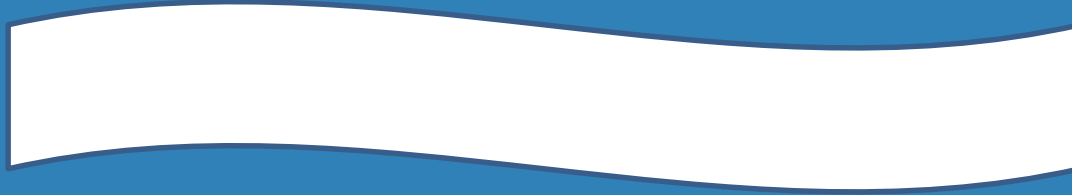


# My Trip to the NIH





Hi! Meet Cuddles. Cuddles has gone to all the places you will go while you are at the NIH. See if you can find Cuddles in any of the pictures you see.



Welcome to the NIH!  
You can get information about your visit from the  
**Information Desk.**

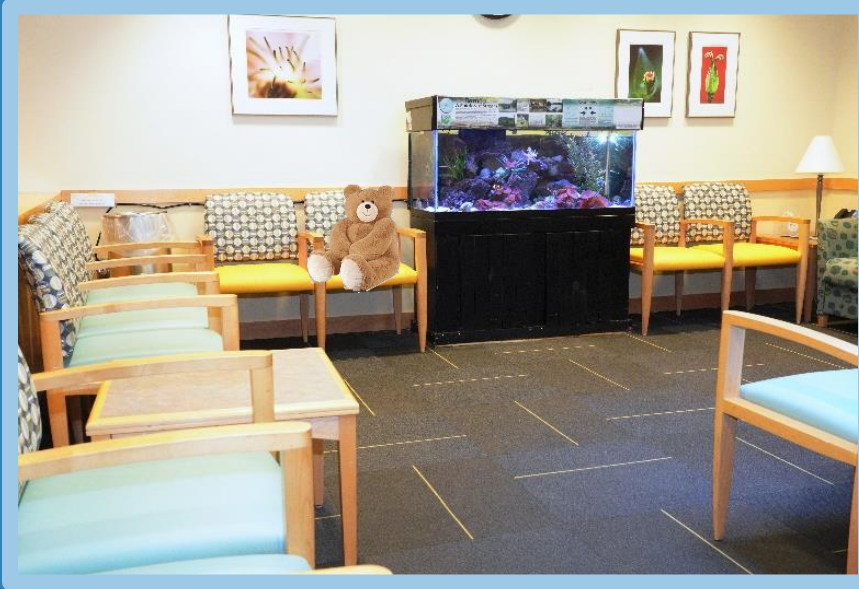


When you get there, you might be asked to put on an NIH mask to wear inside the Clinical Center. The mask might look like one of the pictures you see here.

One of the masks has bears on it, just like Cuddles!



You will visit the NIH badging office to take a picture and get your official ID badge.



