FÉDÉRATION INTERNATIONALE DE MÉDECINE DU SPORT
INTERNATIONAL FEDERATION OF SPORTS MEDICINE

Consensus Statement on direct-to-consumer genetic testing for sports performance and talent identification

Recent years have witnessed the rise of an emerging market of Direct-to-Consumer (DTC) marketing tests that claim to be able to identify children's potential for athletic talent. Targeted consumers include coaches, trainers and parents.

The general consensus amongst sport and exercise genetics researchers is that genetic tests, based on current knowledge, do not meet the basic requirements of diagnostics and have little or no role to play in talent identification or individualised prescription of training to maximise performance.

The most commonly offered test is for the R577X variant in the *ACTN3* gene sometimes called 'the speed gene". This accounts for at most only 2% of inter-individual variability in muscle strength or sprint speed. As an example of the value of this test, there are tens of millions of people living in the UK who have the genotype associated with sprint speed, but only a tiny fraction of those people will be elite sprinters.

There are currently many issues surrounding the information provided by the companies engaged in DTC genetic diagnostics for athletic talent or individualized exercise prescription:

- Exaggerated claims – claims of benefits not supported by scientific data are commonly used as inducements to pay for testing
- Lack of disclosure - of the 39 companies identified worldwide offering this service 21/39 did not state which genes/markers were being tested
- Quality control – For example, an independent report identified that samples of DNA from the same people were sent under different names and to different laboratories yet different gene variants were reported for the same individual.
- Inducement to purchase expensive supplements – some companies offer nutritional and lifestyle information based upon limited and not-validated genetic diagnostics and the individual is encouraged to purchase multivitamin and mineral products at much higher prices than available on the market.
- Consent - There is a consensus in the medical scientific community that genetic tests should be carried out only after the person concerned has given free and informed consent. This would include relevant information about the risks, benefits, limitations and implications of the genetic tests.
- Ethical issues - the risks of genetic testing for talent identification may not be immediately obvious. Psychological, social, and financial issues have been identified. For instance, the psychosocial consequences might include impaired self-esteem, social stigma, and, in terms of sport selection, may include employment limitation.

Consequently, in the current state of knowledge, no child or young athlete should be exposed to DTC genetic testing to define training regimens or to identify talented individuals for athletics.

This statement does not relate to genetic testing to identify people at risk for disease or for sudden cardiovascular events during exercise.

This consensus document reflects the current state of knowledge and will need to be modified over time based on scientific advances. It is intended that this document will be formally reviewed and updated prior to 1 June 2017.

List of Contributors:

FIMS

Nick Webborn, Chair of Scientific Commission, International Federation of Sports Medicine, Centre for Sport and Exercise Science and Medicine (SESAME), University of Brighton, Eastbourne, UK

Fabio Pigozzi, President, International Federation of Sports Medicine, University of Rome "Foro Italico", Rome, Italy

Paul Dijkstra, Director of Medical Education, Aspetar - Qatar Orthopaedic & Sports Medicine Hospital, Doha, Qatar

Jae Chul Yoo, Sungkyunkwan University School of Medicine, Seoul, Korea

Klaus-Michael Braumann, Abt. Sport- und Bewegungsmedizin, Fakultät für Psychologie und Bewegungswissenschaft, Universität Hamburg, Hamburg, Germany

Hans-Hermann Dickhuth, Ehemaliger Ärztlicher Direktor, Abt. Sportmedizin, Freiburg, Germany

Luigi di Luigi, Chief of Department Section of Health Sciences, University of Rome "Foro Italico", Rome, Italy

Norbert Bachl, Department of Sports and Physiological Performance, Centre for Sports Science and University Sports of the University of Vienna, Vienna, Austria

Genomics Symposium

Ildus Ahmetov, Volga Region State Academy of Physical Culture, Sport and Tourism, Kazan, Russia

Mohammed Alsayrafi, Anti-Doping Lab Qatar (ADLQ), Doha, Qatar

Euan Ashley, Mikael Mattsson, Matthew Wheeler - Center for Inherited Cardiovascular Disease, Co-Director Clinical Genomics Service, Stanford University, Stanford, US

Claude Bouchard, Tuomo Rankinen, Mark Sarzinsky - Human Genomics Laboratory, Pennington Biomedical Research Center, Baton Rouge, US

Steven Britton, Lauren Koch - University of Michigan, US

Nuala Byrne, Bond Institute of Health and Sport, Faculty of Health Sciences & Medicine, Gold Coast, Australia

Malcolm Collins, Department of Human Biology, University of Cape Town, Cape Town, South Africa

Nir Eynon, Institute of Sport, Exercise, and Active Living (ISEAL), Victoria University, Melbourne, Australia

Paul Franks, Department of Clinical Sciences Genetic and Molecular Epidemiology, Lund University, Malmo, Sweden

Noriyuki Fuku, Graduate School of Health and Sports Science, Juntendo University, Japan Eco de Geus, University and VU medical centre, Amsterdam, Netherlands

Valentina Ginevičienė, Vilnius University, Vilnius, Lithuania

Vassilis Klissouras, Professor Emeritus of Ergophysiology, University of Athens, Greece

Alejandro Lucia, Universidad Europea and Research Institute i+12, Madrid, Spain

Kamiel Maase, Netherlands Olympic Committee * Netherlands Sports Confederation (NOC*NSF), Elite Sport Unit, Netherlands

Colin Moran, Physiological Epigenetics Research Group, University of Stirling, Stirling, UK

Kathryn N. North, Fleur C. Garton, Murdoch Childrens Research Institute, Department of Paediatrics, University of Melbourne, Royal Children's Hospital, Victoria, Australia

Yannis Pitsiladis, Guan Wang - FIMS Reference Collaborating Centre of Sports Medicine for Anti-Doping Research, University of Brighton, Eastbourne, UK

Robert Scott, University of Cambridge, Cambridge, UK

Alun Williams, MMU Sports Genomics Laboratory, Department of Exercise and Sport Science, Manchester Metropolitan University, Crewe, UK

Ethical and Legal

Mike McNamee, Professor of Applied Ethics, College of Engineering, Swansea University, UK

Silvia Camporesi, Department of Social Science, Health & Medicine, King's College London,

Nils Hoppe, Centre for Ethics and Law in the Life Sciences, University of Hannover, Germany and Coram Chambers, London, UK

Søren Holm, Professor of Bioethics, School of Law, University of Manchester, UK

Jane Kaye, Professor of Health, Law and Policy, HeLEX - Centre for Health, Law and Emerging Technologies, Nuffield Department of Population Health, University of Oxford, Oxford, UK