

Medications and Other Triggers of Sudden Cardiac Arrest

1. Sudden Cardiac Arrest Survey

We are asking these questions of you if you have a child who has had a sudden cardiac arrest (SCA). This survey provides the information to inform a research study to identify the general characteristics of children who experience SCA and learn if any warning symptoms or signs are commonly present. Additionally, we would like to know if certain medications, substances (caffeine, energy drinks, drugs, etc.) illnesses, or other disease conditions could be triggers associated with a SCA.

If there are questions that you don't feel you can answer, there are many options in which you can indicate that the answer is unknown, not applicable, or that you don't remember. For the multiple choice questions with boxes, check all that apply when appropriate. For the multiple choice questions with buttons, only one answer is allowed. Try to answer each question, as best you can if it applies to your child.

The benefit of participating in this research study is that the knowledge gained from this research may help improve the care of children with similar problems in the future.

There are no physical risks to participating in this study, but we recognize that this survey may trigger memories, and thus, may be difficult to complete. You do not need to answer any questions that make you feel uncomfortable.

Your information will be anonymous and confidential. We will not be able to connect you or your child with any of the answers. We appreciate your assistance with this survey. Thank you so much for helping other families and for helping us learn more about SCA in youth.

By completing this survey, you are consenting to participate in this research study.

1. Did your child have a sudden cardiac arrest?

☐ Yes

☐ No

2. Did your child survive?

☐ Yes

☐ No

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2. Symptoms

Symptoms such as chest pain, dizziness, fainting (syncope), shortness of breath, palpitations or racing heart and trouble with exercise may be seen in conditions that cause sudden cardiac death and might be warning symptoms. Many children will have these symptoms with no problems so their presence doesn't make a diagnosis of a cardiac condition.

3. Did your child complain of fatigue or have trouble with exercise or keeping up with their friends within a month of their sudden cardiac arrest?

- ☐ Yes
- ☐ No
- ☐ I don't remember
- ☐ Other (please specify below)

If yes, during what activity?

4. Did your child complain of chest pain in the year prior to their sudden cardiac arrest?

- | | |
|--|---|
| ☐ No chest pain | ☐ Yes, chest pain after exercise |
| ☐ Yes, chest pain at rest | ☐ I don't remember |
| ☐ Yes, chest pain during exercise | |

5. If the answer to the previous question was yes, specify the timing of the most recent chest pain prior to the sudden cardiac arrest.

- | | |
|--|---|
| ☐ Less than 1 week | ☐ Greater than 3 months |
| ☐ 1-4 weeks | ☐ Not applicable |
| ☐ Greater than 4 weeks | |

Please specify the type of the pain (dull, squeezing, sharp)

6. Did your child have palpitations or complaints of a racing heart prior to his/her sudden cardiac arrest?

- ☐ Yes
- ☐ No
- ☐ I don't remember
- ☐ Other (please specify)

7. If yes, please specify the timing of these symptoms prior to the sudden cardiac arrest.

- | | |
|--|---|
| ☐ Less than 1 week | ☐ Greater than 3 months |
| ☐ 1-4 weeks | ☐ I don't remember |
| ☐ Greater than 4 weeks | |

How long did the symptoms last?

8. Did your child have shortness of breath with exercise?

- | | |
|---|--|
| ☐ No | ☐ Yes, not related to asthma |
| ☐ Yes, and it was diagnosed as asthma, but not treated with medications | ☐ I don't remember |
| ☐ Yes, and it was diagnosed and treated with asthma medications | ☐ Other (specify below) |

Please specify types of asthma medication

9. Did your child complain of dizziness in the year prior to their sudden cardiac arrest?

- | | |
|---|--|
| ☐ No dizziness | ☐ Yes. Dizziness after exercise |
| ☐ Yes. Dizziness at rest | ☐ I don't remember |
| ☐ Yes. Dizziness during exercise | |
| ☐ Other (please specify) | |

10. If the answer to the previous question was yes, specify the timing of the most recent dizziness prior to the sudden cardiac arrest.

- | | |
|--|---|
| ☐ Less than 1 week | ☐ Greater than 3 months |
| ☐ 1-4 weeks | ☐ Not applicable |
| ☐ Greater than 4 weeks | |

11. Did your child experience fainting in the year prior to their sudden cardiac arrest?

- | | |
|---|---|
| ☐ No fainting | ☐ Fainting during exercise |
| ☐ Fainting, but more than a year ago | ☐ Fainting after exercise |
| ☐ Fainting at rest | ☐ I don't remember |
| ☐ Other (please specify) | |

12. If the answer to the previous question was yes, specify the timing of the most recent faint prior to the sudden cardiac arrest.

