What Are The Possible Benefits From Helping This Project?

The results of this project may improve the scientific understanding of this disease and how these features and symptoms change over time. Results may assist in developing better tools for early diagnostics of multiple genetic syndromes and promote research for drug discovery and effectiveness.

What Is The Purpose Of This Project?

Many genetic syndromes are associated with the appearance or gradual development of distinctive facial characteristics in affected patients. FDNA has developed a technology that analyzes facial photos to identify facial morphology associated with rare diseases. This is a free tool used by hundreds of geneticists worldwide and the technology converts facial photos into a de-identified mathematical algorithm that describes the characteristics of each facial feature. FDNA is collecting data from images of patients with confirmed diagnosis of many different genetic diseases to improve this technology further. As more data is collected, the technology learns and becomes more accurate for the benefit of the entire genetic expert community and their patients. To learn more about FDNA, please visit www.Face2Gene.com.

What Do I Have To Do To Help?

You are invited to upload or send in facial photos of patients with confirmed diagnosis of Gaucher disease to this secure and private portal dedicated to help training the technology. Serial photos of the same patient at different ages are particularly useful for showing changes over time, so you are encouraged to provide current and past photos. For each photo, please write the estimated age at the time the photo was taken, gender and ethnicity as well as the exact confirmed diagnosis (name of syndrome, specific test results, if available).

If I Take Part In This Project, How Will My Privacy Be Protected?

Access to all information uploaded in this portal, including facial photos, will be limited to the FDNA research and development team and to a selected group of medical researchers who collaborate with FDNA for the duration of this particular research project. After completing this research, the photos will be converted into de-identified mathematical information and stored in a secure and encrypted repository. This information will not be sold or shared with any third party for commercial purposes.

FDNA applies the highest standards of security for this online portal to ensure the most stringent privacy compliance. Please contact us for any questions.

