



By April Frawley Birdwell

Found in translation

UF's Clinical and Translational Science Institute is forging unusual partnerships that could change health care

The premise sounds simple. For \$100 — and a test tube full of spit — the website promises to look into the genetic crystal ball and reveal your chances for developing diabetes, Alzheimer's disease and a slew of other conditions. Even baldness. Or what a child's IQ might be, revealed in one quick cheek swab

It's an enticing prospect and entirely believable in a world where DNA is a household name. It's also misleading.

"These websites are way beyond where the science is right now," says Debbie Treise, Ph.D., a researcher in the UF College of Journalism and Communications. "People get these results back, and they don't understand them. The research shows people are making horrible decisions based on these tests. Whether or not they get married, whether or not they have children."

As part of a Clinical and Translational Science Institute project to understand more about companies offering direct-to-consumer genetic testing, Treise and fellow communications researcher Norman Lewis, Ph.D., teamed with experts in the College of Medicine. They conducted a content analysis study, reviewing the sites to find out everything from what sorts of promises they made to customers and whether they offered genetic counseling to

how they conducted their tests and whether the industry was regulated. Their findings reveal a landscape that falls woefully short of disclosing the information required for consumers to fully understand the validity and utility of the tests being sold.

"It turned out (these sites) failed utterly," says Stephen Hsu, M.D., Ph.D., the R. Glenn Davis associate professor of clinical and translational medicine, and a molecular geneticist who worked on the project. "In some sense, you cannot escape your genetics, but how your genes get expressed depends on so many other factors. At each turn, we are discovering increasing levels of complexity that are independent of the DNA sequence and clearly argue against strict genetic determinism. Card-carrying molecular geneticists are appalled by (online services offering direct-to-consumer genetic profiling) based on a very simplistic understanding of the role of genetic variation in predicting



PHOTO BY MARIA BELEN FARIAS

College of Journalism and Communications researchers Norman Lewis and Debbie Treise collaborated on a project with molecular geneticist Dr. Stephen Hsu and other Clinical and Translational Science Institute researchers. Their research may play a role in whether the FDA regulates direct-to-consumer genetics testing companies.

with any certainty complex human traits such as IQ or risk for heart disease. Yet it's a huge cottage industry and completely unregulated."

For patients, the extent to which they encounter information about these companies online or in the news is likely to affect whether and how they consider genetic testing options in a clinical or research setting — which, for example, might help determine the safest and most effective medication or dosage for a patient.

The study, which is in press for publication in the journal *New Genetics & Society*, is just one of the ways Treise and colleagues in the College of Journalism and Communications are using their expertise in mass media to make a difference in health care and science as part of the CTSI. The partnership may seem unusual — its experts have vastly different areas of expertise and methodologies — but Hsu says it is these differences that make the collaboration potentially revolutionary. It also makes UF unique. Of the 60 institutions who have received the Clinical and Translational Science Award in the country, UF is the only one with a communications college on board at the program level.

Like epidemiology, communications research is not the type of science that can be conducted in a laboratory, there are no white coats and beakers, but it is just as crucial when it comes to bringing scientific discoveries to the people who need them, says Hsu. And that is what the CTSI is all about.

"Translating what we learn from research into actual health advances is a long and complicated process. At nearly every turn, that process is affected by our ability to inform and motivate others — whether colleagues, patients, policymakers or communities," says David Nelson, M.D., director of the UF CTSI. "Collaborating with

health communication researchers presents an enormous opportunity to better understand and navigate these real-world dynamics."

Making the connection

Until the CTSI was established in 2008, finding collaborators in the Health Science Center wasn't always easy for Treise and other communications researchers. In some ways, it still isn't, though they are making progress through the CTSI.

Part of the challenge has been getting physicians and health scientists to understand not only how communications research can enhance their own studies, but also that the College of Journalism and Communications has researchers.

"Typically what happens is they say we need a press release or public service announcement, without thinking about how we should have been involved on the research part of it," Treise says. "There is so much research that goes on to craft the appropriate message."

Ronald Shorr, M.D., found Treise when he was searching for information on health communication at UF prior to joining the university and the Malcom Randall Veterans Affairs Medical Center in 2007. In the Geriatric Research, Education and Clinical Center, Shorr and colleagues Rebecca J. Beyth, M.D. M.Sc., and Connie Uphold, Ph.D., A.R.N.P., are focused on finding new ways to improve patient care, particularly helping people become more informed consumers of health care. To them, teaming with Treise was a logical step — and has already yielded results.



PHOTO BY MARIA BELEN FARIAS

Staff members of the CTSI Biorepository Rosia Kizza, Antony Higgs, Melissa Rawley-Payne, Dhane Stomp and Eric Elmadani (from left) stand in front of new robotic freezers that were recently installed.

The CTSI Biorepository

For many investigators, obtaining and studying human tissue samples are critical steps on the path to discovery. But procuring and maintaining those samples can be a challenge in terms of time, space and resources.

The UF Clinical and Translational Science Institute Biorepository was established to serve as an institutional resource, giving researchers a place to obtain high quality specimens that can be used in studies that will lead to better care for patients, says Melissa Rawley-Payne, M.A., assistant director of the Biorepository.

Housed in the College of Medicine department of pathology, the new Biorepository is equipped with the latest technology, including a robotic freezer that stores samples at a chilly 80 degrees below zero, Rawley-Payne said.

