



Senator Shenna Bellows

Let ME  
spread the  
word on  
AUTISM

**AUTISM SOCIETY**  
Improving the Lives of All Affected by Autism  
Maine

# Maine Autism

## Connections

### Advocacy and Hope

by Laurie Raymond

The Autism Society of Maine was honored to have Senator Shenna Bellow, of Maine's 14th District as our guest speaker at our annual meeting. Senator Bellows provided strategies to advocate and influence social policy in our state, she left us with a sense of hope as we head toward 2018!

#### Some ideas she shared included:

- Map out who influences the decision makers on any issue—identify commonalities (i.e. geographical, community, social and organizational connections).
- Ask what do you have in common with policy makers?
- When advocating for an issue, be clear about what you want the elected official to do (i.e. to vote a certain way)
- Clarify the top few things you want to say to them.
- Tell your honest story
- Meet with your representatives 1:1 to ask for what you want.
- Testify with families in action alerts. If you don't want to speak publicly, you can send an email, provide written testimony or sit in solidarity with the others speaking.
- Don't give up—your input, calls, voicemails, letters, all make a difference.

These bullets do not do justice to Senator Bellows talk on October 6, 2017. However, if this has sparked your interest to learn more, stay tuned for an upcoming webinar featuring Senator Bellows on the topic of "Advocacy and Hope" through the Autism Society of Maine. It will be available to review on our website.

There are many other amazing leaders in our legislature who

Winter 2017

support the autism community. While we do not have the space to list them all, we wanted to give a shout out to some other members who have demonstrated a commitment to the autism community---Sen. Amy Volk, Sen Ben Chipman, and Representatives Gattine and Hymansen. Because of the work of the Maine Legislature, Adult Developmental Community Based Services under Section 29 (Medicaid) have been significantly increased, allowing individuals with autism and intellectual disabilities to receive more than 20 hours of support each week, insuring that individuals and their families receive necessary supports. This passed with 2/3 majority and was signed by our Governor in May, 2017, so there are many supporters in the Maine Legislature. We thank everyone who supported this critical policy change!

We also celebrate the strong members of the Maine legislature who demonstrate an understanding of autism and its' impact to individuals and families. A member of our Board of Directors, Representative Richard Farnsworth, from Maine's 32nd district, has made a career of supporting our state's most vulnerable citizens through legislative work, non-profit agency leadership and civic engagement. As a member of the Education and Cultural Affairs Committee, Rep. Farnsworth will be active in the consideration of legislation that will most certainly impact our children and families. His understanding of early childhood education, service delivery systems, and the issues faced by families and the systems that support them, will bring critical experience to the table of these discussions



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**Maine Autism Connections**  
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Visit us online at:  
<http://www.asmonline.org>

Stay up-to-date for Legislation issues, fund-raising events, volunteer opportunities, and upcoming happenings.



<https://www.facebook.com/pages/Autism-Society-Of-Maine/107781499258293>



## President's Message

ASM has a lot to accomplish in the coming years and we look forward to working collaboratively with our legislative leaders, ASM membership, state and federal policy makers, advocacy groups, provider community and our community family organizations. Together, our collective voice, truly makes a difference in our state of Maine and on the national level. Please take the time to reach out to your representatives, letting them know your concerns and how they can best represent you---it really makes a difference!

As we wind down from the past year at ASM, we always do a year in review at our annual meeting. We spend this evening celebrating what we have accomplished and acknowledging the stars in our state that make a real difference.

Some of the Society's work this year includes:

Autism Society of Maine is one of 90 Affiliates of the Autism Society of America who are meeting or exceeding best practice standards in advocacy, increasing awareness and connecting individuals with services.

Our Society in Maine now has 33 Information Specialists across 13 counties. We continue to apply for grants to further grow this number because we know it is not enough.

ASM provided written and verbal testimony on 4 bills and followed another 44 bills.

Our ASM website had 90,217 hits this past year. 1,527 Calls

ASM fundraised over \$150,000 this year and ALL that money stays in Maine to support programs and services in our state. Services include lending library, information specialist program, family respite weekend, summer camp and trainings. This year we hosted our first annual fall conference in Orono. It is our intention to continue to offer this free conference, with a national speaker and vendors in the Bangor region each year.

*All the Best, Laurie*



## FREE CDC Milestone Tracker



Never miss a milestone moment with CDC's new **FREE app: Milestone Tracker**. Use a new, free, and parent-friendly app from the Centers for Disease Control and Prevention (CDC) to track and celebrate your young child's development from ages 2 months through 5 years, see photos and videos that illustrate milestones, try new activities to support your child's early development, get helpful reminders for appointments, and more!

Learn more and get a sneak peek at [www.cdc.gov/MilestoneTracker](http://www.cdc.gov/MilestoneTracker).

Editorial Notes: Maine Autism Connections and Autism Society of Maine programs and services are made possible by donations from people like you and funding from the Maine Department of Health & Human Services. We hope you will also visit us online at <http://www.asmonline.org>, where we have a great deal of information available about autism, programs, resources, news, a calendar of events, legislation and more.

## Future Newsletter Printings

The Autism Society of Maine will be going paperless for three of the newsletters starting in our next fiscal year. We will still publish 4 quarterly newsletters but only one will be printed for the spring 2019. All other editions will be available online. If you don't have any way to print or look at newsletter please contact us and we can get you a printed copy.