- | | |
|--|---|
| ☐ Less than 1 week | ☐ Greater than 3 months |
| ☐ 1-4 weeks | ☐ Not applicable |
| ☐ Greater than 4 weeks | |

13. How many times did your child faint?

- | | |
|--------------------------------|----------------------------------|
| ☐ None | ☐ 6-7 |
| ☐ One time | ☐ 8-9 |
| ☐ 2-3 | ☐ 10 or more |
| ☐ 4-5 | |

14. How long was your child unconscious when he/she fainted?

- | | |
|---|--|
| ☐ Less than a minute | ☐ Over twenty minutes to an hour |
| ☐ One to two minutes | ☐ Over an hour |
| ☐ Three to four minutes | ☐ Unknown |
| ☐ Five to ten minutes | ☐ Not applicable |
| ☐ Ten to twenty minutes | |

15. Was your child ever diagnosed with a seizure disorder

- ☐ Yes
- ☐ No
- ☐ I don't remember
- ☐ Other (please specify below)

If yes, specify circumstances of seizure and medications used to treat

16. Was your child nervous, anxious, or emotionally upset at the time of their cardiac arrest?

- ☐ Yes
- ☐ No
- ☐ I don't know

Provide any information regarding this question that you feel would be helpful

17. Did you or your child complain to a physician about any of the above mentioned symptoms?

- ☐ Yes
- ☐ No
- ☐ I don't remember

Describe which symptom and how physician responded



18. Did your child receive medical evaluation for chest pain symptoms?

- ☐ Yes
- ☐ No
- ☐ I don't remember

19. If the answer to the previous question was yes, specify the timing of medical evaluation for chest pain prior to the sudden cardiac arrest.

- ☐ Less than 1 week
- ☐ 1-4 weeks
- ☐ Greater than 4 weeks
- ☐ Greater than 3 months
- ☐ Not applicable

20. Did your child receive medical evaluation for shortness of breath symptoms?

- ☐ Yes
- ☐ No
- ☐ I don't remember

21. If the answer to the previous question was yes, specify the timing of medical evaluation for shortness of breath prior to the sudden cardiac arrest.

- | | |
|--|---|
| ☐ Less than 1 week | ☐ Greater than 3 months |
| ☐ 1-4 weeks | ☐ Not applicable |
| ☐ Greater than 4 weeks | |

22. Did your child receive medical evaluation for palpitations or racing heart symptoms?

- ☐ Yes
- ☐ No
- ☐ I don't remember

23. If the answer to the previous question was yes, specify the timing of medical evaluation for palpitations or racing heart prior to the sudden cardiac arrest.

- | | |
|--|---|
| ☐ Less than 1 week | ☐ Greater than 3 months |
| ☐ 1-4 weeks | ☐ Not applicable |
| ☐ Greater than 4 weeks | |

24. Did your child receive medical evaluation for dizziness or fainting symptoms?

- ☐ Yes
- ☐ No
- ☐ I don't remember

25. If the answer to the previous question was yes, specify the timing of medical evaluation for dizziness or fainting prior to the sudden cardiac arrest.

- | | |
|--|---|
| ☐ Less than 1 week | ☐ Greater than 3 months |
| ☐ 1-4 weeks | ☐ Not applicable |
| ☐ Greater than 4 weeks | |

26. Did your child receive medical evaluation for trouble with exercise as a symptom?

- ☐ Yes
- ☐ No
- ☐ I don't remember

27. If the answer to the previous question was yes, specify the timing of medical evaluation for trouble with exercise prior to the sudden cardiac arrest.

- | | |
|--|---|
| ☐ Less than 1 week | ☐ Greater than 3 months |
| ☐ 1-4 weeks | ☐ Not applicable |
| ☐ Greater than 4 weeks | |

28. The medical evaluation was performed because of which of the following? Please check all that apply.

- | | |
|--|---|
| ☐ Chest pain as a symptom | ☐ Finding on athletic clearance or preparticipation evaluation |
| ☐ Palpitations as a symptom | ☐ Finding on sick child visit |
| ☐ Fainting as a symptom | ☐ Evaluation for family history of cardiac condition |
| ☐ Trouble exercising as a symptom | ☐ Evaluation for family history of sudden cardiac arrest |
| ☐ Heart murmur | ☐ Positive genetic test in family |
| ☐ Hypertension | ☐ Not applicable/No testing performed |
| ☐ Marfan stigmata | ☐ Other (please specify below) |
| ☐ Finding on routine well child exam (please specify below) | ☐ I don't remember |

Please explain the reason for evaluation

29. If your child did receive medical evaluation prior to their cardiac arrest, what type of testing was done (Specify symptom or reason for evaluation in box below. Please check all that apply.)

