Liam
- Pauline Pratt
- Kevin LaFontiere

Charitable Appeal
- United Way of The Tri-Valley Area
- Maine State Employees Combined

Matching Pledges
- UNUM Group for Trudi Parker

Library Donations
-日内野旅

**Library Store**

You may purchase these and more items on the ASM website at: [https://www.asmonline.org/441/productcat/p/home.asp](https://www.asmonline.org/441/productcat/p/home.asp) or call 1-800-273-5200.

- **Gel Autism Awareness Bracelet**
  
  1 1/4” Pin $1.00

  7/8” Earrings $15.00

  7/8” Pendant $8.00

- **Silver-tone stretch bracelet $8.00**

- **Guardian Angel Pin $8.00**

- **Mini Magnet 2” x 4” $3.00**

- **"Safe and Sound" decal for your window $3.00**

- **Dichroic Glass Jewelry is hand crafted and unique (sterling silver plated bail and earring hooks)**

- **Ivory Awareness Lanyard $6.00**

- **Autism Awareness Lapel Pin $5.00**

- **Autism Ribbon Keychain**
  
  Price $5.00

- **Autism Awareness Window Cling 8” x 3 7/8” $5.00**

- **Dichroic Glass Jewelry is hand crafted and unique (sterling silver plated bail and earring hooks)**

- **Your order will be a random design and color.**

**Welcome to the Autism Society of Maine Library!**

Library materials can be borrowed two items at a time for two weeks (not including mailing time), and renewed if there is not a waiting list. If you cannot visit the library in person, materials can be mailed to you and return postage will be included for your convenience. You do not have to be a member of ASM to access the library.

Although the library collection is essentially on autism, there are many categories in which to keep updated with new material. We take into consideration all requests that are made and appreciate the interest.

E-mail: library@asmonline.org 1-800-273-5200

Online Library Page: [www.asmonline.org/library.asp](http://www.asmonline.org/library.asp)

**Riding, Hiding, Food and Fear (DVD)**

Watching the Series

Children will learn about asking and answering WHY questions, prepositions, and things that go together while having fun learning to ride a bike, having a water balloon toss, and tasting new foods. The video models language skills, motor skills, academic skills, self-help/functional skills while addressing counting, money prepositions, less/more, categories, safety, manners and more.

Children learning social skills in the natural setting help build a strong foundation for continued learning.

Answering Autism From A-Z

by Karen J. Crystal

Creatively written and offers useful, informative instruction and a wealth of firsthand knowledge. It was written from a position of authority; as a mother of a child with Autism, I have “been there, done that” in terms of everything that is in the book. Answering Autism From A-Z walks the reader through the challenging processes of dealing with educators, doctors, and government agencies with the compassion, humor, and insight that only comes from firsthand experience. It gives the reader a better understanding of “A” – Advocating for the person with Autism all the way through “Z” – Zoning in on one’s strengths.

**Different, Not Less: Inspiring Stories of Achievement and Successful Employment from Adults with Autism, Asperger’s, and ADHD by Temple Grandin**


This book is a compilation of success stories from adults with autism and Asperger’s Syndrome. One of the most important missions Temple Grandin has is making sure people with autism and Asperger’s make something of their lives.

**Full Life with Autism: From Learning to Forming Relationships to Achieving Independence By Chantal Sicil-Kira, Jeremy Sicil-Kira**

RELEASE DATE: March 27, 2012

Autism expert Chantal Sicil-Kira and her son Jeremy offer real solutions to a host of difficult questions, including how young adults of different abilities and their parents can navigate this new economy where adult service resources are scarce & coping with the difficulties of living apart from the nuclear family.


RELEASE DATE: April 11, 2012

When a child is diagnosed with an autism spectrum disorder (ASD), what the family really need, and often lack, is positive reassurance and understanding from those closest to them. This book is packed with advice on how extended family members and friends can provide the necessary support.

**Watch Me Learn Series**

- Autism Awareness 8” x 3.5” $5.00

- Autism Awareness Gel Magnet 8” x 3.5” $5.00

- Autism Awareness Window Cling 8” x 3 7/8” $5.00

- “Safe and Sound” decal for your window $3.00

- Autism Awareness Lapel Pin $5.00

- Autism Awareness Keychain Price $5.00

- Dichroic Glass Jewelry is hand crafted and unique (sterling silver plated bail and earring hooks)

- Your order will be a random design and color.

**Autism Awareness Window Cling 8” x 3 7/8” $5.00**

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**7/8” Pendant $8.00**

**Autism Awareness Lanyard $6.00**

**Autism Awareness Lapel Pin $5.00**

**Autism Ribbon Keychain Price $5.00**

Your order will be a random design and color.
Support our Services: Give to the Autism Society of Maine!

The Autism Society of Maine is a statewide nonprofit organization that for over 35 years has served Maine individuals with autism and their families, professionals, and communities by providing education, advocacy, referrals, and resource development. We rely on donations and fundraisers to help cover the cost of our programs and activities that bring awareness and community to individuals and families affected by ASD. Here’s how you can help:

• General donations may also be made anytime of the year online using our secure donation forms (or you can download and print our PDF forms) at: http://www.asmonline.org/involved_donations.asp
• Memorial donations to the Society in memory of a friend or loved-one may also be made at: http://www.asmonline.org/involved_donations.asp
• Donations through Network For Good may be made at: https://www.networkforgood.org/donation/ExpressDonation.aspx?ORGID2=010407346
• Donations via Facebook, powered by the Network for Good, may be made at: http://apps.facebook.com/causes/238491?m=3f1cca43
• Donations through United Way can be directed to the Autism Society of Maine. For more information, visit: http://www.asmonline.org/involved_donations_united_way.asp
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For other ways to contribute, contact us at asm@asmoline.org. Thank you for supporting our mission!

Become a Member!

The Autism Society of Maine invites you to join families and professionals in the pursuit of knowledge about autism spectrum disorders, treatments and support for Maine children and adults with autism.

You may register online at: www.asmonline.org/involved_joinasm.asp
or call ASM at 1-800-273-5200

Call us at: 1-800-273-5200 or visit us online at www.asmonline.org