

Clinical Trial for Swallowing Difficulty in Adult Patients with Cystinosis

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Muscle weakness (myopathy) and difficulty swallowing (dysphagia) are common in nephropathic cystinosis, significantly impacting quality of life. Previous research has demonstrated that breathing exercises may enhance swallowing function in individuals with severe dysphagia. In a long-term follow-up study of patients with dysphagia, we observed impairments in both the oral and pharyngeal stages of swallowing. Despite a general progression of muscle weakness, some aspects of swallowing showed improvement, possibly due to a delayed positive effect of breathing exercises or the psychological influence of repeated swallowing evaluations. To further optimize swallowing function, we are conducting an interventional clinical trial to evaluate the efficacy and safety of three different exercises: (1) respiratory therapy, (2) tongue exercises, and (3) biofeedback training. This study aims to identify the most effective therapeutic approach for improving swallowing in patients with nephropathic cystinosis.