## Annual Appeal

For over 40 years the Autism Society of Maine (ASM) has been a much needed resource for children, families, individuals and professionals in Maine. One of the greatest challenges, and one of our most successful areas, has been reaching all Maine residents in need. ASM has many different programs which benefit families all over the state. The Autism Information Specialist Program, Lending Library, Family Retreat Weekend and Children's Summer Camp have all been great successes for everyone involved.

Unfortunately, like everything else; they require money to keep running. ASM holds fundraising events throughout the year to ensure that these programs continue to thrive.

Did you know?

- ASM fundraises for nearly half of their annual budget? Because of this, we rely on the generosity of our members and communities to help us keep these important programs running.
- It costs \$600 per child to attend Summer Camp? ASM pays for all who attend.
- \$150 could sponsor a family to attend our annual Family Retreat, giving some families the only vacation they will have?
- Donations that we receive can buy new books and research materials for our library, training materials for our Information Specialist Program, or may also be put into our Lynda Mazzola Scholarship Fund, helping to ensure that

her legacy lives on in future Speech Pathologists?

- ASM hosts a fall conference on autism which is FREE for all who attend?

We appeal to you to consider making a tax-deductible, direct donation to the Autism Society of Maine. A gift of \$15, \$25, \$50, or more will go a long way to help keep our programs up and running. No amount is too small and all donations mean so much to us and all the children, individuals and families in this state whose lives have been affected by autism.

Donations can be made on ASM's secure online donations page at [www.asmonline.org](http://www.asmonline.org) or by phone at

1-800-273-5200, you may also fill out the included form and mail your donation in the envelope provided.

Thank you for your generosity, it is greatly appreciated.



## How Can You Help?

Are you on our Volunteer List? Interested in Volunteering for a new Project? Would you donate a Day of your time? Actually, just a couple of hours, just for one event, just two or three times a year?

We are revamping the ASM Volunteer Program, we understand that we have not been efficiently utilizing our volunteers, and there has been a lack of communication, we are working very hard to change this. ASM is looking for trustworthy, caring, and dependable people to help at our events as well as behind the scenes. We depend greatly on our volunteers to assist us in our many events throughout the year. For more information on becoming a volunteer, or to request an application, email [tara@asmonline.org](mailto:tara@asmonline.org) or call ASM at 1-800-273-5200.

If you are already on our volunteer list, know that the 2 or 3 hours of time you donate two or three times a year make a big difference in the lives of families affected by autism. Thank you for all that you do in sharing the precious gift of your time.

# ASM Annual Meeting

The Autism Society of Maine's Annual Meeting was held on October 6, 2017 at the Augusta Country Club in Manchester, ME.

The Autism Society of Maine (ASM) Board of Directors welcomes newly elected board member Jonathan Youde. Mr. Youde graduated from the University of Maine at Augusta and earned a Bachelor's Degree in Public Administration.

**Board members re-elected:** Katie Crowley, Sherry Pike, Nancy Ponzetti-Dyer, Chris Osgood, Brigid Rankowski, Tiffany Rooney and Terri Valcourt.

**Board members whose terms of service have finished:** Melody Altschuler, Kerrie Moody, and Sarah Tacket-Nelson.

**Guest speaker Senator Shenna Bellows** presented to members and guests about importance of community outreach to representatives and best practice.

- Ken Huhn, Treasurer, provided ASM's financial report of the year
- Cathy E. Dionne, Executive Director, presented ASM's yearly fundraisers and activities in the community.
- Dennise Whitley, Legislation Liaison, provided ASM's annual legislation report.
- Laurie Raymond, President, Led the awards ceremony.

**A scholarship is given annually in memory of Lynda J. Mazzola**, founding member of the Autism Society of Maine. It is awarded to a Maine student who has completed a bachelor's degree, or is soon to graduate and has been accepted to a master's or doctoral degree program in speech and language pathology or occupational therapy.

**Lauren Doak was acknowledged as recipient of this year's scholarship fund.** Lauren attends the University of New Hampshire, Communications Sciences and Disorders Master's Program. In addition, Lauren is a dedicated volunteer in the community engaging with children with autism.

**Autism Society of Maine Professional Providing Services Award** was presented to

Dr. Kathryn M. Loukas for her dedication as a LEND Training

Director (Leadership, Education in Neurodevelopmental Disorders) at the University of New England.

The LEND program has opened doors to meeting the occupational needs of the community.

**Autism Society of Maine Service Award** was presented by Dr. Nancy Ponzietti-Dyer, ASM Vice President to Dr. Stephen Meister, Dr. Amy Belisle and Nancy Cronin, MA, for their combined efforts in early identification and referral for children impacted by autism.

Their contributions directly impacted the developmental screening rates (calculated by MaineCare) that nearly tripled for children age one, rose more than seven times for children age two, and nearly doubled for children aged three in Maine.



Left: Laurie Raymond, ASM President and Dr. Kathryn M. Loukas  
Right: Dr. Nancy Ponzietti-Dyer, ASM Vice President, Dr. Stephen Meister, Dr. Amy Belisle, Nancy Cronin, MA, and Dr. Kathryn M. Loukas



Left to right: Cathy Dionne, Executive Director, Susan Vincent, Communications Director, Tara Perry, Office Assistant, Tena Hinds, AIS Coordinator, Dennise Whitley, Legislation Liaison

## ASM on Social Media!

The Autism Society of Maine has a wonderful Facebook Community including parents, professionals, individuals and anyone interested in autism. If you are not already a friend of our Facebook page, we welcome you to join us!

