

Sarah Linde, MD

Email interview, 3/4/2013

**What is your job title?**

Chief Public Health Officer at HRSA, the Health Resources and Services Administration, an agency of the federal Department of Health and Human Services. HRSA is a “sister” agency to NIH. I am also a family physician and an officer in the United States Public Health Service. I would like to note that my day to day work is not related to genetic medicine or the human genome project. In addition, I am participating in this interview as a family friend who is a physician, not in my official government role.

**How has the HGP helped doctors treat and cure diseases?**

The HGP has helped in lots of ways. For example, if you know someone’s individual DNA sequence, or gene pattern, then you might know if they have or will develop a particular disease and/or if he or she might pass it on to his or her children. Depending on the disease, you might be able to get a genetic counselors to help provide information and support to families. Genetic counselors can review available options with the family, let them know about current research, and maybe connect them with other families going through the same thing.

Another way the HGP has helped is that if you know the genetic information, then you can take actions to prevent the disease or develop treatments for the disease. Cancer is a great example.

**What was the medical community's reaction to the complete sequencing of the human genome?**

I cannot really speak for others, but I personally think it is an amazing achievement to have figured this out. The human body has always fascinated me, and to understand how it is made, how it is “programmed”, and how that information can be used to help people is just awesome.

**How will personalized medicine improve treatments in the medical field?**

A lot of times in medicine, we recommend treatments based on what we think will help because we have general information about how a treatment works in groups of people. However, since not everyone is made exactly the same way, each person may respond (or not) in his or her own individual way to a treatment. If we can use a person’s individual information to help guide

treatment decisions, then there is a better chance of doing something that really helps and hopefully has little or much fewer possible side effects.

### **Can information from the HGP be misused? How?**

Lots of folks are concern about possible misuses of the information. For example, could someone who might give you a job or give you health insurance look at your genetic information and decide not to give you a job or health insurance because of what disease your genes say you might develop? Some folks think that would not be fair. Also, usually information about someone's health is considered private, so another possible misuse would be if your personal information is made available to others without your permission.

### **What are positive and negative consequences of learning one's genetic information?**

As we have discussed, if you know certain information, then sometimes there are steps you can take to prevent something from happening or develop special treatments in case something does happen. However, sometimes you learn information about something that may or may not happen, and then you spend a lot of time worrying and that might prevent you from enjoying your life.

### **Are doctors for or against knowing one's genetic information?**

I think that depends on the individual doctor, just like it depends on the individual patient. Some people like having any and all information that is available, and other people don't want to know, especially if there is nothing they can do about whatever it is.

### **Should healthy people have their genomes sequenced?**

I think that depends on the individual. If there is a strong family history of a disease that could be prevented if you know about it early on, before any symptoms develop, then yes, maybe healthy people should consider having their genome sequenced. However, if a person were to find out information that he or she couldn't do anything about or find out information that makes them worry a lot about something that may never happen, then maybe it is better not to have the genome sequenced.

**This is the 10th anniversary of the sequencing of the human genome. What are your thoughts about how this will benefit us in the future?**

I think the big benefit will be the ability to prevent the development of certain diseases, and also to develop treatments that help an individual person fight an specific disease.