

Attachment 15.c.

## Clinic Visit Prep Guide

The clinic visit consists of 5 parts: (1) conducting a developmental evaluation of your child, (2) conducting a parent interview, (3) conducting a brief physical exam of your child, (4) obtaining blood and saliva samples from your child and (5) obtaining blood and saliva samples from you and, if he is available, a saliva sample from your child's father. <Optional: We created a picture story to help guide you and your child through the clinic visit.> Please let us know if you have additional questions after you review <optional: the picture story and> this prep guide.

It will take up to 5 ½ hours to complete the clinic visit. However, if we also need to spend some time completing any remaining study forms with you, the visit will take longer. The study forms were sent to you earlier. There were 6 <Optional: 7> in all. If we need to complete all of these forms with you, the visit might take an additional 1 ½ - 2 hours. Thus, we ask that you please complete all forms prior to the visit. <Optional: We are happy to help you with these over the phone.>

Please plan to arrive 15 minutes before your scheduled visit to help your child become familiar with the clinic. We ask that you meet us at <Address of clinic: e.g., the Marcus Autism Center at 1920 Briarcliff Road NE in Atlanta, GA> to complete this clinic visit. <Optional: The visit is sometimes easier for children if seen in a clinic since there are few distractions in a clinic setting. As such, the child may perform better and the visit may take less time when performed in a clinic.>

### **Home Visits (site specific)**

<Optional: If you cannot come to the clinic, you can choose to have project staff come to your home to complete the clinic visit. In order to do the evaluation in-home, you must be able to provide a private and quiet area. This area must be free from distractions. It is preferred that you find childcare for your other children so that you can sit with your child during the evaluation.

Project staff will need to look in your home for the most appropriate place to conduct the assessment. Staff will then need to set-up the room without your child present. After the room has been set-up, the evaluator will play with your child in order to make him/her more comfortable. The evaluation will begin after your child is comfortable with the evaluator.>

### **What to expect during the Developmental Evaluation:**

A trained professional will conduct the evaluation. The evaluator will first introduce herself and answer any questions you may have. She will then play with your child in order to make him/her more comfortable. The evaluation will begin after your child is

comfortable with the evaluator. You can sit with your child during the evaluation in order to make him/her more comfortable. The evaluation will consist of two tests that take about 1 ½ hours to complete. The tests will involve asking your child some questions and engaging him/her in some structured play activities. Your child will be able to take a break if needed. You can come back at another time if your child cannot complete the evaluation.

How to prepare for the developmental evaluation:

Children must be able to walk by themselves in order to complete the evaluation. The evaluation also requires that your child does not have any significant and uncorrected hearing or vision impairments.

<Optional: You may want to review the picture story and bring one of your child's favorite toys for them to play with during breaks in the visit. You also may want to bring a favorite snack in a small plastic container. Please tell us if your child has any food allergies.>

**What to expect during the Parent Interview:**

As part of this study we would like to ask you questions about your child's development. All of the information you give will help us learn more about why children may develop differently. The interview will ask about your child's personal and social skills, development, and current services and treatments. It will take up to 3 hours to complete. You can skip any question that makes you feel uncomfortable.

How to prepare for the parent interview:

Please look through your child's baby book or baby calendar to recall when your child reached developmental milestones. Write down what age your child first rolled over, sat alone, crawled, walked, used single words, and spoke in phrases or short sentences. If there was a period when your child seemed to lose skills, please write down what skills he/she lost and at what age (months or years) the skill was lost.

*Optional: the following paragraph can be removed from the Guide if the Services and Treatment questionnaire is included in the SAP: Please take some time before the interview to write down all of the services and treatments your child is now receiving. The services and treatments list on the last page can help you remember what services and treatment your child is currently receiving. During the interview we will ask you to look at the list in this guide. All you need to do is have looked at the list before your appointment and have it with you during the interview.*

**What to expect during the form completion:**

We have mailed forms to you to complete <Optional: on your own or over the phone with one of our staff members> prior to the clinic visit. These forms are about your child's development and your family's health.

How to prepare for the form completion:

If you are unable to complete these forms prior to the clinic visit, we will complete them with you in person. This can take up to an additional 1 ½ - 2 hours to do.

