

Instructions for Stanford Chronic Fatigue Syndrome Patients

Disclosure: Dr. Montoya does not have any potential conflict of interest to report regarding the manufacturers of the drugs he advises or prescribes for patients with CFS. He does not have any commercial or financial stake in the laboratories where patients' specimens are tested.

For Emergencies or Urgent Health Concerns:

- If you are experiencing a medical emergency, please call 911.
- If you have a medical question, please call the Stanford Infectious Diseases Clinic at (650) 736-5200, fax: 650-725-6908

General Instructions

New Patients

- Dr. Montoya has expanded the CFS clinic so patients can be seen in a timely manner. To this end, he has hired three physician's assistants who will aid him in the clinic beginning April 2012.
- If you would like to be placed on the waiting list for Dr. Montoya, please contact the New Patient Coordinator at (650) 736-5200, fax (650) 320-9443

Dr. Montoya's CFS clinical Team

- Dr. Montoya's CFS clinical team consists of:
 - Jane Norris, PA e: jl Norris@stanford.edu t: (650) 492-3835
 - Aimee Jadav, PA e: ajadav@stanford.edu t: (650) 421-3082
 - Amity Hall, PA (on a temporary leave starting August 2013)
- Please contact Jane Norris, Aimee Jadav or the Stanford infectious disease clinic regarding patient care, this includes discussing lab results. You may also schedule visits at the clinic with Jane or Aimee, if you need to follow-up any sooner than Dr. Montoya's schedule allows.
- **Urgent medical questions should always be directed to the clinic.**

Dr. Montoya's CFS Research Team

- Dr. Montoya's team consists of:
 - Diana Dobbs, research assistant e: drdobbs@stanford.edu t: (650) 723-8970
 - Ian Valencia, research coordinator e: ivalenci@stanford.edu t: (650) 723-7328
 - Jane Norris, research coordinator e: jl Norris@stanford.edu t: (650) 723-8126
- **The members of Dr. Montoya's ME/CFS Research Team are Stanford University employees, not clinic staff. The research coordinator and research assistants are not responsible for handling issues pertaining to patient care.**
- **Questions regarding prescriptions and insurance coverage should always be directed to the clinic, as the Research Team is not equipped to handle these issues.**
- The purpose of the Research Team's involvement in Dr. Montoya's clinic is twofold:
 - To enhance the quality of CFS research conducted through patient interaction

- To assist with Dr. Montoya's workload in the CFS clinic
- Research Team members are happy to help facilitate communication with Dr. Montoya in certain limited circumstances, but have many other responsibilities unrelated to clinic and cannot guarantee a response to messages within a certain timeframe. For your health and safety, it is important to direct any and all health related questions to the Stanford infectious disease clinic.
- For more information about our research team and clinic efforts please visit our website: <http://mecfs.stanford.edu>

Scheduling Follow Up Appointments

- CFS treatment and follow up is a long-term process. Therefore, Dr. Montoya requests to see patients for follow up visits every **6-12 months**.
- If you would like to have a follow up appointment with Dr. Montoya, it is crucial that you **make a future appointment at check out**. If you do not, we cannot guarantee that you will be seen within the timeframe Dr. Montoya recommends.
- As one of the only doctors in the area who treats CFS from an infectious diseases perspective, Dr. Montoya is extremely overloaded in his clinics. He may not be able to see patients for follow-up visits as frequently as he would like. Please call the Stanford Infectious Diseases Clinic **at least 6 months in advance** to schedule an appointment.
- If you are unable to make a follow up appointment within the time frame Dr. Montoya requested, please reserve the **next available appointment with the clinic**. If you would like to be seen sooner than your appointment time, please request to add yourself to the cancellation waiting list through the clinic. Then if there is a cancellation before your appointment time, you will be called to take the sooner appointment.
- Please note that it is not necessary to have new lab results for every visit with Dr. Montoya. He orders lab tests no more frequently than every 6 months. **Do not** cancel an existing appointment with him for the reason that you could not get the lab work done before the appointment. It is more important that you keep your appointment as scheduled than that you have new lab results.

Expect Delays

- Dr. Montoya takes the necessary time for each patient during his or her scheduled appointment. Sometimes that requires him to take longer than the scheduled time with a patient, which can cause him to run behind for his other appointments that day. Please be aware that this can happen, and consider bringing a book to read on your appointment day.
- Dr. Montoya answers his messages in the order of medical urgency. If a message is left regarding anything that is NOT medically urgent, it may take **days to weeks** for him to respond, depending on his schedule.

