

The Sid Foundation Donor Update 2019

The generous gift from the Sid Foundation was used in two parts. First, the funds were used to support three key research projects all investigating the impacts of certain pharmaceuticals in treating Progressive Bronchiolitis Obliterans Syndrome and Cytomegalovirus Infections. While the physicians were supported with large research grants from federal programs and funds from private enterprise, the \$3,000 from the Sid Foundation was used primarily for travel, lab overhead (materials, staffing, and space) and miscellaneous research expenses. The abstracts are below.

Research Project 1: Extracorporeal Photopheresis for the Management of Progressive Bronchiolitis Obliterans Syndrome in Medicare-Eligible Recipients of Lung Allografts. Funded by The Centers for Medicare Services (Medicare) and Therakos, Inc.. Principal Investigator, 2019.

Abstract: Enrolling patients with chronic lung rejection after lung transplantation that is refractory to standard medical therapy. Patients can randomize either to Photopheresis or control arm. If randomized to photopheresis, they will have a PORT placed and treated biweekly for 3 months then monthly for another 3-6 months. They will have spirometry performed. The goal is to slow down the decline in spirometry or stabilize the spirometry reading. Chronic lung rejection is the leading cause of death in patients surviving more than 1 year after lung transplantation, with an incidence of 40-50% the first 5 years and 70-80% if patients survive 10 years.

Research Project 2: A Phase III, Prospective, Multicenter, Randomized, Controlled Clinical Trial to Demonstrate the Effectiveness and Safety of Liposomal Cyclosporine A (L-CsA) Inhalation Solution Delivered via the PARI Investigational eFLOW Device plus Standard of Care versus Standard of Care Alone in the Treatment of Bronchiolitis Obliterans Syndrome in Patients post Double Lung Transplantation. Funded by Breath Therapeutics. Principal Investigator, 2019

Abstract: This is a study of inhaled Cyclosporine for patients in the early stages of chronic lung rejection. Patients are randomized to inhaled cyclosporine vs control (no study medication). They will have spirometry performed. The goal is to slow down the decline in spirometry or stabilize the spirometry reading. Survival is secondary goal.

Research Project 3: “A Phase 3, Multicenter Randomized Open label Active controlled Study to Assess the Efficacy and Safety of Maribavir Treatment Compared to Investigator assigned treatment in transplant recipients with Cytomegalovirus Infections”, Funded by Shire Pharmaceuticals, co- PI, University of Kentucky, 2017-2019.

Abstract: This is a study for lung transplant recipients who have Ganciclovir resistant CMV infection. This is a serious condition in that Ganciclovir is the first line of therapy for this viral infection (CMV is the most common viral infection after lung transplantation). Patients will be randomized to receive either the study drug (Maribavir) or standard of care (IV Foscarnet/Ganciclovir combination). The standard of care therapy is associated with high kidney toxicity and bone marrow suppression, something that Maribavir does not have.

Care Package Update

Transplant Nursing leadership reports that the Care Packages were a HUGE success and we so well loved by patients. All packages provided by the Sid Foundation were distributed to patients. The following items were noted as patient favorites:

-sunblock

-masks

-journals

While all the items were appreciated, the nursing staff did want to pass along that patients receive a pill box and an incentive spirometer from the hospital while they are inpatient. These items could potentially be replaced with something else or it can't hurt to always have a back up!

Thank you so much for this thoughtful and practical gift for our patients.