



Conquering Diseases Programs



Conquering Diseases May 2017 Newsletter



Clinical Research Volunteer Database

We're sending out surveys about clinical study participation to our research volunteers. We appreciate all feedback! Please complete and return your survey to Conquering Diseases. (Docket # H-12562)



American Stroke Awareness Month

Eighty percent of strokes are preventable. That means the vast majority of stroke deaths and disabilities never have to happen. Learn how to keep your blood pressure under control to reduce your stroke risk.



May 2017

Studies of interest

Deaf ACCESS Focus Groups (Docket # H00012702)

The second stage of our two-stage, formative process is to gain further insight into the knowledge of, attitudes toward, and experience with informed consent in the Deaf community by conducting four focus groups with Deaf adults. For more information, please contact Melissa Anderson at 774-670-4486 or Melissa.Anderson@umassmed.edu.

Detection of changes in physical activity: Evidence and Translation for a new Clinical Outcome Tool (Docket # H00012261)

Knee osteoarthritis is a common problem that can limit physical activity. We often treat the pain from this disorder with cortisone or gel injections. The aim of this project is to determine if the physical activity level of a patient changes in response to intra-articular (IA) joint injection. Additionally, we hope to learn if a research-grade activity monitor and a consumer-grade activity monitor provide similar measures of change in physical activity level. For more information, please contact Jennifer Baima at 508-334-6210 or Jennifer.Baima@umassmemorial.org.

The VISTA Study: Versartis Long-Term Safety Study of Somavaratan (Docket # H00011759)

This study is to see how well Somavaratan, a long acting human growth hormone, works to help children with growth hormone deficiency grow better, and to see how safe and tolerable it is when given to children over a long period of time. The standard treatment for growth hormone deficiency is daily injections of human growth hormone. Somavaratan is made of human growth hormone but it has been modified to make its effects last longer and is given by injection twice a month. For more information, please contact Carol Ciccarelli at 508-856-2828 or Carol.Ciccarelli@umassmed.edu.

Sexual Dysfunction in Women with Parkinson's Disease (Docket # H00009669)

The purpose of this research is to study the effect of Parkinson's Disease on sexual dysfunction, mainly in women, through conducting an anonymous questionnaire. For more information, please contact Anindita Deb at 508-334-2527.

The Prevalence of Micropenis in Boys with Down Syndrome (Docket # H00012164)

The purpose of this study is to determine the frequency that boys with Down Syndrome have a small penis. Our study will involve obtaining permission from patients' parents to take measurements of the patient's testicles and penis length, as well as access their medical records for other medical diagnoses, lab data, and imaging studies that may be pertinent in our study of the frequency of small penis size in boys with Down Syndrome. For more information, please contact Anna Chin at 508-387-7393 or Anna.Chin@umassmemorial.org.

Vocal biomarkers in Parkinson's disease and healthy controls using a smartphone application (Docket # H00011523)

We are studying a new smartphone application for Parkinson's disease. This study will involve Parkinson's disease patients and healthy controls who do not have Parkinson's disease or any other neurological condition. The application will use speech to monitor Parkinson's disease symptoms. Participation will involve a single initial study visit and 4 weeks of daily use of the application at home. Participants must have a smartphone and must pass a brief cognitive test to be eligible. For more information, please contact Kara Smith at 774-455-4209 or Kara.Smith@umassmemorial.org.



Biorepository

Volunteer to donate a small amount of blood that will be stored in our Biorepository and used by UMass researchers. (Docket # H-12647)



For more information, stop by the Conquering Diseases office. We are open 8:00 AM – 4:00 PM
Conquering Diseases Program
UMass Medical School
Ambulatory Care Center
55 Lake Ave North
Worcester, MA 01655
508-856-2557
Toll-free 855-937-2067
www.umassmed.edu/conqueringdiseases/



Do you have Lou Gehrig's disease or a related motor neuron disease? Are you a healthy individual over the age of 18? (Partners Protocol # 2015P002034)

If you answered yes to either question, you may be eligible for the CABB Study! The main purpose of this study is to collect blood from people with ALS and related motor neuron diseases (MND) and those without ALS or MND (controls). These samples are used to understand and develop new therapies for ALS and will be shared with researchers across the globe performing promising research. Participants come to one in-person visit during which medical history and clinical information will be gathered and blood will be drawn. People with ALS may also participate in follow-up visits 6 and 12 months later, which may be done in person, over the telephone, or by collecting information from medical records. For more information, please contact Catherine Douthwright at Catherine.Douthwright@umassmed.edu or Diane McKenna-Yasek at Diane.McKenna-Yasek@umassmed.edu.

The Aviation Study (Docket # H00012137)

The Aviation study is a clinical trial of an experimental drug called R05285119, which is being developed as a possible treatment to improve social behavior and communication in people with autism spectrum disorder (ASD). Autism spectrum disorder is a group of brain development disorders that causes persistent difficulties in social communication and social interaction. Currently, there are no medications available to treat these core symptoms of ASD such as social behavior and communication deficits. R05285119 works by blocking a brain receptor of a hormone (the vasopressin receptor) that is associated with control of socialization, stress, anxiety, affection and aggression. Participants are aged 5-17 with a diagnosis of ASD. Participation lasts for up to 39 weeks and for 24 of those weeks, participants will take daily doses of either the investigational study drug or a placebo (a look-alike) that contains no medicine. Participants and their parent or guardian will visit a study clinic around once every 6 weeks (about 7 times in total). For more information, please contact Lauren Venuti at 774-455-4100 or ChildResearch@umassmed.edu.

A Phase 3, Randomized, Double-Blind, Placebo-Controlled, Multicenter Study to Investigate the Efficacy and Safety of Mongersen (GED-0301) for the Treatment of Subjects with Active Crohn's Disease (Docket # WIRB20151742)

This is a clinical trial evaluating an investigational new treatment in people with moderate to severe Crohn's disease. The investigational treatment is taken by mouth. Subjects must be at least 18 years old, have been diagnosed with Crohn's Disease for at least 3 months, and have active Crohn's that did not improve or stay improved after trying at least one Crohn's therapy, or had to stop therapy because of side effects. The study may last up to 15 months, will require visits to the study center every 4 weeks and up to three colonoscopy examinations. For more information, please contact Anne Foley at 774-442-4098 or IBDClinicalTrials@umassmed.edu.

A pilot study of the Common Sensing Gocap prefilled insulin pen dose tracking cap (Docket # H00011644)

This study is a pilot study of the Common Sensing prefilled insulin pen dose tracking cap. We are testing a new device called Gocap. The Gocap is a Bluetooth cap for a Lantus or Apidra insulin pen that connects to an application on an Android smartphone. The cap helps to wirelessly track when the insulin is taken, and stores the information on the smartphone application. Patients will use the Gocap, as well as an Agamatrix Jazz Wireless 2 meter (a bluetooth meter that also connects to the smartphone application) for about 1 month, and will then be asked to return for a brief focus group. Participants must use a Lantus or Apidra insulin pen, and must be comfortable using a basic smartphone application. For more information, please contact Dan O'Brien at 774-443-7137 or Daniel.Obrien3@umassmed.edu.

Understanding Adolescent Knowledge and Attitudes toward Sugar Sweetened Beverages: Focus Groups among Worcester, MA Youth (Docket # H00010993)

This is a focus group study that will try to understand adolescents' knowledge, attitudes and behaviors regarding sugar sweetened beverages. For more information, please contact Christina Haughton at Christina.Haughton@umassmed.edu.