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Boston University
NEW ENGLAND'S FIRST SUPPORT GROUP FOR PATIENTS WITH SPASTIC DYSPHONIA

Boston, Mass.--The first support group in New England for sufferers of spastic dysphonia--an uncommon, incurable speech disorder that can psychologically devastate its victims and ruin personal and professional lives--is being established by the University Hospital (UH).

Spastic dysphonia, a neurological disorder that can strike suddenly or come on gradually, causes the vocal cords of its victims to spasm. The voice becomes a strangled, nonrhythmic and unmelodic noise, and sometimes no sound is produced at all.

"Just speaking becomes embarrassing, which can destroy personal and professional lives," says Glenn Bunting, speech pathologist at UH and leader of the support group. "Patients are afraid to apply for jobs, meet new people in any setting, or even communicate about the simplest issues."

Disappointed by traditional treatments--consisting of largely unsuccessful speech therapy or surgery to cut vocal cord nerves--and ashamed of their present condition, many patients become depressed and isolated and begin to lose hope of ever communicating normally again. "Because the disease is rare, most patients have never known the support offered by others with the same problem," says Bunting.

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Bunting hopes UH's new support group will offer spastic dysphonia patients a place where they can share experiences, receive emotional support, learn new coping skills, and find out about the latest research and treatment from psychiatrists, physicians, speech therapists, surgeons and each other.

For instance, in one of the first group sessions several patients will share their experiences as participants in clinical trials of a promising new treatment. Called botulinum-toxin therapy, the treatment consists of tiny injections of botulinum toxin that relax the vocal cords, stop the spasms and produce more normal speech patterns.

The University Hospital, founded in 1855, is a principal teaching hospital of Boston University School of Medicine and a member of Boston University Medical Center.