- | | |
|--|---|
| ☐ Electrocardiogram (ECG or EKG) | ☐ General cardiology consult |
| ☐ Echocardiogram (ultrasound of heart) | ☐ Electrophysiology consult |
| ☐ 24 hour Holter (ambulatory ECG) or event monitor | ☐ Genetic testing |
| ☐ Exercise stress test | ☐ None |
| ☐ Magnetic resonance imaging (MRI) or computed tomography (CT) of heart | ☐ Other (please specify below) |
| ☐ Pediatric cardiology consult | ☐ I don't remember |

Explain reason for evaluation

30. Approximately how many well-child checkups and/or preparticipation physical evaluations (PPE) did your child have up to their SCA/SCD?

- | | |
|----------------------------|--|
| ☐ None | ☐ 11-15 |
| ☐ 1-2 | ☐ Greater than 15 |
| ☐ 3-5 | ☐ I don't remember |
| ☐ 6-10 | |

31. Prior to my child's cardiac arrest, he/she was diagnosed with the following conditions. Please check all that apply.

- | | |
|---|--|
| ☐ Long QT Syndrome (LQTS) | ☐ Congenital heart disease, please specify type below |
| ☐ Kawasaki disease | ☐ Mitral valve prolapse |
| ☐ Brugada syndrome | ☐ Bicuspid aortic valve |
| ☐ Short QT syndrome | ☐ Myocarditis |
| ☐ Wolff-Parkinson-White Syndrome (WPW) | ☐ Marfan's syndrome |
| ☐ Catecholaminergic polymorphic ventricular tachycardia (CPVT) | ☐ Coronary artery disease (heart attack) |
| ☐ Ventricular tachycardia | ☐ Hypertension |
| ☐ Supraventricular tachycardia | ☐ Overweight/Obesity |
| ☐ Hypertrophic cardiomyopathy (HCM) | ☐ High cholesterol |
| ☐ Arrhythmogenic right ventricular dysplasia/ cardiomyopathy (ARVD/ARVC) | ☐ No diagnosis made |
| ☐ Dilated cardiomyopathy (DCM) | ☐ Not applicable |
| ☐ Anomalous origin of the coronary arteries | |
| ☐ Other (please specify type of condition diagnosed) | |

Medications and Other Triggers of Sudden Cardiac Arrest

3. Family History

Some of the conditions that cause sudden cardiac arrest are found in multiple family members and may be inherited. These questions will help to determine if other family members could have similar symptoms or conditions to your child's symptoms or conditions.

If your child is adopted and/or there is limited family history, please answer the following questions to the best of your knowledge. If there is no known family history, skip to the next section.

32. Please select any of the following that may apply to your child.

- ☐ Child was adopted
- ☐ Family history not known on mother's side
- ☐ Family history not known on father's side

33. Have any family members had sudden cardiac arrest or sudden cardiac death? Please check all that apply.

	Child's mother	Child's father	Child's grandmother	Child's grandfather	Child's sister	Child's brother	Child's cousin	Child's aunt	Child's uncle
Yes	☐	☐	☐	☐	☐	☐	☐	☐	☐
Yes, infant with SIDS/SUID (sudden infant death syndrome/sudden unexpected infant death)	☐	☐	☐	☐	☐	☐	☐	☐	☐
Yes, under 35 years of age	☐	☐	☐	☐	☐	☐	☐	☐	☐
Yes, over 35, but under 50 years of age	☐	☐	☐	☐	☐	☐	☐	☐	☐
Yes, over 50 years of age	☐	☐	☐	☐	☐	☐	☐	☐	☐

Other (please specify any additional comments)

34. Were any of the child's blood relatives known to have any of the following conditions diagnosed prior to your child's sudden cardiac arrest? Please check all that apply.

