



Your Visit to the Fragile X Center

What is Fragile X?

- DNA is a molecule that tells the body how to function
- Fragile X is caused by a change in DNA
- This change in the DNA disrupts the connection between nerve cells
- Nerve cells have a harder time communicating

What are the effects of Fragile X?

- Fragile X can cause a variety of developmental issues including:
 - Intellectual disabilities
 - Learning disabilities
 - Autism
 - Epilepsy
 - Anxiety
 - Attention Deficit Hyperactivity Disorder

Does Fragile X have physical features?

- Some people with Fragile X display the following physical features:
 - Large ears
 - Soft skin
 - Large testicles (in males)
 - Low muscle tone
 - Hyper-flexible joints
 - High arched palate (in mouth)

How is Fragile X treated?

- Everyone with Fragile X is different
- There is no cure, but there are many effective treatments

You can learn more at these sites:

- [Children's Hospital of Pittsburgh – Fragile X Brochure](#)
- [Fragile X Parent's Handbook](#)
- [Your Genes, Your Health – Fragile X](#)
- [Fragile X Research Foundation](#)
- [National Fragile X Foundation](#)

What services does the clinic offer?

- Medical examinations
- Behavioral, developmental, and sleep assessments
- Treatment recommendations
- Community and advocacy connections
- Assistance with Individualized Education Plans
- Referrals for therapeutic intervention and support services

Medical home

- A team of specialists will work with you
- The team is coordinated by a doctor
- The goal is to provide comprehensive care
- You will always have a place to go with your questions and concerns

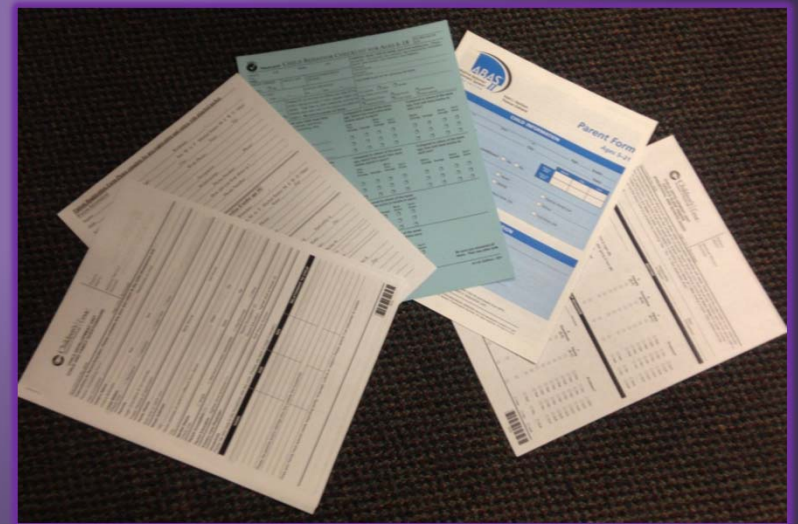
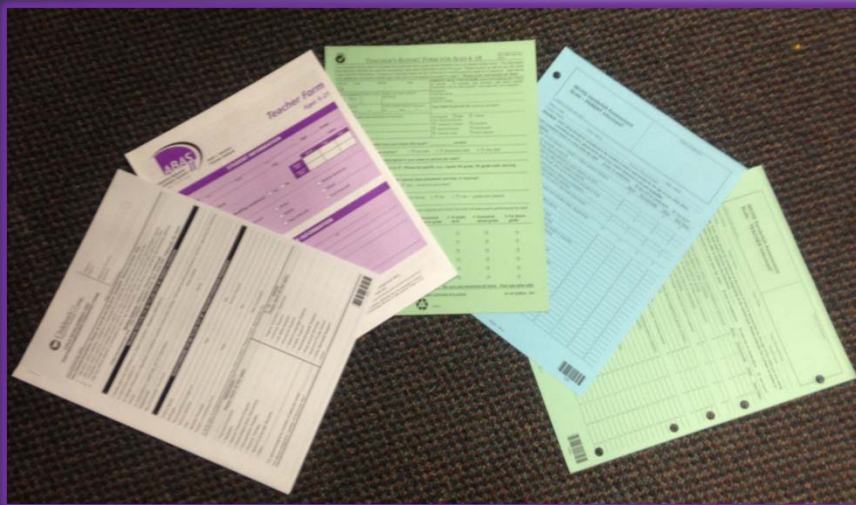
Who is seen at the clinic?

