Senate Finance Committee Interested Party Testimony Mark D. Bej, M.D. – Neurologist / Epilepsy Specialist June 13, 2019

Chairman Dolan, Vice Chairman Burke, Ranking Member Sykes, and Members of the Finance Committee, my name is Dr. Mark Bej. I am a neurologist, subspecialty trained in clinical neurophysiology (Jefferson Hospital) and then in epilepsy at the Cleveland Clinic, where I remained for a total of 10 years. Subsequently I stepped out into a private practice and am currently in a group practice, Northern Ohio Medical Specialists, based in Sandusky. I am the only epilepsy subspecialist spanning the gap between Toledo and Cleveland. I thank you for the opportunity to testify in front of this committee regarding the difficulties encountered by my patients with vagus nerve stimulation (VNS).

Epilepsy affects about 1.5% of the population. This translates to 4.9 million people in the U.S., or 175,000 Ohioans. Of this number, approximately one third have medically intractable epilepsy, meaning that medications alone do not fully control their seizures. Thus, about 60,000 Ohioans have drug-resistant epilepsy. The devastating impact of such diagnosis is often difficult to appreciate. One cannot drive. As a result, most patients cannot hold down a job. Even those who are employed are often let go from their jobs because of safety concerns, absenteeism, liability concerns, or simple prejudice. Such patients are often left with welfare and Medicaid as their only options.

Certain patients in this category qualify for resective surgery (brain surgery) to try to control the epilepsy. However, even so aggressive an approach does not control all seizures for everyone. Other patients have one or more disqualifying factors that preclude surgery. For the latter 2 groups, options are very limited, and in fact were non-existent before the advent of VNS. Without VNS, their prospects were grim: uncontrolled seizures, often resulting in falls, which then result in fractures, concussions, and brain injuries. I am thinking of one patient in particular who, over the 15-plus years during which I have cared for him, has deteriorated from a cheerful, walking, talking, gregarious individual to one who is no longer able to speak and has to be brought into the office by his crippled father in a wheelchair. At best I can get him to smile.

Approximately 3,000 Ohioans currently have a vagus nerve stimulator implanted. For Ohio Medicaid patients specifically, about 70 *new* and about 90 *replacement* VNS implants are performed per year. This may seem to be a small number statistically, but having a non-drug therapy makes a substantial positive impact in their lives. VNS has also been shown to significantly reduce healthcare utilization for drug-resistant epilepsy patients — fewer breakthrough seizures means fewer doctor visits, fewer Emergency Room visits, and fewer hospital stays; and for some, it means sufficient seizure control to become self-sustaining members of society.

As an epilepsy specialist, I have been screening my patients for VNS eligiblity, arranging for implantation, and handling device programming (dosing, if you will), ever since this therapy has been available. These surgeries have been performed for my patients at Mercy Allen Hospital, a critical access hospital in Oberlin — that is, until 2017, when the Mercy system decided no longer to offer VNS therapy due to declining Medicaid reimbursement.

The 3M Enhanced Ambulatory Payment Grouping (EAPG) system, calculating the outpatient reimbursement for Ohio hospitals, results in a reimbursement that is a mere 52% of the Medicare rate. This inadequately accounts for the cost of VNS devices, with per-implantation losses of \$10,000 being typical. Smaller, and especially rural, facilities simply do not have the financial buffer to be able to sustain such losses, and thus they cannot afford to offer this option to drug-resistant epilepsy patients.

With only big-city hospitals still implanting VNS devices, a major access-to-care issue is created for rural and poor Ohio patients, who would otherwise be eligible. Many of these Medicaid patients already find travel to be difficult: reaching the Cleveland Clinic or University Hospitals from Lorain County requires 3 separate buses in each direction. Many do not have the funds, or enough family or friends able to take time off work, to make the trip. In effect, access to this therapy is simply impractical.

The version of HB 166 passed by the House included language that would increase the reimbursement rate for VNS to 75% of the Medicare rate. This would certainly be an improvement, though a reimbursement rate of 90-100% of Medicare would be preferable. Another way to restore VNS as an option would be for Ohio Medicaid to pay for VNS "outside of the system" through published fee schedules, supplemental payments, or at-hospital-invoice cost, as other states have done. I understand that this provision is still under consideration by the Senate. For all the reasons outlined above, I would respectfully request that appropriate language be included in the Senate's final version of the budget to address this issue, which is so important to so many patients who truly do not have a voice.

I thank you for the opportunity to testify before the Committee and for allowing me to share a physician's perspective. I am happy to entertain any questions the Senators may have.