- | | |
|---|--|
| ☐ Long QT Syndrome (LQTS) | ☐ Congenital heart disease, please specify type below |
| ☐ Kawasaki disease | ☐ Mitral valve prolapse |
| ☐ Brugada syndrome | ☐ Bicuspid aortic valve |
| ☐ Short QT syndrome | ☐ Myocarditis |
| ☐ Wolff-Parkinson-White Syndrome (WPW) | ☐ Marfan's syndrome |
| ☐ Catecholaminergic polymorphic ventricular tachycardia (CPVT) | ☐ Coronary artery disease (heart attack) |
| ☐ Ventricular tachycardia | ☐ Hypertension |
| ☐ Supraventricular tachycardia | ☐ Overweight/Obesity |
| ☐ Hypertrophic cardiomyopathy (HCM) | ☐ High cholesterol |
| ☐ Arrhythmogenic right ventricular dysplasia/ cardiomyopathy (ARVD/ARVC) | ☐ No diagnosis made |
| ☐ Dilated cardiomyopathy (DCM) | ☐ Unknown |
| ☐ Anomalous origin of the coronary arteries | ☐ Not applicable |
| ☐ Other (please specify) | |

35. Other family members including parents, siblings, cousins, etc. were evaluated after my child's death.

- ☐ Yes
- ☐ No
- ☐ Unknown

Please specify whether the family member was a parent, sibling, cousin, etc.

36. After your child's sudden cardiac arrest, were other family members diagnosed with any of the following conditions? Please check all that apply.

- | | |
|---|--|
| ☐ Long QT Syndrome (LQTS) | ☐ Congenital heart disease, please specify type below |
| ☐ Kawasaki disease | ☐ Mitral valve prolapse |
| ☐ Brugada syndrome | ☐ Bicuspid aortic valve |
| ☐ Short QT syndrome | ☐ Myocarditis |
| ☐ Wolff-Parkinson-White Syndrome (WPW) | ☐ Marfan's syndrome |
| ☐ Catecholaminergic polymorphic ventricular tachycardia (CPVT) | ☐ Coronary artery disease (heart attack) |
| ☐ Ventricular tachycardia | ☐ Hypertension |
| ☐ Supraventricular tachycardia | ☐ Overweight/Obesity |
| ☐ Hypertrophic cardiomyopathy (HCM) | ☐ High cholesterol |
| ☐ Arrhythmogenic right ventricular dysplasia/ cardiomyopathy (ARVD/ARVC) | ☐ No diagnosis made |
| ☐ Dilated cardiomyopathy (DCM) | ☐ Unknown |
| ☐ Anomalous origin of the coronary arteries | ☐ Not applicable |
| ☐ Other (please specify) | |

37. How many other family members have been identified with the condition diagnosed in your child after his/her sudden cardiac arrest?

- | | |
|----------------------------|-------------------------------|
| ☐ None | ☐ 5-10 |
| ☐ 1 | ☐ Over 10 |
| ☐ 2-4 | ☐ Unknown |

Medications and Other Triggers of Sudden Cardiac Arrest

4. Medications and Other Triggers for Sudden Cardiac arrest

It is not known if certain medications can trigger a sudden cardiac arrest in healthy children or in those who might have an undiagnosed or diagnosed cardiac condition. The fact that certain classes or medications are listed in this section does not indicate that they have or can cause sudden cardiac arrest.

38. Was your child ever diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD)?

- ☐ Yes
- ☐ No
- ☐ I don't remember

39. Was your child on medication for ADHD or ADD at the time of their cardiac arrest or death?

- ☐ Yes
- ☐ No
- ☐ I don't remember

40. What type of ADHD or ADD medication was your child taking? Please check all that apply.

- | | |
|--|---|
| ☐ Amphetamine salts (for example, Adderall, Adderall XL, Vyvanse, and more) | ☐ Not applicable |
| ☐ Methylphenidate (for example, Ritalin, Focalin, Concerta, and more) | ☐ Unknown |
| ☐ Atomoxetine (for example, Strattera) | |
| ☐ Other (please specify) | |

41. How long prior to their sudden cardiac arrest was your child on ADHD or ADD medications?

- | | |
|---|---|
| ☐ Less than 1 week | ☐ Greater than 6 months |
| ☐ 1 week to 1 month | ☐ Greater than 1 year |
| ☐ 1 to 3 months | ☐ Not applicable |
| ☐ 3 to 6 months | |

