NHLBI Sudden Cardiac Death Prevention Working Group

“Focus on Prevention in the General Population”

May 20, 2016
Bethesda, MD
Sudden Cardiac Death

Public health burden:
- ~250,000 SCDs per year in US
- ~60-90 SCDs/100,000 person years
- Reductions in SCD Incidence not kept pace with other causes of CHD

Majority of SCDs occur in “low-risk” populations:
- Prevention focused on High Risk Groups:
  - For 55% of men and 64% of women, SCD is the first manifestation of heart disease

Treatment of Cardiac Arrest:
- Requires the arrest to be witnessed: (~50%)
- Majority occur at home (~70%)

Advancements in Prediction and Prevention of SCD in the General Population are Needed.
Overview of the Task

CHARGE:
• Identify research barriers and outline possible novel solutions to prevent sudden cardiac death in the general population.

DELIVERABLE:
• 5 Recommendations that would serve to enable major advances in research efforts directed at SCD prevention in the general population
• Establishment of short term and long term goal, with a focus on the next 5 years

COMPOSITION:
• Experts in pediatric and adult cardiology, emergency care medicine, cardiac electrophysiology, neurology, pathology, epidemiology, biostatistics, and the establishment and use of cardiac arrest registries
Working Group Members

Chair
Christine Albert, MD, MPH, Harvard University

Members
Robert A. Berg, MD; University of Pennsylvania
Mercedes Carnethon, PhD; Northwestern University
Sumeet Chugh, MD; University of California, Los Angeles
Rajat Deo, MD, MTR; University of Pennsylvania
Sam P. Gulino, MD; City of Philadelphia Department of Public Health
Jeffrey Olgin, MD; University of California at San Francisco
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Establish a common lexicon to be employed in sudden cardiac death (SCD)/sudden cardiac arrest research (SCA), which will allow cross-discipline collaboration and merging of available datasets/resources to perform large-scale studies on SCD/SCA prevention.

Members: Sumeet Chugh, Robert Berg, Sam Gulino, Kristin Burns

Identify and characterize SCD sub-phenotypes, utilizing data obtained prior to and post arrest, to minimize underlying heterogeneity and improve ability to identify specific “omic” markers of risk.

Members: Nona Sotoodehnia, Yi-Ping Fu, Jonathan Kaltman

Consider novel approaches to sudden death prevention including incorporation of big data, specifically that from the diverse array of remote monitoring technologies that are existing or underdevelopment, to improve SCD/SCA prediction, phenotyping, and treatment.

Members: Jeff Olgin, Rajat Deo, Albert Lee

Design population based and or targeted interventions based upon our present understanding of SCD risk factors which might be tested in large-scale, pragmatic studies.

Members: Christine Albert, Mercedes Carnethon, Paul Sorlie
The Working Group made several recommendations to address the identified knowledge gaps and barriers in the prevention of SCD in the general population.

1. To facilitate making SCD an uniformly reportable condition, develop a standard, common lexicon for SCD that includes standardized reporting methods, death certificates with required data elements, and post-mortem examinations to permit the accumulation of sufficient numbers of well characterized deaths and the circumstances surrounding them.

2. Support the ascertainment and confirmation of SCD events and their sub-types through the collection of standard SCD data elements in existing and new data sets; e.g., in NHLBI-supported clinical trials and observational studies, clinical trial networks, the Precision Medicine Initiative, and PCORnet Centers.

3. Create opportunities for collaborative analyses of SCD datasets to arrive at sizeable numbers of SCD sub-phenotypes both to minimize underlying heterogeneity for genomic and biologic marker studies and to arrive at targeted preventive approaches in subpopulations.

4. Establish a SCD registry in adults, similar to the Sudden Death in Young Case Registry. This could include an autopsy element, hospital-based and EMS-based information as well as supplemental data from next of kin and patients who survive.

5. Facilitate the development, validation, and implementation of scalable, easy-to-use sensors (devices) to better identify risk factors for and triggers of SCD/SCA.
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**Today**: How do we make SCD a reportable Condition


2. Create standard elements for death certificates, so that SCDs can be tracked.

3. Add SCD to upcoming large-scale cohorts and studies.