

ELGAN Study Orientation Packet For Participating Families



**Child and Adolescent NeuroDevelopment Initiative
(CANDI)**

Child and Adolescent Psychiatry
University of Massachusetts Medical Center

To help you prepare for your visit, we have designed this orientation packet in two parts:

Part I: For the Parent

- Who We Are
- How to Get Here
- What to Expect When You Get Here
- How to Prepare for Your Visit

Part II: For the Child

- What to Expect!

Who We Are



Karl Kuban, M.D.

Chief of the Division of Pediatric Neurology at Boston University Medical Center
is the Principal Investigator of the ELGAN study.
He has been working on the study since it began ten years ago.



Jean A. Frazier, M.D.

Vice Chair and Director of Child and Adolescent Psychiatry
at the University of Massachusetts Medical Center
Is the Principal Investigator for your hospital.

The ELGAN Study is based out of Boston Medical Center in Boston, MA and includes doctors, researchers, radiologists, and statisticians working in 12 other sites across the country.

What We Will Want to Know About Your Child Before their Visit

To help us prepare for your visit, we will want to know a few things ahead of time:

- Medical equipment that your child may need during the evaluation
- Food allergies and preferences
- Vision and/or hearing impairments
- Motor impairment, especially in use of hands
- A diagnosis of ADHD
- A diagnosis of Autism Spectrum Disorder
- Special anxieties

If we missed any of these things when we talked to you on the phone please feel free to call Lauren at 774-455-4100 to let her know!

What to Bring With You When You Visit Us

- 1.** The name of your child's main teacher (current or most recent if it is summer) and your child's school address.
- 2.** The name of your child's pediatrician and their address.
- 3.** A book or something to do if your child's assessment takes longer than your portion of the visit (we do have free Wi-Fi at our office!)
- 4.** Any special item that will make your child more comfortable (doll, action figure, etc.)

How to Prepare for Your Visit

In addition to reading through this orientation packet, these are a few steps you can take to make sure you and your child are ready for your visit:

- Read Part II of this booklet with your child so they know who they will be meeting and what they will be doing. This should help make them feel more comfortable when they arrive!
- Feel free to pack a lunch or bring snacks during for your visit. We will give you and your child breaks during the assessments so also feel free to bring quiet toys or books.

How to Get Here

Directions to UMass Medical School - University Campus of UMass Worcester

The UMass Worcester Campus is located in Worcester Massachusetts just north of Route 9, on the west side of Lake Quinsigamond, between Plantation Street and Lake Avenue North. The address is 55 Lake Avenue North however **GPS systems do not have the location correct.**

By Automobile

From the Mass Pike:

Eastbound: At exit 10, take I-290 east to exit 21, turn right at end of ramp and follow Plantation Street south.

Westbound: At exit 11, turn left onto Route 122 north for one mile, turn right at third light onto Sunderland road, left at first light onto Lake Avenue for 2.5 miles and cross Route 9. Make U-turn at second break in divider, and then turn right into campus.

From I-495:

Northbound: At exit 23, take Route 9 west. Follow Route 9 west for approximately 11 miles. After crossing the Lake Quinsigamond Bridge, take first right onto Lake Avenue.

Southbound: At exit 25, take I-290 west to exit 22, turn right at end of ramp, at second traffic light turn left at onto Plantation Street and proceed south.

From I-190:

At the merge with I-290 Shrewsbury exit (watch for exit ramp on left), take I-290 east to exit 21, turn right at end of ramp and follow Plantation Street south.

From I-290:

Eastbound: At exit 21, turn right at end of ramp and follow Plantation Street south.

Westbound: At exit 22, turn right at end of ramp, at second traffic light turn left onto Plantation Street and proceed south.

