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The Incidence of Pediatric Cardiomyopathy: The Prospective Pediatric Cardiomyopathy Registry

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Background: Population-based data on the incidence of pediatric cardiomyopathy are rare because of the lack of large prospective studies.

Methods: The NHLBI-sponsored Pediatric Cardiomyopathy Registry collected data on all patient newly diagnosed by age 18 years with cardiomyopathy. The diagnosis had to have been made by a pediatric cardiologist and had to meet study criteria. All children diagnosed during 1996, 1997 and 1998 in 2 geographically distinct regions of the United States: New England (MA, ME, NH, VT, RI) and the Central Southwest (TX, OK, AR) were included in the Registry.

Results: Over the three years and two regions we identified 350 cases for an overall annual incidence of 11.8 per million patient-years (95% CI: 10.6, 13.1). Younger age (<1 year old) at diagnosis had a significantly higher incidence rate than older age (1-18 years old) (110.4 vs 6.9, $P < 0.0001$). The incidence of cardiomyopathy was lower in White (8.6) than in Black (22.6, $P < 0.0001$) or Hispanic children (23.8, $P < 0.0001$). Boys had a higher incidence of cardiomyopathy than girls (13.1 vs. 10.4, $P = 0.028$). A significant regional difference was noted (New England = 14.2 vs. Central Southwest = 10.6, $P = 0.010$). When divided by functional type, we found that 40% of the incident cases were hypertrophic, 49% were dilated, 3% were restrictive or other types, and 8% were unspecified. Incidence did not change significantly over the three years of study.

Conclusion: The incidence of pediatric cardiomyopathy has been established for two large regions of the U.S. Most cases are identified at an early age and differences due to gender, region, and ethnic origin exist.