Invisible disorder

UF experts help patients with a little-known affliction: The inability to swallow

By Michelle Koidin Jaffee

His nostrils pinched by a nose clip, Bert Ranum purposefully coughs as hard as he can into a handheld device that measures the velocity of the air he exhales. Emily K. Plowman, Ph.D., CCC-SLP, is impressed by the reading. "He's like an Olympic cougher at this point," she says, prompting grins from Ranum and his wife.

The exercise is among a set of breathing and swallowing exercises Plowman leads to help Ranum strengthen his airway defense, or his ability to keep food from "going down the wrong pipe," which can cause aspiration pneumonia. For now, this isn't a problem for him. But it is expected to become one.

Ranum, 58, was diagnosed last year with amyotrophic lateral sclerosis, or ALS. The neurodegenerative disorder progressively weakens muscles, including those involved with chewing and swallowing. He now practices daily exercises learned from Plowman.

"I occasionally get something down my windpipe and cough," says Ranum, an attorney who lives in Gainesville. "But when we do the swallowing analysis, I'm safe. So far, I'm pretty good."

Swallowing is a process that seems automatic to most and generally goes unnoticed — unless it's not working. And yet dysphagia, or difficulty or discomfort in swallowing, affects a significant portion of the population: One in 25 American adults per year report a swallowing problem, according to the journal Otolaryngology—Head and Neck Surgery. That's an estimated 9.4 million adults.

The inability to execute a healthy swallow is a common and debilitating symptom of several diseases, including stroke, Parkinson's disease and traumatic brain injury. In young children, swallowing problems can stem from congenital disorders that cause weakness or spasticity in the head and neck, such as cerebral palsy. Dysphagia can also develop as a side effect — an unfortunate consequence of necessary medical treatment such as surgery to fuse the spine or radiation therapy to treat cancer in the head or neck.

That inability to swallow can then significantly affect quality of life, from detrimental weight loss to distress in social situations like restaurant meals or holiday gatherings.

And it's a condition that is often suffered in silence.

At University of Florida Health, swallowing experts Plowman and Ianessa Humbert, Ph.D., CCC-SLP, are working to advance treatments for this devastating disorder.

"When someone is living with a swallowing impairment, you don't see it," Plowman says. "It's like this invisible disorder, and yet it leads to such huge psychosocial and medical issues. We need to swallow for survival, and when it's taken away, people are very isolated from society. They're sitting there spitting into a handkerchief because they can't even manage their own saliva."

With few researchers nationwide dedicated to the relatively new but growing academic field of swallowing disorders, Plowman and Humbert in August 2015 joined the department of speech, language and hearing sciences in the UF College of Public Health and Health Professions as associate professors. They were part of a cluster recruitment and merged their labs — previously at the University of South Florida and the Johns Hopkins School of Medicine, respectively — to establish the one-of-a-kind Swallowing Systems Core they now co-direct.

Ianessa Humbert, Ph.D., CCC-SLP, left, and Emily K. Plowman, Ph.D., CCC-SLP, helped establish the Swallowing Systems Core at UF.

The duo chose UF as their field gains increasing recognition for its contributions toward not only improving quality of life but also preserving life — by preventing dangerous events such as choking or aspiration.

Energized by the opportunity to collaborate with another swallowing expert already at UF, Karen Wheeler Hegland, Ph.D., CCC-SLP, and multidisciplinary teams in their new college and the Evelyn F. and William L. McKnight Brain Institute of the University of Florida, Humbert and Plowman saw a path to take their field to new heights.

Now, their National Institutes of Health-funded research team is carrying out a wide array of studies that extend all the way from mouse models to human clinical trials, while also treating patients in clinic and serving as leaders in education and outreach.

In December, Humbert and Plowman hosted a first-ever Swallowing Think Tank for experts from across the country who came together to discuss the latest research and, importantly, solutions for swallowing disorders. Sixteen internationally recognized experts attended.

Humbert, 40, notes the swallowing disorders field is younger than she is.

"Within speech pathology, swallowing has only come around since the 1980s," Humbert says. "We're trying to get some sun so we can grow. Ultimately, swallowing makes a big difference in terms of medical status.

"If somebody cannot walk but is otherwise healthy, or cannot speak but is otherwise healthy, that is not the same kind of medical concern. Swallowing is how you get your nutrition, your hydration, your meds — so while we might not get as much sun as we'd like, the patients really need this exposure."