- People of all ages with a diagnosis of Fragile X and its spectrum
- Family members and involved community members

What should I do before the appointment?

Mail back to the clinic:

- Completed intake paperwork
- Questionnaires completed by the family, therapists and teachers



How to get to the clinic?

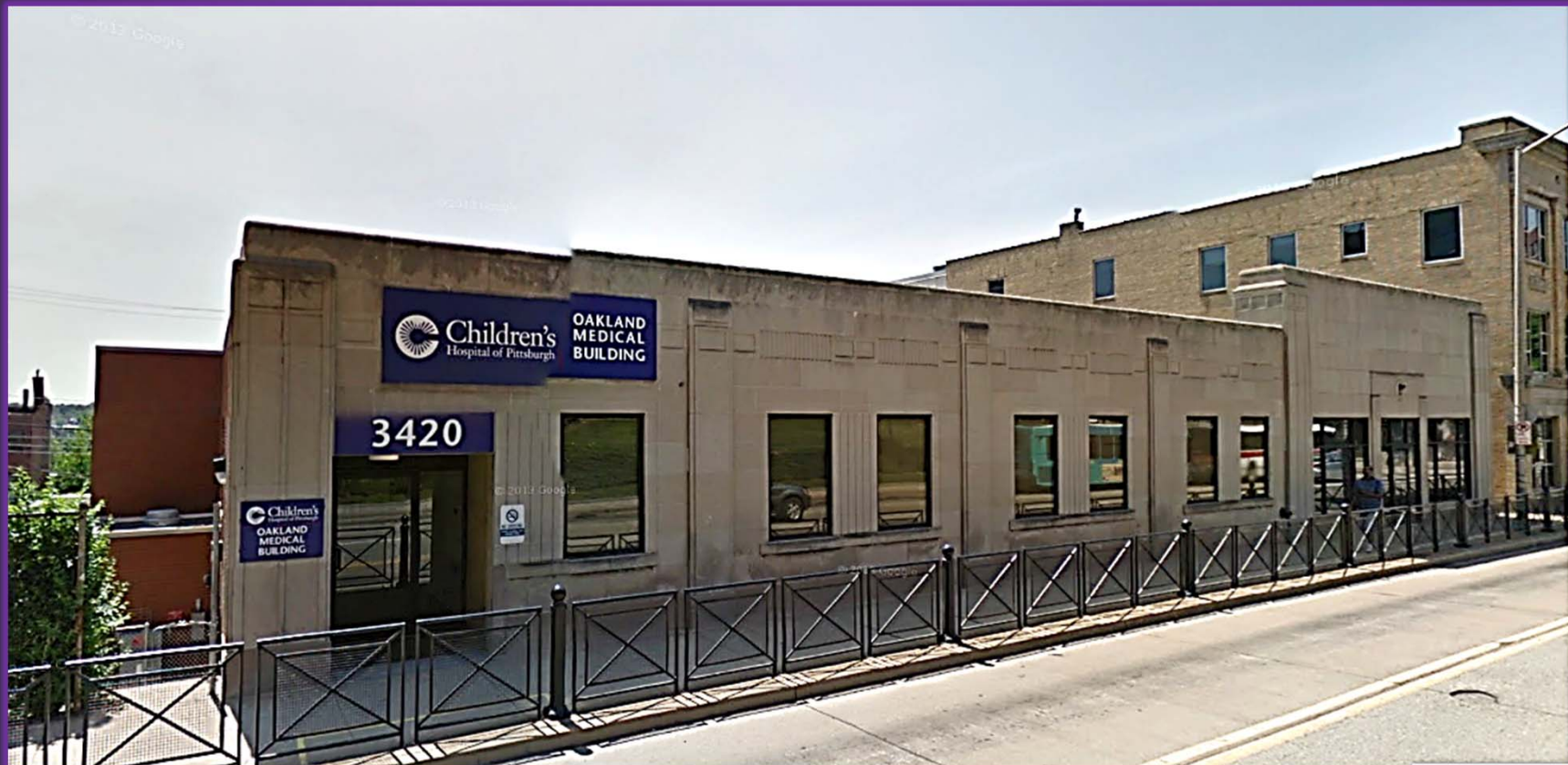
- Click on the link below and enter your address:
 - [Get directions.](#)
- The building is located behind the Arby's restaurant
- Call (412) 692-5560 if you get lost

Where do I park?



Park in the gated lot next to the Children's Hospital office building.

