[P-M-461] ANTIPHOSPHOLIPID ANTIBODY SYNDROME IN THE THROMBOPHILIA PILOT PROJECT

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Introduction: Antiphospholipid syndrome (APS) is an autoimmune disorder characterized by thromboembolic events, adverse pregnancy outcomes, and the presence of antiphospholipid antibodies. Management of these patients can be complicated by recurrent events and difficulties with monitoring therapy. Consequently, many of these patients are referred to specialized Thrombosis Centers for management.

Methods: A web-based data registry was implemented at the 8 Thrombophilia Pilot Centers in August 2003. Information collected includes demographics, referral patterns, and medical history, diagnostic laboratory and radiographic data.

Results: Of 2983 unique patients enrolled in the Registry as of October 2006, 285 (9.6%) were referred for APS. Most were female (n=205; 72%) and Caucasian (n=234; 82%). Twenty-seven were pediatric (9.5%). The primary referral sources for APS patients were Hematology/Oncology (n=68; 24%), Internal Medicine (n=40; 14%), and Family Medicine (n=38; 13.3%). Clinical manifestations included venous thromboembolism (deep venous thrombosis: n=158; 55.4%; pulmonary emboli: n=82; 28.8%), arterial thromboembolism (stroke: n=50; 17.5%), and adverse pregnancy outcomes (n=47 of 205; 23%). Sixty-six patients (30%) had a concurrent autoimmune disorder. Fifty-one women (25%) were referred for pre-pregnancy counseling or pregnancy management. Venous thromboembolism in unusual locations was not uncommon (intraabdominal: n=11 (3.9%); cerebral sinus: n=9 (3.2%); inferior vena cava: n=8; (2.8%); intraocular: n=8; (2.8%)). A positive family history was reported by 52 patients, with thrombosis (n=29; 56%) and stroke (n=13; 25%) being the most common manifestations reported in family members. Most patients were subsequently followed through the Thrombosis Center (n=214; 75%).

Conclusions: Patients with APS are frequently referred to specialized Thrombosis Centers for evaluation and management of their disease. Almost 10% are pediatric, and a family history of thrombosis is frequently present.

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