

**Ed Richards CEO  
OFCOM  
Riverside House  
2a Southwark Bridge Road  
London  
SE19HA**

**Chairman  
British Society for Human Genetics  
c/o National Genetics Reference Laboratory and  
Regional Molecular Genetics Service  
St Mary's Hospital  
Hathersage Road  
Manchester M130JH**

12<sup>th</sup> November 2007

Dear Mr Richards,

**ITV1 programme 'The killer within' broadcast on Thursday November 8<sup>th</sup> at 21.00**

I am writing to make a formal complaint following the above broadcast under Section 5 of the OFCOM Broadcasting Code dealing with *Community Standards* on the grounds that the programme failed to offer due impartiality and due accuracy and gave undue prominence to a single view and opinion (the scientific basis and interpretation of the tests shown). In addition we cite Section 10, *Commercial References* in particular rules 10.3 and 10.6 in this case concerning the undue prominence amounting to the promotion of a services within the programme. We argue that the programme makers' failure to present any dissenting voices expressing scepticism about the tests constitutes giving undue prominence to the single service illustrated.

This complaint is lodged in response to concerns expressed to me by many members of the British Society for Human Genetics. The BSHG is lodging a separate complaint with ITV under its procedure. The Society represents researchers and the scientists, doctors and counselors who develop and provide NHS services for individuals and families at risk of inherited disease.

The programme followed four celebrity clients of a UK company called Genetic Health through a genetic screening test. The programme showed the process leading up to the test decision including a discussion of their family history of conditions such as Alzheimer's disease and prostate cancer and summarised the results of the test by showing the test result counselling session.

The programme portrayed these genetic tests as useful predictors of future ill health without any discussion around the scientific basis of the testing offered. Analysis of common genetic variants to predict disease susceptibility may have some potential but most scientists and doctors who have expertise in this field would agree that the scientific evidence is currently preliminary and the performance of this type of test in health risk discrimination is unsubstantiated and unvalidated. In summary the programme amounted to undeclared advertising for the company without sufficient detail or discussion to allow that audience to properly weight the content.

A great deal of effort has been made in the UK to engage the public in a debate on the issues surrounding genetics and human health. The BSHG is concerned that the uncritical journalistic and broadcasting standards demonstrated in this programme risk undermining the confidence of the public in the application of genetics which has great potential to improve healthcare.

There was undoubtedly a public service programme to be made to discuss the current status of the science behind the test offered. This could have been presented in the context of the framework of regulation, guidance and professional good practice. The programme could have shown the balance between the benefits of health advice against the potential harm following assurances given to the clients that they were at low risk of particular health conditions.

I look forward to your reply

Yours Sincerely

**Dr Rob Elles (Chairman British Society for Human Genetics)**

Copies: Chairman ITV, Chairman Human Genetics Commission, Genetics Unit Department of Health

Dr Rob Elles  
Chairman  
British Society for Human Genetics  
c/o National Genetics Reference Laboratory and Regular Molecular  
Genetics Service  
St Mary's Hospital  
Hathersage Road  
Manchester M13 OJH

30 November 2007

Dear Dr Elles

**The Killer in Me, ITV1 8 November 2007 21.00**

Thank you for your letter dated 12 November, which has been passed to me for response.

The programme followed the personal and emotional journeys of four celebrities as they confronted the health risks they faced in terms of their family medical histories, their lifestyles and by undertaking the Genetic Health genetic test. It was never intended to be a documentary investigating genetic screening.

You are correct that the programme did not go into detail about the science behind the test, or include a detailed critique of it. In a one-hour programme intended to follow the celebrities' personal health journeys, their family histories and current lifestyles as well as showing their undertaking the test, it was not editorially appropriate or necessary to include a detailed analysis of the science behind the test. Furthermore, it was not incumbent upon the producers to include such analysis. However, ITV had a duty to explain the test in a way that was fair and duly accurate, and we are confident that the programme did this.

The programme never stated or implied that the scientific evidence behind the test was settled and undisputed. On the contrary, it was made clear that the test's abilities to ascertain risk were the claims of Dr Jenkins and Genetic Health. It also made it clear that the science behind the test is at a relatively early stage and is still evolving. Dr Jenkins also talked about starting to determine a person's genetic predisposition to a particular disease, and when giving the results of the test he talked about genes that were "implicated" (not proven) in the development of certain diseases.

/cont'd

We do not accept that the programme unfairly or inaccurately portrayed the Genetic Health test as a "useful predictor of future ill health" or that it included "assurances given to the clients that they were at low risk of particular health conditions". It did quite the opposite. The test was described in several places as one designed to reveal a person's genetic risk to disease, as opposed to overall risk. The commentary made it clear that genetic profile is only one factor contributing to disease, and emphasised the importance of lifestyle and environmental factors. Dr Jenkins also emphasised this, stating several times that a genetic risk did not necessarily mean a person will develop the relevant disease and stressing the importance of lifestyle in preventing disease. One contributor also remarked that the test was not diagnostic and made the further point that it was still important to follow a healthy lifestyle even though he had been assessed as being of a low known genetic risk of a particular disease. Other contributors made the point that it is important to follow a healthy lifestyle. Following her test result showing a genetic risk of heart disease, Fiona Phillips told how she had undergone tests on her heart which revealed it to be healthy, and that she had been advised this was because of her healthy lifestyle. We feel that this exposed the potential limitations of the genetic test as a predictor of ill health.

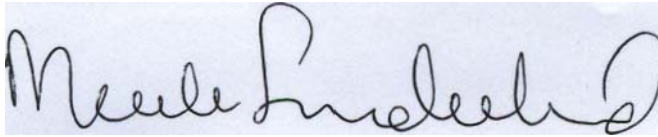
We do not accept that "uncritical journalistic and broadcasting standards" were applied the programme. Firstly, the programme was objective, and made it clear that the claims about the test were Dr Jenkins'/Genetic Health's claims, not ITV's. Secondly, although the programme did not explore every criticism made of genetic screening, we do believe it reflected some of that criticism. In particular, it focussed on the issue of whether it is right and desirable to do the test and to receive information about your genes and genetic susceptibility to disease. A major theme in the programme was whether the celebrities thought it was right or useful to do the test. Several contributors expressed reservations about the test. One (Michael Portillo) said he would not want to take the test at all. Another (Fiona Philips) ultimately decided not to receive her results in respect of her potential risk to Alzheimer's.

We also do not accept that the programme served as "undeclared advertising" for Genetic Health. Genetic Health did not fund the programme or make any financial contribution to ITV. Furthermore, any references to Genetic Health and their test were limited and were justified by the programme's editorial requirements. The programme in no way created the impression that ITV's editorial independence had been compromised by either Genetic Health or Dr Jenkins. In fact, the doubts about the test expressed by some contributors in the programme suggest the opposite.

As such, we are satisfied that given the nature and content of the programme, it was duly impartial and duly accurate on the issue of the genetic test it depicted. We are also satisfied that it did not give undue prominence to Genetic Health or the genetic testing service it offers.

I trust that this answers your queries. Since you have written to Ofcom in similar terms I am copying this response to them for information.

Dr Rob Elles  
30 November 2007  
Page 3

A handwritten signature in black ink on a light blue background. The signature is written in a cursive style and appears to read "Mark Sunderland".

Mark Sunderland  
Programme Lawyer

Cc Ed Richards, Chief Executive Officer, Ofcom