

Progress Report: Date: 8/21/16

Project: ASFA Registry Study

To date there has been steady progress since the registry was IRB approved last year. Since last continuing review, there was an amendment to change PI from Edward Wong to Jennifer Webb in July 2016, because of Dr. Wong leaving as a full time faculty member at Children's. He is still participating as a special volunteer at Children's and has both an adjunct status at George Washington School of Medicine and Health Sciences in the Departments of Pediatrics and Pathology and as a prn attending physician in the Division of Hematology and Laboratory Medicine. Currently there are 250 patients that have been retrospectively added to the database. These include 30 Neuromyelitis Optica (NMO) patients (increased from 17 patients since last continuing review), 10 Wilson's disease patients (no change since last continuing review), 15 MUSK positive Myasthenia Gravis patients (no change since last continuing review) and 195 leukemia patients (increased from 95 since last continuing review). No additional abstracts were submitted except one that was presented at the 2015 AABB national meeting by Chisa Yamada on the MUSK positive Myasthenia Gravis registry. The previous data on both Wilson's disease and MUSK positive myasthenia gravis has been published in JCA. A letter to the editor of the Journal of Clinical Apheresis was submitted in response to the development of the ASFA registry and why ASFA should be the organization responsible for an outcome registry of apheresis patients. A paper by Monica Pagano et al, has been accepted for publication in Transfusion (see below). Of note, because of the success of the ASFA registry, a new full standing committee named the Research Committee has been established by ASFA, which was announced at the ASFA May 2016 National meeting.

Abstracts

Yamada C, Pham HP, Wu Y, Cooling L, Kim H, Morgan S, Schwartz J, Winters JL, Wong E. Report of the ASFA apheresis, on muscle specific kinase antibody, positive, myasthenia gravis. To be presented at the AABB National Meeting, Anaheim, CA, October 2015 (oral presentation).

Papers

Pham HP, Schwartz J, Cooling L, Hofmann JC, Kim HC, Morgan S, Pagano MB, Schneiderman J, Winters JL, Yamada C, Wong EC, Wu Y. Report of the ASFA apheresis registry study on Wilson's disease. J Clin Apher. 2016 Feb;31(1):11-5. doi: 10.1002/jca.21396. Epub 2015 Aug 14. PMID: 26275240

Yamada C, Pham HP, Wu Y, Cooling L, Kim HC, Morgan S, Schwartz J, Winters JL, Wong EC. Report of the ASFA apheresis registry on muscle specific kinase antibody positive

myasthenia gravis. J Clin Apher. 2016 Mar 6. doi: 10.1002/jca.21454. [Epub ahead of print] PMID: 26946363

Pagano MB, Harmon C, Cooling L, Connely-Smith L, Mann SA, Marques MB, Schlueter AJ, Case R, King KE, Cataife G, Wu Y, Wong ECC, Winters JL. Use of hydroxyethyl starch in leukocytapheresis procedures does not increase renal toxicity. Transfusion (in press)

Letter

Raval JS, Park YA, Wong EC; American Society for Apheresis Clinical Applications Committee. Registry development for thrombotic microangiopathies: Biting off more than can be chewed? J Clin Apher. 2016 Apr 19. doi: 10.1002/jca.21464. [Epub ahead of print] No abstract available. PMID: 27093677

Amendments since the last continuing review:

The study was amended on 6/28/16 (CNMC) to change PI from Edward Wong to Jennifer Webb, and to change Edward Wong to Co-PI for the study.

Respectfully submitted,

Jennifer Webb, MD, PI

Edward Wong, MD, Co-PI