

P.O. Box 5010
Atlanta GA 30302-5010

Phone: 404/413-6200
Fax: 404/413-6207



Dear Parent,

We need your help!

We are conducting a study to improve early detection of autism spectrum disorders. Our goal is to improve doctors' knowledge about when to refer a child for an autism evaluation, and/or when to refer a child for early intervention services relevant for children with possible autism spectrum disorders. Treatment for autism is more effective when it starts very early. We have already screened more than 8,000 children in the metro-Atlanta area, but our goal is to screen 10,000 more children in the next five years.

Pediatricians and family practice doctors located within 60 miles of downtown Atlanta, GA are invited to participate. Once a physician is participating in the study, all of their patients will be offered the opportunity to fill out the screening questionnaire, the Modified Checklist for Autism in Toddlers (M-CHAT) during 18-and 24-month well child check-ups. Families who qualify will receive a free diagnostic evaluation as part of the study. **Please note that parents cannot directly enroll their children in the toddler screening study.** If you want your child to be in the study, your child's doctor must enroll in the study.

Please give the attached packet to your child's pediatrician or family practice physician. Please encourage your child's doctor to enroll in the study.

If you have any questions about this study, please contact us at 404-413-6472.

Sincerely,

A handwritten signature in black ink that reads "Diana L. Robins, Ph.D.".

Diana L. Robins, Ph.D.
Assistant Professor

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Dear Physician,

You are invited to participate in a research study being conducted at Georgia State University. The aim of this study is to improve the early detection of autism spectrum disorders. As you probably know, autism and related disorders are difficult to detect in very young children. However, research suggests that early intervention improves prognosis. All physicians who conduct well-child check-ups in toddlers 16-30 months old AND who practice within a 60-mile radius of downtown Atlanta are eligible to join the study.

The Modified Checklist for Autism in Toddlers (M-CHAT) is a brief parent-report questionnaire designed to improve the early detection of autism spectrum disorders. The M-CHAT does not mention "autism" to prevent parents from biased responding. It is extremely simple to administer and can be completed by parents in 5 minutes. It is designed to be given at the 18 or 24 month well-child visit. The current study is pilot testing the new M-CHAT-R, which we expect will have very high sensitivity and a lower false positive rate than the original M-CHAT.

The M-CHAT study has been ongoing at Georgia State University since 2005. We have screened approximately 8000 children so far, and expect to screen 10,000 new toddlers over the next several years. We need the cooperation of pediatricians and family practice doctors who see toddlers in their practices to continue this study. Preliminary results from this study were published in the journal *Autism* in 2008. We are happy to share a copy of this paper upon request.

If you agree to participate in the M-CHAT study, your staff will be asked to give the research packet, which includes informed consent and the M-CHAT-R questionnaire, to every parent whose child is being seen for the 18 or 24 month well-child visit. Your office will return completed questionnaires to us at GSU, in postage-paid envelopes. The time required by your office staff is minimal, and the potential return for your patients is tremendous. Clinical evaluations often cost \$1500 or more, and waiting lists exceed one year at some clinics. However, children identified through the study will be seen free of charge, and we attempt to see every child within three months of the initial screening. We will alert you about all patients from your practice who qualify for the free evaluation.

Once you agree to participate, Dr. Robins or one of her research associates will ask to attend a staff meeting in your office. She will provide a 5-10 minute overview of the study and provide you with a packet of materials, including copies of the M-CHAT-R and consent form, and self-addressed, postage-paid envelopes for the return of the checklist. We will ask you to name a contact person in your office, and we will alert that contact person when we offer a diagnostic evaluation to one of your patients.

If you are interested in participating in the study, please photocopy the enclosed enrollment letter on your letterhead and return Attn: Dr. Diana Robins Department of Psychology, Georgia State University, PO Box 5010, Atlanta, GA 30302-5010, or fax to 404-413-6207. We thank you for your time and look forward to working with you. If you have any questions, do not hesitate to call me at 404-413-6472 or send an email to DevNeuro@gsu.edu.

For more information about the ongoing study, please see www.MCHATscreen.com.

Sincerely,

A handwritten signature in cursive script that reads "Diana L. Robins Ph.D."

Diana L. Robins, Ph.D.
Assistant Professor of Psychology

Dear Dr. Robins,

I agree to participate in the M-CHAT study. I understand that my participation involves offering the M-CHAT questionnaire to parents at their child's 18 or 24 month well-baby visit, and returning completed checklists to GSU for scoring.

If I have any questions I will contact Dr. Robins at 404-413-6472 or DevNeuro@gsu.edu.

