

# **Educating Children with a Metabolic Condition: What and When Do Parents Want Their Children to Know about a Gaucher Diagnosis?**

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Childhood is a time of many transitions, physically, neurologically and socially. Children with a lysosomal storage disorder may struggle with these transitions, especially if there is a limited understanding of their genetic condition. A review of the literature has revealed that a primary way children gain information about their chronic condition is from their parents. Furthermore, literature has shown a lack of material reflecting how parents educate their children about lysosomal storage disorders. The purpose of this cross-sectional study was to assess what and when parents educate their children about a chronic genetic condition. We accomplished this through a detailed online questionnaire of parents who have at least one child with Gaucher disease Type I. The questionnaire was designed to gather information about demographics and then answer the following three questions: What Gaucher-related information do parents feel is most relevant to teach their children? At what age do parents feel children should be taught this relevant information? How or by what means do parents feel this information is best taught? Ultimately, the questionnaire aimed to identify the current unmet needs in the area of Gaucher education. Upon completion of the study we found that parents value education about Gaucher disease. Specifically, parents ranked topics of emotional well-being and treatment/management as the most important issues to teach their children. Most parents felt that topics of emotional well-being should be taught between the ages of 4-8 years and topics related to treatment/management should be taught between the ages of 4-12 years. Lastly, parents felt that education about Gaucher disease is best taught to their children through a discussion with a health care professional. By understanding what and when parents teach their children about Gaucher disease, health professionals and genetic counselors can help address the educational needs of families in the future.