

New Paradigms of Collaborative Infrastructure: Impact of the “Fabric” Supporting Safety Registry Efforts **NHLBI view**

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**National Heart
Lung and Blood Institute**

NHLBI and CV Registries

A Long History

NHLBI-sponsored CV Registries

- **Completed**
 - PTCA I, II and III (1977 – 1997)
 - Catheter Ablation Registry (1986 -1991)
 - Ballon Valvuloplasty Registry (1987 – 1994)

- **On-going**
 - Dynamic Registry
 - Interagency Registry for Mechanically Assisted circulatory support (INTERMACS)
 - Pediatric Cardiomyopathy Registry

Background

Is a Safety Registry of AF Ablation Part of NHLBI Mission?

NHLBI Mission: Provide global leadership through research and education to enhance the health of all individuals so that they can live longer and more fulfilling lives. (E. Nabel, Feb, 2007)

NHLBI Strategic Plan (“a scientific blueprint for the next Decade”)

Goal: What are the “best practices” for the medicine of today and tomorrow?

Challenge: To enhance the evidence available to guide the practice of medicine, and improve public health

Goal: To translate research into practice for the benefit of personal and public health

Challenge: Evaluate the risks, benefits and costs of diagnostic test and treatments in representative populations and settings

Creating a Collaborative Infrastructure

NHLBI Strategies to Address Challenges

- Establish National standards for nomenclature
- Establish and expend collaborative resources for clinical research
- Extend the infrastructure for clinical research
- Support multidisciplinary teams

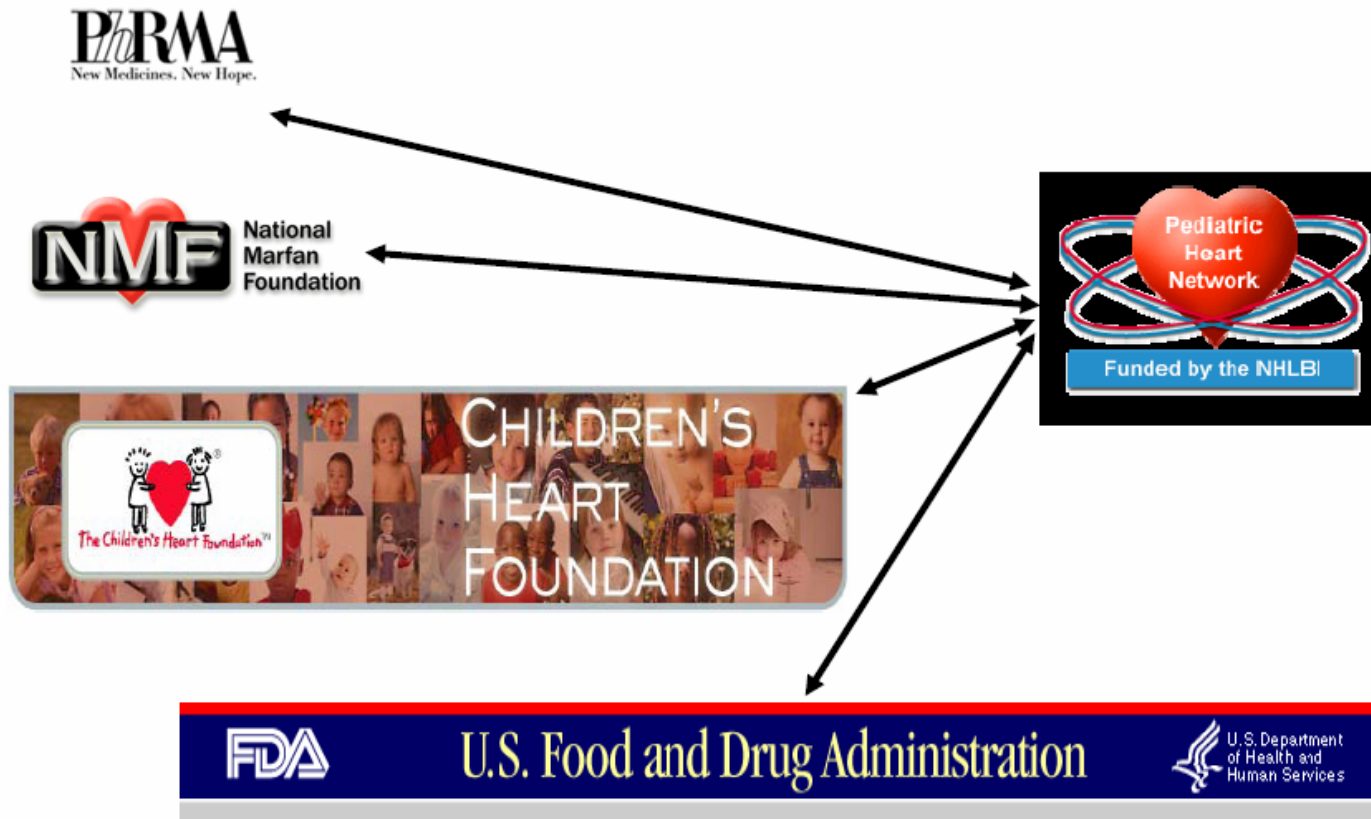
NHLBI and CV Registries

Criteria for Participation

- Important Public Health Problem
 - Early clinical trials results often not confirmed: need on going evaluation in a “real life” clinical setting
 - Different practices
 - Different populations
 - Relevant to patient care: safety, efficacy, cost
- Relevant Research Questions
 - Scientific research rigor
 - Using common methodologies and definitions from an early stage on
 - Identify questions that need to be answered by an RCT

Creating a Collaborative Infrastructure

NHLBI Experience



Creating a Collaborative Infrastructure

NHLBI Approach

International
Organizations

Researchers

Professional
Societies

Federal-State-
Local
Agencies

Our Approach

Work in partnership in an ever
evolving environment.

Voluntary
Health
Organizations

Corporations

Patient
Advocacy
Groups

Foundations

Community
Organizations