

Remembering Dr. Julaine Florence, DPT

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We are publishing the obituary of Dr. Julaine Florence. Dr. Florence was a leader in the field of clinical trials in Duchenne muscular dystrophy (DMD). A physical therapist, Dr. Florence and neuromuscular neurologists at Washington University School of Medicine (where she spent her whole career), Ohio State University College of Medicine, University of Rochester, and Vanderbilt University Medical Center were pioneers in studying the natural history of Duchenne muscular dystrophy and developing multi-center clinical trials, using a number of different medications in an attempt to slow down the course of this disease. The four center partnership, known as the CIDD (Collaborative Investigation of Duchenne Dystrophy) group, developed first- of-their-kind protocols for describing the natural history of the disease and then essentially defined the role of “clinical evaluator” in neuromuscular clinical trials. The group then performed cutting edge investigator initiated clinical trials in the disorder. The other senior members of the initial CIDD group were Dr. Jerry Mendell and Wendy King (Ohio); Dr. Robert (Berch) Griggs and Shree Pandya (Rochester);

Dr. Gerald Fenichel and Jenny Robinson (Vanderbilt, Tennessee); and at Washington University, Dr. Michael Brooke (and then Dr. Alan Pestronk) and J Phillip Miller. The work of this group paved the way for the explosion of progress in the treatment of DMD now led by industry. Without the two plus decades of work in the 1970s/80s and early 90s, the field would never have progressed to its current stage. Probably the most extraordinary and surprising discovery of Dr. Florence and the CIDD group were the randomized clinical trials demonstrating that prednisone dramatically slowed down the progression of DMD. Since then, every boy with DMD is put on prednisone to keep them walking as long as possible. The work of Dr. Florence and her colleagues also served as a template for the study of other neuromuscular diseases including facioscapulohumeral dystrophy, myotonic dystrophy, spinal muscular atrophy and Charcot-Marie-Tooth disease among many others. Dr. Florence was also a superb teacher who participated in countless neuromuscular conferences and courses over the years, contributing her knowledge, insights and experience to any discussions related to neuromuscular disorders. The field of neuromuscular disease, and all patients and families who deal with a neuromuscular disorder (and especially DMD), owe a debt of gratitude to Dr. Florence and the entire CIDD group. Dr. Florence was a key leader of the CIDD group and those who knew her will remember her and her highly successful career.