



Predictive Testing in Children

Healthier Kids. Healthier Future.



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The Panel

- **Andrew Court- Child psychiatrist**
- **Rony Duncan- Ethicist**
- **Michael Hayman- Paediatric neurologist**
- **Rachel Skinner- Paediatrician- Adolescent medicine**

Predictive Testing

- **Testing prior to clinical onset of disease**
- **Implications for person and their family**
- **Huntington disease= greatest experience**
- **Over 5000 HD predictive tests worldwide**

Predictive testing in children

- **Where there is a preventive treatment, no issue**
 - eg: adrenoleukodystrophy, retinoblastoma
- **Where there is no preventive treatment and onset is always in childhood- some controversy**
 - eg: Krabbe, metachromatic leukodystrophy
- **Where there is no preventive treatment and onset is usually in adulthood- much controversy!!!**
 - eg: Huntington disease, ADCA

Guidelines

- **Predictive testing for adult onset conditions for which no preventive treatment exists should not be done until:**
 - **Age of majority (International Huntington Association/ World Federation of Neurology)**
 - **When an adolescent is able to make a free and informed decision (other non-disease specific groups)**



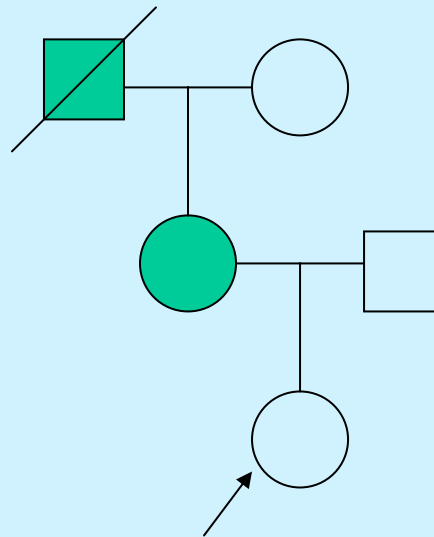
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Why the fuss?

B

- **Presented to paediatrician at 14 requesting predictive test for autosomal dominant spinocerebellar ataxia**

B's pedigree



Autosomal dominant spinocerebellar ataxia

- **Progressive neurodegenerative disorders**
- **SCA 1, 2, 3,.....29**
- **Genes identified for about half**
- **SCA 1, 2, 3, 6 CAG repeat disorders**