You will meet your new doctors and nurses  
in the **Pediatric Clinic.**

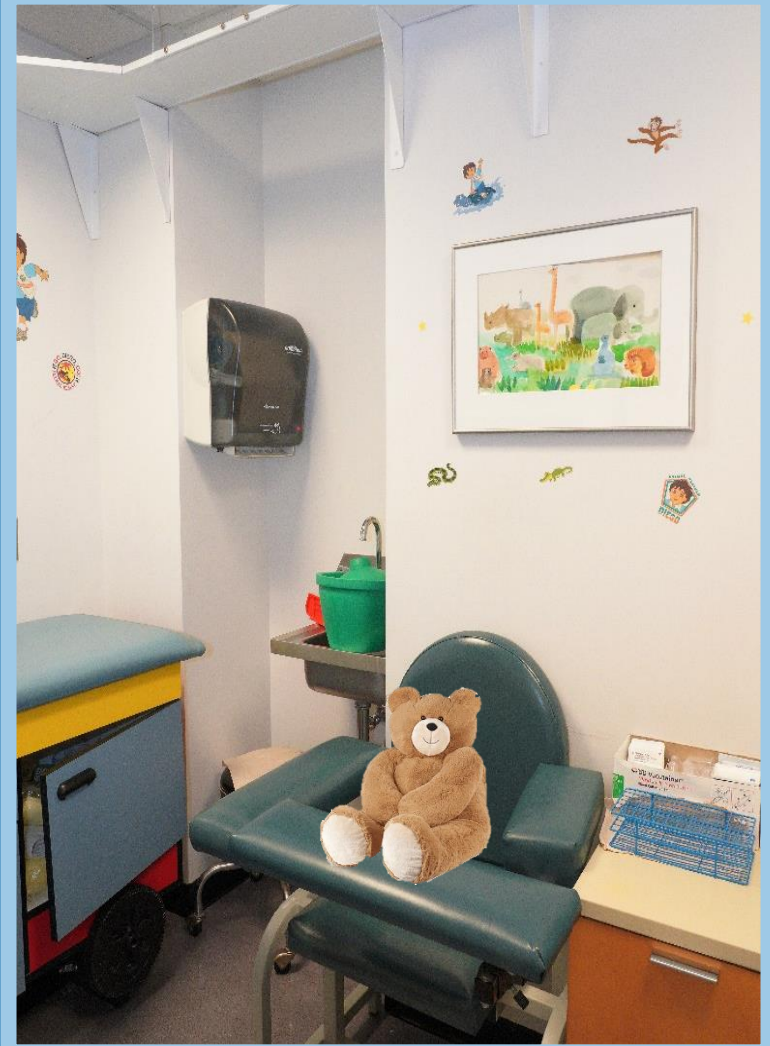
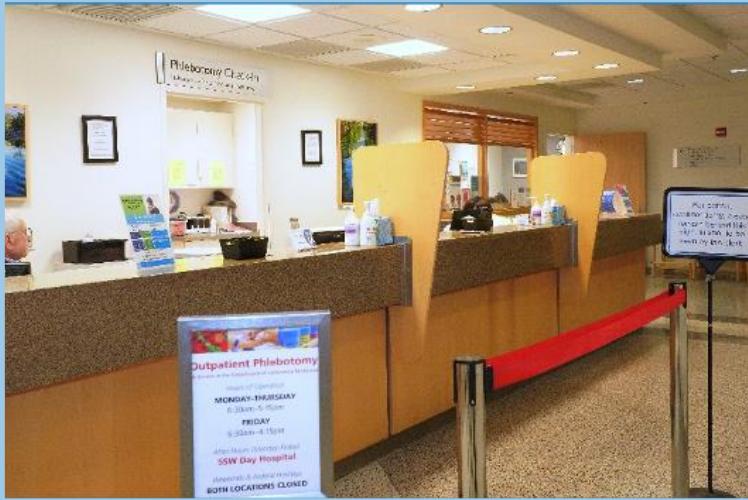


Here are pictures of the team that will be taking care of you when you are at the NIH. We are excited to meet you!

