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The cuban program for predictive testing of hereditary ataxias: 11 years and 1050 individuals

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Abstract

Having reported the world's highest prevalence of SCA2, Cuba developed a program for the predictive testing of this condition. Between February 2001 and December 2011 a total of 1050 individuals requested their inclusion in the presymptomatic testing program. Their medical records were retrospectively analyzed in the present descriptive study. The presymptomatic testing uptake was 34.06%. A total of 768 participants completed the protocol, 204 withdrew and 78 were excluded. Females predominated and 70.96% were non-carriers. Their main motivations were risk assessment in their descendants, physical and psychological preparation to cope with the disease and planning for the future. Predictive testing protocols are tributaries of continued supervision and must be adequated through a case-by-case approach, since every consultant brings along a unique story. The profile of Cuban participants in the predictive testing program is similar to the one reported for other programs all over the world, nevertheless the genetic counseling education at the community level is a distinctive aspect, which is valuable in providing at-risk individuals with wide and proper knowledge before their testing inclusion request. The SCA2 predictive testing program is renowned in our population and has a favorable impact in the affected families.

Biography

Tania Cruz Marino is a MD from the Medical University of Holguin, Cuba, and First and Second Degree Specialist in Medical Genetics, as well as PhD (Medical Sciences) from the Superior Institute of Medical Sciences, Ciudad Habana, Cuba. She heads the Predictive Genetics Department at the National Center for the Research and Rehabilitation of Hereditary Ataxias where she conducts the presymptomatic and prenatal testing programs for SCA2. She has published more than 20 papers in peer reviewed journals.

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