42. Was your child on asthma medication at the time of their cardiac arrest or death?

- ☐ Yes
- ☐ No
- ☐ I don't remember

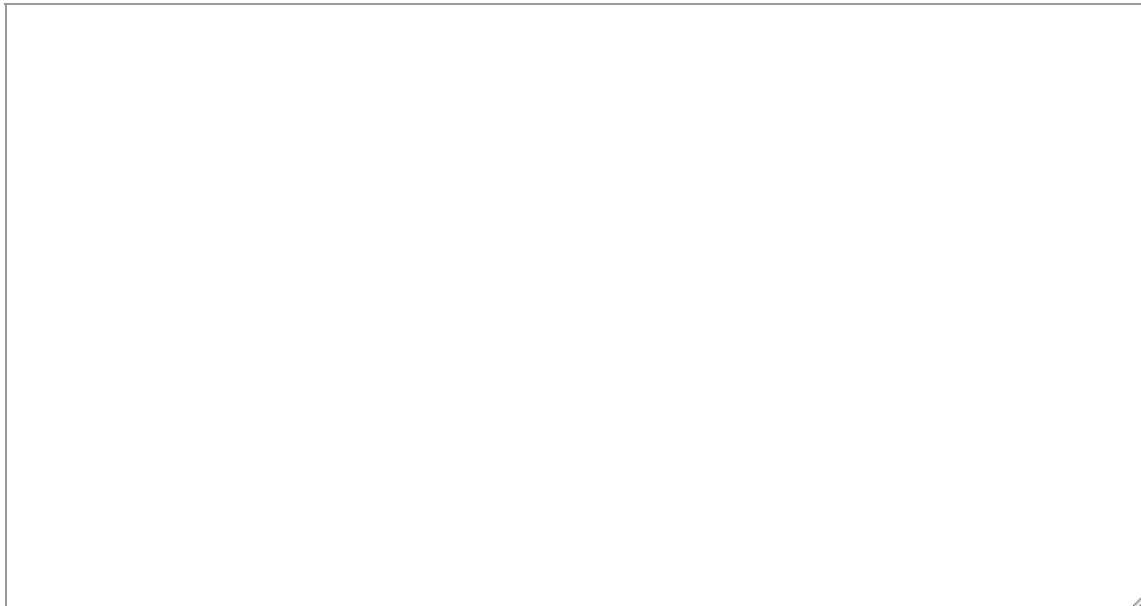
Please specify types of medication



43. Was your child on antibiotics at the time of their cardiac arrest or death?

- ☐ Yes
- ☐ No
- ☐ I don't remember

Please specify types of antibiotic



44. Was your child taking anxiety, depression, or other psychotropic medications at the time of their cardiac arrest or death?

☐ Yes

☐ No

Please specify types of antidepressants or other medications

45. Was your child sick with a flu-like syndrome (upper respiratory illness or fever) within a month of their sudden cardiac arrest?

☐ Yes

☐ No

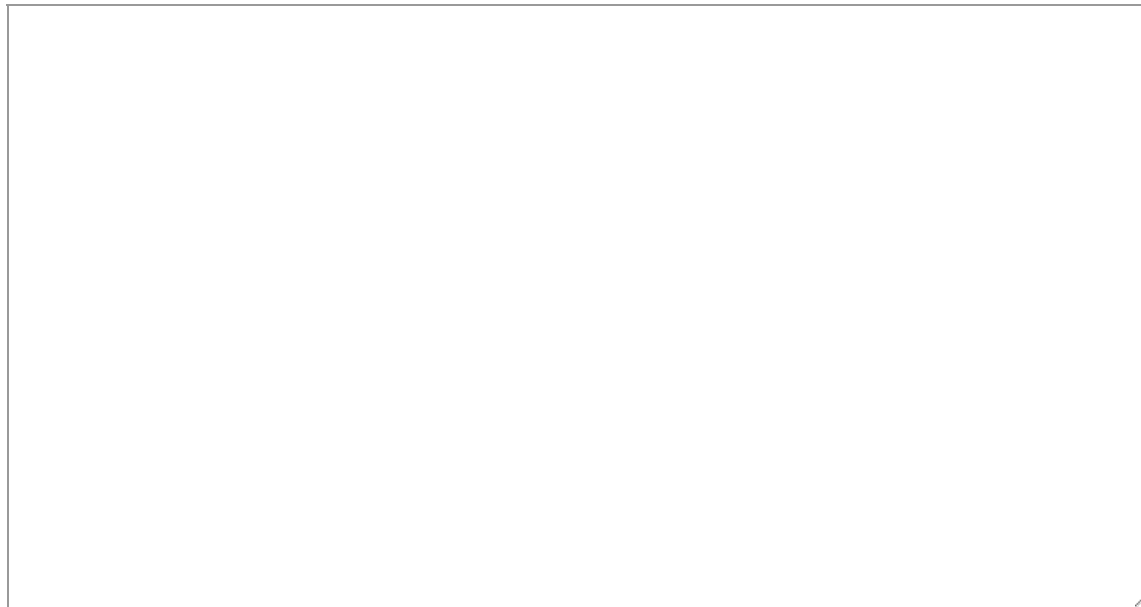
☐ I don't remember

☐ Other (please specify)

46. Was your child on antihistamines, decongestants, cold medications, or other medications at the time of their cardiac arrest or death?

