OTHER NEWS

Burning Platform for Change Drives Success in Pediatric Rheumatology

Written by Wayne Kuznar

Key success features for pediatric rheumatology have included an improvement in the pipeline of talent and the development of a research network to improve the care of children with rheumatic disease. Christy Sandborg, MD, Stanford University, Palo Alto, California, USA, discussed threats to the survival of the field of pediatric rheumatology in North America, the response to those threats, and future directions.

The American Board of Pediatrics (ABP) had considered dropping pediatric rheumatology subspecialty certification in the late 1990s owing to a lack of infrastructure and compromises in academic productivity as a result of burgeoning clinical loads, which had the additional effect of distracting from research. Interventions were subsequently instituted to enhance the training of pediatric rheumatology fellows, culminating in the ABP accrediting >25 fellowship programs. As a result, there are currently 312 board-certified pediatric rheumatologists, compared with 92 in 1992 (the year of the first certification examination), and ~90 fellows in training, with >25 graduating per year. Given the prevalence of pediatric rheumatic diseases (estimated at 200 to 300 per 100,000 children), a >75% increase in the number of pediatric rheumatologists is required to provide adequate clinical care for children with rheumatic disease, said Dr. Sandborg. As of 2012, ten states did not have any boarded pediatric rheumatologists.

The Childhood Arthritis and Rheumatology Research Alliance (CARRA) is a multicenter investigator-driven research network that was established and designed to take advantage of collaboration to conduct efficient, results-oriented clinical research and treatment trials. CARRA includes the vast majority of practicing pediatric rheumatologists and trainees in the United States and Canada, with >390 members and 107 institutions.

The Arthritis Foundation has provided core infrastructure support for 13 years. Its efforts have led to federal funding of the CARRA registry, creating a platform to learn from every patient, said Dr. Sandborg. The registry is compiled from data gathered at CARRA sites about pediatric rheumatology patients, their disease, and their treatments, resulting in a unified infrastructure through which researchers can readily gather information. There are currently >9000 patients in the CARRA registry, 71% of whom have juvenile idiopathic arthritis (JIA), 12% systemic lupus erythematosus (SLE), 7% juvenile dermatomyositis, 4% localized scleroderma, and 6% other rheumatic conditions.

One goal of the CARRA network was to provide access to participation in one or more clinical studies for all children with rheumatic diseases in the United States and Canada by 2012. At the time of this presentation in November 2013, there were 35 research studies and 4 major clinical trials that had been supported by CARRA. The clinical trials include the Atherosclerosis Prevention in Pediatric Lupus Erythematosus [APPLE; Schanberg LE et al. *Arthritis Rheum* 2012]; Trial of Early Aggressive Treatment of Polyarticular JIA [TREAT JIA; Wallace CA et al. *Arthritis Rheum* 2012]; Randomized Placebo Phase Study of Rilonacept in the Treatment of Systemic JIA [RAPPORT; NCT00534495], and Rituximab in Myositis [RIM; Oddis CV et al. *Arthritis Rheum* 2013]. The CARRA registry can also serve as a foundation for long-term safety studies; for example, understanding the safety of biologic agents and new drugs in the context of disease and multiple exposures.

CARRA has also engaged experts to develop consensus treatment plans for juvenile localized scleroderma [Li SC et al. *Arthritis Care Res* 2012], newly diagnosed proliferative lupus nephritis in juvenile SLE [Mina R et al. *Arthritis Care Res* 2012], and moderate juvenile dermatomyositis [Huber AM et al. *Arthritis Care Res* 2012].

The editors would like to thank the many members of the American College of Rheumatology 77th Annual Scientific Meeting presenting faculty who generously gave their time to ensure the accuracy and quality of the articles in this publication.