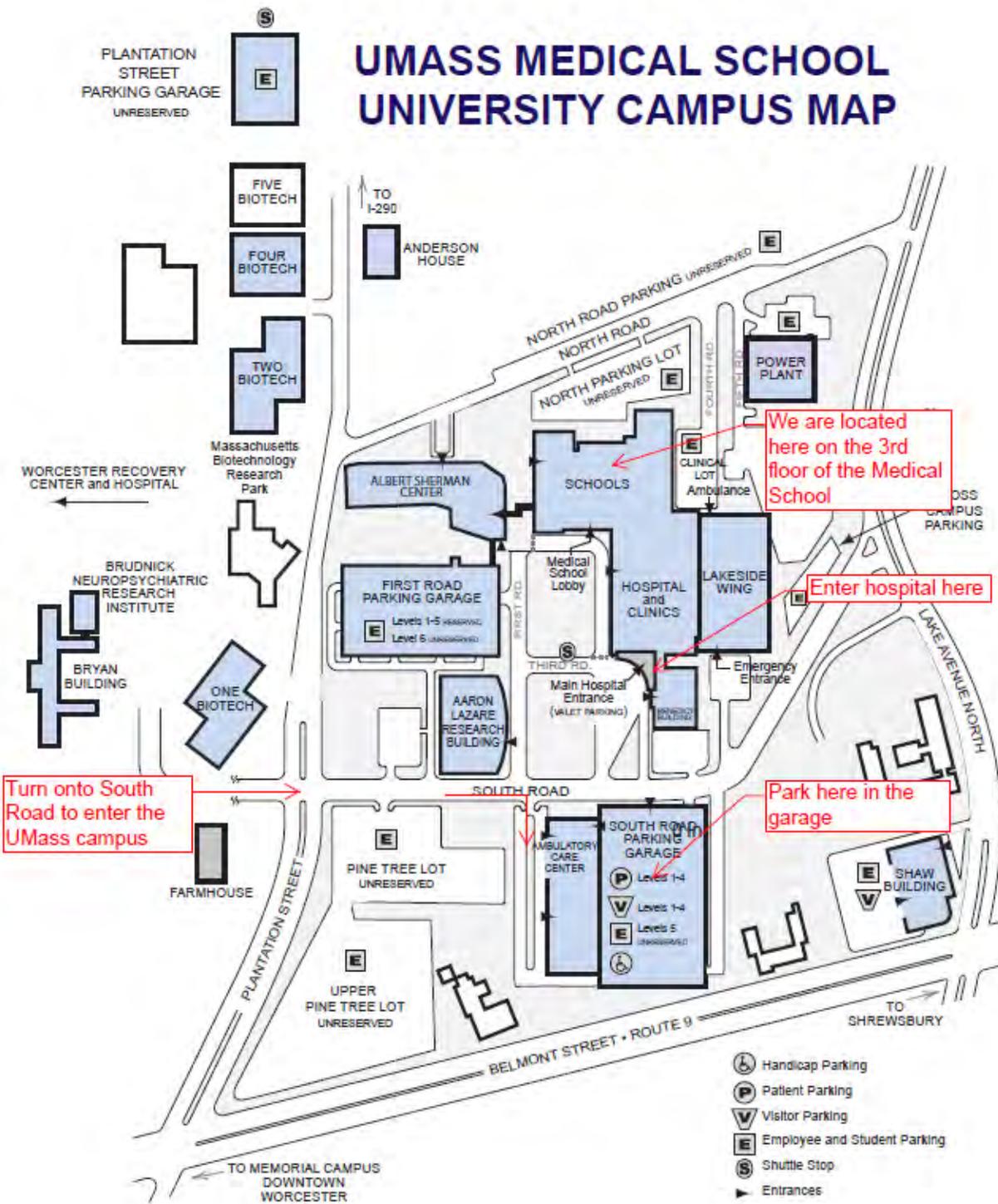
Parking:

When you take your turn off Plantation Street onto South Rd and enter the UMass Campus you will see signs for parking to your right in a garage across from the main campus building. Please take a ticket and park in the garage. See below for a more detailed map of the campus.

By other transportation

Locally, the Worcester Regional Transit Authority's #24 bus (Belmont Street/Lake Avenue) provides service to the UMass Worcester Campus. Please call the WRTA at (508) 791-9782 for the route and schedule.

UMASS MEDICAL SCHOOL UNIVERSITY CAMPUS MAP



What to Expect When You Get Here

Directions to **CANDI** once you get into the hospital:

- Our offices are located in the school side in suite S3-301.
- When you first enter the hospital and are facing the information desk head down the corridor to your left (the one that the gift shop is located on).
- Walk to the end of this corridor (you will pass the cafeteria on your right, keep going) and enter the school side of the building.



- Once you get to the end, there will be a set of elevators on your right called the “clinical wing elevators”.



- Take these to the 3rd floor and look for the CANDI signs directing you to our office which is Suite S3-301.

On the following page is the approximate schedule for the day (there can be variations based off of families needs) and at the end we will compensate you for your time and travel with \$165 cash and a \$20 gift certificate to Toys-R-Us for your child.