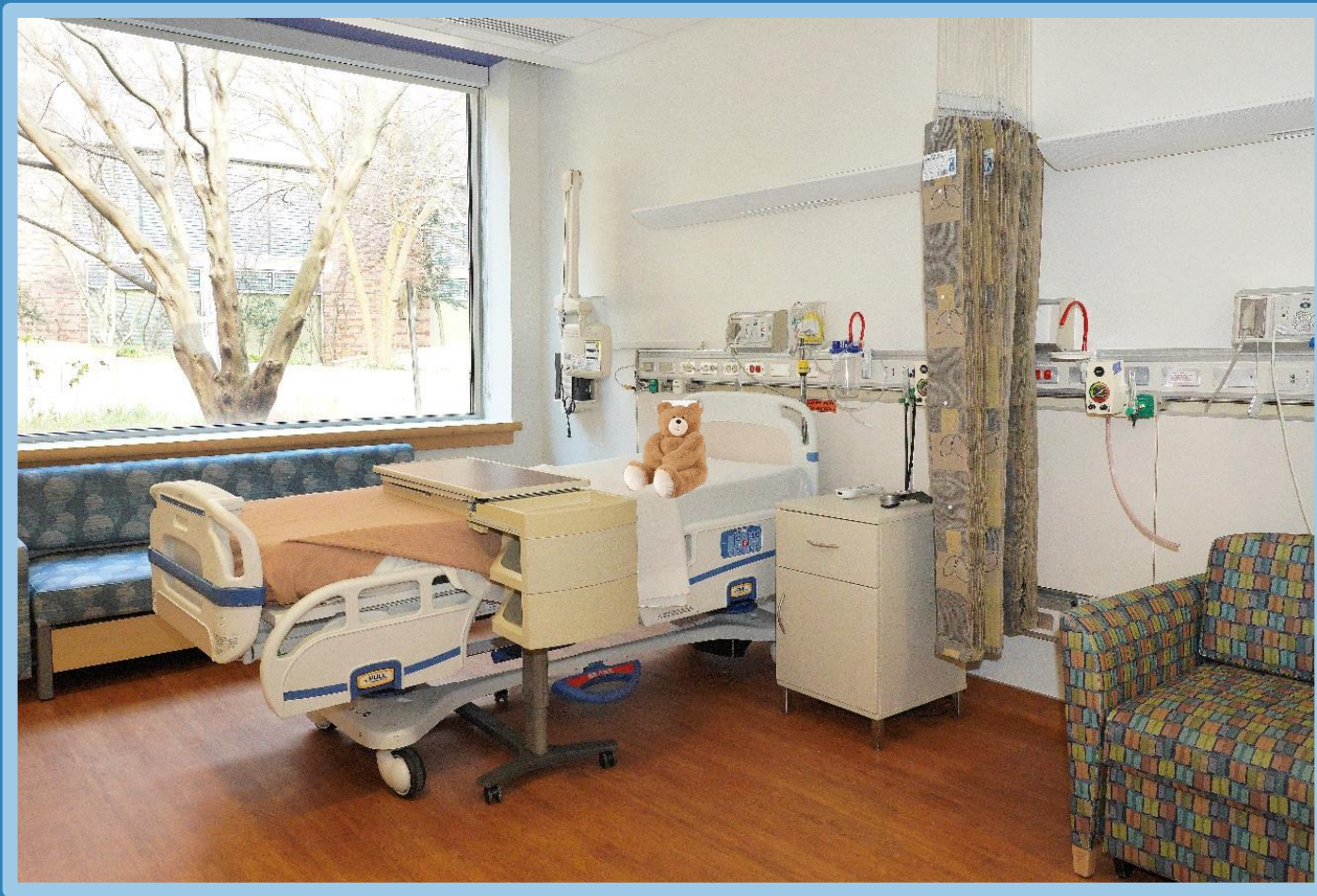


A tech or nurse may take your vitals – including: measuring your weight and height and taking your blood pressure and your temperature. The medical team may also ask you some questions about your health.





You may have your labs drawn in the Pediatric Clinic or in **phlebotomy** depending on whether you already have a line or port.



You may have a room in the **day hospital** or **1NW Pediatrics**. If you stay overnight, a parent will be able to stay with you.