Fifth Avenue Entrance



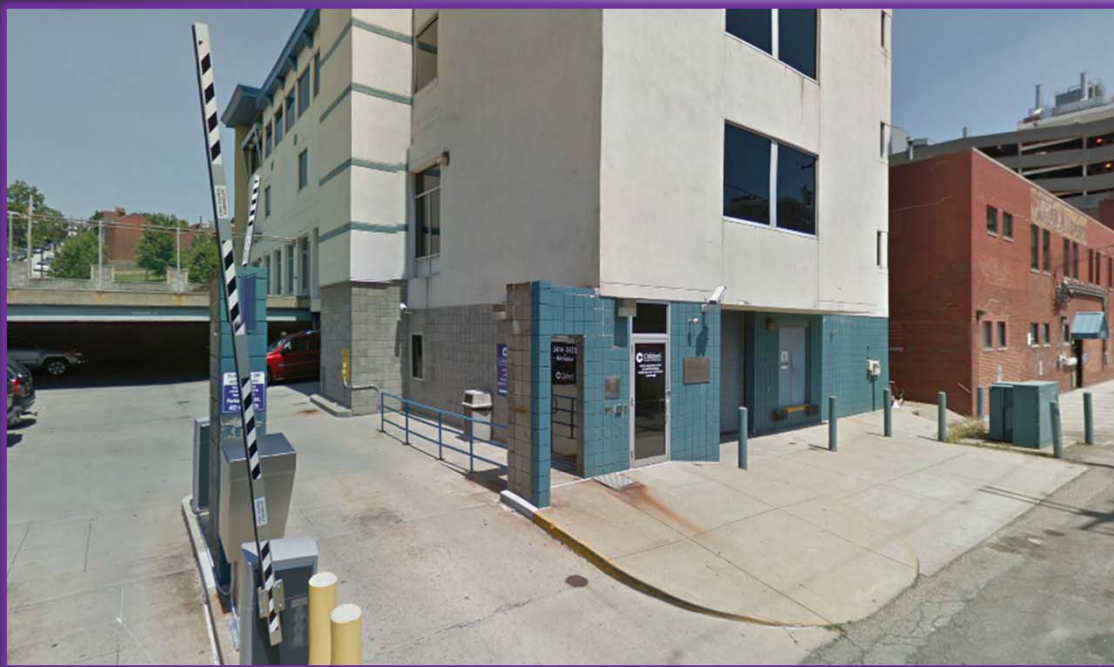
From the Fifth Ave. entrance, you will step into the lobby.

Fifth Avenue Lobby



You will register for your appointment at the desk.

Euler Way Entrance – Open Air Lot



There are also entrances on Euler way. This is a picture of door #1 on Euler way and the stairway you will see when you step through the door.

Euler Way Entrance (Behind Arby's)



The is door #2 on Euler way.

