AAoM Mission

OUR MISSION

The mission of Autism Alliance of Michigan is to lead collaborative efforts across the state that will improve the quality of life for individuals with autism through education, comprehensive services, community awareness, inclusion efforts, and coordinated advocacy.

HOW WE INVEST IN THE MISSION

The Autism Alliance of Michigan (AAoM) is leading efforts to make Michigan a better place to live for people with autism and their families. Our impact on families, communities, lawmakers, and service providers is not possible without the generous support of our corporate, foundation, and individual donors.
Research has found that Autism Spectrum Disorder (ASD) can be detected as early as 18 months or younger. By age 2, a diagnosis by an experienced clinician can be considered very reliable. However, many children do not receive a diagnosis until they are much older. This delay means children with ASD may not get the help that they need during their early years, which has been deemed so effective.

The earlier ASD is diagnosed, the earlier treatment can begin. Screening tools are designed to help identify children who might have developmental delays. Screening tools do not provide conclusive evidence and do not result in a diagnosis. A positive developmental screening result for autism should be followed up with a referral to a developmental specialist, psychologist or autism evaluation center.

**Types of Screening Tools**

The American Academy of Pediatrics (AAP) recommends that all children receive autism-specific screening at 18 and 24 months of age, in addition to broad developmental screening at 9, 18, and 24 months.

There are many different developmental screening tools that may be administered by professionals, community service providers, and in some cases, parents. Examples of screening tools include:

- Ages and Stages Questionnaire (ASQ)
- Communication and Symbolic Behavior Scales (CSBS)
- Parents Evaluation of Developmental Status (PEDS)
- Checklist for Autism in Toddlers (CHAT)
- Modified Checklist for Autism in Toddlers- Revised (M-CHAT-R)
- Pervasive Developmental Disorder Screening Test II (PDD ST II)
- Screening Tool for Autism in Toddlers and Young Children (STAT)

This list is not exhaustive, and other screening tests are available.
At 18 months does your child...

- Look and point when he wants to show you something?
- Look when you point to something?
- Use imagination and pretend play?

If the answer is NO the child may be at risk for autism.

These items are based on the M-CHAT-R (Checklist for Autism in Toddlers) and should be asked of parents at well child visits.

Recent research has identified 5 signs of autism in young children:

### The Five Early Signs of Autism in Infants

1. **Unusual visual fixations.** Unusually strong and persistent examination of objects.
2. **Abnormal repetitive behaviors.** Spending unusually long periods of time repeating an action, such as looking at their hands or rolling an object.
3. **Lack of age-appropriate sound development.** Delayed development of vowel sounds, such as “ma ma, da da; ta ta.”
4. **Delayed intentional communication.** Neutral facial tones and decreased efforts to gesture and gain parent attention.
5. **Decreased interest in interaction.** Greater interest in objects than people and difficult to sustain face-to-face interactions.

### Las Cinco Primeras Señales de Autismo en Infantes

1. **Fijaciones visuales inusuales.** Cuando un infante examina los objetos de una manera intensa y persistente.
2. **Los comportamientos repetitivos y anormales.** Cuando un infante repite la misma acción por mucho tiempo. Por ejemplo: Mirando a sus manos o haciendo rodar un objeto.
3. **La falta de desarrollo de ciertos sonidos cuando habla.** Cuando un infante tiene un retraso en los sonidos vocales, como “ma ma” o “da da.”
4. **Un retraso en la comunicación intencional.** Cuando un infante tiene una expresión facial que permanece neutral y no trata de hacer gestos o llamar atención de sus padres.
5. **No quiere interrelacionarse con otros.** Cuando un infante prefiere más jugar con objetos que con otras personas. Cuando un infante tiene dificultades para mantener interacciones cara a cara.
M-CHAT-R™ (Modified Checklist for Autism in Toddlers Revised)

Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer no.