- ☐ Yes
- ☐ No
- ☐ I don't remember

Please specify types of medication if known

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47. Other medications or substances that my child was taking, Please check all that apply.

- | | |
|---|---|
| ☐ Herbal supplements | ☐ Hallucinogens (for example, mushrooms, salvia, and more) |
| ☐ Body building substances, please specify below | ☐ Opioids (for example, cocaine, oxycodone, morphine, Vicodin, and more) |
| ☐ Caffeine | ☐ Ecstasy/MDMA |
| ☐ Energy drinks | ☐ Stimulant Medications (not prescribed) |
| ☐ Tobacco | ☐ Other recreational drugs, please specify below (Optional) |
| ☐ E-cigarettes/Vapes | ☐ None |
| ☐ Alcohol | ☐ I don't remember |
| ☐ Marijuana/CBD | |
| ☐ Other (please specify) | |

48. Are there any other medications or substances that you think may have contributed to your child's sudden cardiac arrest?

☐ Yes

☐ No

Please specify medication or substance

49. Which symptoms occurred in association with any of the above mentioned medications?
Please check all that apply.

☐ Chest pain

☐ Seizure

☐ Shortness of breath

☐ Trouble exercising

☐ Palpitations/racing heart

☐ Emotional upset

☐ Dizziness

☐ None

☐ Fainting

☐ Other, please specify below

Specify which medications/substances were associated with the symptoms that occurred

50. Did your child have any other known chronic medical conditions prior to their sudden cardiac arrest? Please check all that apply.

- ☐ Diabetes
- ☐ Obesity
- ☐ Hypertension
- ☐ Other (please specify)
- ☐ Kidney disease
- ☐ None/Not applicable

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5. Activity Level of Child

51. How would you describe the activity level of your child at the at the time of the child's cardiac arrest?

- | | |
|--|--------------------------------|
| ☐ Active/exercising | ☐ Resting |
| ☐ Immediately after exercise | ☐ Sleeping |
| ☐ Awake but not active | |

Other (please specify)

52. If active at the time of the cardiac arrest, in what type of activity was your child participating or had recently been participating? Please check all that apply.

☐ Not active

☐ Basketball

☐ Football

☐ Running/jogging

☐ Cycling

☐ Track and field events

☐ Soccer

☐ Rugby

☐ Lacrosse

☐ Field Hockey

☐ Ultimate Frisbee

☐ Swimming

☐ Physical Education/Gym class

☐ Gym workout routine

☐ Other (please specify)

☐ Crossfit Training

☐ Weight lifting

☐ Gymnastics

☐ Cheerleading

☐ Tennis

☐ Bowling

☐ Golf

☐ Dancing

☐ Volleyball

☐ Rollerblading

☐ Ice skating

☐ Snow sports (for example, skiing, snowboarding, tubing)

☐ Unknown

☐ Not applicable

53. What types of sports teams was your child on?

☐ Basketball

☐ Cross Country

☐ Football

☐ Track and field

☐ Soccer

☐ Swimming

☐ Cycling

☐ None

☐ Other (please specify)

54. How many hours per week was your child active in the month prior to their sudden cardiac arrest?

☐ Less than 30 minutes/week

☐ Over 10 hours per week

☐ One hour per week

☐ Over 20 hours per week

☐ 2-4 hours per week

☐ I don't remember

☐ Over 4 hours per week

Other (please specify)

Medications and Other Triggers of Sudden Cardiac Arrest

6. Circumstances of Cardiac Arrest

We would like to learn some of the details of the circumstances that surrounded your child's sudden cardiac arrest.