By "liking" ASM's Facebook page you can help us spread the word to hundreds of new supporters!



<https://www.facebook.com/pages/Autism-Society-Of-Maine/107781499258293>



We have a great collection of videos and will be adding more throughout the year!

<https://www.youtube.com/user/AutismSocietyofME>



Follow us on Twitter as we 'tweet' about autism!

<https://twitter.com/autismsocietyme>



My Autism Team logo A reputable and friendly place to connect with other parents in Maine.

<http://www.myautismteam.com/>

# Fall Autism Conference

By Tena Hinds

Q. What do some committed, passionate caregivers do on a beautiful November Saturday in Maine, after a stressful week of state wide power outages? A. They gather at a conference center, in Orono, to learn how they can better meet the needs of individuals on the Autism Spectrum!

On Saturday, November 4th, 200 people attended what ASM hopes to become an annual “Autism Conference” addressing topics that impact individuals with ASD. Caregivers, professionals, educators, as well as individuals came together for a full day of learning and information gathering. We want to thank all of you that took time out of your weekend to attend. We want to also thank our speakers: Jed Baker, Matt Brown, Carla Tanguay, Connor Archer and Libby Stone- Sterling. After months of planning it was a joy to see all the participants engaged and identifying supports amongst each other, and with local agencies, businesses and organizations.

This year we were so fortunate to have Dr. Jed Baker, an international speaker on the topic of social skills and managing challenging behaviors, join us for an amazing morning keynote. His message described how caregivers can best think about difficult moments, remembering that these moments are “temporary”, not “forever”, and how maintaining “HOPE” leads to better outcomes. He supplied his audience with ways to think about behaviors, and many tools to help manage challenges. His sense of humor and ability to personalize his message had participants fully engaged.

4 Breakout sessions followed, providing participants an opportunity to hear others speak on different topics:

Connor Archer developer of the non profit organization: “The Courageous Steps Project” is devoted to helping children and young adults with developmental challenges. Through their mission and vision statement, they are committed to raising awareness of developmental challenges, and channeling resources to programs that help individuals in school and life. Through his speaking engagements, Connor works to engage the audience by providing personal experiences that impact adults and children in our society. His “Can do” message was applauded by all.

Matt Brown, a retired probation officer described Autism Spectrum Disorders, with a special emphasis on those characteristics and challenges unique to this population can create crisis situations in almost any setting. He explored prevention and response to meltdowns and discussed the importance of implementing individualized safety plans in collaboration with local law enforcement and other first responder agencies. Matt’s passion for this problem is evident as he shared personal experiences and offered insight into how communities can better equip themselves for a potential crisis situations.



Carla Tanguay, a Music Therapist uses music to help improve communication, social skills, emotional expression, motor skills and auditory processing. This presentation demonstrated how music can be an effective treatment method for people with ASD. She engaged the audience as she used different instruments to demonstrate how to work on skills such as: turn taking, waiting, fine motor, gross motor, academic skills and more. Who knew music could be a tool to improve basic skills?

Libby Stone- Sterling, despite some significant Audio- Visual problems, persevered and captivated her audience with a discussion focused on new opportunities for pre-employment transition services available through the Division of Vocational Rehabilitation (DVR) and shared examples of partnerships (with schools, employers and organizations) that are occurring around the state to help young people gain the vocational and soft skills needed for employment. Questions and Answers were beneficial to all.

*“Thank you for this wonderful opportunity.”*

*“The sessions I attended were all valuable.”*

*“Dr. Baker gave some great information and did so in a very engaging way.”*

*“Make it 2 days next year.”*

*“Will use the information I gained in my classroom on Monday.”*

We had 14 vendor tables that helped to support this event.

Special thanks goes to our Silver level sponsor Developmental Disabilities Council and Bronze level sponsors Catholic Charities, Spurwink, and Maine Cite. Two grants were received for the conference from The Penobscot Foundation for Developmental Services and The Hussman Foundation. Without this support we could not offer a free conference.

# Upcoming Events

## 16th Annual Walk for Autism

April 29, 2018

11:00 am Registration starts

12:00 noon Walk for Autism starts

Registration is Open! Start Your Team!

<http://www.firstgiving.com/ASMMaine/walk-for-autism-2018>

5 locations: Bangor, Biddeford, Belfast, Farmington, Fryeburg, NEW site Portland!

Each site is slightly different, from Farmington's petting zoo to Bangor's Ice Cream Truck, there is guaranteed to be something for everyone! There will be local vendors, balloons, face painting, snacks, and plenty of fun for all! Be part of a team, family, school, agency, or.. just come by yourself to support someone with autism.

## 6th Softball Tournament for Autism

June 23, 2018

9:00 am to 7:00 pm

Union Street Athletic Complex, Bangor

This is a Co-Ed Softball Tournament for Autism. If you love softball and want to raise money to help support our programs, this is the tournament for you. Each team needs at least 10 players with a maximum of 13 and a team captain. Prizes are awarded to the team that wins the tournament, and also the team that raises the most money. This can be done by asking businesses to sponsor you or your team, or by asking friends and family to donate. Each corporate

sponsor, depending on the level they sponsor, will be offered advertisement, and the team will get the credit. The corporate sponsorship can also be put towards the \$250 team entry fee. There are also plenty of raffles to be won!