1. If you point at something across the room, does your child look at it? (FOR EXAMPLE, if you point at a toy or an animal, does your child look at the toy or animal?) Yes No
2. Have you ever wondered if your child might be deaf? Yes No
3. Does your child play pretend or make-believe? (FOR EXAMPLE, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?) Yes No
4. Does your child like climbing on things? (FOR EXAMPLE, furniture, playground equipment, or stairs) Yes No
5. Does your child make unusual finger movements near his or her eyes? (FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?) Yes No
6. Does your child point with one finger to ask for something or to get help? (FOR EXAMPLE, pointing to a snack or toy that is out of reach) Yes No
7. Does your child point with one finger to show you something interesting? (FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road) Yes No
8. Is your child interested in other children? (FOR EXAMPLE, does your child watch other children, smile at them, or go to them?) Yes No
9. Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (FOR EXAMPLE, showing you a flower, a stuffed animal, or a toy truck) Yes No
10. Does your child respond when you call his or her name? (FOR EXAMPLE, does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?) Yes No
11. When you smile at your child, does he or she smile back at you? Yes No
12. Does your child get upset by everyday noises? (FOR EXAMPLE, does your child scream or cry to noise such as a vacuum cleaner or loud music?) Yes No
13. Does your child walk? Yes No
14. Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her? Yes No
15. Does your child try to copy what you do? (FOR EXAMPLE, wave bye-bye, clap, or make a funny noise when you do) Yes No
16. If you turn your head to look at something, does your child look around to see what you are looking at? Yes No
17. Does your child try to get you to watch him or her? (FOR EXAMPLE, does your child look at you for praise, or say “look” or “watch me”?) Yes No
18. Does your child understand when you tell him or her to do something? (FOR EXAMPLE, if you don’t point, can your child understand “put the book on the chair” or “bring me the blanket”?) Yes No
19. If something new happens, does your child look at your face to see how you feel about it? (FOR EXAMPLE, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?) Yes No
20. Does your child like movement activities? (FOR EXAMPLE, being swung or bounced on your knee) Yes No

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The Modified Checklist for Autism in Toddlers (M-CHAT-R), one of the AAP recommended tools, is a validated developmental screening tool for toddlers between 16 and 30 months of age. It is designed to identify children who may benefit from a more thorough developmental and autism evaluation. The M-CHAT-R can be administered and scored as part of a well-child check-up, and also can be used by specialists or other professionals to screen for developmental delay and autism.

Billing Code: 96110
M-CHAT-R Scoring Algorithm

‘No’ responses that should be counted as 1 point indicating ASD risk
All questions except 2, 5, 12

‘Yes’ responses that should be counted as 1 point indicating ASD risk
Only questions 2, 5, 12

Risk Assessment

- High Risk for autism group
  - Total Score of 8-20
- Medium Risk for autism group
  - Total Score of 3-7
- Low Risk for autism group
  - Total Score of 0-2

Management Recommendations

- High Risk Group
  - Refer to developmental specialist, or autism diagnostic clinic

- Medium Risk Group
  - Administer the follow up (available at www.mchatscreen.com - if the child’s score remains above 2 then the child falls in the High Risk Group and should be referred as above. If the child’s score drops below 2 then the child is Low Risk and should be re-screened at future well-child visits.

- Low Risk Group
  - If the child is younger than 24 months, screen again after the child’s 2nd birthday. No further intervention is required unless surveillance indicates risk for ASD.
Surveillance of Head Size

In addition to behavioral signs of autism, early neurobiological signs identified within the first year of life can also be helpful in identifying children at risk for autism.

Recent studies have shown that when brain size findings are organized according to age, a clear pattern of early brain overgrowth followed by normal brain size in adulthood emerges. Data reveal a period of pathological brain growth and arrest in autism that is largely restricted to the first years of life, before the typical age of clinical diagnosis. Careful monitoring of brain growth with accurate measurement of head circumference at all well-child visits, especially during the first years of life, may be helpful in identifying children who may be at risk for developing autism.

