



# Genetic Testing: NEW TECHNOLOGIES. NEW QUESTIONS.

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If you think there won't be increasingly frequent tension between advocates of the healthcare benefits of predictive genetic testing and those concerned with safeguarding the privacy of individual genetic information, think again. Every day, more advancements are made in the field of genetic testing. New gene markers are identified that allow for the early detection of risk factors for developing deadly diseases, and existing methods for determining an individual's proclivity for inheriting potentially fatal conditions are constantly made more sophisticated by technological and scientific innovation.

Here are just a few of the breakthroughs achieved since May 1, 2009:

- Genetic Risk Factor for Testicular Cancer Discovered by Penn Researchers<sup>1</sup>
- The Discovery of a Novel Marker of Colorectal Carcinoma<sup>2</sup>
- New Universal Breast Cancer Marker Predicts Recurrence and Clinical Outcome<sup>3</sup>
- 25 New Genes that May Trigger Diabetes Identified<sup>4</sup>
- Novel Genetic Risk Factors for Kidney Disease Revealed by Study<sup>5</sup>
- New Evidence Ties Gene to Alzheimer's<sup>6</sup>
- Genetic Screening of Patients with Hypertrophic Cardiomyopathy as a New Diagnostic Strategy for Risk Stratification<sup>7</sup>

This kind of scientific progress will have tremendous implications for the prevention and/or treatment of some of the most common and life-threatening diseases people face. Unfortunately, however, many individu-

als are either unaware of the scientific advancements or choose to forego genetic testing and miss out on the potentially life-saving or health improving benefits it may offer.

Within the same time span as the above-mentioned advancements in the field of genetics, scientific researchers and doctors have written several articles both advocating the increased employment of genetic testing by at-risk individuals and also bemoaning the current underutilization of the many readily available predictive genetic tests for disease.<sup>8</sup> If the medical benefits of genetic testing are championed by those in the healthcare field, why are individuals reluctant to follow the proverbial "doctor's orders"?

Take the hypothetical case of a mother diagnosed with breast cancer. Should the daughter undergo genetic testing to see if the breast cancer gene has been inherited? Change the hypothetical a bit and dramatic new issues develop — what if the two women work for the same employer? What if they have the same health insurance carrier? Now privacy concerns become much more relevant.

Privacy concerns seem to be the general barrier for people who might otherwise opt for genetic testing as a method of promoting their individual well-being. Fears that the results of predictive genetic testing might negatively impact their employment and/or insurance prospects have discouraged people from submitting to genetic testing, even if the results might very well save their lives. In general, people who feel well may be afraid to find out the results of some unfamiliar testing regimen. Also, the cost

factor and who pays for it is another issue.

Can an employer ask an employee to undergo genetic testing? Consider the interesting case of Eddy Curry, the former first round NBA draft pick of the Chicago Bulls. But first a bit of past relevant basketball/medical history. In March of 1990, Hank Gathers, who played for Loyola Marymount and was a projected pro player, collapsed and died on the court during an intercollegiate game, apparently due to sudden cardiac death. He suffered from ventricular tachycardia, reportedly the same condition that affected Eddy Curry<sup>9</sup>.

In 1993, Boston Celtics star Reggie Lewis collapsed on the floor during a play-off game. He was diagnosed by one team of cardiologists as having ventricular tachycardia.<sup>10</sup> Lewis got a second opinion because a diagnosis of VT would have ended his career. The second set of doctors told him he had a non-life threatening condition. A few days later, while shooting baskets on the practice court, he collapsed and died.<sup>11</sup>

In Eddy Curry's case, Curry was advised by Barry Maron (Director of Hypertrophic Cardiomyopathy Center at the Minneapolis Heart Institute Foundation) to be tested for a genetic predisposition to hypertrophic cardiomyopathy, a condition frequently associated with sudden death in young athletes. Maron: "It is known, however, that young athletes with cardiovascular disease... may die suddenly during or immediately after vigorous exertion."<sup>12</sup> Genetic testing is available to determine if individuals possess the genetic mutations that are related to the development of these heart conditions.

(Continued on page 42)

## Genetic Testing: New Technologies. New Questions. (Continued from page 8)

Curry refused to undergo the requested DNA testing citing privacy concerns and shortly thereafter was traded by the Bulls to the New York Knicks.<sup>13</sup>

Cuttino Mobley of the Clippers and Knicks retired in December 2008 when diagnosed with hypertrophic cardiomyopathy because it would have been life-threatening for him to keep playing basketball.<sup>14</sup> It is unknown what, if any, testing Curry may have undergone on his own or what specific testing the Knicks may have required before completing the trade with the Bulls. Curry is still under contract with the Knicks.

Legislation on both the State and Federal level is very clear on certain relevant considerations: 1) an employer cannot demand that an employee undergo genetic testing; 2) it is illegal to discriminate against an employee based on the genetic makeup of that individual; 3) an insurance company cannot discriminate based on the genetic makeup of a prospective insured.