ELGAN Visit Schedule for PARENT NAME
Date & Time

Approximate Schedule:

- 9:00 am Greeting and ELGAN visit orientation, sign consent forms and provide contact information (cell phone, email, etc...)
- 9:15am - Education/Medical History & Social Factors questionnaires
11:00am Communication Function Classification System & Pediatric Quality of Life forms
Child Symptom Inventory-4, Seizure Screen, and Handedness forms
Social Responsiveness Scale
- 11:00 am Break/Snack with CHILD NAME (if needed)
- 11:30 am - Social Communication Questionnaire
12:30 pm Gross Motor Functional Classification
Scale & Fine Motor Classification Scale
Kaufman-Brief Test
- 12:45 pm Measure head circumference,
Wrap-up the visit and gift for CHILD NAME
- 1:00 pm Home
-

OR if Autism Diagnostic Interview-Revised (ADI-R) is indicated:

- 1:15 pm Autism Diagnostic Interview-Revised (your child will be engaged in a leisure activity with the research assistant during this interview)*
- 3:15 pm Wrap-up the visit and gift for CHILD NAME*
- 3:30 pm Home*

Part II: For your Child

Hi! Welcome to the ELGAN Study. This book will show you where you'll be coming for our exciting day together, and it will tell you about what we'll be doing. We are all very eager to meet you and your parents. We'll see you soon!!

When you first get to UMASS, your parents will park in the parking garage. This is a picture of the building with the garage inside. Look at all those windows!



This is a picture of the building you and your parent will enter to come find our offices.



Once you are in the hospital you should head down the corridor on the left to get to the elevators that will take you to our office.

As you walk down the corridor and pass the cafeteria look up! You'll see a sign that tells you when you enter the school!



Once you pass under this sign you'll take the elevators on your right to the 3rd floor.

When you get off look for our signs!

CANDI



This is what the entrance to our offices looks like



and these are some of the many friendly people who work here. We can say hi to them!



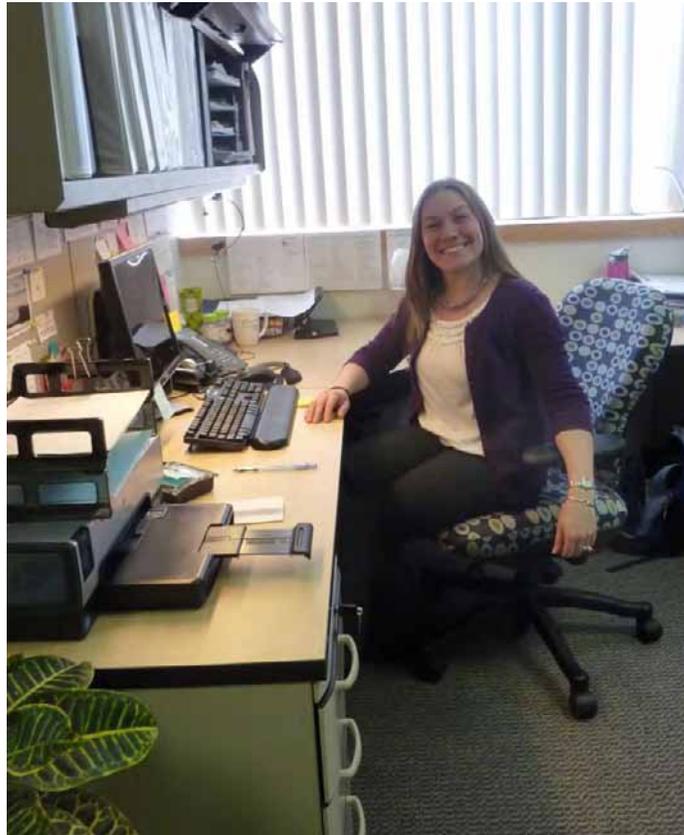
These are some people you might see sitting in their offices!



This is Candice our Teddy bear! She also hangs out in our office.



You will probably see Lauren there!



Lauren will talk with you and your parents about your day. She'll tell you about the interesting things you will be doing with us.

Then Lauren and your parents have their own work to do...

...while you do several activities with us!

First we will ask you to do puzzles and play some brain games with us!



This is one of Mollie's favorites.



It's one of Candice's favorites too!

Then we will measure you to see how tall you and how much you weigh.



Martha is getting ready to take these measurements here!

Sometimes we will be talking to the person who brought you today for a few hours in the afternoon. When that happens, we will let you watch a movie!
These are the movies we have...



...but you can also bring your own from home!

At the end of the day we will give your parents some money to thank them for all their help...



...and before you leave, you will get a gift certificate to Toys-R-Us for all your help.



Bye!

We'll be sad to say good-bye at the end of our day, but we'll see you again next time!