**Autism Evaluations in Michigan**

**Medicaid**

Medicaid HMO

MI Child

Refer family to the Community Mental Health Department (CMH) in the county in which they live [www.Michigan.gov/mdhhs](http://www.Michigan.gov/mdhhs)

CMH departments will assist family in scheduling ASD evaluation and accessing services

**Private Insurance**

Refer family to their insurance provider to determine if Autism evaluations & services are a covered benefit

If Autism benefits are provided, have the family ask their insurance provider where they can schedule an autism evaluation. Each private insurance company has specific criteria for diagnosing autism and authorizing payment for treatment. For example, BCBS of Michigan and BCN require an Approved Autism Evaluation Center (AAEC) or have a specific process for ASD assessments

If autism services are not covered by the medical insurance provider, contact the Autism Alliance of Michigan at 877-463-AAOM as we may be able to suggest other options for the family to explore
According to the American Academy of Pediatrics, there is growing evidence that early intervention services have a positive influence on the developmental outcome of children with established disabilities or those considered at risk for disabilities and their families.

If developmental delays are suspected, a referral for early intervention services should be made by contacting the Early-On Program in Michigan at 1-800 EARLY-ON or www.earlyon.org.

Early Intervention services may include speech, occupational, and physical therapy, play based programming and social skill building, parent and family support, and preschool programming.
Behavioral Symptoms of Autism

**Social Difficulties**
- May be aggressive with siblings
- May sit alone screaming or crying rather than asking for assistance
- May not notice when parent leaves or returns from work
- May show no interest in interactive games (e.g. Peek-a-boo)
- May resist being hugged, kissed
- May not lift arms to be picked up from crib when parent reaches out

**Sensory Processing Difficulties**
- May have extreme difficulty tolerating music, noise, textures, and new experiences or environments
- The greater number of sensory exposures the more likely a sensory ‘meltdown’ will occur due to being overwhelmed
- May be oversensitive to sensory input (and defensive) or under-sensitive (and seeking)
- Unable to tolerate seat belts
- May gag at common household smells
- May spin objects close to face
- May appear deaf, not startle at noises, and at other times hearing seems normal
- May have difficulty tolerating outdoor clothing in winter
- May resist having clothing changed
- May rip at own clothes
- During summer may insist on wearing winter clothing

**Communication Deficits**
- Avoids eye contact
- Resort to ‘hand-leading’ the parent using them as a tool to get what they want
- Appear uninterested in communication of any kind
- Will not use nonverbal communication effectively such as pointing
- Will present with delayed verbal communication

**Safety Issues**
- No sense of danger
- Doesn’t recognize situations where he/she may get hurt
- No fear of heights
- May avoid cautions to touch something hot
- May approach an unfamiliar animal without fear
- Frequent tendency to wander aware from safety of caregiver
- May wander near water
- No traffic safety awareness

**Repetitive Behaviors**
- Hand flapping
- Spinning
- Lining up items, such as cars
- May show no interest in toys but become attached to other objects- e.g. a space heater
- May pick lint in the sunlight, or notice other small items that others would not
- May not play appropriately with toys and instead focus only on one aspect- like spinning the wheels of a toy car
- Obsessively switching on and off lights or water
- May eat unusual objects like clothes
- Flicks fingers in front of eyes
- Finds ways to get deep pressure to body (e.g. hiding in small spaces)
- Smearing feces
- Finds ways to get heavy impact to body- such as crashing into things

**Motor Issues**
- Can exhibit motor abnormalities
- Some may have exceptional motor skills in one area and yet impaired in others
- Fine motor deficits
- Poor coordination
- Toe-walking
- Range from exceptional balance to clumsy
- Drooling or low muscle tone

**Self-Injurious Behavior**
- Head banging
- Self-biting with no apparent pain
- Picking or scratching at skin
- Pulling out tufts of hair
Psychiatric Problems Associated with Autism

- Attention Deficit Hyperactivity Disorder (ADHD)
- Anxiety
- Obsessive Compulsive Disorder (OCD)
- Depression
- Bipolar Disorder
- Schizophrenia
Medical Problems Associated with Autism

Genetics

ASD is a complex heritable disorder that involve multiple genes and demonstrates great phenotypic variation. Estimates of recurrence risks, based on family studies of idiopathic ASD, are approximately 5% to 6% (range: 2%–8%) when there is an older sibling with an ASD and even higher when there are already 2 children with ASD in the family.