For more information please contact ASM at  
1-800-273-5200

## Teen Social Group

WHEN: Friday December 15th at 6:00 pm to 8:00 pm

WHERE: Autism Society of Maine, 72B Main Street, Winthrop

### Requirements for the Youth Group:

Youth must be between the ages of 11-18 years

Youth must have a diagnosis of Autism Spectrum Disorder

Youth must be willing to verbally communicate with others to get the most benefit out of the group

Youth must have a responsible adult with them when attending group or events

All electronics (cell phones, iPods, Game Boys, DS games, laptops, etc) must be left at home. Please DO NOT bring them to group.

### NEW to the group:

Please call the office prior to attending for first time. We would like to find out more about the teen and provide you with information about the group.

If you have questions please feel free to contact Cathy at [asm@asmonline.org](mailto:asm@asmonline.org) or 1-800-273-5200

## Legislative Update

### A New Way To Contact Our Congressional Delegation.

As we all know, the best way to influence our members of congress is to contact them by letter, by phone or email and tell them how we feel about an issue and how we would like them to represent us. Now there is a new way to communicate with our elected officials through our cell phones. It's through a program called "Resistbot." and you can have your voice heard in Congress in less than 5 minutes. Just text "resist" to 50409.

Resistbot will ask for your name and information to find your elected officials. Your representatives will know you're a constituent—that's who matters to them. The following information is from the Resistbot website:

How does it work? Resistbot, a free service that turns texts into faxes that are then sent to politicians across the country in the simplest and easiest way possible. The people who manage Resistbot are working hard behind the scenes to make sure that the messages are delivered and that your representatives take them seriously.

### *By Dennise Whitley, ASM's Legislative Liaison*

Will my message really count? Yes! There's a lot of information floating around saying that only certain ways of speaking up really count. We've confirmed that Resistbot messages are received and read by actual Congressional staffers.

What happens after I send my message? Resistbot starts simple, with just your two Senators. Over time, it will ask you for more information so it can do a better job representing you, including in the House of Representatives.

Does Resistbot tell me what to say? Unlike a lot of other tools, Resistbot doesn't tell you what to say. Our research shows that form letters are totally ignored by Congress. Only original, unique messages count. But they don't have to be complicated or fancy. Just a few sentences from a real-life voter gets their attention. Don't worry about typos or mistakes, that just proves you're a real person.

Can I send more than one message? You sure can. Just text "Resist" to the bot at any time. Give it a try!

# 2017 Ride for Autism

By Tara Perry

On Saturday September 23, The Autism Society of Maine held their 11th annual Ride for Autism at the beautiful Conservation Trust Building in Kennebunkport. We could not have asked for a better day! The weather was sunny and the temps were perfect. All the riders had the option of riding a 10, 25 or 50 mile loop, taking advantage of the beautiful coastal scenery our state offers. The riders returned to the Trust to enjoy some delicious pulled chicken sandwiches, pasta salad, and homemade beans prepared and served by equally wonderful volunteers. After a delicious lunch, this year's top fundraisers were announced. The first place prize for individual fundraising, Patriots and beer package (\$450 value), was won by Conrad Sastre (\$1,475). The second place prize (\$350 value) was won by LuAnn Littlefield (\$1,145) and the third place prize (\$250 value) went to Dan Butler (\$830)

The Ride for Autism was started because of an amazing young man named Marston Poore, this year he joined his dad to draw the winning raffle ticket for the brand new bike donated by Kennebec Bicycle Company. (This opportunity goes to anyone who raises \$100 or more.) This year's lucky recipient worked so hard to raise as much money as he possibly could for his team, it seemed only fitting that the winning ticket that Mason pulled belonged to his cousin, Garrett Dupee! We hope you are enjoying your new ride Garrett. Also recognized were the top fundraising teams Team Marston, Team Abby, and Butler Biking Buddies. Congratulations to all! Because

of the dedication and fundraising efforts we were able to raise over \$21,000! This money will help us continue supporting programs to benefit children, individuals, and families touched by autism. Great job and thank you to everyone who rode and donated.

We would also like to thank our Silver Sponsors, Bull Run Striping and The Pine Tree Society, your generosity is greatly appreciated. A big shout out to all of our sponsors and volunteers for your hard work and generosity as well. Its people like you who make this event possible. Be sure to check back with us for the date for next year's ride! We look forward to seeing you all!



By Deb Lipsky

While at Crawford Notch at the Appalachian Mountain Trail gift shop I spotted a book on hikes for seniors. In that moment it became the perfect solution for losing those stubborn pounds that clung to my waist and hips like barnacles on a boat's bottom (and mine). Admittedly I am not in the best of shape and never really hiked a day in my life, but by AARP standards at 56 years old I am considered a senior. My current hiking experience revolves around walking from my handicap spot at Walmart to the sporting goods section in the back of the store. Since the book is tailored for people in their "golden years", I felt sure this would be a walk in the park for me (pun intended).