Prescription Refills

- To ensure that you do not run out of medication, your pharmacy must submit a refill request to the Infectious Disease clinic at least one month in advance. If your request is not received **at least one month in advance**, we cannot guarantee that your prescription will be refilled in time. Dr. Montoya is often traveling out of the country for work meetings and cannot accommodate last-minute refill requests.

- Please make sure your pharmacy has the new fax for refill requests: (650) 736-0513.
- You can call the clinic at (650) 736-5200 to check that they received your refill request and to follow up on the status of the refill.

MyHealth

- Please speak with the Stanford Infectious Disease clinic staff if you would like to activate your Stanford MyHealth account.
- **Please be aware that Dr. Montoya does not communicate with patients via MyHealth.** If you need to contact Dr. Montoya, please call the Stanford Infectious Disease clinic at (650) 736-5200.

Blood Work

- For most routine follow-up visits, Dr. Montoya orders blood work for patients no more frequently than **every 6 months**. Based on his clinical and research experience, Dr. Montoya does not believe it is necessary to order blood work more frequently because he has observed that change in antibody titers is only clinically useful to track over a long period of time.
- If you **need** to have blood tests completed before your next visit with Dr. Montoya, please make sure to have your blood drawn **2-3 weeks prior to your visit**. It can take a couple of weeks for all the test results to be analyzed and received by Dr. Montoya's office. If you are unable to have your blood drawn in advance of the appointment, please know that if you cancel the appointment for this reason, you will likely not be able to reschedule for several months.
- Dr. Montoya will discuss patients' lab results only during clinic visits. If you would like to discuss your lab results, you may contact one of the members of his clinic staff.
- None of Dr. Montoya's research staff can discuss lab results over the phone. If necessary, you may request that your lab results be mailed or faxed to you. We are not able to email lab results (this is Stanford's policy).
- Dr. Montoya requests that almost all blood tests be done by FOCUS laboratories. This is most easily done if blood is drawn at Stanford. Please use any blood-drawing station at Stanford Hospital and Clinics.
- Since treating CFS patients with antivirals is still in the research phase, there is no standardized way of evaluating if a patient's titers are "high" or "low." Therefore, Dr. Montoya can only compare patients' titers to the results of his clinical trial. In order to do this the blood must be analyzed by FOCUS laboratories, since FOCUS was the lab used in the clinical trial. Different labs analyze blood in different ways and use different reference ranges to report results, so it is not possible for doctors to compare results from one lab to another. It may not be useful for Dr. Montoya to look at lab results from any other lab for the following tests:
 - Babesia Microti Antibody, Bartonella Species, Brucella Antibody, Chlamydia Antibody Panel, CMV Antibody, Coxiella Burnetti Antibody Panel, Coxsackie A Antibody Panel, Coxsackie B(1-6) Antibody Panel, EBV Panel, Echovirus Antibody Panel, Ehrlichia Chaffeensis, Ganciclovir Antiviral Serum Level, HHV-6 Antibody, HHV-7 Antibody, HHV-8 Antibody, HSV-1/2 Antibody Panel, Mycoplasma Pneumoniae Antibody, Parvovirus Antibody, VZV Antibody Panel, HHV-6 PCR Quant, Parvovirus PCR Quant

Primary Care Physicians

Dr. Montoya specializes in Infectious Diseases and cannot function as a Primary Care Physician. Please make sure that you have a primary care physician to handle claims for disability and follow all other medical needs and check-ups. **If you do not have a Primary Care Physician, Dr. Montoya will not be able to serve as your Infectious Diseases consultant.**

Disability forms and letters

- Please request that these be completed and submitted by your Primary Care Physician. Dr. Montoya will not be the main provider of disability claims, and will only be able to support the disability paperwork and letters submitted by the Primary Care Physician.
- If you would like to obtain a letter supporting your disability claim from Dr. Montoya, please contact the Stanford infectious disease clinic or Dr. Montoya's clinical care team.

Patient Assistance programs

- If you cannot afford a medication, consider looking at the following websites, which offer information about patient-assistance programs for reduced- or no-cost medications to those who qualify:
 - NeedyMeds: <http://www.needymeds.org>
 - The Partnership for Prescription Assistance: <http://www.pparx.org>
 - PatientAssistance.com: <http://www.patientassistance.com>
 - RxAssist: <http://www.rxassist.org>
- Your primary care physician or local health clinic may also provide you with information on how to afford your medication. You can also contact the manufacturer of the medication to see if a patient-assistance program is offered.

