



National Human Genome Research Institute
National Institutes of Health
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Dear Clinseq™ Participant,

Thank you for your participation in the Clinseq™ study. We are looking forward to meeting with you on **Thursday, February 16th**. This initial visit will take place in the Clinical Center (Building 10N) at the National Institutes of Health (NIH). This letter contains information about the materials enclosed in this packet, including information that you must complete prior to your visit. It also contains information on how to get to the NIH campus via car, bus or Metro rail, as well as information on campus security and parking.

FORMS TO COMPLETE FOR YOUR VISIT

<If relevant, insert:

Payment for your Visit

Please read this information on how you will receive the incentive for your upcoming visit. As you are aware, you will be given a \$100 incentive for your participation in the study. You will be given \$30 of this money in cash on the day of the visit to help pay for your meals and transportation. The other \$70 will come as a check that is mailed to your home 2-4 weeks following your appointment. The check is processed and mailed by the Department of the Treasury, so we are not able to expedite the process. In addition, the DOT may withhold the check if you are found to owe back taxes, child support, etc. In order to receive this money, you must complete the enclosed voucher form, and bring the voucher confirmation print out with you to your appointment. In addition, you must be sure to turn these forms in at the voucher office immediately following your registration with Admissions (see maps for directions). By doing this, you will be able to return to the \$30 in cash at the end of your visit. **If you do not follow these steps, you will have to wait for a check for the \$100 amount to be mailed to you following your visit. This process can take several months to complete.**

Please note that we do not provide any reimbursement for the cost of transportation to or from your visit, meals purchased while at your visit or any hotels or lodging associated with your visit beyond the \$30 in cash that you will receive at your appointment. Please notify us if you do not wish to receive this compensation or need to request supplemental reimbursement for financial or medical need.

Consent Form

First, you will find a copy of the consent form for the ClinSeq™ study on the left side of this folder. Please read through this entire form in order to ensure that you are willing to participate in the project. There is no need to sign or date the consent form prior to your visit. Someone from our research team will go over the form with you when you come in for your appointment, and answer any questions that you may have before you sign the form.

Medical Intake Form

In this folder, you will also find a form that is called the “Participant’s Medical Intake”. It asks you questions about your medications and how long you’ve taken them, as well as your medical history and some demographic information. Please be sure to complete that form before your visit with us.

Family History Form

Next, please find the family history initiative form. You need to completed this form and bring it to your appointment. If you prefer, you may complete this form online instead of filling out the form in your folder. Instructions for doing this are listed below. Your family history will be reviewed with you during your appointment.

Instructions for Completing Family History Online

If you use the online version, **please save a copy for your records and print a copy and bring it to your appointment with you.** You can save and print a copy of your family tree by doing the following:

1. Go to: <https://familyhistory.hhs.gov/fhh-web/home.action>
2. After entering your family history, you can save the file to your computer. This action will save your family history as a “XML” file, which you can modify or update at a later date. We also recommend saving this file in another format. Please see the **note** below.
3. Once you have saved your file, choose **VIEW DIAGRAM AND TABLE**. You will be brought to a new screen
4. Click on **“PRINT HISTORY”** at the top of the screen. You will be brought to a new screen where you will see your family tree and the chart
5. Print your family history tree (drawing) and the accompanying chart
6. Please bring your family tree and chart to your appointment

NOTE: Since the family history online tool is only available for a short time, we strongly recommend that you save your family history to your computer as a “.pdf” file after Step 6 above, once you are in “Adobe” or print a copy for your records. Once it is not available, you will not be able to access the “XML” file (Step 1 above). It is important that you have a copy for your records to share with family members and health care providers.

TRAVEL TO THE NIH CLINICAL CENTER

Identification and Security at the NIH

The NIH operates under a heightened level of security. Please be sure to bring a government issued photo ID with you to your visit and arrive at least 40 minutes prior to your first appointment to allow time to pass through security checkpoints and travel to the Clinical Center.

Getting to the NIH Clinical Center via Car

1. Drive to the NIH
 - *If traveling from points North of Washington DC:* Take I-95 south toward Washington, DC. At I-495 (Capital Beltway), head west toward Silver Spring/Bethesda. From the Beltway (I-495), take Exit 34, which is Rt. 355 (Wisconsin Ave./Rockville Pike) and head south toward Washington/Bethesda.
 - *If traveling from points South of Washington DC:* Take I-95 north toward Washington, DC. At I-495 (Capital Beltway), head north toward Silver Spring/Bethesda. From the Beltway

(I-495), take Exit 34, which is Rt. 355 (Wisconsin Ave./Rockville Pike) and head south toward Washington/Bethesda.