On May 21, 2008, President Bush signed the Genetic Information Nondiscrimination Act (H.R.493). This legislation passed the senate unanimously and passed the House of Representatives by a vote of 414 to 1. It had been debated in congress for over 13 years. Under the provisions of the Act, it is unlawful: 1) for employers to fail/refuse to hire, to discharge, or to limit in any way as to deprive of employment opportunity, any employee because of genetic information;<sup>15</sup> 2) for an employer to request, require, or purchase genetic information;<sup>16</sup> 3) for insurers to establish rules for eligibility or to adjust premium/contribution amounts based upon genetic information.<sup>17</sup> It is lawful, however, for an employee to provide prior, knowing, voluntary, and written authorization to genetic information.<sup>18</sup>

In the State of Illinois, the Genetic Information Privacy Act was approved on June 23, 1997 and effective January 1, 1998. Under the provisions of this Privacy Act: an insurer may not seek information derived from genetic testing for use in connection with a policy of accident and health insurance;<sup>19</sup> an insurer that receives information derived from genetic testing, regardless of the source of that information, may not use the information for a non-therapeutic pur-

pose as it relates to a policy of accident and health insurance;<sup>20</sup> an insurer may consider the results of genetic testing if the individual voluntarily submits the results and the results are favorable to the individual.<sup>21</sup> Furthermore, under the Illinois Act, it is unlawful for employers to fail/refuse to hire, to discharge, etc. and it is also unlawful for employers to solicit, request, require or purchase genetic testing results.<sup>22</sup>

### POLICY CONSIDERATIONS

The Department of Transportation requires alcohol and drug screening before a truck driver is hired and requires random drug testing periodically.<sup>23</sup> The purpose is to protect the public at large. The same objective exists for requiring truck drivers, pilots, soldiers, or policemen to undergo genetic testing if, in fact, that testing will benefit the public at large.

Obviously, any genetic test results can't be conveyed to anyone other than the employer in limited situations regarding public safety and the individual employee or prospective employee. What ethical obligations do physicians have, or other healthcare providers, when they determine that someone has a fatal/incurable disease as a result of genetic testing? Huntington's Disease can be determined by genetic testing. It is a fatal, incurable, disease. Would an individual want to know that eventually he or she will be stricken with a disease like Huntington's Disease? Does the medical provider have an obligation to tell the patient/test taker of the results if the onset of the disease is many years in the future and there is nothing that can be done to improve the individual's condition in the interim? Can the employee or prospective employee sign away his right to know if the results come back positive for a fatal/incurable disease?

Public policy and ethical issues are center stage in this debate. Genetic testing may go a long way toward reducing medical costs in the future by bringing about lifestyle changes to prevent disease or medical treatment that restores a patient's good health. Other considerations come into play. What about the obligations on an individual who applies for life insurance who is aware of genetic information that relates to life expectancy?

Does the employer have a right to consider an employee's "good genes" as provided in an employment application or resume? Does an insurer have a right to provide lower premiums to an individual with "good genes" as documented by the individual? Does State and Federal legislation allow for such favoritism?

The debate is far from over. Consider this quote:

*In young people and active sportsmen, HCM [hypertrophic cardiomyopathy] is the most common cause of SCD [sudden cardiac death]. An early detection and adequate management can avert the life-threatening cardiac arrest and malign tachyarrhythmias. Genetic analyses open new possibilities for the prevention of these severe complications. Genetic screening of HCM patients would enable an early detection of asymptomatic or preclinical HCM as well as the identification of patients at high-risk for SCD. From this point of view, genetic analysis fulfils the criterion of a crucial diagnostic tool in modern management of HCM patients.<sup>24</sup>*

The testing is not designed just to benefit NBA players. This test and other specific tests quite possibly lower health care costs, promoting good health and eventually lowering the reluctance of individuals to undergo such testing and for insurers to pay for it. The trick is to preserve privacy rights and for businesses and insurers to follow the law regarding genetic testing and the confidential nature of the information.



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### FOOTNOTES

1 *Medical News Today*, June 1, 2009

2 *Science Daily*, May 22, 2009.

3 *Id.*, May 7, 2009.

4 *The Hindu*, May 12, 2009.

5 *Medical News Today*, May 11, 2009.

6 *EurekAlert*, May 6, 2009.

7 Hudcovova K, et al. *Bratisl Lek Listy* 2009; 110(2):85-92.

8 "Genetic Testing for Breast or Ovarian Cancer Risk may be Greatly Underutilized, News-Medical.Net, May 22, 2009; "Families of Sudden Unexplained Death Victims Should Receive Comprehensive Cardiogenetic Testing," *Medical News Today*, May 26, 2009; "Expert Urges Testing for Genetic Disorders," *Cleveland Jewish News*, May 29, 2009; "Our Genetic

Code Should be No Secret," *The Times*, May 30, 2009; "Pre-operative Genetic Testing May Improve Treatment for Thyroid Cancer Patients, Pitt Study Finds," *Medical News Today*, May 7, 2009.

9 Neil Osterweil, "Full Court Press on Hoop Star Curry to Get DNA Testing," *MedPage Today*, Sept. 29, 2005.

10 *Id.*

11 *Id.*

12 *Id.*

13 *Id.*

14 "Mobley Forced to Retire," December 11, 2008, <http://sports.espn.go.com/nba/news/story?id=3762828>.

15 Genetic Information Nondiscrimination Act, H.R. 493, 110th Cong. § 202(a).

16 Genetic Information Nondiscrimination Act, H.R. 493, 110th Cong. § 202(b).

17 Genetic Information Nondiscrimination Act, H.R. 493, 110th Cong. § 102(b)(1)(B).

18 Genetic Information Nondiscrimination Act, H.R. 493, 110th Cong. § 202(b)(2)(B).

19 410 Ill. Comp. Stat. Ann. 513/20(a).

20 *Id.*

21 410 Ill. Comp. Stat. Ann. 513/20(b).

22 410 Ill. Comp. Stat. Ann. 513/25(c).

23 United States Department of Transportation, Federal Motor Carrier Safety Administration, Federal Motor Carrier Safety Regulations Handbook § 382.305(a).

24 Hudcovova, *supra* note 7, at 91.