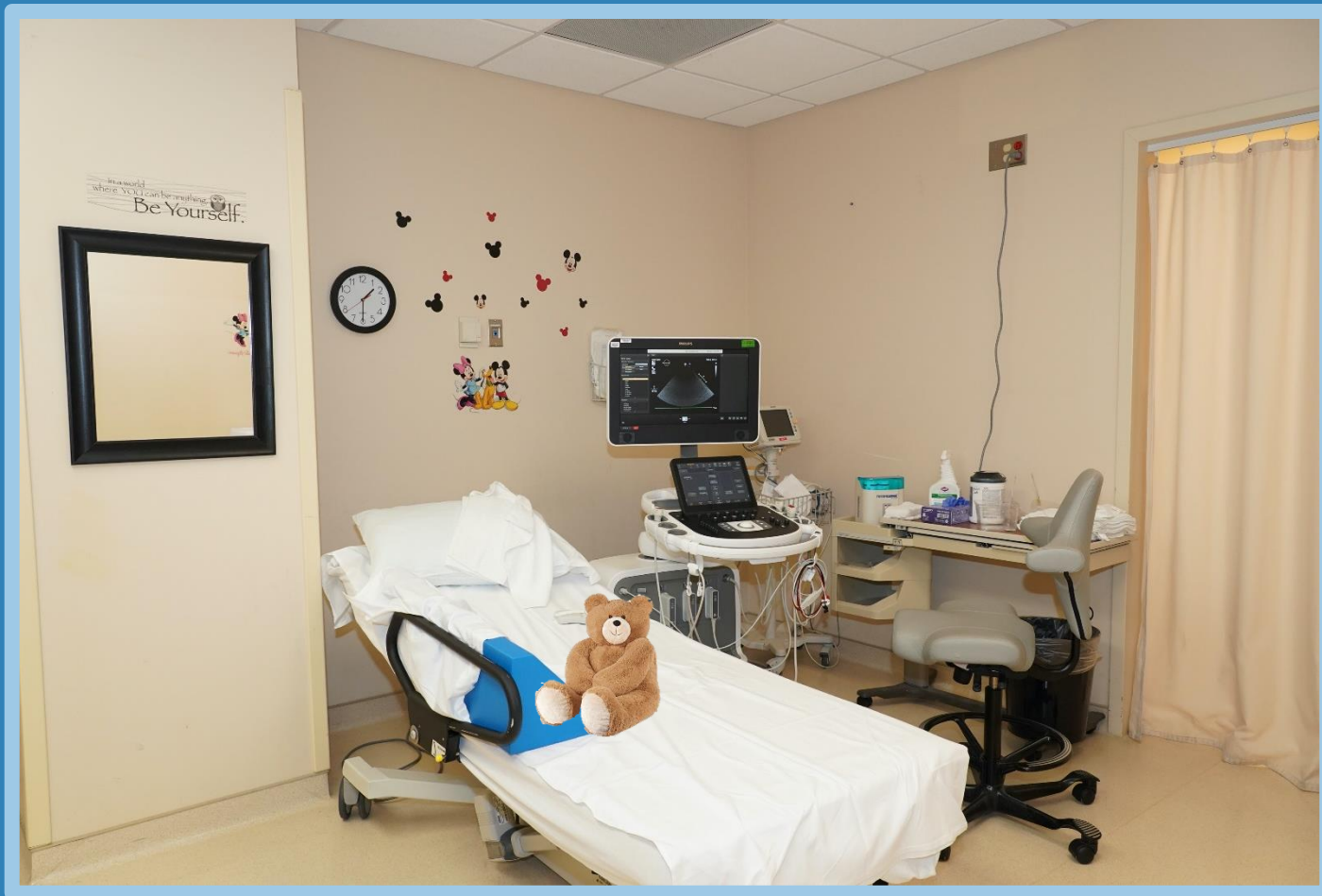
Your family can spend time in the family lounge on  
**1NW Pediatrics.**



You will have time to play in the  
NIH playrooms!