Insurance Issues

It is worthwhile to follow up on denied insurance claims. Corresponding back with the insurance company will often get coverage on tests, medications and doctor's visits. This website gives tips to help you correspond with your insurance company: <http://www.bankrate.com/brm/news/insur/20020619a.asp>

Clinical Advice

While in recovery, please do NOT overexert yourself.

- A lot of our patients report that their level of functioning feels like a rollercoaster. This description shows that the patient is overdoing it, and we believe that this behavior may seriously jeopardize the patient's potential for a full recovery. As soon as patients start to feel better, it is natural to want to increase their activity level; however, this is not advisable during the initial recovery process because it will likely lead to a crash.

- We hypothesize that these crashes, or episodes of heightened fatigue, may have a cumulative effect on a patient's health, and may compromise the patient's potential for a full recovery.
- Imagine that every time you crash, your immune system overreacts as a response (as CFS may be an autoimmune disorder). As a result, the immune system attacks your body's own cells in the Central Nervous System (CNS). Once these cells are damaged they may never recover. Even in the best-case scenario, when the viruses have been successfully treated and kept at bay, the damage that has already been done to the CNS may never be repaired. This may prevent the patient from fully regaining his or her cognitive and physical capacities. Theoretically this is how overdoing it and the subsequent crashing which results may have a long-term negative effect on health.
- Each patient is unique and should develop a routine level of physical and cognitive functioning that is appropriate for him or her. Patients should feel like their functioning level is constant from day to day, so that they are not experiencing any crashes. We feel that only once patients have learned to function under their threshold for crashing have they optimized their treatment plan and their chances for a full recovery.

If you start to feel better...

- After 3-6 months of experiencing the benefit of treatment, it may be appropriate to gradually increase levels of activity. Again, it is important to ensure that this is a very gradual process. If the patient experiences a crash during this time, please reduce activity level until functioning is stable again.
- Please take it easy. Patients can slowly begin to increase their physical and cognitive undertakings in VERY small increments. Please avoid all stressful situations and drastic changes in lifestyle.
- Week by week, patients can slowly start to add small things to their daily routine. Please make sure to proceed slowly, and make sure new activities will not lead to a crash.
- We believe that the full recovery process may take between 1-2 years.

Worsening

- Many of our patients experience a worsening of symptoms during antiviral treatment. As these antiviral treatments are still in the research phase, we do not know what is "normal" and what is "abnormal".
- If the worsening is concerning, please call the clinic at 650-736-5200 and leave a message for Dr. Montoya.
- If the worsening is unbearable, please call the clinic, leave a message with the doctor, discontinue medication, and contact your Primary Care Physician.
- If the worsening leads to an emergency, please dial 911 and contact your Primary Care Physician.

Research disclaimer

- We cannot guarantee that treatment with antiviral or antimicrobial drugs for CFS will work and that the patient will respond positively.

- In our clinical trial we observed about 70% of the patients responded positively to treatment with Valcyte. This means that roughly 30% of patients did not respond to treatment. Further research is needed to identify why some patients responded and others did not.

Prescribing Valcyte

- If you have decided to begin Valcyte treatment, please speak with your Primary Care Provider (PCP) about monitoring your monthly safety labs. **Dr. Montoya will only prescribe Valcyte to patients who have a PCP.**
- Taking Valcyte with a fatty meal will increase your absorption of the drug. We recommend that you take each dose with a fatty meal. Some examples of fatty foods that patients have eaten with Valcyte include eggs and avocado. Please speak to your primary care provider for suggestions of foods to include in a fatty meal that are appropriate for you.
- Valcyte warnings:
 - In animals, Valcyte has been known to cause cancer (see package insert).
 - Although we have not observed clinically significant side effects in our patient population at this time, we must warn patients that Valcyte is a strong antiviral drug with short-term risk for bone marrow and liver toxicity.
 - Please be sure to monitor Complete Blood Count (CBC), Liver Function Tests, and Creatinine Clearance during the period you are on Valcyte. Please see the Stanford Public Protocol for Valcyte Treatment for detailed instructions.
- Valcyte cost:
 - For some patients Valcyte treatment has presented problems with affordability. Please check with Roche's Patient Assistance Program to see if you qualify for assistance. Please understand that we have no influence in this process.

Many thanks to all of the patients who have given their input to improve this document. If you have suggestions of things to add that other patients might find useful, please let us know!