

# Reducing the Clinical and Public Health Burden of Familial Hypercholesterolemia

## A Global Call to Action

### RECOMMENDATIONS

#### AWARENESS

Awareness should be enhanced regarding the importance of severe hypercholesterolemia and FH as a global public health issue; awareness should be raised in a broad range with the general public, educational institutions (both public and medical), the general medical community, and health care delivery systems.

#### ADVOCACY

Establishment of country/region specific advocacy organizations, focused on the implementation of the recommendations herein, is of utmost importance. Organizations should be a partnership of patients, physicians, and other health care professionals needed for FH care. Governments and national institutes of health should be made aware of the existence of this health hazard.

#### SCREENING, TESTING, AND DIAGNOSIS

Screening for FH should be performed according to country-specific conditions and guidelines. Screening, testing, and diagnosis may be based on cholesterol levels (with cutoff levels adapted to the country/target population) or positive genetic tests for an LDL cholesterol receptor function defect.

#### TREATMENT

Treatment for FH, to prevent premature ASCVD, should be person-centered, available and affordable. Ideally, treatment should begin in childhood and continue over the life course.

#### SEVERE AND HOMOZYGOUS FH

Create, as a special case, separate guidelines for severe and homozygous FH, defined as either the presence of LDL cholesterol level > 400 mg/dL or a pathogenic gene variant in any of the FH-related genes on 2 different alleles.

#### FAMILY-BASED CARE

Develop a family-based care plan with opportunities for patient involvement and shared decision-making over the continuum of the life span.

#### REGISTRIES

Fund national and international FH registries for research to quantify current practices and identify the gaps between guidelines and health care delivery, to publish outcome metrics for monitoring and standardizing care, identify areas for future resource deployment, dissemination and defining best practices, as well as facilitating FH awareness and screening.

#### RESEARCH

Conduct basic science, genetic, epidemiologic, clinical, and implementation science research to improve FH care.

#### COST & VALUE

Understand value in FH care, both for the family and for society, including gained years of life expectancy, gained years of life without disability, and lost productivity.