**What to expect during the Physical Exam**

We ask that you allow a project staff to conduct a brief exam on you and your child. A trained professional will measure your child's height, weight, and head circumference. We will also measure your height and head circumference.

How to prepare for the physical exam:

<Optional: You may want to review the picture story prior to the physical exam.>  
We will ask you and your child to remove your shoes so we can obtain accurate height and weight measurements. If you or your child's hairstyle includes braids on their head, if possible, we ask you not to have them in at the time of the visit. The braids interfere with our staff obtaining an accurate measure of head size and height.

**What to expect providing blood and saliva samples:**

We ask that you allow us to get a sample of blood and saliva from you and your child, and a sample of saliva from your child's father if he is available. These samples will help us learn more about the biology of developmental problems.

Saliva Samples: Each person will answer questions about when they last brushed their teeth and ate food. The clinic staff will assist you in collecting the samples using one of two methods. The first method is to collect saliva by spitting directly into a tube. The second method uses a small sponge to soak up saliva from your mouth. We will give you specific instructions for the method you choose. It can take about 10 minutes depending on how much saliva you make. You or the staff will collect your child's sample.

Blood Sample: A trained professional will wrap your arm with a latex band and insert a small needle into your arm to get the blood. Please tell us if you or your child has a latex allergy. We will do everything we can to make you feel at ease. If you decide to use the numbing cream for your child, we will first put the cream on your child's arm for a few minutes. The trained staff member who has experience working with children will then remove the cream and insert a small needle into your child's arm. We will do everything we can in order to make your child feel at ease. You can decide to stop at any point during the blood draw.

How to prepare for the blood and saliva samples:

You may want to <Optional: review the picture story and> talk with your child before the visit to explain the blood draw and saliva collection procedures. You may also want to tell staff which type of collection method you prefer; if you think your child will have difficulty with spitting into the tube then we can use the sponge method. We ask for you to wait at least 30 minutes after eating, drinking or chewing gum before we collect the saliva samples. <Optional: The picture story book is an excellent tool to review with your child before the visit.>

You may also want to bring a favorite snack or treat that can be given to your child after he/she has completed this part of the study.

You may want to wear, and dress your child in, a shirt or dress with sleeves that are loose fitting and can comfortably be pulled above your elbow. A loose long sleeve shirt may also be more comfortable for your child after the numbing cream is put on to distract your child from the cream.

<Optional: the following Services and Treatments List can be removed from the Guide if the Services and Treatment questionnaire is included in the SAP.>

### **SERVICES AND TREATMENTS LIST**

During your clinical visit, you will be asked questions about your child's services and treatments and current use of complementary and/or alternative or biological treatments. To help you answer the question specific to your child's use of biological treatments, various available treatments are listed below. The brand name is in parentheses.

The list below is not a complete list so if the treatment your child receives cannot be found below, please tell us about it during the interview. Also, if you have the medicine bottles or packages, we ask that you keep those items handy during the interview. Having these items handy will help you answer the questions in the interview.

<b>Services and Therapies</b>
<p><b>Preschool Program (general):</b> Provides a classroom learning experience for young children before they are old enough to enter kindergarten.</p> <p>Preschool program (general) provides a classroom learning experience for young children before they are old enough to enter kindergarten. A general preschool classroom does not provide specialized services for your child's special needs.</p>
<p><b>Preschool Program (special needs):</b> Provides special help in a classroom for children who have developmental problems such as ASD or developmental delays in communication,</p>

learning motor skills, social skills or self-help.

Preschool program (special needs) provides special help in a classroom for children who have developmental problems such as ASD or developmental delays in communication, learning motor skills, social skills or self-help. A special needs program may simply mean that the child's therapist comes to the preschool location to provide services.

**Respite Care:** Is the provision of short-term, temporary care for a child with a disability that provides a short break for the caregivers of children with a developmental disability.

**ABA Behavior Modification:** ABA is a behavior modification program. ABA methods include careful structure, repetition, and rewards to improve social skills, communication skills, and adaptive living skills. An ABA program may include many teaching methods, for example breaking down skills into sub-skills and teaching them one at a time and teaching within the natural environment.

