September 24: Dinner in Waltham, Mass.

**Ancestry DNA Testing and Privacy**

DNA testing for ancestry has increased in popularity in recent years, but how much do you know about these tests and about what happens to your genetic information once you submit a sample? At the New England Chapter’s next meeting—on Monday, September 24, at the Best Western/Copper House Tavern in Waltham, Mass.—Dr. Sheldon Krimsky, professor of urban and environmental policy and planning at Tufts University, will speak on “Ancestry DNA Testing and Privacy.”

Tracing one’s genealogical roots using DNA ancestry methods is largely a recreational activity. There are no quality assurance guarantees for any of the commercial direct-to-consumer DNA ancestry tests and no methods of validation. The tests cannot determine with any precision where ancestors might have lived or the specific ethnic group to which they might have belonged. And frequently, the DNA sample that people submit for commercial ancestry tests is sold to other companies, so consumer privacy cannot be guaranteed.

Dr. Krimsky will provide background and discuss ongoing efforts to inform and educate the public about direct-to-consumer ancestry DNA testing and the privacy issues associated with these tests.

Dr. Krimsky earned his BS and MS in physics at Brooklyn College and Purdue University, respectively, and an MS and PhD in philosophy at Boston University. He has served on the Recombinant DNA Advisory Committee of NIH, chaired the Committee on Scientific Freedom and Responsibility of AAAS, is an elected fellow of AAAS, and has been a consultant to the U.S. Congress Office of Technology Assessment. He is on the Board of Directors of the Council for Responsible Genetics, serves on the editorial board of several journals, and has published numerous essays on the social and ethical aspects of science and technology. He is the author of several books, including *Genetic Alchemy, Biotechnics and Society, Hormonal Chaos, and Science in the Private Interest*, and coeditor of *Social Theories of Risk*. His current research focuses on the role of science in public policy, environmental policy, social theories of risk, biotechnology, and chemicals in the environment.

You won’t want to miss this first meeting of the New England Chapter’s 2018-19 year. Come early for the social hour to catch up with friends and make new acquaintances while you network over drinks. Then enjoy a nice dinner with fellow medical writers, followed by Dr. Krimsky’s presentation and a Q&A session.

As always, guests and prospective members are welcome.

—Brian Head
President-Elect/Program Director
CHAPTER CALENDAR

The New England Chapter’s year begins in mid-June, when a new slate of officers takes over. The chapter’s Board of Directors meets during the summer, but there are no general activities during July and August.

The chapter holds six regular meetings from September through June. Four of these meetings are in the Greater Boston area, and two are in Connecticut. Typically, these meetings start with a social hour, followed by dinner (except for a Sunday brunch, usually in the winter), then a program with a speaker, panel presentation, or roundtables.

In addition to the regular meetings, the chapter occasionally schedules other events, ranging from informal networking lunches or evening meetups to workshop programs.

Every fall, at the national AMWA meeting, attendees from New England get together for an informal dinner at a restaurant near the conference site.

AMWA Annual Conference

The 2018 AMWA Medical Writing & Communication Conference—the premier event of the year for health and biomedical communicators from around the country and beyond—will be held in Washington, D.C., from Wednesday, October 31 through Saturday, November 3. For all the details and registration information, go to: https://www.amwa.org/page/conference.

November 1
Chapter Dinner
AMWA Annual Conference
Washington, D.C.
If you're attending the 2018 AMWA Medical Writing & Communication Conference in Washington this fall, plan to join your New England colleagues for a private dinner at a restaurant near the conference hotel on Thursday, November 1.

The chapter dinner at the national convention is a longstanding tradition. It is always a popular event that gives New England AMWA members a chance to spend some time together. No other conference events are scheduled for that evening.

Watch the AMWA New England E-News for details. You won’t have to pay in advance, but you’ll need a reservation.

TBD
Fall Dinner Meeting
New Haven, Conn.
Watch the AMWA New England E-News for announcements regarding the Connecticut fall dinner meeting, which will take place in November, most likely in New Haven.

[NOTE: Anyone with an interest in helping to plan Connecticut meetings, please contact Margaret Burke, vice president for Connecticut, at mburkepharmd@cox.net.]

Other Events in New England

September 20
STC New England
Boston, Mass.
The New England Chapter of the Society for Technical Communication will hold a dinner program from 6:00 to 8:30 p.m. at Sonos in downtown Boston, featuring a presentation on “The Interplay of UX and Technical Communication.” For information: http://stcnewengland.org/event-3046500.