Euler Way Lower Level Lobby



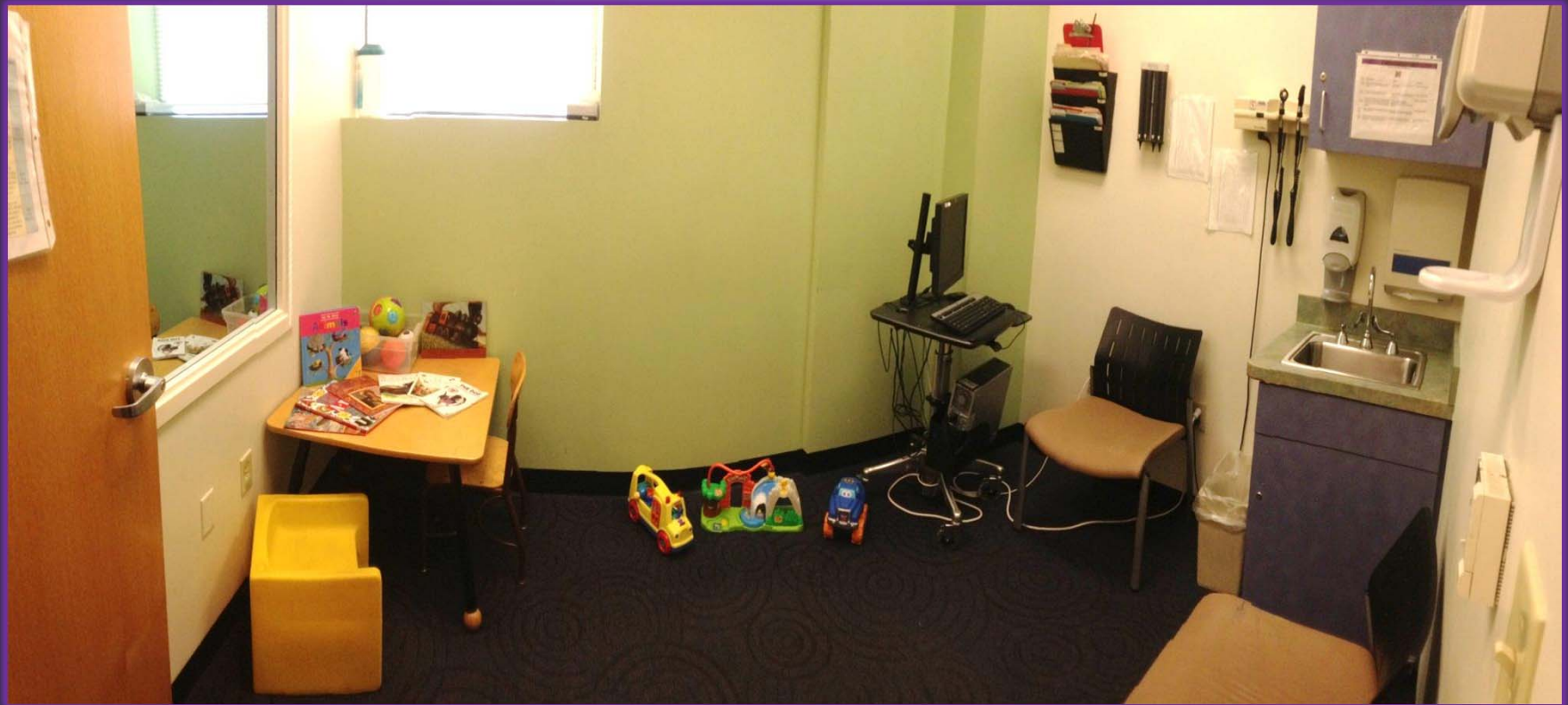
The elevator on the left side of the picture will take you to the clinic. Take the elevator up one floor.

Clinic Check-In / Waiting Room



When you step off the elevator, you will see this waiting area. You can register for your appointment here as well.

Clinic Room



This is the room in which you will have your appointment.

What if I forgot to mail in the paperwork?

- Bring it on the day of the appointment

What you can tell your kids about the Fragile X Center

- There will be no pinches or shots
- There will be nice, friendly people to meet who want to see them and get to know more about them and how they are growing
- You can bring a snack and/or a favorite toy
- The Fragile X Center has lots of toys to play with
- It is a time to play and relax and when you leave you get a treat

What should I bring to the appointment?

- You should bring:
 - Other pertinent medical records
 - Fragile X laboratory results
 - A list of questions that you have
 - Your child's Individualized Education Program (IEP)
 - School records

Who can come to the visit?

- Anyone who knows your child and can help us to better know your child
 - Another family member
 - A therapist
 - An involved community member

What is going to happen when I arrive at the Fragile X Clinic

- You will check in at the front desk
- You and your family will be seated in the waiting area
- Medical staff will bring you to the clinic area
 - Your child will be weighed and measured
 - A nurse will ask you medical, developmental, and behavioral questions
- The Fragile X team will begin the appointment
- The appointment will take between 1 and 2 hours

What is going to happen during the appointment?

- The team will:
 - Review your family and medical history
 - Discuss your concerns
 - Answer your questions
 - Perform a physical and neurological examination
 - Provide you with information regarding the diagnosis and resources
 - Provide a discharge summary outlining all recommendations, when to return to the clinic, and important contact information

Who will help with my appointment?

Sandy

Scheduling appointment &
appointment related questions



Ellen

Billing and insurance questions



Who will I meet at my appointment?

Paula

Fragile X Registry and family
liaison



Gale

Nurse

Reviews brief medical history



Who will I meet at my appointment?

The Fragile X Team Doctors



Robyn Filipink, MD



Rebecca Kronk, PhD, CRNP

What if I have more questions?

- Appointment related questions, call Sandy at (412) 692-5561
- To speak with Paula, leave a message with Sandy, (412) 692-5561
- Billing or insurance related questions, call Ellen, (412) 692-7089
- For prescription refills, 412-692-5560, option 3
- Questions for the nurse, 412-692-5560, option 4
- Billing or insurance questions, 412-692-5560, option 5