

Living with MS

Current MS Research being done at Saunders Medical Center

Assessing the Role of the CYP2J2 Gene with Serum Vitamin D Levels in Multiple Sclerosis

This is an investigator initiated study which means it was our idea and is run by us not a pharmaceutical company. We are studying serum levels of vitamin D, calcium and prolactin as well as genetic associations between these serum levels and MS. We initially enrolled 460 subjects for this study and only looked at a small region of the genome. Now we want to look at the entire genome through a genome wide association study (GWAS). This study involves a one-time blood draw with no exam and no follow-up. For this study, we need adults ages 19 and older who have not participated in this study before. We need both MS patients and controls who do not have MS. There is no charge to participate in this study. The blood draw and all associated testing will be covered by research funds. You will receive your vitamin D level free of charge as well.

The Effects of Alpha-GEE on Injection Site Reactions from Subcutaneous Peginterferon Beta-1a Injections

This study is also an investigator initiated study. It is assessing if the Alpha-GEE cream helps and/or prevents the injection site reactions caused by the injectable drug Plegridy. Alpha-GEE is an all-natural amino acid based cream that is similar to ibuprofen without the negative side effects. We will compare patient reported redness, pain, etc. with and without the cream. For this study, we need adults ages 19 and older who are currently experiencing injection site reactions with Plegridy. You will receive the cream free of charge but there is no reimbursement for the study.

A Metabolomics Approach to Diagnose Multiple Sclerosis

This is an investigator initiated study that we are doing in collaboration with the University of Nebraska –Lincoln. We will be collecting urine and blood samples and comparing the metabolites found in those body fluids for MS patients vs controls. For this study we need adults ages 19 and older who do not have confounding factors that would affect their metabolites (e.g., smoking, pregnancy, other diseases, etc.). There is no compensation for this study.

A Multicenter, Global, Observational Study to Collect Information on Safety and to Document the Drug Utilization of Tecfidera (Dimethyl Fumarate) When Used in Routine Medical Practice in the Treatment of Multiple Sclerosis (ESTEEM)

This is a study initiated by the pharmaceutical company Biogen, the manufacturer of Tecfidera. This study examines when and how Tecfidera is used and any safety concerns with the product. Patients are asked to fill out surveys routinely to document any changes while on Tecfidera. For this study, we can only enroll patients who are naïve to Tecfidera, meaning they have never taken it. You are paid \$25 each visit that you fill out the surveys.

If you are interested in participating in any of our studies please call Samantha Jack, our research coordinator, at 402-443-1457. Thank you.

1760 Co. Rd. "J"
Wahoo, NE 68066
(402) 443-4191



MS Specialty Clinic
Mary Filipi, PhD, APRN
Melissa Fulton, APRN
402-443-1456

Thank you to our sponsors



Zinbryta being pulled from market

Zinbryta has been voluntarily withdrawn from the market. Currently, we are in a transition period where patients who have received Zinbryta may receive one more dose before April 30th. If you started the process to begin treatment with Zinbryta but never received a dose you are not eligible. It will no longer be available as of April 30, 2018. If you are currently taking Zinbryta please contact your healthcare provider as soon as possible. If you have questions regarding Zinbryta you can contact your healthcare provider or Biogen at 1-800-456-2255.

Upcoming Events:

- April 18th – SMC's Linda Maly is having a Medicare program
 - 6pm @ SCC Learning Center 536 N Broadway Wahoo, NE
 - Call 1-800-234-7119 to register, space is limited
- May 3rd – Patient education program
 - 6 pm @ Regency Marriott Hotel
10220 Regency Cir, Omaha, NE 68114
 - Register at My-MSEvents.com or by calling 1-866-955-9999
- May 12th – Lincoln MS Walk – our office will have a table in the MS Wellness Village
- May 19th – Omaha MS Walk - our office will have a table in the MS Wellness Village
 - After the walk, Mary will be speaking at a patient education program
 - 1pm @ Embassy Suites Omaha-La Vista Hotel & Conference Center
12520 Westport Pkwy, La Vista, NE 68128
 - Register at My-MSEvents.com or by calling 1-866-955-9999
- We would like to let our patients know that the MS Clinic will be closed May 29th through June 1st for the International MS Consortium. **Please plan ahead.** Routine medication refills will not be done by our office during this week and routine phone calls will not be returned. If there are any urgent needs during this time please contact Saunders Medical Center at 402-443-1475 to speak with the hospital nurses who will triage the calls.

General Information/Tips

If your either your health insurance or prescription insurance has changed please contact Patti at 402-443-4191 ext. 533 or Katherine at 402-443-4191 ext. 539.

Due to the continued growth of our patient base we are requesting two weeks to complete any forms, including disability forms. We also would like to ask our patients to arrive a half hour before their appointment to ensure there is adequate time for the check in process and our providers do not get behind for other patients.

If you would like to receive the newsletter by email instead of by mail or if you have suggestions/questions regarding the newsletter, please email Sam at sjack@smcne.com.

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