October 26-27
STC New England
InterChange 2018
Lowell, Mass.
InterChange, the annual technical communication conference of the New England Chapter of the Society for Technical Communication, will take place on Friday, October 26 and Saturday, October 27, at the UMass Lowell Inn and Conference Center in Lowell, Mass. For information: http://stcnewengland.org/interchange.
June Meeting Report

Health Literacy

At the New England Chapter meeting in June, our AMWA colleague Helen Osborne, MEd, OTR/L, spoke about the effects of inadequate health literacy and provided strategies that medical writers can use to improve patients’ understanding of health and the healthcare system. She also traced the evolution of attitudes toward health literacy.

Helen began by talking about what spurred her to launch a career in health literacy more than 20 years ago. She was an occupational therapist, directing patient education in the psychiatric unit of Carney Hospital, when she read a study in JAMA showing that many hospital patients couldn’t “perform the basic reading tasks required to function in the health care environment.” She was struck by the realization that many of her patients could not absorb the treatment and self-care information she and other staff members were providing. Soon afterward, she left clinical practice and dedicated herself to helping the public understand health information.

Defining Health Literacy

The U.S. Department of Health and Human Services defines health literacy as the ability of patients to “obtain, process, and understand basic health information and services needed to make appropriate health decisions.” Helen explained that health literacy is necessary for patients to successfully navigate all aspects of healthcare: making lifestyle choices (where possible) to help maintain wellness; obtaining healthcare insurance and providers; working with providers to understand diagnoses, treatment options, and treatment instructions; and managing their self-care.

Ensuring that patients are knowledgeable participants in all aspects of their care, she said, is now seen as the joint responsibility of patients and care providers to “communicate in ways that the other can understand.” The medical establishment once viewed health and literacy as distinct, unrelated realms, and expected patients to improve their own health understanding. Now they are seen as interconnected, and the healthcare system is taking initiatives to align its practices and communication with the learning needs, abilities, and interests of patients and the public.

Why It Matters

The stakes are high. “There are thousands of health literacy studies,” said Helen, “and nearly all make a compelling case why health literacy matters.” When patients don’t understand the information they are given, poorer health outcomes follow, including lower adherence to recommended medication, vaccination, and mammography schedules, and higher rates of hospitalization and emergency care. Among older adults, consequences also include poorer overall health and higher mortality. As seemingly simple a statement as “Your biopsy came back positive” is an example of language that could confuse patients unfamiliar with medical terminology, she noted.

How Medical Communicators Can Help

To prevent misunderstandings, medical communicators as well as clinicians should use plain language as much as possible. In addition to overall reading ability, fluency in English, and familiarity with medical language, a number of factors can weaken a patient’s ability to take in medical information. Anyone who is ill, anxious, in pain, from a different social/cultural background, or experiencing declining vision or hearing, for example, faces additional hurdles when trying to process health information.

Helen pointed out two free online tools to help health communicators assess whether patients will be able to understand and act on information they are given. The Patient Education Materials Assessment Tool from the HHS Agency for Healthcare Research and Quality can help test the clarity of both print and audiovisual materials. And the CDC offers the Clear Communication Index. Involving patients in the planning and review of information materials is particularly important.

Other strategies to help patients understand written information include: understanding the viewpoint and characteristics of the audience, communicating in ways other than the printed word (speaking/podcasts, pictures, video, infographics), limiting content length, and offering additional sources for more information. Helen has found cartoons especially effective. They set a friendly, informal tone, and provide an alternative avenue for visual learners.

*Using pictures to communicate is an effective way to reach patients,* says Helen Osborne. (Cartoon courtesy of Health Literacy Consulting.)

Health Literacy continued on next page
Health Literacy continued from previous page

Opportunities for Plain Language Health Writers

In a follow-up email, Helen added that work for plain-language writers and editors is most often done by consultants like herself and freelancers. She said, however, that she has seen a growing number of jobs with “health literacy” in the title, primarily at large health organizations. A certification process for health literacy specialists does not yet exist, but soon will. The Institute for Healthcare Advancement has developed a model job description outlining necessary competencies.

For more on health literacy, visit Helen’s website, healthliteracy.com, and her 175+ Health Literacy Out Loud podcasts in which she interviews people whose work is helping to improve health literacy. Helen is president of Health Literacy Consulting in Natick, Mass, and is the author of the award-winning Health Literacy from A to Z: Practical Ways to Communicate Your Health Message, now in its second edition.

—Jessica Solodar

New Members

The New England Chapter cordially welcomes those from our six-state region who have recently joined AMWA, reestablished their affiliation with the association, or moved here from another chapter area. We are also happy to welcome AMWA members from outside of New England who are planning to move here in the near future or have personal or professional ties here.