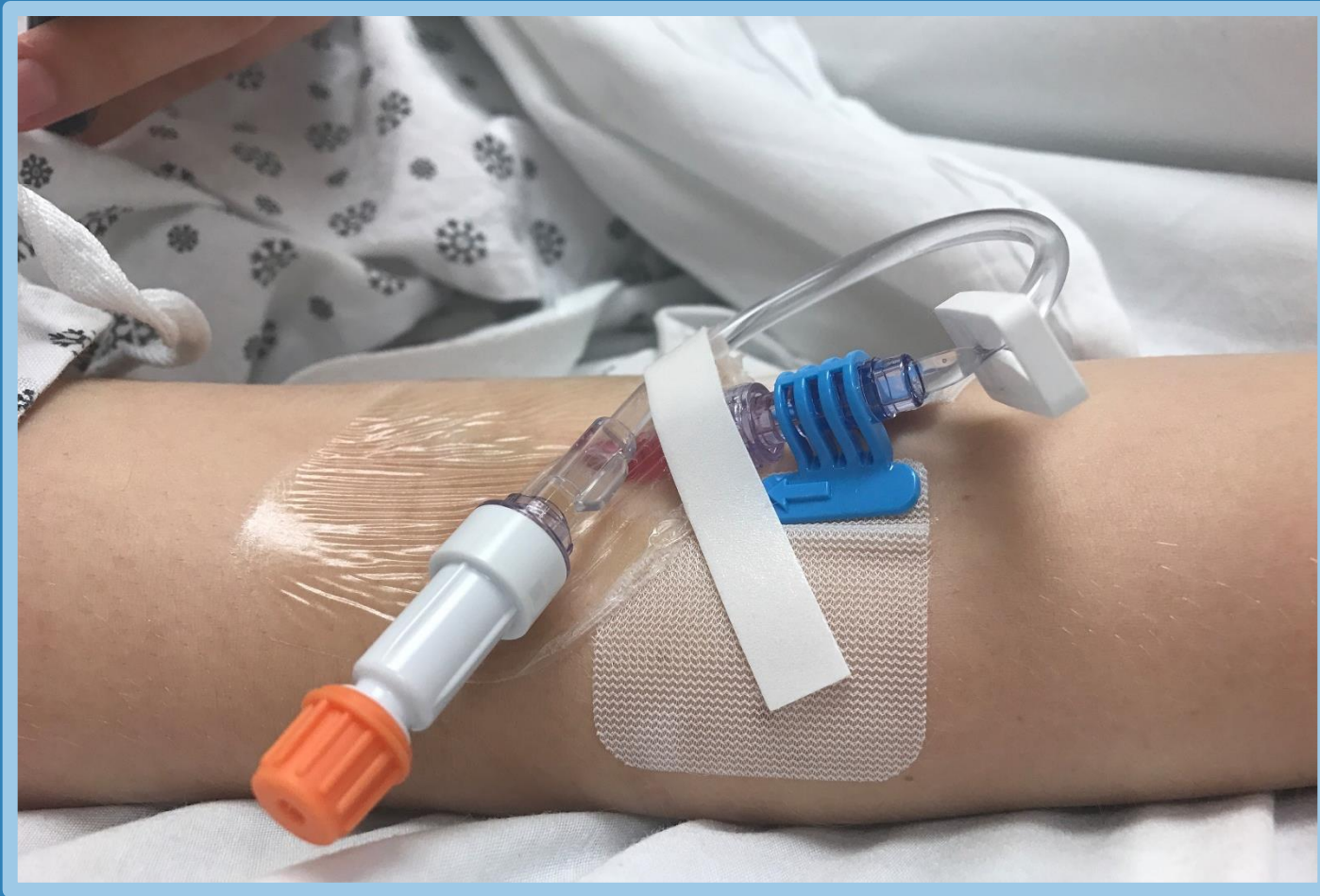
The **Heart Station** is where you will have an EKG (electrocardiogram). You will have stickers placed on your chest to show your heart rate and rhythm.



An echo (echocardiogram) is an ultrasound test for your heart, which will be performed in our **Echo lab**. You will have a warm gel placed on your chest with a microphone-like device that uses sound waves to view your heart.



You may have an appointment in **Radiology** for a CT scan or MRI. These big machines can help us take pictures of your organs and tissues in your body. You may need to drink contrast or have an IV medication before this test.



The IV is a small, bendy straw that the nurse will use to give you medicine to help your body. The IV will go into a vein inside your arm or hand. This is what it will look like.





**Nuclear Medicine** is another department that can do tests, such as a PET scan, to show detailed pictures inside of your body. You will receive a special IV medication before you have the scan.



At the pre-anesthesia clinic, your doctors and nurses will do a check up and listen to your lungs and heart.



You may also have a bone marrow biopsy and lumbar puncture. The morning of this procedure, you will go to the **1NW Day Hospital** to have an IV put in.



Next, you will go to the **Operating Room (OR)** for the bone marrow biopsy.

