Remarks to Capitol Hill Staff at the Health IT Now! Coalition Briefing

Presented by Sharon F. Terry, MA on March 14, 2008

My name is Sharon Terry. I am President and CEO of Genetic Alliance. We proudly join the Health IT Now! Coalition and call on Congress to promote the deployment and adoption of health information technology.

Genetic Alliance transforms health through genetics. We accomplish this by integrating individual, family, and community perspectives to improve health systems and services; bringing together diverse stakeholders to create novel partnership in advocacy; and promoting individualized decision-making through increased access to information.

Genetic Alliance's network includes more than 650 disease-specific advocacy organizations and partnerships with universities, companies, government agencies, and policy organizations. The network is an open space for thousands of shared resources, hundreds of creative tools, and dozens of focused programs.

There are close to 7,000 genetic conditions, some of them quite rare. One in 12 Americans— that's 25 million people—lives with these chronic genetic conditions. These patients need many kinds of support, beginning with freedom from fear of genetic discrimination and including quality genetic testing, access to clinical trials, and quality information. Moreover, these patients need health IT to allow them to integrate healthcare and support research toward treatments and therapies.

In the digital age, consumers are provided with online technology to check on the status of bank loans, purchase groceries, book travel, pay credit cards, apply for new jobs, and more. However, we have yet to harness technology in a way that fully empowers consumers, or their providers, in their own health management and outcomes.

This technology is even more critical for the chronically ill. Those who spend significant time consulting multiple medical professionals to manage complex symptoms are often forced to carry the burden of relaying details of vital health information to medical professionals: shuttling test results between offices, trying to correctly recall medications and dosages, and remembering allergies and side effects. Why have we as a nation digitized our finances but relegated our health information to file cabinets and shoe boxes?

I am the mother of two children with a genetic condition, pseudoxanthoma elasticum (PXE). It causes blindness. When they were diagnosed 13 years ago, there was no registry of people with this disease in the country. I called dozens of ophthalmologists, and none could tell me if they had another patient with PXE—there were no electronic records, no way to search across patients for diseases, signs, symptoms. I established a foundation, built a registry, and now have a state-of-the-art clinical database. Isn't it odd that a layperson has to develop systems to document diseases progression, treatment efficacy, diagnostic algorithms, and epidemiological studies? When I ask those same ophthalmologists, they still have no way to aggregate patients for clinical trials or other research studies. Sadly, I am not unusual; thousands of us have built similar systems. They are all imperfect, part of the cottage industry that is healthcare in this nation.

We have invested billions of dollars in biomedical research that makes it possible to personalize medicine. But we do not have the health information technology we need to access up-to-date medical records so healthcare professionals can improve diagnoses and treatment; monitor adherence to care plans; eliminate costly, and sometimes painful, duplicate testing; and provide information to encourage prevention.

We urge Congress to pass a bill that will establish a public-private process to determine standards—that will offer federal financial incentives for practitioners to accelerate health IT adoption—and that will use federal leadership to resolve critical policy issues such as privacy.

For the sake of the 25 million Americans we serve and the millions more who would benefit, we ask Congress to pass a health IT bill this year.