Sincerely,

Signature: _____ Date: _____

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: (_____) _____

Procedures for M-CHAT Autism Screening Study

WHO:

- Parents of toddlers at 18-month well-child visit.
- Parents of toddlers at 24-month well-child visit.
- For children who are off schedule, any child coming in for a well checkup between **16 and 30 months** is eligible for the study.

WHAT:

- Offer M-CHAT packet.
- Please avoid mentioning “autism” – introduce as study of children’s development.
- Collect completed packet before family leaves office. Note: If a parent does not sign the consent form, we cannot follow up with the family in any way.
- If a parent chooses not to be in the study, please put their blank M-CHAT packet in the envelope to us. This is how we record participation rates.
- All parents who complete the M-CHAT should get the parent copy of the consent form.
- Return completed packets to Georgia State University in self-addressed stamped envelopes. Please use large envelopes when you have collected 10-20 packets, and use the small envelopes only if you have an M-CHAT you would like us to see immediately.
- Check the “Office Use Only” box in top right corner if physician has concerns about an autism spectrum disorder.
- If a parent has multiple children eligible for screening (e.g., twins), each child should receive a separate form.
- Please attempt to screen **all** children who come for 18- and 24-month well-child visits.
- If a parent chooses not to participate, you are welcome to use the M-CHAT clinically, but please do not use the research packet to do so.

You are welcome to keep a copy of the study materials in the child’s chart, but it is not required. Parents are entitled to a copy as well.

To the extent you and your staff feel comfortable, please encourage eligible families to participate. This study is a great benefit to the family if there are developmental concerns, since they will be offered a free and rapid diagnostic clinical evaluation with recommendations for intervention. And for all families, there is benefit to helping us learn about child development.

Steps of the M-CHAT Study

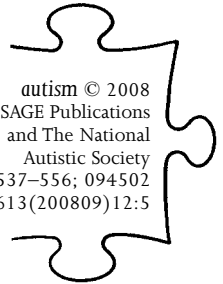
1. Children are screened during well-child visits between 16 and 30 months. Please note, our goal is to screen children at multiple visits to address the question of whether one age is best for autism-specific screening.
2. Pediatric practice returns completed M-CHATs to GSU for scoring.
3. If a child screens positive on the M-CHAT, we first conduct the M-CHAT Follow-up Interview (usually on the phone), which is a structured interview to clarify responses and elicit examples of target behaviors.
4. If the child screens positive on the M-CHAT Follow-up Interview, we invite them to attend a clinical evaluation. Evaluations are **FREE OF CHARGE**, and are scheduled as quickly as possible (nearly always within three months). All evaluations are completed by a licensed psychologist and one more students working under her supervision.
5. Families who attend the evaluation receive verbal feedback at the end of the appointment, and a full report 4-6 weeks after the session. Reports contain background information, informal observations, test results, diagnosis (if appropriate), and recommendations targeted to the child's strengths and weaknesses.
6. We alert your office to all children who screen positive on M-CHAT and Follow-up Interview. This is done by fax unless your office requests a different procedure.
7. We also alert your office to children we are not successful reaching for the Follow-up Interview.
8. Parents are encouraged to share the clinical report with their primary care provider and any intervention providers or other specialists involved in the child's care.
9. Most families who are invited for the evaluation are also invited to participate in a longitudinal study of children's development. This includes three additional sessions over 2 years, and a free follow-up evaluation when the child is 3.5 years old, to evaluate progress and confirm diagnosis. Our data shows that 25% of toddlers who are diagnosed with an autism spectrum disorder around age 2 who get intensive intervention **NO LONGER HAVE AUTISM** by 3.5-4 years old!!!

See the M-CHAT website for useful downloads and more information:

<http://www.MCHATscreen.com>

Screening for autism spectrum disorders in primary care settings

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ABSTRACT The need for autism-specific screening during pediatric well-child visits has been established. However, additional support for specific screening instruments is needed. The current study used the Modified Checklist for Autism in Toddlers (M-CHAT) and the M-CHAT Follow-Up Interview to screen 4797 children during toddler checkups. Of the 4797 cases, 466 screened positive on the M-CHAT; of the 362 who completed the follow-up interview, 61 continued to show risk for autism spectrum disorders (ASDs). A total of 41 children have been evaluated; 21 children have been diagnosed with ASD, 17 were classified with non-ASD delays, and three were typically developing. The PPV of M-CHAT plus interview was .57. It is notable that only four of the 21 cases of ASD were flagged by their pediatrician. These findings suggest that the M-CHAT is effective in identifying ASD in primary care settings. Future research will follow this sample longitudinally.

KEYWORDS
autism;
M-CHAT;
screening;
toddlers

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