

# Psychological Concomitants of Morquio Syndrome (The MAP Study)

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Mucopolysaccharidosis IV, also known as MPS IV or Morquio disease, is a rare autosomal recessive genetic lysosomal storage disorder. Research thus far regarding lysosomal storage diseases (LSDs) in general, including Morquio, has primarily focused on exploring the causes of and finding a treatment for the physical aspects of the various diseases. Less attention has been paid to the psychological or emotional toll of these diseases, whether they are direct symptoms of the diseases themselves or reactions to living with a chronic progressive disease.

It is well established in the health psychology literature, however, that the interaction between our physical health and our psychological health is bidirectional; that is, just as our physical health affects us emotionally (e.g. chronic pain can contribute to depression), so can our psychological health affect us physically (e.g. anxiety can contribute to feelings of chest pain). It is thus critically important to pay attention to the emotional and psychological symptoms associated with all lysosomal storage diseases, including Morquio, and expand our treatment standard of care to include mental health treatment, if necessary.

The first step in understanding and treating psychological conditions in Morquio disease is determining the natural occurrence of psychological symptoms in this population in comparison with non-medical populations. As little has been done in this regard, a pilot study documenting the occurrence rate of psychological issues and overall quality of life in patients with Morquio is the first item in order and will be the focus of this study.

Approximately 20 patients with Morquio disease will be invited to participate, recruited through Emory's Lysosomal Storage Disease Center, as well as through attendance at Morquio support groups and relevant regional, national and/or international meetings. Once consented, patients will be asked to complete three different self-report questionnaires, including the Achenbach System of Empirically Based Assessment (ASEBA) Adult Self-Report (ASR) or Older Adult Self-Report (OASR) questionnaire, the Short Form 36-item Health Questionnaire (SF-36), and the Brief Pain Inventory (BPI). Group aggregate data only will be reported; individual questionnaire content and results will be held confidential, except as in accordance with Georgia law relating to reporting of child or elder abuse, suicidal and/or homicidal intent. Completion of these questionnaires will complete subjects' participation in this pilot study.