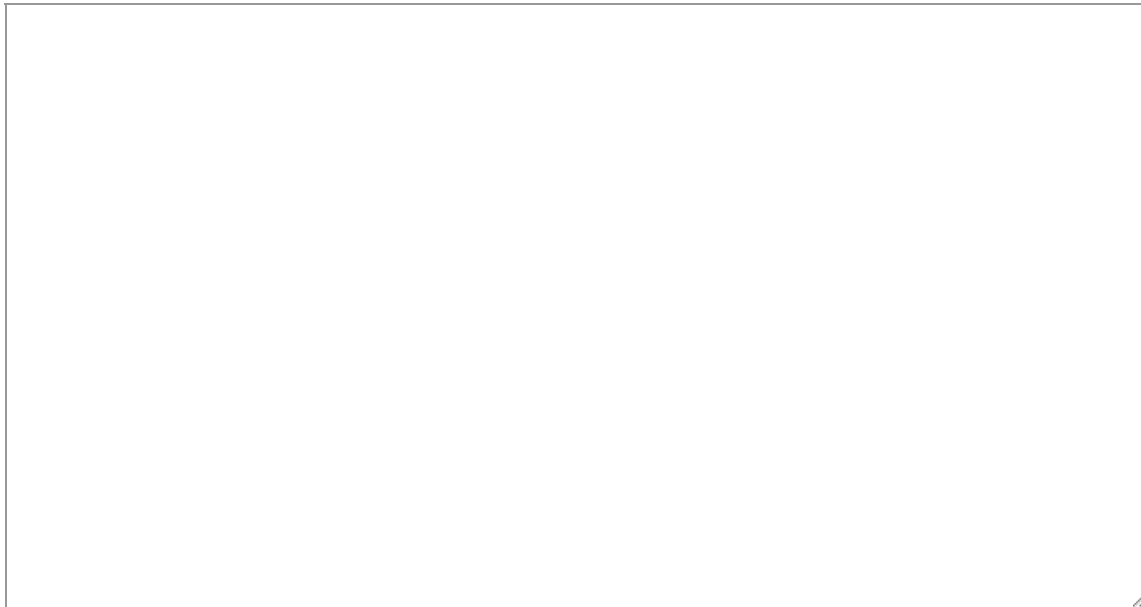
55. Was your child's cardiac arrest witnessed (seen by anyone at the time it happened)?

☐ Yes

☐ No

☐ I don't remember

Indicate if family member in home or other witness outside of home

A large, empty rectangular box with a thin black border, intended for the respondent to provide details about the circumstances of the cardiac arrest. A small cursor icon is visible in the bottom right corner of the box.

56. Where did your child's cardiac arrest occur?

- | | |
|--|--|
| ☐ Home | ☐ Non school related organized sports activity |
| ☐ Home, in bed sleeping | ☐ Non organized play |
| ☐ School, in educational class | ☐ Health club |
| ☐ School, in health class/gym/recess | ☐ Mall/Shopping area |
| ☐ School, during or after athletic event | ☐ Movie theater |
| ☐ After school activity | |
| ☐ Other (please specify) | |

57. My child received the following at the time of their sudden cardiac arrest. Please check all that apply.

- ☐ CPR, bystander (for example, family member, friend, or witness)
- ☐ CPR, EMS or medical professional
- ☐ AED was present on site
- ☐ AED applied
- ☐ AED with shock
- ☐ Police transport
- ☐ EMS/911 transport
- ☐ None
- ☐ Unknown

Other (please specify)

58. Approximate time from cardiac arrest to arrival of emergency medical services (EMS)

- | | |
|--|---|
| ☐ EMS not called | ☐ EMS not on site for over 15 minutes |
| ☐ EMS present at event where arrest occurred | ☐ Unknown |
| ☐ EMS on site in less than 5 minutes | ☐ Not applicable |
| ☐ EMS on site in 6 to 10 minutes | |

Other (please specify)

59. After EMS transported my child to a hospital.... (Please check all that apply.)

- ☐ Not applicable
- ☐ They were treated in the Emergency Room
- ☐ They were admitted to the hospital
- ☐ They were discharged from the hospital

60. If your child was discharged from the hospital, please indicate their level of neurologic deficit.

- ☐ No neurologic deficit (normal memory and activity)
- ☐ Mild to moderate deficit (conscious, adequate thinking functions, etc.)
- ☐ Severe neurologic deficit (severe disability in thinking, impaired brain function, dependence on others for daily support, etc.)
- ☐ Coma or vegetative state (not interactive, unresponsive)

61. A postmortem exam/autopsy was performed on my child.

- ☐ No
- ☐ Yes, Standard Autopsy
- ☐ Yes, Molecular Autopsy (genetic testing postmortem)
- ☐ I don't remember

Add any other findings you feel would be helpful

62. After your child's sudden cardiac arrest, was your child diagnosed with any of the following conditions? Please check all that apply.