2. Enter the NIH Campus

- *If you arrive before 7:00 am:* Enter the NIH campus using the main entrance at Route 355 (Rockville Pike). You will have to stop at the security checkpoint and have your car searched. Please be sure to have government-issued photo ID with you in order to enter the campus. Once you go through the security checkpoint, make a right on Center Drive. After the second stop sign, continue on Center Drive and follow signs to “Clinical Center”. The main entrance to the Clinical Center will be to your left on Center Drive. “Patient Parking” is just past the main entrance and also to your left.
- *If you arrive after 7:00 am:* Use the patient entrance on West Cedar Lane, which is just off of Route 355 (Rockville Pike). You will have to stop at the security checkpoint and have your car searched. Please be sure to have government-issued photo ID with you in order to enter the campus. Once you go through the security checkpoint, you will see the main entrance to the “Clinical Center” straight ahead, up the hill. Make a right on Center Drive, and follow signs for “Patient Parking”, which will be to your left on Center Drive.

3. Park at the Clinical Center Building using one of the free options listed below:

- *Self-park* in the Patient Parking garage (P1), which is on the west end of Building 10 off Convent Drive. Parking attendants will be available to assist you. You’ll enter the new hospital through a new lobby on the lower (B1) level. Stop by the Hospitality desk to validate your parking ticket. *** If you arrive before 7 AM and do not receive a parking ticket, you may receive a validated ticket at the Hospitality desk prior to leaving NIH campus. The South Elevators serve the parking garages.
- *Use the valet parking service for patients* by driving to the Clinical Center’s main entry (see map). Valet parking is available Monday through Friday, 7 am -10 pm. When you arrive, have your valet claim ticket validated at the Hospitality desk.

Getting to the NIH Clinical Center via Metrorail or Bus

1. Travel to the NIH

- *If traveling via Metro:* Take Metro’s red line to the Medical Center Station. Take the escalators or elevators up out of the station. Walk directly into the building in front of you, which is called the NIH Gateway Center or Building 66.
- *If traveling via Bus:* From the bus station, proceed directly into the building across from you, which is called the NIH Gateway Center or Building 66.

2. You must go through NIH Gateway Center in order to complete the NIH security check. Please note that you must bring a government-issued photo ID in order to complete the security check. The security check usually takes approximately 20 minutes to complete.

3. After leaving the security check, you will be issued a visitor’s pass. Please display the pass at all times while on the NIH campus.

4. Take the campus shuttle to get to your first appointment in the Clinical Center (Building 10N). As you exit the Gateway Center Building, the NIH shuttle stop is to your right. The shuttle marked “NIH Campus” (red line) will take you to the Clinical Center. It begins running at 6:30 AM and a bus departs every 10-15 minutes. Take the shuttle to Building 10 North stop, which is the 3rd shuttle stop. Enter the building and follow the directions on your enclosed schedule to your first appointment.

NAVIGATING THE CLINICAL CENTER & APPOINTMENT INFORMATION

Getting around the Clinical Center (Building 10N)

Hospitality desks are located throughout the Clinical Center, including at the main entrance and in the lobby adjacent to the Patient Parking garage. Staff can answer your questions and provide directions. Maps of each floor will be available at the Hospitality desks.

Admissions <insert: & Collecting Your Incentive>

If this is your first time participating in a study at the NIH, the first appointment on your schedule will be with Admissions. Please see the enclosed maps for the location of Admissions. ***After registering with Admissions, <insert: **please proceed to your first appointment** listed on your schedule.> OR <insert: **please proceed to the voucher office to turn in your paperwork in order to be compensated for your visit.** Once you have turned in that paperwork, please proceed to your first appointment listed on your schedule.>

Meals During Your Visit

Please remember not to eat anything after midnight on the night before your visit. On the morning of your visit, do not eat or drink anything except water. If you take regular, daily medications, please remember to take all of them on the morning of the appointment EXCEPT FOR YOUR DIABETES MEDICATION. Instead, bring your diabetes medication with you and take it here at your appointment.

You will be given a light breakfast by the nurse once you arrive in the outpatient clinic. You may also be provided with a light snack in the afternoon if your appointment is taking a long time, but if you would like to eat lunch while you are here, please bring a meal or snacks that do not require refrigeration or heating from home. Alternatively, there are several coffee bars and cafeterias in the building where you can purchase your lunch.

Please find enclosed your complete appointment schedule and additional information for you to complete prior to your visit with us. If you have any questions or concerns prior to your visit, please contact Frances Wright at 301-443-6160. We look forward to seeing you soon!

Sincerely,

Lenita Smith
Patient Care Coordinator
National Human Genome Research Institute