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First Results from the Austrian LQTS Registry

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Aim: The registry was initiated in 2006 as a multicentre project aiming at collecting data from all patients with documented LQTS up to the age of 18 years. Approval was given by the ethics committee.
Results: By the end of 2010 the registry contains data from 47 patients (23m, 24f) with an actual age from 3 to 22 years. 26 patients (14 m, 12 f)(55%) presented with symptoms. Mean age at diagnosis was 3.5 years in male and 6.5 years in female patients. Symptoms were stress associated syncope, palpitations and documented ventricular tachycardia (TdP). 17 patients (36%) are still asymptomatic. 4 patients (3 m; 9%) died suddenly.
By the end of 2010 all 43 surviving patients are treated with ß-blockers, 10 had either an implantation of a pacemaker (4), or an ICD (6). Genetic analyses were performed in 38 patients and revealed presence of LQT 1 in 17(6m, 11f), LQT 2 in 8 (3m, 5f) and LQT 3 in one patient (m). The remaining results are still pending. In addition to collecting data from patients diagnosed in the participating paediatric cardiology units it was possible to identify 39 family members with so far undiagnosed LQTS (16m, 23f). From 2006 to 2010 we noted a relative increase of newly diagnosed patients.
Summary.The registry is a useful instrument for providing data both on actual numbers and treatment of patients with LQTS less than 18 years in our country. Annual data presentation in the working group leads to more awareness of LQTS and may also contribute to the reduction of secondary deaths in families.