Eager to take a hike I started reading, but the 1st half of the book profiled hikers in their 80's with impressive credentials like hiking Mt. Kilimanjaro, the Swiss Alps, Nepal, and the Rockies. Since I don't read biographies (nothing factual of personal interest to me) I skipped that part. I totally missed the clue that these seniors were lifelong hardcore hikers and obviously not part of the church suppers and BINGO persuasion. The next part of the book talked about dealing with arthritis and hip/knee replacements and getting in shape with exercises, but the photos depicted a very 30 something year old woman and man contorting their bodies into weird positions under the guise of an exercise regime. It's been decades since I was limber enough to attempt such unnatural body positions without the help of a chiropractor. I decided to skip this part too (it wasn't very senior friendly) and get right into the suggested hikes section.

I chose Arethusa Falls in N.H. Because the difficulty level according to the book classified it as an "easy" hike. My 75 year old friend Sister Francanne asked to come along as she loves nature walks and her hiking experience was close to mine. It was only 1.4 miles to the fall with an elevation of 2000 feet. My 1st mistake was that my math translated the 1.4 miles into 1 mile and 4 steps. While 1 mile and 4 steps didn't seem that long I completely forgot to calculate the return trek distance (also 1.4 miles) and worse yet, it wasn't 4 steps but almost another ½ mile!! So the entire hike was almost 3 miles long!! On top of that the book stated a vertical climb of 900' over 1 mile. Not being a hiker I had no clue what that meant, but I felt if the 75+ year old crowd weren't concerned over this than neither should I. 900' vertical climb turns out is very vertical!

Clad in my jeans, T-shirt, Timberline boots, and walking stick, I considered the walk from across the parking area to the start of the path as my "warm up" exercises. Right from the start the hike was up hill over some really tough rocky terrain. It was very uninviting towards seniors but surely the path would level and smooth out as we went further. The ascent however got steeper and jagged. We began climbing over boulders on our hands and knees huffing and puffing ourselves into exhaustion. Still hanging on to the illusion that the path would level and smooth out, we ventured on. I was hoping to see a senior

(which I didn't) with a cane or walker so I could ask them what the trick was in navigating the steep difficult trail. Frequently (like every 10 steps or so) we plopped ourselves down on the rock outcroppings to catch our breath and salvage our dignity. Other climbers zoomed past us as if we were a broken down sedan in the breakdown lane of a very busy freeway. To add insult to injury I watched a fair share of hikers obviously in their 70's waltz by us in their North Face attire complete with L.L. Bean accoutrements and a Larabar snack bar in their hand.

Just as I was contemplating quitting and heading back, I received encouragements to forge on from the returning hikers who said the view was spectacular and a once in a lifetime experience. One "senior" hiker had these amazing powers of being able to talk while bounding over the huge rocks without being out of breath. He even asked (as he flew by me) if I was enjoying the beauty around us, to which I replied, "Yes this is an enjoyable place to drop dead from exertion."

My friend and I forged ahead on this extremely arduous climb up the side of the mountain. While every muscle in my body pleaded for mercy, it was the vision of a spectacular waterfall that motivated us forward. At one point I felt I hit the lottery when I sat on a very large rotting moss covered log. Sinking into the heart of it, heavens, it felt like a plush recliner. That would become the most enjoyable memory of the trip. I can only imagine what a sight it must have been to see a 75 year old nun wearing her black habit trying to hoist up with great difficulty a beached whale off the plush mossy covered log. With only 1 bottle of water between us I was hit with an epiphany....nowhere in the book did I read the word "beginner level".

Anyway, like a child who constantly asks, "are we there yet", I asked descending climbers we met on the "path" (trail would have been too kind of a description for the gateway of hell we were on) to be specific on how much farther the Falls were. Their generic reply of "not much farther" or "up a little ways" didn't go far in satisfying my autistic need for clarity, but a joint decision to forge ahead was made. Despite all odds we did reach the Falls. I guess the Kodak moment would have been the expression on my face.



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# SPARK NNE Update

SPARK Northern New England, a research partnership between Maine Medical Center Research Institute/Maine Behavioral Healthcare and the Simons Foundation Autism Research Initiative, began recruiting Mainers in April 2017. Since then, the research team has travelled the state sharing information about this landmark study. We have enrolled participants as far south as York and as far north as Madawaska. The people who have taken the time to participate in SPARK so far are shaping the future of autism research.

Many readers have wondered what SPARK has learned to date. Each one of our participants contributes to our understanding of autism. As of now, about 50 genes are associated with autism, but researchers suspect that countless more may be involved. SPARK aims to accelerate this process of discovery. Only 16.6% of our participants report undergoing genetic testing related to autism before joining SPARK. Now, less than two years after SPARK's inception, 18,089 individuals with autism are participating in this groundbreaking genetic study.

We have already accumulated a great deal of information about our participants. There is a 4:1 ratio of male to female participants under 18, which is consistent with figures reported in other autism studies. This indicates that SPARK is starting to develop an accurate picture of families affected by autism. Among adults, the ratio of males to females is 2:1, which is higher than expected based on national averages. We have also learned that, on average, individuals born before the year 2000 were diagnosed with autism 10 years later (age 14 for males and 15.8 for females) than



*By Maggie Foster & Ellyn Touchette, Research Assistants*

younger participants. Additionally, 87% of our participants are verbal to some degree, and 58% are able to use long and complex sentences. Of all individuals with autism enrolled, 15,302 are children and only 2,787 are adults.

