
PREFACE

Over the past few decades, advances in genetics and genomics have exceeded our greatest expectations and have revolutionized the way we think about health. While genetics has been traditionally associated with pregnancy, birth defects, and newborn screening, almost every disease is influenced in part by an individual's genetic make-up. Therefore, it is important to consider the impact of genetics for any condition throughout a patient's lifetime.

The purpose of the manual is to provide a genetics educational resource for patients and health professionals in the District of Columbia and increase awareness of specialty care in genetics. The manual opens with a basic introduction to genetic concepts followed by a description of the different types and applications of genetic tests. Information is also provided about diagnosis of a genetic disease, family-history taking, newborn screening, and genetic counseling. Helpful resources are included to assist in patient care, patient and professional education, and specialty genetics services in the District of Columbia and surrounding areas. At the end of each section, a list of selected references is provided if any additional information is desired. In addition, a series of consumer fact sheets are provided to be copied and offered to patients. These take-home resources will be critical in helping patients understand some of the basic concepts and applications of genetics.

This manual was created by Genetic Alliance with funding from the District of Columbia Department of Health. Genetic Alliance is an international coalition comprised of more than 600 advocacy, research, and healthcare organizations that represent more than 14 million people. With a 20-year history as a 501(c)(3) not-for-profit organization, Genetic Alliance is dedicated to improving the quality of life for everyone living with genetic conditions. Strategically situated at the crossroads of the genetics community, Genetic Alliance provides technical assistance to advocacy organizations, builds and sustains robust information systems to empower an active and dynamic network of stakeholders, and actively works for public policies that promote the translation of basic research into therapies and treatments. In particular, Genetic Alliance identifies solutions to emerging problems and works to reduce obstacles to rapid and effective translation of research into accessible technologies and services that improve human health.

The mission of the Department of Health is to promote healthy lives, prevent illness, provide equal access to quality healthcare services, and protect the safety of all in the Nation's capital. This project was made possible through funding from the U.S. Department of Health and Human Services Health Resource and Services Administration, Grant # 5 H91 MC 00228-03. Additional print copies can be obtained from the Children with Special Health Care Needs Division, DC-DOH Maternal and Family Health Administration at (202) 671-5000. The manual will also be available online (<http://www.geneticalliance.org>) in a downloadable format and updated regularly.