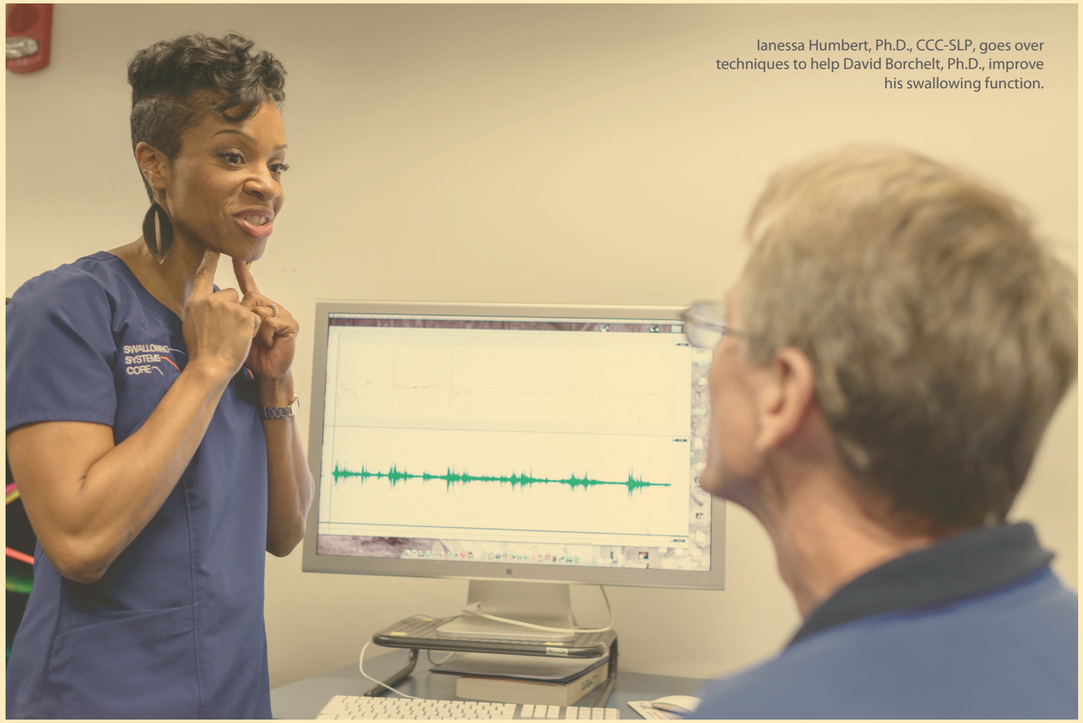
Humbert and Plowman point out that evaluation and treatment of swallowing disorders historically has not been taught to medical students or neurology residents.

This must change, says Michael Okun, M.D., chair of the

Emily K. Plowman, Ph.D., CCC-SLP, helps Bert Ranum improve his breathing capacity.

"When someone is living with a swallowing impairment, you don't see it. It's like this invisible disorder, and yet it leads to such huge psychosocial and medical issues. We need to swallow for survival, and when it's taken away, people are very isolated from society."

– Emily K. Plowman, Ph.D., CCC-SLP



Ianessa Humbert, Ph.D., CCC-SLP, goes over techniques to help David Borchelt, Ph.D., improve his swallowing function.

"One of my coping mechanisms is to order something and just move the food around on my plate like a 5-year-old. That way, you fit in and people, including the wait staff, feel more natural around you."

– Ed Steger

UF College of Medicine's neurology department.

"Aspiration pneumonia is a leading cause of death in multiple neurological maladies," Okun says. "It's amazing we haven't paid attention to it."

To build bridges across the related areas of expertise, Humbert and Plowman crafted the December think tank to bring together speech-language pathologists with UF experts in neurology, neuroscience and neurogenetics as well as anatomy, evolutionary biology, otolaryngology and kinesiology.

Participants pledged to incorporate screenings for swallowing disorders into medical training and address swallowing as part of treatment plans and research strategies for patients with neurodegenerative disorders.

"It was a neat mixture of minds to think about something that flies under the radar but is an extremely important problem," said Todd Golde, M.D., Ph.D., executive director of the McKnight Brain Institute who served on the think tank's scientific expert panel. "Two of our UF experts brought together a group of people to see what we can do and what the gaps in knowledge are to make a difference."

One speaker made an impact as both expert and patient.