We have also learned about the mental health challenges faced by our participants. Adults in SPARK report dealing with anxiety and depression twice as frequently as adults in the general population. Meanwhile, children in SPARK are 3 times more likely than their peers to be diagnosed with ADHD. The more we learn about how these difficulties are related, the better we can support our family members and friends with autism. At this stage, we urge more adults, females, and nonverbal individuals to get involved, so that we may continue to broaden our overarching knowledge of autism in all its diverse forms. Each individual with autism presents differently, and we are optimistic that SPARK will add to a growing knowledge base about how to treat the individual, rather than the disorder.

SPARK is an on-line study that can be done from the comfort of your home. Participants will have access to research findings and experts in the field via the website. Individuals with autism will receive a gift card valued at up to \$50.00 once registration is complete. SPARK participants may also be re-contacted for future studies to help speed up autism research! Our research team is available to answer questions, assist with any challenges, and to schedule in-person support for any step of the process. We look forward to hearing from you!

SPARK NNE Website:

[www.sparkforautism.org/mainemedicalcenter](http://www.sparkforautism.org/mainemedicalcenter)

Phone: 207 661-7620

Email: [sparknne@mmc.org](mailto:sparknne@mmc.org)

## Donations

### In Memory of:

Harold "Chappy" Chapman- Louise Chapman

### Donations/Sponsorships/Employee Matches/Grants

Bull Run Striping

Diversified Communications

Maranacook Family Health Care

Sanford Lodge of Elks

Carrie Sayward

Katahdin Trust Company

Ivy Jordan

Chris Day- Texas Instruments

Sue & John Morton

Epsilon Chapter of Delta Kappa Gamma Society

Warsaw Middle School

Gigi & Corey McAllister

Magarita's/Dave Groder

Terri & Anthony Dostanko

Richard & Wendy Humphrey

Ryan Pitkin

## Go Take a Hike (continued from 8)

Expecting a spectacular mind blowing cascading waterfall vista, all that came over the edge was barely a trickle. I was stunned speechless. The photo in book (which stipulated it was taken in summer) depicted a powerful forceful wall of water rushing over the edge. I could have stayed home and turned on my shower to a trickle and gotten the same result!! My turned on shower head would have been more "majestic" and forceful than that waterfall! Having to repeat the "hike" now in reverse, you could say I "walked away" from the experience slightly aged, and aching all over. At least I know I am going to make it to the senior years because that hike was a free cardio stress test which didn't kill me physically (mentally however it came darn close).

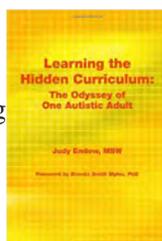
# Welcome to the Autism Society of Maine Library!



ASM's Lending Library is a valuable and free resource for parents, caregivers, educators, children and professionals working with children and adults on the autism spectrum. The Lending Library is a FREE resource for Maine residents. The collection can be viewed on the ASM website or you may request a printed list to be mailed to you. Stop by the office, or have material sent to you (we will include return shipping label) by calling or emailing: 1-800-273-5200 email: library@asmonline.org Online library page: [www.asmonline.org/library.asp](http://www.asmonline.org/library.asp)

## Learning the Hidden Curriculum: The Odyssey of One Autistic Adult *By Judy Endow, MSW*

This book provides readers with a perspective that is critical to anyone working with, caring for, or educating person with autism. This book is designed to teach adults with ASD positive strategies to help guide them through an everchanging, confusing social world.



## Ellie Bean the Drama Queen *By Jennie Harding*

This book offers insights into Ellie's "dramatic" behaviors and provides easy sensory answers for parents and teachers alike. Written by a mom and special education teacher, Ellie's story brings home what its like to grow up with sensory issues and helps a child to understand that he or she is not alone.



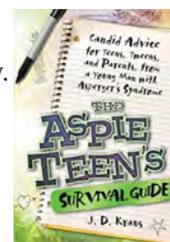
## No More Chasing "Normal" The Emotional Survival Guide for Parents of Children with Disabilities *By Loresa Stansell, LPC*

This book provides an in-depth look at the emotional impacts faced by parents of children with disabilities. This is the stuff your research doesn't tell you.



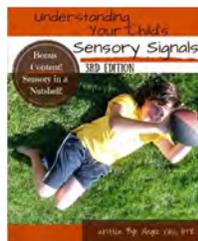
## The Aspie Teen Survival Guide *By J.D. Kraus*

The author offers practical advice to his peers so they can get the most out of middle school and high school both academically and socially. From sensory sensitivity to awkwardness, dating to driving, he tackles it all! Parents and Teachers will love seeing life through J.D.'s eyes, plus "Notes to Parents" sections offer great advice for caregivers and educators alike.



## Understanding Your Child's Sensory Signals 3rd Edition *By Angie Voss, OTR*

This book is for practical, daily use, created and intended to support and guide you in understanding your child's sensory difference and needs. Over 200 of the most common sensory signals and cues with an explanation and ideas to help! This is a great resource for parents, teachers, family members and caregivers.