**Classroom Aide, Paraeducator or Shadow:** Assists teachers or therapists by working individually with children. They often are not licensed as teachers.

**Occupational Therapy (OT), including Sensory Integration Therapy:** OT focuses on helping children cope with emotional, social, and physical challenges. OT teaches living skills to help reach these goals. Some examples of OT are helping a child develop small muscles in the hands (fine motor skills) and helping a child feed or dress himself independently. Sensory integration therapy focuses on organizing sensory input such as touch, sight, sound, and movement.

**Physical Therapy (PT):** A physical therapist will help the child strengthen and develop the large muscles of the body (gross motor skills) to help them become more physically active. The therapist may help the child learn to do things such as sitting, walking and running. They may work with the child to increase strength, maintain flexibility, coordination and improve balance.

**Social Skills Training:** Is a form of behavior therapy used by teachers and therapists to help people who have difficulties relating to others.

**Speech Language Therapy:** A speech language pathologist/therapist may work with the child to understand language (follow directions and answer questions) and use language to communicate (express what he wants and help him be understood when he speaks). Speech language therapists may also help children learn to use lips, jaw, and tongue for proper chewing. They may work on things such as breathing and swallowing. Speech therapists also provide support with alternative and augmentative communication such as picture exchange communication systems.

<b>Complementary or alternative therapies used to treat symptoms of autism</b>
<p><b>Chelation Therapy:</b> Is giving the child chemicals (by mouth or injection) that remove heavy metals from the body.</p>
<p><b>Chiropractic Care or Massage Therapy:</b> Massage includes rubbing, kneading, and/or pressing on muscles and other soft tissue in the body. Massage/can be used for a number of reasons including structural integration, stress reduction, pain management, increase relaxation, and healing injuries. A chiropractor or osteopathic provider</p> <p>Chiropractic and osteopathic practitioners adjust the spine and other parts of the body to improve alignment problems and relieve pain.</p>
<p><b>Gluten and/or Casein Free Diet:</b> A casein-free or gluten-free diet</p> <p><b>A Casein-free diet:</b> Contains no casein, a protein found in milk and other dairy foods.</p> <p><b>A Gluten-free:</b> A gluten-free diet has no products containing gluten, such as wheat, oats, spelt, and foods made from those grains.</p>
<p><b>Yeast Free Diet:</b> A yeast-free diet eliminates foods, like sugar, that are believed encourage the growth of yeast.</p>
<p><b>Diet:</b> Other</p>
<p><b>Dietary or Vitamin Supplements are added to the child's diet:</b> Medications or supplements (purchased over the counter, that include vitamins (such as vitamin C, Vitamin B6, vitamin A, folate and others) or amino acids (for example DMG or dimethylglycine) or essential fatty acids (e.g., Omega 3 fatty acids); usually not purchased by a doctor's prescription and/or recommendation; given in addition to the diet, and not in response to a diagnosed (or suspected) deficit in said vitamin. May be oral or by injection (e.g., vitamin B12)</p>
<p><b>Herbal supplements, medication or tea:</b> A supplement that contains part or all of a plant (e.g., seeds, herbs, leaves, bark), which is consumed due to its presumed therapeutic benefit. It may be in the form of an oral supplement (e.g., pill or capsule) or as part of a beverage (e.g., tea).</p>
<p><b>Hyperbaric Oxygen Therapy (HBOT):</b> Is treatment in which a child breathes in extra oxygen while inside a pressurized chamber</p>
<p><b>Immune treatments (e.g. stem cell transplants or antibiotic or antiviral medications or therapies):</b> Focus on reducing chronic infections and immune disorders with various medications, such as Immunovir (Isopronosine), and prescription antiviral medications, such as Valtrex.</p>

### **Medications used to treat symptoms of autism**

Antidepressants, anti-anxiety, or obsessive-compulsive medications, such as Prozac or Zoloft

Atypical Antipsychotics, such as Risperdal or Abilify

Hypertension agents (as alpha adrenergic agonists), such as Tenex or Clonidine

Medications used to treat seizures, which are also used to stabilize mood, such as Tegretol, Lamictal.

Stimulants, such as Ritalin or Adderall.