Coexisting global developmental delay, severe intellectual disability, especially in the presence of dysmorphic features, increases the likelihood of identifying a known genetic disorder.

Neurogenetic syndromes that seem to play a causative role or otherwise are associated with ASD include, but are not limited to:

- Fragile X Syndrome
- Neurocutaneous Disorders
- Phenylketonuria
- Fetal Alcohol Syndrome
- Angelman Syndrome
- Rett Syndrome
- Smith-Lemli-Opitz Syndrome

If it seems fairly certain, on the basis of general developmental screening and/or available psychometric testing with standardized tools, that a child with an autism diagnosis also has global developmental delay (GDD), intellectual disability, or clinical features (history, family history, physical examination) that are characteristic of a specific genetic or neurologic disorder, referral to a geneticist and/or a child neurologist for an etiologic workup including high-resolution karyotype and DNA testing for fragile X syndrome should be made.

Seizures

Seizure disorder occurs in as many as one third of individuals with autism spectrum disorder. Epilepsy is more common in those who also have cognitive deficits. Some evidence suggests that seizure disorder is more common when an individual has shown a regression or loss of skills. The seizures associated with autism usually present either in early childhood or during adolescence, but may occur at any time.
Sleep Disorders

Children with ASD experience a significantly higher prevalence of sleep disorders than do typically developing children. The prevalence of sleep problems among children with ASD is estimated to range anywhere from 45% to 86%. Sometimes sleep problems may be caused by medical issues such as obstructive sleep apnea or GERD and addressing the medical cause may solve the problem. When there is no medical cause identified, sleep hygiene strategies may be helpful. There is also some evidence of melatonin dysregulation in individuals with autism and while some studies suggest melatonin may be effective for improving sleep in those with autism, more research is needed.

Gastrointestinal Disorders

Gastrointestinal (GI) disorders are among the most common medical conditions associated with autism. These issues range from chronic constipation or diarrhea to irritable and inflammatory bowel conditions. The Centers for Disease Control and Prevention (CDC) recently found that children with autism are more than 3.5 times more likely to suffer chronic diarrhea or constipation than are their normally developing peers. Other researchers have found a strong link between GI symptoms and autism severity in children.

Pain and discomfort caused by GI symptoms can worsen behavior and even trigger regression in persons with autism spectrum disorder. This may be particularly true of nonverbal individuals who have difficulty expressing their distress. Treating GI problems may result in improvement in behavior.

Feeding Problems

Studies suggest that feeding problems can affect as many as 80% children with autism or developmental difficulties. The causes for such difficulties may vary from sensory related issues, food aversion, dysphagia, or restrictive and ritualistic behaviors that affect eating habits. Some individuals limit what they eat so much that it results in nutritional deficiencies that lead to weight loss, malnutrition and inadequate growth. Referral to speech and occupational therapists or behavior specialists can be helpful in treating feeding problems in individuals with autism.
Coordination Disorder

Many individuals with autism experience difficulty with muscle tone and or coordination that can affect their ability to function at age appropriate levels. Deficits may be present in both fine and gross motor skills as well as in motor planning and execution. Proprioceptive difficulties may also be present.

Pica

Pica can be a normal part of development in children between the ages of 18 and 24 months; however, in children with autism, it may persist beyond this typical time frame. It is not uncommon for children with autism beyond two years of age to show signs of persistent mouthing of fingers or objects, including dirt, chalk, clay, or paint chips. Consider testing for elevated blood levels of lead, especially if there is a known potential for environmental exposure to lead.

