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iii. **The Genetic Information Nondiscrimination Act**

[GINA] prohibits discrimination based on an individual's genetic information in both the health coverage (Title I) and employment (Title II) contexts. In addition to the nondiscrimination provisions, section 105 of Title I of GINA contains new privacy protections for genetic information, which require the Secretary of HHS to revise the Privacy Rule to clarify that genetic information is health information and to prohibit group health plans, health insurance issuers (including HMOs), and issuers of Medicare supplemental policies from using or disclosing genetic information for underwriting purposes.

### **ACTIVITY 6.1: HILLTOP MEMORIAL HOSPITAL**

Hilltop Memorial Hospital (HMH) is an acute care general hospital in Windsor County. It is owned and operated by a private, nonprofit corporation, and it has tax-exempt status under federal and state tax laws. HMH provides a large volume of uncompensated care and service to Medicaid patients, but it receives no public funds from the county government.

Windsor County has no public hospital. The only other hospital in the county is a for-profit facility that provides relatively little uncompensated care. Therefore, HMH is the safety-net hospital for uninsured, underinsured, and Medicaid patients in the region. Under these circumstances, HMH relies heavily on its insured patients to subsidize its indigent care and its losses on Medicaid patients.

On April 6, 2013, George Long went to the outpatient department of HMH for diagnosis and treatment of back pain. Long had made an appointment for that outpatient visit, and he arrived at HMH on schedule. Long had been to HMH many times for his back pain and for treatment of his mental health conditions. As indicated by his medical record at HMH, Long had a history of mental health problems, including episodes of delusion.

On that particular day, Long was escorted to an examining room in HMH's outpatient department and was instructed to wait for the nurse.

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A few minutes later, the nurse arrived to find Long running around the examining room in an agitated manner. The nurse was unable to calm him and immediately called for the doctor. The doctor and nurse held Long's arms for about one minute until he became calm. After Long assured them that he could remain calm, the doctor completed examination of his back and instructed him to return in two weeks if he was still in pain.

One week later, Long went to the office of a private, nonprofit advocacy organization called Patient Rights of Windsor County (PRWC) to discuss his recent experience at HMH. Long told the president of PRWC that during his visit to HMH on April 6, 2013, the doctor and nurse at HMH had slapped him in the face and hit him in the stomach.

With the help of the president of PRWC, Long called the local newspaper and gave this same account to a reporter. The reporter took detailed notes of the conversation with Long and then called the CEO of HMH to hear her side of the story. However, the CEO replied that, because of privacy laws, she could not comment or provide any information about any individual patient at HMH. The local newspaper published a story about Long's allegations, including the details of his statement and the fact that HMH's CEO had no comment. Long has not filed a complaint with the police or with any government agency about this alleged incident, nor has he filed any legal action against HMH or the individual healthcare professionals.

During the next few weeks, members of PRWC participated in a series of demonstrations on the public sidewalk in front of HMH. Many of the PRWC members carried signs that stated "Stop HMH from beating patients." The local newspaper published three stories about those demonstrations, in which the newspaper repeated Long's allegations and HMH's refusal to comment.

In the three months since the first newspaper report about Long's allegations, HMH has experienced a severe drop in visits by patients who have coverage through commercial health insurance or employer-based health plans. It appears that a substantial majority of those insured patients have chosen to receive care at the for-profit hospital in the county or at hospitals in other counties. HMH relies heavily on those insured patients to subsidize its indigent care and its losses on Medicaid patients. HMH has determined that it will be unable to pay all of its operating expenses if this situation continues for another six months.

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The CEO of HMM attempted to communicate with Long in an effort to resolve the matter or, at least, obtain his consent to allow HMM to release his medical record to the local newspaper. The CEO even suggested that it might be possible to make a financial settlement with him, in exchange for a neutral press release that would be acceptable to both sides. However, Long refused to discuss any type of settlement and refused to consent to the release of his medical record.

The board of trustees of HMM ("the board") held an emergency meeting to discuss the situation and consider its options. After receiving an update from the management of HMM, members of the board suggested various alternatives. Board member A argued that HMM must continue its current position of refusing to make any comment or provide any information about an individual patient. In contrast, board member B took the position that Long gave up his privacy by giving the mass media information—albeit false information—about his treatment at HMM. Therefore, Long would have no right to complain if HMM were to set the record straight by releasing his medical record, which would show that he has a long history of delusional episodes. Board member C stated that only a stupid law would prevent HMM from defending itself and its staff under these circumstances, and disclosing a small amount of information about Long's medical history would be a technical violation at most. Finally, board member D argued that ethical considerations require disclosing Long's history of delusional episodes, because the potential harm to Long from his loss of privacy is vastly outweighed by the greater good of preserving the community's safety-net hospital, which is at serious risk of insolvency.

Please evaluate HMM's alternatives from both an ethical and a legal perspective, including consideration of the federal HIPAA privacy rule. Also, please decide whether the current law should be clarified or amended. Be prepared to explain the reasons for your conclusions.

## Notes

1. American Medical Association, *Code of Medical Ethics, Principles of Medical Ethics, Preamble*, point IV (2001). [www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/principles-medical-ethics.page](http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/principles-medical-ethics.page).