

Lupus research in the Pediatric Clinic at BC Children's Hospital- going strong!

Lori B. Tucker, MD
Director of Research, Division of Pediatric Rheumatology
BC Children's Hospital
Vancouver, BC
Canada

The Pediatric Rheumatology Team at BC Children's Hospital not only cares for most of the children and adolescents with lupus in BC, but we also have one of the most active research programs in Canada focused on pediatric lupus. Our entire pediatric rheumatology team (5 pediatric rheumatologists, pediatric rheumatology nurse specialists, physiotherapist, occupational therapist, social worker and research staff) are involved in our lupus research program. Pediatric lupus research takes place in our clinics- children and their families participate in research projects during their regular clinic visits for the most part. Nearly every pediatric lupus patients is involved in research- a fact of which we are very proud! Currently, we have one project ready to publish, two studies which are active and enrolling new patients, and two studies ready to begin in the next 3 months. In the next few issues of the Lupus Lighthouse, we would like to take this opportunity to let you know about the exciting research taking place at BC Children's Hospital.

Exercise and fatigue in adolescents with SLE:

In this study, we have been examining the levels of fitness and fatigue in a group of adolescents with SLE. We know that fatigue is a major issue for adults with SLE, but it has never been studied in children or teens with SLE. In addition, we know that often, active lupus or side effects of treatment interfere with teen's ability to remain physically active after the diagnosis of lupus. For teens with lupus, maintaining regular physical activity is important role in preventing weight gain from steroids, improving bone health, and maintaining normal social connections. Dr. Kristin Houghton, a pediatric rheumatologist at BCCH and expert in sports medicine and kinesiology, has studied 15 teens with lupus using the most up-to-date exercise physiology testing to determine their fitness levels; we have also measured their levels of usual daily fatigue and normal activity levels using questionnaires. Our results (in the process of being published!) show that all the teens with lupus tested had significantly low fitness levels compared with healthy teens, and nearly all also reported significant fatigue. There did not seem to be any relationship between fatigue and level of disease activity with fitness. Dr. Houghton was able to show that a simple test, the 6 minute walk test, is actually a reasonable 'quick' test of fitness in these patients.

These results are important to teens with SLE; the information provides a baseline from which we can develop 'exercise prescriptions' to improve patient's fitness levels. We plan to continue this research, hoping to include routine exercise testing into the care of children and teens with lupus.

Preventing weight gain for children taking corticosteroids:

Nearly all children and teens with lupus will require corticosteroid (or prednisone) treatment at some time during their disease, and for many, the frequent side effect of weight gain due to high

dose steroids is one of the worst parts of their disease. Jenny Tekano, one of the nurses in the Pediatric Rheumatology Clinic at BC Children's Hospital, together with Dr. Lori Tucker and Parveen Khattri, a pediatric nutritionist, performed a study to determine if intensive nutritional counseling given from the first time steroids are prescribed would limit the amount of weight gain from steroids. All children who were starting on steroids for lupus or other autoimmune diseases were eligible to enroll; they received intensive nutritional counseling at every clinic visit with materials to take home. Nutritional advice was given regarding limiting fats, calories, and salt, while maintaining a balanced diet to promote healthy growth. The results of this study (also being written up for publication!) show that the children given nutritional counseling still gain weight when put onto steroid therapy, but the weight gain is significantly less than in previous groups of patients given similar doses of medication. Parents and children also appreciate the information they are given, as well as the sense of being able to be involved in their care plan in a positive way. We hope to use this data to advocate for regular nutritionist availability for children with lupus and their families, which currently is not available due to funding issues.

1000 Canadian Faces of Lupus:

This is an important study for all patients with lupus across Canada, and pediatric patients are included in the study. The study, with the main coordinating centre in Winnipeg, seeks to enroll at least 1,000 Canadians with lupus from all across the country in a long term outcome study; there is special interest in pediatric patients and patients of various ethnic backgrounds including First Nations. The pediatric rheumatology clinics in Canada who follow large numbers of children and teens with lupus have been enrolling patients; we currently have over 100 children and teens entered into the study. Patients will be followed-up yearly to look at how they are doing with respect to their disease, quality of life, and access to health care. With this study, we will have the opportunity to learn about the outcomes of pediatric lupus, as well as study the factors seen early in disease which may predict good or poor outcomes.