- | | |
|---|--|
| ☐ Long QT Syndrome (LQTS) | ☐ Anomalous origin of the coronary arteries |
| ☐ Kawasaki disease | ☐ Congenital heart disease, please specify type below |
| ☐ Brugada syndrome | ☐ Mitral valve prolapse |
| ☐ Short QT syndrome | ☐ Bicuspid aortic valve |
| ☐ Wolff-Parkinson-White Syndrome (WPW) | ☐ Myocarditis |
| ☐ Catecholaminergic polymorphic ventricular tachycardia (CPVT) | ☐ Marfan's syndrome |
| ☐ Ventricular tachycardia | ☐ Coronary artery disease (heart attack) |
| ☐ Supraventricular tachycardia | ☐ Commotio cordis (sudden blow to chest) |
| ☐ Hypertrophic cardiomyopathy (HCM) | ☐ No diagnosis made |
| ☐ Arrhythmogenic right ventricular dysplasia/ cardiomyopathy (ARVD/ARVC) | ☐ Unknown |
| ☐ Dilated cardiomyopathy (DCM) | |
| ☐ Other (please specify) | |

63. How long has it been since your child's cardiac arrest?

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7. Demographics

This information will help determine if there are differences between ages, genders, races, ethnicities and regions of the country with regard to the factors associated with sudden cardiac arrest.

64. My child is

- ☐ Female
- ☐ Male
- ☐ Other (please specify)

65. My child's age at the time of his/her cardiac arrest

- | | |
|---------------------------------------|-----------------------------------|
| ☐ Under one month | ☐ 13-14 years |
| ☐ 1-3 months | ☐ 15-16 years |
| ☐ 4-6 months | ☐ 17-18 years |
| ☐ 7-11 months | ☐ 19-20 years |
| ☐ 1-2 years | ☐ 21-22 years |
| ☐ 3-4 years | ☐ 23-25 years |
| ☐ 5-6 years | ☐ 26-30 years |
| ☐ 7-8 years | ☐ 31-35 years |
| ☐ 9-10 years | ☐ >35 years |
| ☐ 11-12 years | |

66. The race or ethnicity of my child is Please check all that apply.

☐ White/Caucasian

☐ Native American

☐ Black/African-American

☐ Hispanic/Latino

☐ Asian (please specify below)

☐ More than one race (please specify below)

☐ Pacific Islander

Other (please specify)

67. At the time of my child's sudden cardiac arrest, the area where we lived would be considered

☐ Urban/large city

☐ Suburban

☐ Urban/medium sized city

☐ Rural

☐ Small town

☐ Frontier

68. At the time of my child's sudden cardiac arrest, the area of the country we lived in was considered

☐ Northeastern (New England: CT, ME, MA, NH, RI, VT) (Middle Atlantic: NJ, NY, PA)

☐ Midwestern (East North Central: IL, IN, MI, OH, WI) (West North Central: IA, KS, MN, MO, NE, ND, SD)

☐ Southern (South Atlantic: DE, DC, FL, GA, MD, NC, SC, VA, WV) (East South Central: AL, KY, MS, TN) (West South Central: AR, LA, OK, TX)

☐ Western (Mountain: AZ, CO, ID, MT, NV, NM, UT, WY) (Pacific: AK, CA, HI, OR, WA)

69. My zipcode is (optional)

70. I am the child's

☐ Mother

☐ Father

Other (please specify)

71. Do you wish to add any other comments about the possible triggers you have considered to play a part in your child's sudden cardiac arrest or other general comments?

☐ No

☐ Yes, please provide comments here

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8. Services

After the sudden cardiac arrest of a child, there may be services that could be offered that would be helpful to the family. The following questions will help us learn which services you or your family received. We would also like to learn your opinion about other services that would be helpful to families who have this experience.

72. What services were provided to your family? Please check all that apply.

- | | |
|--|---|
| ☐ Medical evaluation of surviving child | ☐ Mental health services |
| ☐ Medical evaluation of parents | ☐ Social work services |
| ☐ Medical evaluation of siblings | ☐ Support groups |
| ☐ Genetic counseling | ☐ Informational websites and user groups |
| ☐ Genetic testing of family members | ☐ None |
| ☐ Genetic testing of child who had SCA including postmortem genetic testing | ☐ Other |
| ☐ Bereavement services | |

Other (please specify)

73. Please describe any services that could be helpful to families who have experienced or who will experience the sudden cardiac arrest of a child.

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9. Additional Comments

74. Are there other questions that have not been asked above that you feel should be included in such a review?

75. We would like to thank you for the help that you have provided by taking this survey.

Please provide any additional comments in the space below.