“Global Call to Action on FH - Recommendations”

1) DIAGNOSIS AND TREATMENT

As inherited lipid disorders are diagnosable and treatable in the primary health care context, treatment in childhood and over the life course should be available on a fair basis of risk when compared to other chronic disorders. This includes:

- Case identification through cascade and/or universal screening based on lipid and/or genetic testing
- Early treatment, especially during adolescent years
- Unrestricted access to essential therapies for lipid management at low or no cost
- Managed life-long

2) AWARENESS

Awareness should be made of the existence of this global public health concern/hazard.

- Government programs should be implemented
- Broad education: public, schools, and among healthcare professionals
- Target primary health care (vs. specialty care) to implement existing recommendations and guidelines
- Role of genetic testing in diagnosis

3) NATIONAL AND INTERNATIONAL POLICY AND PUBLIC HEALTH PROGRAMS

Guidelines should be issued for identification, diagnosis and medical management of inherited lipid disorders. Guidelines components should include:

- FH-specific treatment recommendations including youth with FH
- Strategies for cholesterol screening (universal and cascade)
- Affordability of essential therapies globally
- FH specific tools for implementation of recommendations
- FH as a genetic disorder to be identified as part of cascade screening and the WHO Genetics Programme

4) FAMILY-BASED CARE

Family-based care must be provided:

- Developmental-specific counseling (parent, child, pregnancy, nutrition, risk for two parents with HeFH when conceiving, psychology, stigma, medical, drug compliance, social work, access to care)
- Genetics evaluation where available
- Focus on initiating care earlier in the life course to provide life long lower cholesterol levels

5) HOFH MANAGEMENT

HoFH management have available:

- Initiate treatment at diagnosis
- Access to new therapies
- Treatment
- Apheresis

6) FH REGISTRY AND RESEARCH FUNDING

- Fund research into the genetic and environmental factors influencing the expression of inherited lipid disorders, the development of atherosclerosis and the pharmacology and efficacy of lipid-lowering drugs. On-going research should include factors influencing heart disease, and how to intervene in the pathogenesis of atherosclerotic
- Fund national and international FH registries for research, define outcome metrics, surveillance, collaboration for defining best practices, and care improvement

7) ADVOCACY

- Establishment of active patient organizations, focused on the implementation of the above mentioned recommendations, is of utmost importance
- A special emphasis of advocacy organizations should be screening of FH in childhood and early initiation of treatment
- Protection against genetic discrimination because of a genetic diagnosis

8) COST

Understand the cost of FH, both personal and social

- Personal cost
- Social cost