

15q Clinical Research Network Clinic Preparation Checklist

The 15q Clinical Research Network is happy to learn you made your initial appointment at one of our clinics. Below is a checklist to help you think through and prepare for your appointment prior to your visit. We want you to have the best possible experience as well as maximize the benefits these clinics have to offer. If you have any questions, please contact the 15q Clinical Research Network Coordinator, Zoe Dannenberg, at 15qnetworkcoordinator@dup15q.org.

Clinic Questions:

- How is the appointment day structured?
 - *Clinic Appointment example:*
 - 8:30am-12:00: AS/Dup15q education, clinician assessments, guardian interviews and questions
 - 12:00-1:30: Lunch on own
 - 1:30- Afternoon (varies): Assessment results, intervention recommendations
- Appointment logistics:
 - Travel, overnight accommodations, parking
 - Food accessibility? Refrigerator/microwave available?
- What clinicians are going to be available at *my* visit?
- What medical and developmental history should I provide ahead of my appointment?
 - What is the best way to provide this information?
 - How far in advance should I provide this information?
- Will my child receive cognitive testing?
 - If so, is it possible for testing to occur around (*insert time*), when my child is rested and fed?
 - How much participation can I, the parent, assist in the testing process?
 - What will that look like with a child who is non-verbal? Should/can we bring communication devices/PECS?
- Are there any recommendations to help my child transition into this new environment and get the best data possible?
 - Snacks, iPad, favorite toys?

Guardian Preparation:

- Enroll into LADDER and fill out the necessary forms. Gather and provide the following information to your clinic prior to your appointment:
 - Significant lab and test results (E.g. MRI, EEG, genetic reports, blood work)
 - Significant notes from previous clinicians (E.g. neurology, genetics)
 - Developmental history (E.G. milestones achieved, milestones currently working on)
 - <https://www.cdc.gov/ncbddd/actearly/milestones/index.html>
 - Family history
- Prepare a list of questions for each clinician including any needed resources or documentation. This is a critical component as questions strategically address a patient's individual needs.
 - Seizure education: signs/symptoms of AS/Dup15q seizures, medications, how to stop seizures
 - AS/Dup15q best practices concerning diet, nutrition, and supplements
 - Address specific medical issues: sleep/use of sleep aids, vision issues, GI issues
 - Individualized therapeutic recommendations addressing PT, OT, and speech therapy
 - Educational concerns, government resources, medical equipment
 - Are there any research studies/clinical trials available to my child?
- If possible, bring along a caretaker to allow for minimally interrupted discussion and questions.
- Utilize these clinicians as resources at the appointment and as consultants in the future.