



Quality in Genetic Testing

A Patient and Family Perspective

Alastair Kent

Director

Genetic Interest Group

The need for a Genetic Test



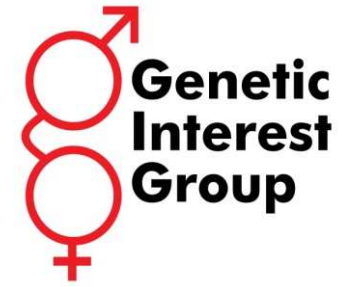
- Not curiosity driven
- A possible problem

A Family Perspective



- Stress/anxiety
- Hope
- The value of an “all clear”
- Disaster
- Potentially life limiting
- Revised future plans

Getting a Diagnosis



- Know where you stand
- Plan
- Gain and retain control

The Importance of Quality



- Trust
- Understanding
- Utility

The Dimensions of Quality



- Timely
- Available
- User Friendly
- Patient and Family Focussed
- Robust
- Evolutionary
- Reliable
- Process and Outcome Balanced
- Honest
- Fair

The ACCE Framework

(Developed by Wyle Burke and others)



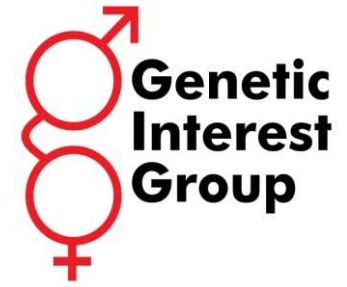
- Availability
- Comprehensible
- Compassionate
- Equitable

The Patient and Family ACCE Framework



- Availability
- Comprehensible
- Compassionate
- Equitable

Patient Lead Information (Eurogentest Unit 6)



- Information that patients want and need
- In words that they can understand
- At a time that they can use it
- Checked and validated by people like them
- In friendly format

Current Titles



- Amniocentesis Test
- Chromosome Translocations
- Chromosome Changes
- Chorionic Villus Sampling (CVS) Test
- Dominant Inheritance
- Frequently Asked Questions
- Genetic Glossary
- Recessive Inheritance
- Some information about your genetic test
- What is a Genetic Test?
- X Linked Inheritance





Thank you

Genetic Interest Group
Unit 4D Leroy House
436 Essex Road
London
N1 3QP

www.gig.org.uk

+44 (0)20 7704 3141

alastair@gig.org.uk