## Superflex- A Superhero Social Thinking Curriculum *By Stephanie Madrigal*

Superflex: A Superhero Social Thinking Curriculum provides educators, parents and therapists fun and motivating ways to teach students with Asperger Syndrome, high-functioning autism, ADHD and other diagnosed and undiagnosed social difficulties how to build social thinking skills. Superflex combines a book, comic book and CD to create a curriculum that develops in each student's brain their own superheroic thinking processes that can overcome the challenges in different social situations that arrive across the school and home day. The curriculum works best with elementary school children (grades K-5) as well as with immature older students who respond to visual books.



## Life on the Autism Spectrum A Guide for Girls and Women *By Karen McGibbon forward by Tony Atwood*

Why is Autism Spectrum Disorder so misunderstood in girls and women and why do so many go under the radar without the support that they need? This practical guide explains the unique issues that affect females with autism and provides tools and strategies that girls, women and their families can use in day-to-day life.





You may purchase these and more items on the ASM website at:  
<http://www.asmonline.org/asm-storefront.aspx>  
 or call 1-800-273-5200.

Adult Coloring Book  
 (60 pages)

"Color Up the Spectrum" by  
 Heather Down

\$10.00



Autism Awareness Lanyard  
**\$6.00**



**\$8.00**



**\$9.00**



**\$9.00**

Silicone Chew Necklaces  
 All necklaces are 24" in length and have a break-away clasp and are made of 100% food grade silicone – Assorted Colors : Call ASM to request specific color

**ELEPHANT**  
 3" x 2 3/4" Pendant (hole size is 1/8")  
**ROUND**  
 2" Pendant (hole size is 1/2")  
**TEAR DROP**  
 2" x 3"  
**OWL**  
 3" x 3" Pendant



**\*NEW\***

**Puzzle Galore Folding Tote Bag NEW!!**

Colorful puzzle hearts decorate our chic lightweight tote, accented with faux-leather details. The bag neatly folds in a snap for easy storage. Nylon & faux leather, Zippered and snap closure, Interior zippered pocket, 15" H x 17" W x 3.5" D (38.1 x 43.2 x 9 cm)

**Folded: 7.5" x 5" (19 x 12.7 cm)**

**\$16.00**



Hand crafted Dichroic Glass Pendant with Sterling Silver Plated bail (includes black silk cord); 5/8" x 7/8" random design and color

**\$10.00**



**\$8.00**



Autism Awareness Mug (red) features words: "Embracing the Amazing" porcelain (do not microwave – hand wash)  
**\$11.00**



Multicolored Puzzle Piece Heart Hanging Charm  
 1" x 1" and Sterling Silver plated  
**\$3.00**



Big Heart Autism Ribbon Key Chain  
 1.5" x 1.5" and comes in embossed gift box. Sterling Silver plated  
**\$6.00**



**Walk for Autism T-Shirt**  
 Special 15th Anniversary Design, size large or x-large  
**\$10.00**



Silver Cuff Bracelet  
 Puzzle piece design cuff bracelet  
 Sterling silver plated 7" and flexible for fit (gift box included)  
**\$10.00**



Puzzle Piece Car Magnet  
 4" x 8" **\$6.00**



Autism Stretch Bracelet  
 Sterling Silver plated  
**\$4.00**



Gel Autism Awareness Bracelet  
**\$3.00**



Autism Touches Us All Hanging Charm  
 1" x 1" and Sterling Silver plated  
**\$3.00**



Autism Ribbon Earrings  
 Sterling Silver plated  
 Includes Embossed Gift Box  
**\$8.00**



Hand Crafted Dichroic Glass Earrings  
 Sterling silver plated wire fish hooks; 5/8" x 7/8" random design & color  
**\$15.00**



Autism Ribbon Keychain  
**\$5.00**



Autism Awareness Magnet  
 8" x 3.5"  
**\$5.00**



Mini Magnet  
 2" x 4"  
**\$3.00**



Autism Awareness Lapel Pin  
**\$5.00**

# Happy Holidays

By Susan J. Vincent

**The end-of-year has snuck upon us once again!** The holidays are just around the corner with Jack Frost nipping at our nose! We know you're busy, but it's nice to take some time out for activities that the family will enjoy, maybe with a craft or baking adorable melting snowman cookies (shown). You can see more crafts, gift ideas, and strategies and tips on the ASM website

holiday page: <http://www.asmonline.org/News/107/Article/7225/>

*All of us at the Autism Society of Maine wish you and your families*

*Happy Holidays and a happy New Year!*



## Melted Snowman Sugar Cookies

*(This is a Betty Crocker™ recipe and you can use their ingredients as suggested in directions or you can get creative and use your own sugar cookie recipe as well as decorative icing!)*

### Ingredients

- 1 pouch Betty Crocker™ Sugar Cookie
- 1 pouch each Betty Crocker™ Cookie Icing in white, red, blue, and green
- 1 tube Betty Crocker™ black Decorating Gel
- 1 pouch Betty Crocker™ Candy Shop decors rainbow chips
- 1 bottle Betty Crocker™ Chocolate Sprinkles
- 12 marshmallows

### Steps

1. Follow baking directions on sugar cookie pouch, dividing dough evenly into 12 round cookies.
2. On cooled cookies, draw a "snow puddle" with Betty Crocker™ White Cookie Icing.  
TIP: Draw the outline of the puddle, then go back and fill in the shape.
3. While the icing is still wet, immediately place a marshmallow to one side of the cookie.
4. **MAKE THE ARMS:** Once the icing and marshmallow have set, pipe two "branches" onto each cookie using black gel. Add fingers with chocolate sprinkles.
5. **MAKE THE FACE:** Using a small dot of white cookie icing, stick two "coal" eyes and a nose onto the marshmallow with Rainbow Chips. Pipe a small dot for the mouth with black gel.
6. **MAKE THE SCARF AND BUTTONS:** Using blue, red, or green cookie icing; carefully draw scarves around the base of the marshmallow. Using a small dot of white cookie icing, stick three "coal" buttons beneath the scarf with Rainbow Chips.
7. Allow cookies to set for at least one hour before serving.