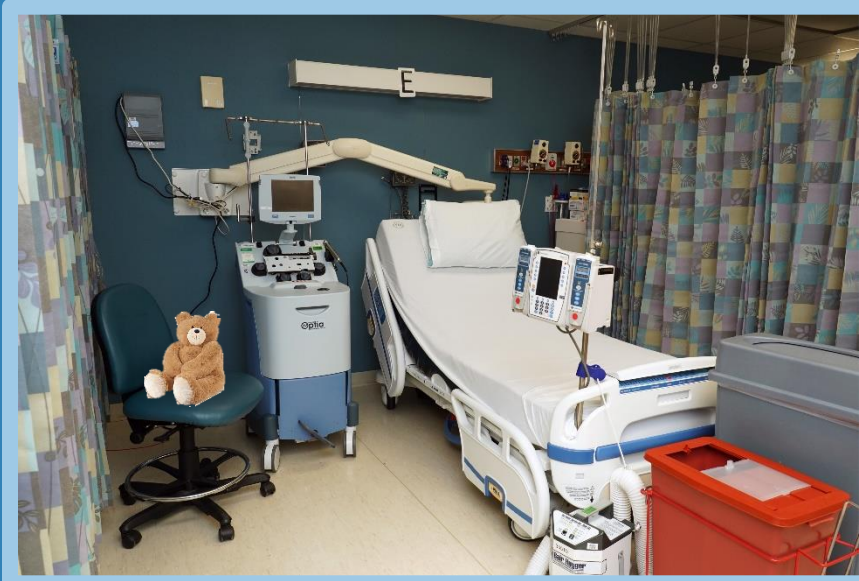
Don't worry! Your caregiver will get to stay with you until you fall asleep.



After your bone marrow biopsy, you may go to the **1 NW day hospital** to recover. You will soon be ready to eat, drink, and return to the Children's Inn or hotel.



You may come to **IR (interventional radiology)** for your line placement procedure. This line/apheresis catheter will be used to collect your cells.



The **Dowling Apheresis Clinic** is where you will go to have your cells collected. They will connect your new line to a machine that will collect your blood cells that will be used to make your CAR cells for treatment. This can take several hours.



You may meet with different doctors or specialists, including our **neurology and neuropsychology team**. They may test your muscle strength, reflexes, and coordination, and you may be asked to do some activities so they can learn about your attention, memory, language, and problem-solving skills.





You may get to ride on the **NIH Shuttle**.



You may stay overnight at **The Children's Inn.**



At the Children's Inn, you will get your own mailbox where you can get letters and other fun surprises.



There are lots of fun things to do at the Inn, like playing games in the game room.



You can find fun toys to play with in the playroom.



You and your family can cook and eat meals together at the Inn kitchen.



Your first week at the NIH might feel busy. There are a lot of new places to visit! But don't worry, it won't always feel that way. And remember, your caregivers and study team will be there to help you the whole time!



| Pediatric Oncology Branch   |              |                          |  |
|---|--------------|--------------------------|--|
| 1H Pediatric Clinic   | 301-451-9229 | PI:                      | Nirali Shah 240-760-6199               |
| 1NW Day Hospital  | 301-451-7727 | Fellow/NP                | Bonnie Yates 240-760-6204              |
| 1NW Inpatient   | 301-451-0345 | Nurse:                   | Lauren Little 240-858-3536             |
| Admissions  | 301-496-3141 | Nurse:                   | Toni Foley 240-858-3166                |
| NH Page Operator<br><i>For urgent or after-hours contact, call operator to reach the POB fellow</i> | 301-496-1211 | Patient Care Coordinator | Terri Terri.moore@NIH.gov 240-858-3097 |