Violaine Bailey, PhD
Flatley Discovery Lab
Charlestown, Massachusetts

Aarathi Balijepalli
San Diego, CA

Allyson Bower, MS
Agios Pharmaceuticals
Cambridge, Massachusetts

Johanna Bruneau, MSc, PhD
Lowell, Massachusetts

Karen Eisenhauer, PhD
Vertex Pharmaceuticals
Boston, Massachusetts

Carla Eisenstein, PharmD
Boston, Massachusetts

Andrew Fenton, BS, ASCP(C)
Quest Diagnostics
East Longmeadow, Massachusetts

Patricia Fonseca, PhD
Shrewsbury, Massachusetts
Exerpta Medica
[from Southwest Chapter]

Heidi Hirsch, MPH, ELS
Redding, Connecticut
IQVIA

Bethany Ingram, PharmD
Holden, Massachusetts

Joseph Jackson IV, DO, MA
Medford, Massachusetts
IQVIA

Hajira Koeller, PhD, CMPP
Winchester, Massachusetts

Margaret Kruse, PhD
Andover, Massachusetts

Juan Liao, PhD
Cambridge, Massachusetts

LiQun Liu, PhD
Merck & Co.
Boston, Massachusetts

Amy Marcini, MD
Bridgewater, Massachusetts

Molly Rodriguez, BS, MPH
Wakefield, Rhode Island

Dimitria Stefanopoulos, BD
Boehringer Ingelheim
Ridgefield, Connecticut

Lisa Smith, BS
Nightstar Therapeutics
Waltham, Massachusetts

Personal Note

At the AMWA conference in Washington in November, Andrea Gwosdow, PhD, will be named an AMWA Fellow in recognition of her significant contributions to the goals and activities of AMWA as well as her other professional accomplishments.

Since joining AMWA in 1997, Andrea has been actively involved in the New England Chapter. She served as secretary in 2000-01 and as president in 2005-06. She has spoken at chapter meetings, led roundtables, conducted workshops at the Sturbridge conferences, and served as a judge in our writing competitions. She is currently the New England representative to the AMWA Chapter Advisory Council.

She has also been a frequent presenter and workshop leader at national conferences and has served on several national committees.

Andrea is president of Gwosdow Associates Science Consultants in Arlington, Mass.
How to Register for Meeting
You can register for this event either online or by mail, depending on how you wish to pay.

• To pay by credit card, use the electronic registration form on the chapter website (www.amwa-ne.org). Fill it out and continue to the PayPal form, where you can enter your credit card information. (You don’t need a PayPal account, and you will not be charged a fee for the transaction.)

• To pay by check, download the printable registration form from the chapter website (www.amwa-ne.org), print a copy, fill it out, and mail it with your check to the address on the form.

Directions to Meeting
Best Western/Copper House Tavern
380 Winter Street
Waltham, Massachusetts
781-890-7800

The Best Western is east of Route 128/I-95, a short drive from the highway. Heading south on Route 128/I-95, take exit 27A. Heading north, take exit 27A-B.

There is ample free parking.

Need a ride to the meeting?
The hotel is not accessible by public transportation. If you don’t have a car, ask Judy Linn (judyhlinn@aol.com) whether there is someone from your area who might be able to give you a lift.

You can also use the chapter’s LinkedIn page to ask for a ride (or offer one). If you haven’t already signed up for the New England Chapter LinkedIn subgroup, you can do so at www.linkedin.com.

Chapter E-News
Watch for the occasional email from “President@amwa-ne.org” with “AMWA New England E-News” in the subject line.

A few times a month, our chapter president sends an email to all members of the New England Chapter to announce a job opening or to let you know about an upcoming chapter meeting or some other regional event. The messages are usually brief, with just enough information for you to follow up if you wish. Be sure to glance at them so you don’t miss something of possible interest to you.

Volunteer Needed
to Manage LinkedIn Group
We are looking for a volunteer to manage the AMWA New England Chapter LinkedIn group. Responsibilities include posting information about upcoming chapter events, commenting on recently held events, and sharing information relevant to the medical writing profession. If you have experience using LinkedIn and are motivated to help raise the social media profile of our chapter, please contact Debbie Ferguson (deborah.ferguson@yahoo.com).

Board of Directors
Welcomes Comments
The officers and other members of the chapter’s Board of Directors welcome your input regarding chapter activities. If you have questions or suggestions, please let them know. Write to Debbie Ferguson (deborah.ferguson@yahoo.com).

2018-19 BOARD OF DIRECTORS
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IMMEDIATE PAST PRESIDENT: Shawn Watson
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NEWSLETTER: Judy Linn
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NOMINATING COMMITTEE: Brian Head
WEB SITE: Aaron Federman

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Dara Chadwick, Marisa Greenfield, Olivier Morteau, Jill Shuman, Theresa Singleton, Debbie von Rechenberg

REPRESENTATIVE TO AMWA CHAPTER ADVISORY COUNCIL
Andrea Gwosdow