

Dis Colon Rectum. 2004 May;47(5):674-8. Epub 2004 Mar 25.

Inherited colorectal cancer registries in the United States.

Church J, Kiringoda R, LaGuardia L.

David G. Jagelman Inherited Colorectal Cancer Registries, Department of Colorectal Surgery, Cleveland Clinic Foundation, Cleveland, Ohio 44195, USA. churchj@ccf.org

**PURPOSE:** The prevalence of familial adenomatous polyposis-associated cancers in the United States has been conservatively estimated at 15,000, and that of hereditary nonpolyposis colorectal cancer (HNPCC)-associated cancers at 30,000. Every blood descendant of each of these patients is at risk of carrying a germline mutation predisposing them to early onset colorectal and other cancers. Optimal care of these high-risk families involves a center with expertise in the syndromes. This study was performed to see how many such centers exist in the United States and to learn something of how they work. **METHODS:** The mailing lists of three international societies concerned with inherited colorectal cancer were used to send surveys inquiring about the presence of a registry or center, and how that center worked. The Collaborative Group of the Americas, the Leeds Castle Polyposis Group, and the International Collaborative Group on hereditary nonpolyposis colorectal cancer were queried. **RESULTS:** There were 30 centers in the United States: 26 responded, representing 15 states. Eighteen centers that responded had registries for inherited colorectal cancer. There were 1,396 familial adenomatous polyposis families among the 18 registries, 2,058 hereditary nonpolyposis colorectal cancer families, 42 with juvenile polyposis, and 216 with Peutz-Jehger's syndrome. The 18 registries employed 29 genetic counselors or coordinators. Seven used Microsoft Access as a database, five used Progeny, three a SQL server-based system, one Filemaker Pro, one Microsoft Excel and one used Oracle. Cyrillic was the pedigree-drawing program in 6 registries, Progeny in 12, and Ped Draw in 1. Hereditary nonpolyposis colorectal cancer was defined using the Amsterdam I criteria by four registries, Amsterdam II by five, both criteria by six, Bethesda guidelines by one, and by genotype alone in two registries. **CONCLUSIONS:** The United States is underserved by registries for inherited colorectal cancer, having enrolled only a small proportion of the families theoretically available. Registries differ in fundamental aspects of function. More collaboration and more registries are needed.