



An Adult Rheumatologist Needs to Know About a Patient With Pediatric Onset Lupus

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One in five patients with lupus is diagnosed in childhood or adolescence.

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Pediatric onset lupus is more aggressive compared to adult onset lupus. Children and adolescents with lupus tend to have more widespread and severe organ involvement. Compared to adult onset SLE, children and adolescents with SLE are more likely to have CNS and renal involvement, to develop end stage renal disease, and to be hospitalized for lupus. In addition, patients with pediatric onset SLE have consistently higher disease activity and accrue more SLE-related damage than those with adult-onset SLE. Patients with pediatric onset lupus are susceptible to macrophage activation syndrome, a “cytokine storm” characterized by fever, disseminated intravascular coagulation, and end organ dysfunction.

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Pediatric onset lupus has higher mortality compared to adult onset lupus. Even despite having fewer co-morbidities than their adult counterparts, adolescents with SLE have a two-fold higher mortality rate.

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Long term complications of lupus and its treatment start in childhood and adolescence. Surrogate markers of atherosclerosis such as carotid intima medial thickening are already present in adolescents with lupus. Low bone mass can also develop early and because peak bone mass is achieved in the teen years, adolescents and young adults with lupus are at particular risk for poor bone health. Thus efforts to prevent or treat hypertension, dyslipidemia, low bone mass may need to begin early. Because lupus and its treatment increase risk of infection, it is important to keep preventive vaccines updated according to guidelines.

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Teens and young adults are often not ready to care for themselves. Teens and young adults may not yet have well-developed self-management and self-advocacy skills. This can translate into missed appointments and non-adherence to treatment, requiring steady patience and support on the part of the health care team. Particular guidance may be required with respect to reproductive health, substance use (including interaction with medications), and lifestyle choices which minimize the effect of longstanding arthritis on cardiovascular risk.