Sudden Cardiac Death in the Young:
An issue of national and international interest

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## Epidemiology

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Sample</th>
<th>Age (Yrs)</th>
<th>Incidence (per 100,000)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Driscoll</td>
<td>1985</td>
<td>Minnesota</td>
<td>1 – 22</td>
<td>1.3</td>
</tr>
<tr>
<td>Maron</td>
<td>1998</td>
<td>Minnesota</td>
<td>10-12&lt;sup&gt;th&lt;/sup&gt; grade</td>
<td>0.5</td>
</tr>
<tr>
<td>Corrado</td>
<td>2006</td>
<td>Italy</td>
<td>12 - 35</td>
<td>1.9 (athletes)/ 0.8 (non-athletes)</td>
</tr>
<tr>
<td>Maron</td>
<td>2009</td>
<td>US- Athletes</td>
<td>≤ 39</td>
<td>0.6</td>
</tr>
<tr>
<td>Chugh</td>
<td>2009</td>
<td>Oregon</td>
<td>&lt; 18</td>
<td>1.7</td>
</tr>
<tr>
<td>Atkins</td>
<td>2009</td>
<td>US-Canada</td>
<td>&lt; 20</td>
<td>8 (arrests &amp; deaths)</td>
</tr>
<tr>
<td>Meyer</td>
<td>2012</td>
<td>Washington</td>
<td>0 - 35</td>
<td>2.3</td>
</tr>
<tr>
<td>Pilmer</td>
<td>2013</td>
<td>Ontario</td>
<td>2 - 40</td>
<td>0.7</td>
</tr>
<tr>
<td>Harmon</td>
<td>2014</td>
<td>NCAA Athletes</td>
<td>College</td>
<td>2.3</td>
</tr>
<tr>
<td>Maron</td>
<td>2014</td>
<td>NCAA Athletes</td>
<td>College</td>
<td>1.2</td>
</tr>
<tr>
<td>Pilmer</td>
<td>2014</td>
<td>Ontario</td>
<td>1 - 19</td>
<td>0.8</td>
</tr>
</tbody>
</table>

Range: 0.5 – 2.3 per 100,000
Epidemiology

Maron et al. Circulation. 2014
The Public Health Issue

News

High School Football Player Had Heart Attack After Touchdown

AHA statement

Controversies in Cardiovascular Medicine

Should an electrocardiogram be included in routine preparticipation screening of young athletes?

Corrado et al. JAMA. 2006; Maron et al. Circulation. 2007
Increasing Publications, but…

# publications = ECG + screening + sudden cardiac death
Lack of Knowledge

US Preventive Services Task Force's analytic framework for screening

Screening for Sudden Cardiac Death in the Young
Report from a National Heart, Lung, and Blood Institute Working Group

Jonathan R. Kaltman, MD; Paul D. Thompson, MD; John Lantos, MD; Charles I. Berul, MD; Jeffrey Botkin, MD, MPH; Joshua T. Cohen, PhD; Nancy R. Cook, ScD; Domenico Corrado, MD, PhD; Jonathan Drezner, MD; Kevin D. Frick, PhD; Stuart Goldman, MD; Mark Hlatky, MD; Prince J. Kannankeril, MD; Laurel Leslie, MD, MPH; Silvia Priori, MD, PhD; J. Philip Saul, MD; Carrie K. Shapiro-Mendoza, PhD, MPH; David Siscovick, MD, MPH; Victoria L. Vetter, MD; Robin Boineau, MD; Kristin M. Burns, MD; Richard A. Friedman, MD
Epidemiology and etiology of Sudden Cardiac Death in the Young (SCDY)
Develop an SCDY registry to prospectively estimate the incidence of SCDY
Perform case-control studies using registry-defined cases to identify risk factors for SCDY

Performance of the screening methodology in the target population
Perform pilot ECG screening studies to test the characteristics of the ECG in target populations
Perform comparative effectiveness studies to determine the incremental value of various screening methodologies, including history and physical examination, ECG, echocardiogram, and genetic testing

Management of asymptomatic heart disease identified by ECG screening
Develop evidence-based management strategies for asymptomatic patients
Evaluate risk stratification, prevention, and therapeutic strategies
Use novel study designs and innovative recruitment strategies when studying low-prevalence diseases

Impact of a screening program
Evaluate the impact of a screening program on individuals and families using quality-of-life studies and patient-preference measurements
Use decision analysis to evaluate overall effectiveness of a screening program, as well as cost and resource utilization
Sudden Death in the Young Initiative

Goals:

Establish the incidence of sudden death in the young in the United States

Investigate etiologies and risk factors for sudden death in the young
Phase I:
- Develop a *surveillance system* to identify SDY cases
- Create a *registry* of clinical information about each case
  - *death certificates, medical records, death scene investigations, and pathology reports*
- Obtain a *biospecimen* from cases

Phase II:
- Make the registry data available to investigators in scientific community
- Support mechanistic, genetic, and other studies which *use the registry* to evaluate causes of and risk factors for SDY
Phase I

Investigator

Investigator

Investigator

Phase II

Sudden Death in the Young (SDY) Registry

Data Coordinating Center

Biorepository
Recommendations

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Data to Knowledge to Action