

INTRODUCTION

Patients, parents, healthcare providers, and the public are inundated by a constant flow of information from myriad sources, both reliable and unreliable. This bounty of information is ever-expanding, along with opportunities to disseminate it online further and more quickly. Some of the information is credible, and some of it is bunk. We need a way to filter out the meaningless or harmful information so that we may heed the high-quality health information that can have a positive impact on our lives.

On September 22, 2009, the Access to Credible Genetics Resources Network, a cooperative agreement funded by the Centers for Disease Control and Prevention (Grant #5U10DD525036), held a meeting to examine these issues as they pertain to the creation and assessment of health information. ATCG and this meeting help individuals, families, and healthcare providers determine when to “Trust It or Trash It?”

HISTORY OF THE DEVELOPMENT OF THE TRUST IT OR TRASH IT TOOL?

Access to Credible Genetics Resources Network (ATCG) was a cooperative agreement focused on Duchene/Becker muscular dystrophy and Fragile X syndrome. Genetic Alliance—a network of thousands of organizations, including more than 1,000 disease-specific organizations as well as academic institutions, professional societies, government agencies, industry groups, and more—directed the grant activities in partnership with the following organizations:

National Center of Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
Genetic Alliance (lead)
FRAXA Research Foundation
GeneTests
National Coalition for Health Professional Education in Genetics
National Council of La Raza
National Fragile X Foundation
Parent Project Muscular Dystrophy
University of Maryland School of Medicine

Goals of this project included:

- Defining evidence-based information,
- Creating a tool that both guides the creation of accurate, high-quality information and critically assesses the quality of information, and
- Creating an overarching system that allows this process to be replicated.

Objectives included:

- Determining a process to define evidence-based information, including some accessible metrics,
- Determining the background information, people, networks, and the process necessary for disseminating information once it has been defined as evidence-based,
- Creating a tool to analyze patient and provider information in a systematic way,
- Creating a tool to guide the process of creating complete, high-quality, accessible information, and
- Identifying the components needed to create a robust, coordinated system for repeating this process with other health conditions, beyond Duchene/Becker muscular dystrophy and Fragile X syndrome, and even beyond rare conditions.

Audience for the Project

The ATCG audience is anyone who interacts with health information: diagnosed individuals, their families, and their care providers, including physicians, nurses, physician assistants, physical therapists, occupational therapists, educators, directors of health plans, etc. Though the project focuses on health information surrounding rare genetic conditions, it is also applicable to more common health information. We realize that the vast majority of healthcare providers are not experts in genetics, so disease-specific and genetic information developed for consumers is often useful for providers, as well. By defining “evidence-based information,” and by characterizing information based on this definition, we hope to provide an accessible way for our entire audience to determine which information should be trusted.

Principles of ATCG

The ATCG process, including the culminating meeting, progressed according to the following principles:

1. Work is transparent and immediately available for others to use or comment on,
2. The evaluation process is transparent enough that others can understand the process and make their own judgments as needed,
3. The field of evidence-based medicine informs this project,
4. Models from other fields are examined and integrated where possible,
5. Other projects and programs in information, genetics, resources, single gene disorders, common conditions, and genetic testing and screening are examined and their leaders are consulted and invited to participate,
6. The information assessment systems created are patient-focused and replicable, and
7. Our results are meant to be practical – they will not require that “further research be conducted,” nor will we wait to disseminate even preliminary findings, plans and results; all information will be distributed multiple times throughout the project.