"It is a new technology that really improves the quality of tissue," Rawley-Payne says. "The advantage of the robotic system is it is completely enclosed, you don't have to open it at all."

The CTSI Biorepository works closely with the UF CRU Processing Laboratory and the Molecular Pathology & Immunology Core. But as staff members have worked to get the Biorepository running, they did take on one other more unusual partner as well — students from UF's Warrington College of Business Administration. Business students from the college's GatorNest program helped the Biorepository by completing a market analysis. — *April Frawley Birdwell*

"The future of research is going to depend on these unique combinations of points of view. Team science," says Shorr, director of GRECC. "The fact is that the traditional science has only taken us so far, and study after study has shown people are not receiving optimal care. All the lab work in the world is not going to solve that problem."

Working together

Shorr has a term for Treise and her fellow communications researchers. He calls them "the basic scientists of persuasion." And he Beyth and Uphold hope that incorporating the strategies and skills of advertising and mass media into their own work will help change how patients approach health care.

"A lot of people know much more from *Consumer Reports* about what widescreen TV they should get versus what medicine they should be on," Beyth says. "They need to be informed consumers."

The team's first project with Treise involved ways to educate patients with the cardiovascular disease atrial fibrillation about the benefits of taking the drug warfarin, which can reduce stroke risk by two-thirds. But first they needed to know why patients weren't taking it already and how to best reach out to them and their doctors. The end product was a video they plan to test soon.

At a time when patients are exposed to messages from all directions and doctors have less time to communicate one-on-one, coming up with new ways to provide accurate information in an understandable way is more important than ever, Beyth says.

"One of the skills mass communication professionals have to have is translation — that is, we've learned how to gather information from one group, which often is speaking in a 'language' only that group's members can fully understand, and then to translate that information into language tailored for the specific audiences with whom we're communicating," Treise says.

As part of her doctoral work, College of Journalism and Communications student Yukari Takata, M.P.H., is working with the CTSI Biorepository to study the informed consent process. The Biorepository collects tissue samples to be used in research, but patients must give consent to be part of a study first. Takata is working with the CTSI to enhance that process and help patients more fully and easily understand their consent and make an informed decision.

"My research looks at how patients make decisions and how they are influenced, especially with informed consent for research and procedures," Takata says. "We know if someone is wearing a lab coat they are seen as more credible and people are more likely to say 'OK.' That can be a problem for decision-making, because they might say 'OK doc, do whatever you want.'"

As part of her project, Takata aims to look at how user reviews and recommendations can affect this process. Her research has shown that an online expert review outweighs the review of an average person, like the kind you see when you are shopping on Amazon. But when the number of user opinions start to mount, climbing between 100 and 300, the scale tips.

"Taking that 'collective intelligence' concept into the informed consent process, here is this long document, what happens if we have different users discover and share parts they thought were important?" Takata says. "We are trying to see the positive side of user influence. Even if a lot of people highlight something, will people pay more attention and make a better, more informed decision?"

About the CTSI

The UF Clinical and Translational Science Institute helps investigators translate scientific discoveries into medical practice. Now in its third year, the institute supports 140 faculty and staff across 10 programs managing CTSI services, resources and projects.

Research services

The CTSI offers more than 40 services addressing consultation, informatics, laboratory, clinical, recruitment and other needs, including:

- Research project consultants who help researchers navigate the research process and identify resources, tools and collaborators
- REDCap, a free data management platform that enables secure web-based data entry, storage and retrieval
- IRB, regulatory and other consults
- Research coordinator services
- Study design and data analysis
- A centralized biorepository as well as biobehavioral, biomedical mass spectrometry, genotyping and metabolomics core labs
- A network of 13 clinical research units — including the UF Clinical Research Center and the Shands Jacksonville Clinical Research Unit — managing clinical trials across numerous specialties and populations.

Funding

Each year the CTSI awards funding to support pilot projects. The CTSI expects to release its next request for applications this fall.

Professional development

The CTSI supports the training and advancement of clinical and basic science investigators. Numerous opportunities are available for faculty, fellows, Ph.D. students and research personnel. CTSI trainees and scholars represent all six colleges of the UF Health Science Center.

How to access CTSI resources?

- Call the CTSI's research project consultants at 352-273-8700 or email info@ctsi.ufl.edu, and they'll connect you to the resources that best meet your needs.
- Visit the CTSI website at www.ctsi.ufl.edu

PHOTO BY MARIA BELEN FARIAS

College of Journalism and Communications doctoral student Yukari Takata talks with adviser Debbie Treise.

Takata, who studies persuasion theories, has been working with CTSI researchers to enhance the informed consent process.

Opportunities, opportunities

And there are far more prospects for collaboration between communications and the health sciences, Treise says. The college has the country's only public interest communications program, which health science researchers could tap into. Also, Treise says the addition of newsroom and strategic communications laboratories at the College of Journalism and Communications will offer a place for new communications research concepts to be tested.

"There are all kinds of people here who are interested in the communications functions of health and science," she says.

Treise's collaborator Hsu, sees collaborations between disciplines like communications and medicine as being beyond multidisciplinary, thinking of them instead as "transdisciplinary."

"We have to be more holistic and see how different and seemingly unrelated disciplines can come together to create new disciplines with new capabilities. We need all these skillsets. That kind of perspective and paradigm is being explored now but somewhat cautiously," he says. "It is at the interface between science and society. For me it has brought me into domains of creative activity I otherwise would not have had if Debbie had not invited me to join one of her collaborate research efforts." 