Sensory Integration Dysfunction

Many individuals with autism experience difficulty processing and integrating sensory stimuli. Vision, hearing, touch, smell, and taste may all be affected. Deficits in the vestibular system and proprioception may be problematic as well. Sensory Integration Dysfunction may involve hypersensitivity or hyposensitivity. Hyposensitivity may be evident in a child’s increased pain tolerance or need for sensory input.
### Pharmacology

#### Pharmacological Options for Common Target Symptoms of Coexisting Diagnoses in Individuals with ASDs

<table>
<thead>
<tr>
<th>Target Symptoms</th>
<th>Medication Considerations</th>
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</thead>
<tbody>
<tr>
<td>Repetitive Behavior • Rigid Behavior • OCD symptoms</td>
<td>SSRIs (fluoxetine, paroxetine, escitalopram, sertraline, fluvoxamine, citalopram) • Atypical Antipsychotic Agents (risperidone, aripiprazole, olanzapine, quetiapine, ziprasidone) • Valproic Acid</td>
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**Potential Co-existing Diagnoses**
- Obsessive-Compulsive Disorder
- Stereotypic Movement Disorder

<table>
<thead>
<tr>
<th>Target Symptoms</th>
<th>Medication Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hyperactivity • Impulsivity • Inattention</td>
<td>Stimulants (methylphenidate, dextroamphetamine, mixed amphetamine salts) • Alpha-2 Agonists (clonidine, guanfacine) • Amoxetine • Atypical Antipsychotic Agents (risperidone, aripiprazole, olanzapine, quetiapine, ziprasidone)</td>
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**Potential Co-existing Diagnoses**
- Attention Deficit Hyperactivity Disorder

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<tr>
<th>Target Symptoms</th>
<th>Medication Considerations</th>
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<tbody>
<tr>
<td>Aggression • Explosive Outbursts • Self-injury</td>
<td>Atypical Antipsychotic Agents (risperidone, aripiprazole, olanzapine, quetiapine, ziprasidone) • Alpha-2 Agonists (clonidine, guanfacine) • Anticonvulsant Mood Stabilizers (Levetiracetam, topiramate, valproic acid) • SSRI's (fluoxetine, paroxetine, escitalopram, sertraline, fluvoxamine, citalopram) • Beta Blockers (propranolol, nadolol, metoprolol, pindolol)</td>
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**Potential Co-existing Diagnoses**
- Intermittent Explosive Disorder

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<th>Target Symptoms</th>
<th>Medication Considerations</th>
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<tbody>
<tr>
<td>Sleep Dysfunction</td>
<td>Melatonin • Antihistamine • Alpha-2 Agonists (guanfacine, clonidine) • Mirtazapine • Ramelteon</td>
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**Potential Co-existing Diagnoses**
- Circadian Rhythm Sleep Disorder
- Dyssomnia-Not Otherwise Specified

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<th>Target Symptoms</th>
<th>Medication Considerations</th>
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<tbody>
<tr>
<td>Anxiety</td>
<td>SSRIs (fluoxetine, paroxetine, sertraline, fluvoxamine, citalopram, escitalopram) • Buspirone • Mirtazapine</td>
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**Potential Co-existing Diagnoses**
- Generalized Anxiety Disorder
- Anxiety Disorder-NOS

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<th>Target Symptoms</th>
<th>Medication Considerations</th>
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<tbody>
<tr>
<td>Depression</td>
<td>SSRIs • Mirtazapine</td>
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**Potential Co-existing Diagnoses**
- Major Depressive Disorder • Depression-NOS
Summary of Potential Referrals

1. Developmental Pediatrician/Psychiatrist/Psychologist
2. Special Education Department (intermediate or local school district)
3. Audiology
4. Speech therapy
5. Occupational therapy
6. Behavior Specialist
7. Geneticist
8. Pediatric Neurologist
9. Pediatric Gastroenterologist
10. Nutritionist or Dietitian
11. Social Worker
12. Counselor (older children and adults, parents, caregivers)
Optimizing Office Visits for Children with Autism

Children with autism may never look sick. They may look perfectly normal and have attained all of their pediatric milestones.

