
Direct to Consumer Genetic Testing

OSHER 306-001

Dates: Tuesdays: September 1 - October 6

Time: 1:30 pm – 3:00 pm

Location: Online via Zoom

Instructor: Vickie Venne, MS, LCG – after the introduction, the rest of the faculty will be subject matter experts or individuals sharing personal experiences about the specific topics as identified below

Course Description:

Before you break the seal on the gift your family member gave you for Ancestry, 23andMe, or some other genetic testing kit, this class will answer questions you didn't know you had! In addition to the consent process and privacy, experts will discuss the ancestry, health, and drug related components that might be in your report. Finally, individuals who have experienced unexpected surprises will share their stories. This class will include case examples and questions to encourage learner participation. Resources, articles, a TED talk by one of the presenters, and even a few books about the topic will allow interested learners to dive deeper. Given that we are using an on-line platform, Ms. Venne reached out to colleagues around the country to present about some of the topics, which might make this the first OSHER course with a national faculty!

Course Overview:

Week 1: Introduction. Vickie Venne, MS, LGC (recently retired!)

What type of test can be offered directly to the general public? What is the difference between a test offered directly to the public vs. one ordered by a health care provider? What even is a genetic test? When and why might you want to take one?

Week 2: Informed consent/Privacy. Megan Doerr, MS, LGC, Principal Scientist, Governance, Sage Bionetworks

What is informed consent? Do you REALLY have to read the whole document? What if you don't agree with one or two of the items? And what type of private information can companies obtain if I don't give it to them directly? Is my genetic information really private at all?

Week 3: Ancestry. Mary Eberle, JD, DNA Hunters, LLC

Genetic testing can be a powerful addition to completing a family history. This week, we will dip our toes into a fascinating world of DNA testing. For those who are already involved in genealogy, this presentation will provide direction to help you come up with a DNA testing plan to expand your family research.

Week 4: Health. Amanda Gammon, LCGC, Genetic Counselor, Huntsman Cancer Institute

For a while, the FDA stopped direct to consumer genetic testing companies from providing health information. Some health information is back. So how do you understand the clinical information? When do you see a health care professional to learn more into a specific condition? And should your insurance company pay for that? What is the role of the medical family history? What if no one else in your family has this condition?

Week 5: Pharmacogenetics. Christine M. Formea, PharmD, IHC Pharmacogenomics Pharmacy Specialist

For years, people took medicines – sometimes they worked, sometimes they didn't. This new area of genetic testing offers promise of specificity when taking drugs. But is it ready for prime time? Will it work for me? Or did it work for people who have genetic markers similar to mine? And what if I am taking more than one medicine?

Week 6: Stories from the Field

Finally, the last class will include people who spit in a tube and learned something unexpected. Three individuals will share their stories that speak to both the promise and the perils of direct to consumer genetic testing.