David Borchelt, Ph.D., is director of the UF Center for Translational Research in Neurodegenerative Disorders. A professor of neuroscience in the UF College of Medicine, he studies the types of diseases that often result in an inability to swallow.

In 2010, Borchelt underwent radiation to treat throat cancer and, near the end of treatment, required a feeding tube because he couldn't swallow. Over the months that followed, he regained his swallow, but more than four years later he experienced "delayed secondary fibrosis," or a hardening of the muscle fiber in his neck.

"When you swallow, there's a little flap that's supposed to close over your airway, and in my case that little flap is so fibrotic that it doesn't close," says Borchelt. "Now I do a lot of purposeful coughing to make sure I clear the airway."

For him, eating has turned from a pleasure to a chore. Although he's altered his diet to avoid raw foods to keep bacteria out of his airway and in favor of soft, calorie-dense foods, he has still ended up with aspiration pneumonia. He worries about getting it again. And Borchelt, 59, has lost so much weight he could fit into his high-school jeans.

"It's more difficult to go out to eat," he says. "I eat very slowly. Many, many minutes after everyone else is finished, I'm still trying to finish my dinner."

It brings a new dimension to his work studying ALS.

"I've got a firsthand understanding of what dysphagia feels like," he says.

There is a surgical option to ensure safe swallowing: removing the larynx, or voice box, to help prevent food or drink from slipping down the airway. This would mean using an electronic vibrator in the neck to communicate with an artificial voice. But for many patients, the option is viewed as a last resort. For Borchelt, who speaks, lectures and teaches for a living, the prospect of not being able to use his voice is a daunting one.

To help patients cope with the psychological toll, and also to raise public awareness, the nonprofit National Foundation of Swallowing Disorders coordinates support groups and offers resources, such as the online video "Swallow: A Documentary – Dysphagia."

Ed Steger, president of the group, became involved after he was left with severe dysphagia — unable to consume any solid food — due to extensive surgery for head-and-neck cancer. In a restaurant, he says, "One of my coping mechanisms is to order something and just move the food around on my plate like a 5-year-old. That way, you fit in and people, including the wait staff, feel more natural around you."

Steger, of suburban Houston, collaborates with Humbert and Plowman and has great hopes that they will advance the science of assessment, rehabilitation

Humans swallow **2,000** times per day

Swallowing continues while asleep

and treatment.

Current therapies are guided by the cause of the dysphagia and its severity and prognosis, and success rates vary. Treatments range from breathing exercises to strengthen the muscles involved with swallowing to injecting fat to help bulk up the paretic vocal fold or injecting Botox to relax the area.

With nine ongoing externally funded research studies, the Swallowing Systems Core team is working to expand the options. In one clinical trial, under an R01 grant from the National Institutes of Health, Humbert is investigating the use of biofeedback, or using X-rays that show patients live video images of their own swallowing movements to help them understand what is happening on the inside and how well they are protecting the airway.

Plowman, meanwhile, has a new five-year R01 grant from the National Institute of Neurological Disorders and Stroke to determine underlying mechanisms and progression of respiratory, speech and swallowing impairment.

Plowman is also co-investigator of an NIH-funded study with Laura P.W. Ranum, Ph.D., director of the UF Center for NeuroGenetics in the UF College of Medicine, evaluating the efficacy of a set of novel therapeutics in a mouse model of ALS.

As a scientific collaborator, Ranum views Plowman's work through one lens; as the spouse of a patient, through another. Bert Ranum is her husband.

