



"Advancing the treatment of swallowing disorders in our lifetime."

September 23, 2016

To: Dr. Battey and Mr. Wong:

CC: Dr. Shekim, Dr. Collins, and Senator Booker

This correspondence is in response to Dr. Battey's invitation to comment – draft "NIDCD Strategic Plan," dated September 1, 2016.

I am writing as the President of the National Foundation of Swallowing Disorders (NFOSD), a 501(c)(3), non-profit. Our commitment is to provide patient hope and improve quality of life for those suffering from all types of swallowing disorders. Our mission is to advance the prevention and treatment of swallowing disorders in our lifetime. Our programs include patient support, education, research and raising public, professional and governmental awareness. Although the NFOSD was not founded until 2006, we have already developed a strong national membership and are becoming increasingly international in scope. In 2008, Congress unanimously established June as National Dysphagia Awareness Month. This past June, the NFOSD further advanced swallowing disorder awareness by reaching over a quarter million people through our website and social media outlets.

The NFOSD is grateful to Dr. Battey for his invitation to provide feedback on the draft of the NIDCD Strategic Plan. While the NFOSD realizes that the NIDCD funds opportunities beyond what is outlined in your Strategic Plan and Priority Setting, we would like to:

1. Advocate for swallowing disorders (dysphagia) to be included as a priority in the NIDCD Strategic Plan, and
2. Respectfully request a trans NIH committee be established to coordinate and plan support for dysphagia-related research across NIH Institutes and Centers to ensure that this important work is funded at levels that are commensurate with the impact of dysphagia on healthcare, outcomes, quality of life, and healthcare costs.

Dysphagia is the result of many conditions, diseases, and disorders. As such, dysphagia can affect anyone, and in fact, affects millions of Americans and people worldwide. Sura et al. (2012) determined that 300,000-600,000 new patients with dysphagia are identified in the United States each year. After reviewing the 2012 National Health Interview Survey, which identified adults (aged 18 and over) who reported a swallowing problem in the prior twelve months, Bhattacharyya (2014) estimated that "swallowing problems affect 1 in 25 adults annually." Although this is a conservative estimate, it accounts for approximately 9.44 million adults in the U.S. alone. The American Speech-Language-Hearing Association (ASHA) estimates that "25-45% of typically developing children demonstrate feeding and swallowing problems." They further note that this is estimated to be as high as 30-80% for children with developmental disorders.

Common causes of dysphagia may include, but are not limited to:

- Head and neck tumors, oncologic surgery, radiotherapy and chemotherapy
- Stroke and other cerebral-related events
- Head injury
- Spinal cord injury

- Degenerative neurologic disease (Parkinson's disease, Alzheimer's disease, multiple sclerosis, motor neuron disease, amyotrophic lateral sclerosis, dementia)
- Cerebral palsy
- Premature birth
- Genetic disorders (e.g., Down syndrome)

Dysphagia can lead to serious, negative health conditions, including recurring pneumonia resulting in multiple hospitalizations, malnutrition, dehydration, weight loss, and places a burden on an already overwhelmed healthcare system. Other quality of life issues include social isolation, increased dependence on caregivers, and a financial burden on the individual and their family.

The potential impact of research on dysphagia is extremely high at this time. New technologies are advancing our understanding of the neural control of swallowing including brain imaging and neural stimulation; animal models are being developed; stem cell research is leading the way for tissue regeneration, new devices and technology for patient evaluation and rehabilitation are becoming available. New investigators are entering this field and augmenting the ranks of an already dedicated cadre of mid-career investigators making this a particularly opportune time for enormous strides forward.

We believe that dysphagia research merits consideration as one of the NIDCD's program areas because it aligns with your plan's priorities, including:

Priority Area 2: Understanding Diseases and Disorders

Swallowing is a complex sensorimotor behavior and its function can be disrupted by a variety of diseases, disorders, and injuries. Because the etiology of dysphagia is highly variable and spans the entire age-range, our understanding of dysphagia is limited. Efforts should be made to better understand dysphagia in order to diagnose and treat this very serious and common problem.

Priority Area 3: Improving Diagnosis, Treatment, and Prevention

Unfortunately, dysphagia is poorly understood, resulting in frequent misdiagnosis and lack of treatment. Dysphagia is often not identified until it leads to aspiration pneumonia, which leads to increased healthcare costs, morbidity, and mortality. Swallowing shares anatomic and physiologic substrates with speech and voice communication and is within the scope of practice of both otolaryngologists and speech-language pathologists. That is, communication and swallowing overlap in many ways and are often treated and investigated by the same professionals and scientists. Dysphagia practice is relatively new and there are large gaps in knowledge affecting understanding and treatment of this complex disorder. As such, diagnosis and treatment of dysphagia is complex. Further, treating (or in some cases NOT treating) dysphagia has become a tremendous societal cost and is a healthcare burden, particularly in our aging population. Despite these healthcare concerns, funding for research directed at understanding, evaluating, and treating swallowing disorders is tragically lacking.

Importantly, a recent NIH Reporter search of current fiscal year funding of grants that listed both swallowing and dysphagia in their descriptions identified 77 grants, 22 of which were supported by the NIDCD; that is 28.6%. Because many other NIH Institutes and Centers look to the NIDCD as being the primary source for dysphagia funding, if the NIDCD chooses to exclude dysphagia from its program priorities and explicitly from its 2017 – 2021 strategic plan, support for dysphagia research may see a substantial decrease. This would likely create a larger gap in funding for a condition that is already under-funded.

A recent study by Cichero and Altman (2012) found that "financial burden related to dysphagia exceeds \$547 million annually." The NFOSD has recently initiated a project with a well-respected "outcomes" physician/researcher at Vanderbilt University to begin assessing the cost impact of dysphagia on healthcare delivery. We hope to submit an article for peer review to reveal the substantial impact that dysphagia has on our healthcare system and have it published in a high impact journal. We want to scientifically quantify the impact that many individuals experience personally or see in their clinical practice.

With a growing aging population, lack of funding, and uncoordinated NIH effort, patients and families are left with an enormous burden.

- Patients will continue to face poor outcomes: malnutrition, pneumonia, increased mortality, co-morbid disease, isolation and depression.
- Families will be burdened with preparing modified diets that require time and expense, or may not follow through with medical recommendations, leading to additional health problems such as aspiration pneumonia.
- Healthcare costs will continue to rise unnecessarily.

While several NIH Institutes (including the NIDCD, the National Institute on Aging, the National Institute on Neurological Disorders and Stroke, the National Cancer Institute, the National Institute on Child Health and Human Development, and the National Institute of Diabetes and Digestive and Kidney Diseases) have funded *some* research for dysphagia at various times, **none has a program aimed at addressing dysphagia in a coordinated manner.** Thus, research funding for these devastating disorders is inadequate and discernable progress within our lifetimes will be negligible.

In addition to adding dysphagia-related research to the strategic plan, the NFOSD requests that a trans NIH committee be established to develop a coordinated plan of support for dysphagia research across the NIH Institutes and Centers and to facilitate appropriate funding in line with the impact of dysphagia on the health and well-being of U.S. citizens.

Thank you for your time and consideration.

Sincerely,

Edward Steger, President, National Foundation of Swallowing Disorders

With full representation and support from our Foundation and Clinical Advisory Board members
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