Betty Crocker™ cookie recipe:

[www.bettycrocker.com/recipes/melted-snowman-sugar-cookies/91c4a274-78a1-4cba-b890-52563d6cd670](http://www.bettycrocker.com/recipes/melted-snowman-sugar-cookies/91c4a274-78a1-4cba-b890-52563d6cd670)

## Playdough Holiday Tree

Break out the playdough and some beads, buttons and sequins to make a holiday tree! You can make your own play dough (and even add a scent) or use a store brand.



<http://countingcoconuts.blogspot.com.au/2010/12/december-sensory-tub-playdough.html>

## Sensory Bin

A sensory bin can be made from whatever you like and does not cost much, if anything at all!

Add rice, corn kernels, dried beans or peas in a plastic bin and tuck in a few items. Also, add a cup or spoon for scooping and pouring.

<http://countingcoconuts.blogspot.com.au/2010/12/december-sensory-tub-playdough.html>



## Gingerbread Play Dough

- 1 cup all purpose flour
- 1/2 cup salt
- 2 tsp. cream of tartar
- 1 tbsp. ground cinnamon
- 2 tsp. ground ginger
- 1 tsp. ground nutmeg
- 1 tsp. ground cloves
- 2 tbsp. canola oil
- 1 cup water

In a medium saucepan

whisk together dry ingredients. Next mix in the water and oil. Stir until a thick batter is formed. Cook the mixture over med-low heat until a thick dough forms. Turn out onto parchment paper and knead until smooth. Makes about 2 cups of dough.



[www.benandme.com](http://www.benandme.com)

# Autism and the Holidays - Sensory Overload

*Bradley Hospital Center for Autism and Developmental Disabilities  
www.bradleyhospital.org/autism-and-holidays-sensory-overload*

The hustle and bustle of the holidays can be especially stressful for children who have autism. From last-minute shopping trips to holiday parties and family gatherings, the holiday season is often a stressful time for parents. But for children with autism spectrum disorder who rely on structure and routine, the hustle and bustle of the holidays can be extremely unsettling.

**The following tips can make the holidays more fun for everyone involved:**

## **Visiting**

If you will be visiting relatives or friends, let the child know in advance where you are going, who will be there when you arrive, what you will do when you are there and the time you plan to arrive and leave. Follow the same protocol if relatives or friends will be visiting your home. Parents may also want to ensure that a quiet area has been identified where the child with autism can go and relax if the activities become too overwhelming.

## **Holiday shopping**

Holiday shopping with a child who has autism spectrum disorder may present its own set of challenges, especially when the stores are crowded and noisy. Make a list that identifies the items you're shopping for and do not roam the stores trying to decide what to buy. Keeping the trip short and being organized will help minimize the potential for the child to become overwhelmed and have a "meltdown" in the middle of a store.

## **Decorations**

Holiday decorations inside the house - including bright and blinking lights, wreaths, trees, candles and stacks of presents - could be areas of concern. Parents know best what their child with autism enjoys and at what point things may become overwhelming. However, parents should not expect that their child has a higher tolerance simply because it's the holiday season.

## **Preparing siblings**

Since the holidays are a time for the whole family to enjoy, it's important to make siblings aware of how stressful this season can be for their brother or sister with autism. Before the holiday season begins, take the time to remind children of their sibling's sensory issues, communication difficulties, low frustration tolerance and likes and dislikes. Parents can then share the family's strategy for avoiding potential issues and discuss what they will do if their best efforts are unsuccessful.

We often put pressure on ourselves to make the holidays perfect, which is unrealistic. In the end, the most important thing to remember is that the holidays are a time to cherish one another and the joy of being together. Whether it's scaling back or starting new traditions, celebrate in a way that makes the most sense for your family and is something that you, your child and the entire family will all enjoy.





## **Support our Services: Give to the Autism Society of Maine!**

The Autism Society of Maine is a statewide nonprofit organization that for over 36 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 fund-raisers 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](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](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 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](http://www.asmonline.org/involved_donations_united_way.asp)
- Host a fund-raiser with proceeds going to ASM. Some of the past and current fund-raisers have included: Avon, Pampered Chef parties, Mary Kay parties, bake sales at events, selling autism awareness items at conferences or craft events, selling holiday wreaths, selling T-shirts. If any of these fund-raisers interest you, please call us for more information.

### **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](http://www.asmonline.org/involved_joinasm.asp)  
or call ASM at 1-800-273-5200

For other ways to contribute, contact us at [asm@asmonline.org](mailto:asm@asmonline.org). Thank you for supporting our mission!

**Call us at: 1-800-273-5200 or visit us online at [www.asmonline.org](http://www.asmonline.org)**