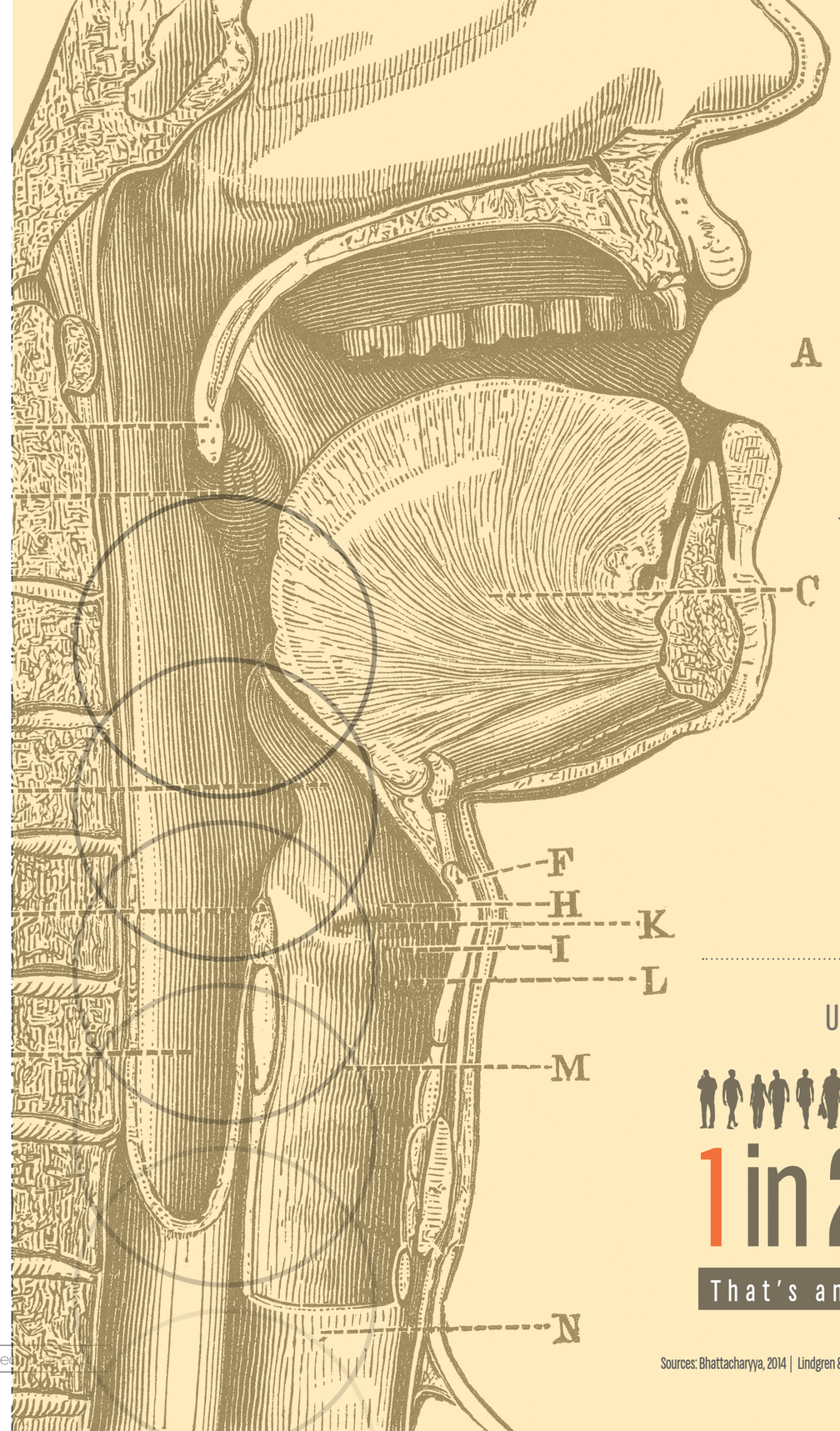
Laura Ranum, a professor of molecular genetics and microbiology, says that from both a research point of view and a health care point of view, she feels fortunate to be in an environment where Plowman and Humbert are working.

In her husband's sessions with Plowman, he works on building strength and endurance, much as one would do pumping iron at the gym.

"Dr. Plowman has figured out how to keep breathing function working, and that's a huge thing not just for ALS patients but also all neurodegenerative diseases," Laura Ranum says. "There's a common thread that many of them die from aspiration and resulting pneumonia, so if you can preserve the function of your breathing and your cough just by pumping a little 'inspiratory and expiratory' iron with these simple devices, I think that really makes a difference.

"We're also excited about some of the therapeutic strategies we are testing in the lab, and we are hopeful the treatments might be available in time. And if not for Bert . . .," Ranum's voice catches as tears fall.

". . . For others," he finishes.



"Aspiration pneumonia is a leading cause of death in multiple neurological maladies. It's amazing we haven't paid attention to it."

– Michael Okun, M.D.

26 pairs of muscles

+5 cranial nerves

1 swallow

UNITED STATES

1 in 25 American adults per year report a swallowing problem

That's an estimated 9.4 million adults.

Sources: Bhattacharyya, 2014 | Lindgren & Jonzon, 1991 | Emily Plowman | Ianessa Humbert | Michele L. Singer | Lauren C. Tabor | Alicia K. Vos