

Creation of the Web-Based University of Chicago Monogenic Diabetes Registry: Using Technology to Facilitate Longitudinal Study of Rare Subtypes of Diabetes

Siri Atma W. Greeley, M.D., Ph.D.,^{1,2} Rochelle N. Naylor, M.D.,¹ Lindsay S. Cook, B.A.,² Susan E. Tucker, B.A.,² Rebecca B. Lipton, Ph.D.,¹ and Louis H. Philipson, M.D., Ph.D.^{1,2}

Abstract

Background:

Monogenic diabetes is a group of disorders caused by mutations in any one of a number of genes. Although a monogenic diagnosis—estimated to represent as much as 2% of all diabetes patients—can have a transformational impact on treatment, the majority of monogenic cases remain unidentified and little is known about their natural history. We thus created the first United States Monogenic Diabetes Registry (<http://www.kovlerdiabetescenter.org/registry/>) for individuals with either neonatal diabetes diagnosed before 1 year of age or with a phenotype suggestive of maturity-onset diabetes of the young.

Methods:

Inclusion criteria and consent documents are viewable on our Web site, which allows secure collection of contact information to facilitate telephone consent and enrollment. Relevant medical, family, and historical data are collected longitudinally from a variety of sources and stored in our Web-accessible secure database.

Results:

We have enrolled well over 700 subjects in the registry so far, with steady recruitment of those diagnosed under 1 year of age and increasing enrollment of those diagnosed later in life. Initially, participants were mostly self-referred but are increasingly being referred by their physicians. Comprehensive survey and medical records data are collected at enrollment, with ongoing collection of longitudinal data. Associated private Facebook and email discussion groups that we established have already fostered active participation.

Conclusions:

Our early success with the Monogenic Diabetes Registry demonstrates the effectiveness of low-cost Web-based tools, including surveys, the Research Electronic Data Capture database program, and discussion groups, for efficient enrollment and support of rare patients, and collection and maintenance of their data.

J Diabetes Sci Technol 2011;5(4):879-886

Author Affiliations: ¹Department of Pediatrics, Section of Adult and Pediatric Endocrinology, Diabetes and Metabolism, The University of Chicago, Chicago, Illinois; and ²Department of Medicine, Section of Adult and Pediatric Endocrinology, Diabetes and Metabolism, The University of Chicago, Chicago, Illinois

Abbreviations: (HIPAA) Health Insurance Portability and Accountability Act, (iBi) Initiative in Biomedical Informatics, (IRB) institutional review board, (MODY) maturity-onset diabetes of the young, (REDCap) Research Electronic Data Capture, (SSL) secure sockets layer

Keywords: diabetes registry, monogenic diabetes, neonatal diabetes

Corresponding Author: Siri Atma W. Greeley, M.D., Ph.D., Instructor of Pediatrics and Medicine, Section of Adult and Pediatric Endocrinology, Diabetes and Metabolism, The University of Chicago, 5841 South Maryland Ave., MC1027, Chicago, IL 60637; email address sgreeley@peds.bsd.uchicago.edu