Some may behave as though they are just lacking firm parental controls, when in fact, they are often very resistant to change when presented with new situations, new experiences, and new people.

Acute changes or worsening in behavior may be related to a medical problem that needs to be addressed (ear/throat infection, dental abscess, stomach ache, constipation).

Optimizing Office Visits

Consider Advance Telephone Conference with the Parent

Advantages include the ability to:

1. Obtain a clear history from the parent without the distraction of the child present.
2. Ask the parent for suggestions for how the visit could be made easier.
3. Ask the parent to bring a motivator (bribe) with them to the visit to assist with the examination.
4. If you anticipate the need for a blood draw then consider prescribing anesthetic cream so that the parent may apply in advance of the visit.
5. Ask parents to to explore the AAoM site or Autism Speaks tool kits prior to visit.

Listen to the Parent

Parents are the experts at reading their child.

Where possible, treat physical symptoms as you would with any child, without letting autism cloud your judgment.
Prepare the Exam Room

A nurse or medical assistant can check in advance with the parent regarding room accommodations. These may include:

• Quiet room
• Room with or without a window
• No bright lights
• Music/no music
• It may be necessary to remove all objects that could be used as potential weapons
• Children may want the same room each visit

Minimizing Wait Time if Possible

Consider:

Scheduling the child as the first appointment of the day, ten minutes earlier will prevent the child from seeing other people or crowds when he/she arrives.

Advantages include:

• Minimizing risk of ‘melt-down’
• Disruption of other families in the waiting room
• Avoid embarrassment for the parent
• Damage to the actual waiting room during the wait
• If possible, register the child by telephone in advance

Things May Not Be As They Seem

• Despite the fact that children with autism may look neglected and/or abused in some cases, consider the following:
• Children with autism can present with severe self-injurious behaviors- biting, head-banging, scratching, etc.
• Limited or no pain-sensation
• No sense of danger or what will hurt them
• Severe sensory issues making it difficult to change the child’s clothing or bathe them
Expect the Unexpected

Be alert for your own safety.

Some children with autism may not understand that you are there to help them, instead they may see you as a threat. They can be calm at one moment and erupt the next and may:

- Head butt
- Bite
- Kick
- Spit
- Punch
- Pull hair
- Bolt

If these behaviors occur, ask the parent or caregiver what works best to calm their child down. Respect the child’s personal space- it may be much larger than usual.

Language Skills

Some children may be able to recite entire Disney videos, however they will be unable to tell you their name or if they are hurt.

They may have difficulty processing auditory information and may need visual instructions as well.

Ability to talk does not always reflect underlying language and cognition.
Impact of Autism on the Family

Having a child with autism, can make everyday, routine activities difficult or impossible. Stress on marriage and siblings can be tremendous. Referral to family and sibling counseling and local support groups may be appropriate.

Consider that for some families, autism can make the following activities difficult or impossible:

- Shopping
- Sleeping
- Cooking
- Vacations
- Dining out
- Going to the movies
- Visiting friends
- Traveling
- Stress free co-parenting
Consider the Impact of Autism on the Entire Family

A lot of effort and attention goes into a child with autism given their pervasive behavioral and communication difficulties. As a result, siblings and marriages may suffer. Remember to refer when appropriate:

- Sib Shops
- Family Support Groups
- Respite services

Autism can create a great deal of physical, emotional, and financial distress in the household. Every parent handles the diagnosis differently. While you will have to monitor parents for signs of stress, fatigue, substance abuse, and other mental health issues, you will also witness parents who become very strong autism advocates in their schools and communities at large.
It’s all about community!
Attend our upcoming events and fundraisers, or volunteer. For more information, visit:
www.autismallianceofmichigan.org

Donate
We can’t do this without you! All of our funds stay in Michigan and go directly to local families. There are many ways AAoM can use your donations of time, support, sponsorships, services, or creativity. www.autismallianceofmichigan.org/fundraise

Connect with us
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