| POB Patient Schedule  |   |
|-----------------------|---|
| Name                  | MRN #   |
| Dates                 | Protocol #  |
| <b>Sunday 7/11</b>    | Arrival day, Check in at Children's Inn   |
| <b>Monday 7/12</b>    | 8:30am- Admissions, 1 <sup>st</sup> Floor<br>9:30am - Consents with Research Nurse, Pediatric clinic, 1 <sup>st</sup> Floor<br>10:30am - Labs, Phlebotomy, 1 <sup>st</sup> Floor<br>11:00am - COVID - 19 testing, Pediatric clinic, 1 <sup>st</sup> Floor<br>12:00pm - Physical exam, Pediatric clinic, 1 <sup>st</sup> Floor<br>1:00pm - Meet with Dr. Lori Wiener, Pediatric clinic, 1 <sup>st</sup> Floor<br>2:00pm - Meet with Dr. Shah/ Shalabi, Pediatric clinic, 1 <sup>st</sup> Floor |
| <b>Tuesday 7/13</b>   | 10:00am- MRI (brain), Radiology, 1 <sup>st</sup> Floor<br>12:30pm - Pre-Anesthesia, Room 2C523, 2 <sup>nd</sup> Floor<br><b>No eating or drinking after midnight</b>  |
| <b>Wednesday 7/14</b> | 7:30am- Arrival in OR<br>8:00am- Bone marrow & Lumbar Puncture, OR, 2 <sup>nd</sup> Floor<br>Recover on 1NW- Day hospital   |
| <b>Thursday 7/15</b>  | 12:00pm - Meet with Dr. Shah/ Shalabi, Pediatric clinic, 1 <sup>st</sup> Floor<br>1:00pm - Neurology, Pediatric clinic, 1 <sup>st</sup> Floor<br>2:00pm - EKG, Heart station, 1 <sup>st</sup> Floor<br>3:00pm - ECHO, 5NE 5 <sup>th</sup> Floor   |

Patient Reminders/Responsibilities

- To arrange travel, call Omega Travel: 301-496-6676
- To reserve your room, call The Children's Inn: 301-496-5672 <http://www.childrensin.org>
- Check your itinerary to determine if shuttle is available for your flight plans. Patient Transportation Desk: 301-496-1161. [http://www.ors.od.nih.gov/pep/dats/transportation/PatientServices/PatientShuttles/Pages/patient\\_shuttles.aspx](http://www.ors.od.nih.gov/pep/dats/transportation/PatientServices/PatientShuttles/Pages/patient_shuttles.aspx)

|                      |  |
|----------------------|--|
| <b>Friday 7/16</b>   | 7:30am - COVID - 19 testing, Pediatric clinic, 1 <sup>st</sup> Floor<br>8:00am - CT scan, Radiology, 1 <sup>st</sup> Floor<br><b>No eating or drinking for six hours prior to scan</b><br>9:30am - PET scan, Nuclear med, 1 <sup>st</sup> Floor - <i>You may eat after</i><br>12:00pm - Labs, Pediatric clinic, 1 <sup>st</sup> Floor<br>12:30pm - Physical exam, Pediatric clinic, 1 <sup>st</sup> Floor<br>1:30pm - Meet with Dr. Shah/ Shalabi, Pediatric clinic for treatment consent, 1 <sup>st</sup> Floor |
| <b>Saturday 7/17</b> | No scheduled appointments ☺  |
| <b>Saturday 7/18</b> | No scheduled appointments ☺  |
| <b>Monday 7/19</b>   | 7:00am- Arrival in 1NW- Day Hospital<br>8:00am- Apheresis Line placement, Interventional Radiology (IR), 1 <sup>st</sup> Floor<br>~11:00am- Apheresis, Dowling clinic, 1 <sup>st</sup> Floor<br>Recover on 1NW- Day hospital and have temporary line removed   |

\*All appointments are subject to change

Patient Reminders/Responsibilities

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- To reserve your room, call The Children's Inn: 301-496-5672 <http://www.childrensin.org>
- Check your itinerary to determine if shuttle is available for your flight plans. Patient Transportation Desk: 301-496-1161. [http://www.ors.od.nih.gov/pep/dats/transportation/PatientServices/PatientShuttles/Pages/patient\\_shuttles.aspx](http://www.ors.od.nih.gov/pep/dats/transportation/PatientServices/PatientShuttles/Pages/patient_shuttles.aspx)

You will get a schedule with a list of all your appointments at the NIH. Your schedule will look a little different than this, but your study team and your caregivers will help you keep track.

# Questions I might ask the NIH team:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_



Thank you for taking a tour with me! See you at the NIH. Your study team can't wait to meet you!