Date: _____

Name of Diagnosed Person in your family: _____

Your name (or child or family member you are filling this form out for): _____

Relationship to diagnosed person: _____

*Address:*_____ *Phone:* _____ *Email:* _____

Date of Birth: _____ *Gender:* __ *M* __ *F*

SADS FOUNDATION
SUDDEN ARRHYTHMIA DEATH SYNDROMES

1. Have you been diagnosed with a SADS condition (LQTS, Brugada, CPVT, Short QT) or a related condition (WPW, ARVD)? __ No __ Yes

If yes, which one? __LQTS __Short QT __ CPVT __Brugada, __Timothy's Syndrome
__ WPW __ ARVD __ Jervell Lange-Nielsen __Other _____

2. At what age was a SADS diagnosis made? _____ Date of diagnosis: _____

3. If you were diagnosed, what, if any treatment applies?
__ None __ Pacemaker __ Beta blockers __ Mexiletine __ Flecainide
__ ICD/Pacer __ Sympathectomy __Denervation

4. What, if any, of the following symptoms or family history have you had?

__ None __ Palpitations __ Cardiac arrest __ Fainting (syncope) __ Chest pain __ Fatigue
__ Deafness __ Near fainting __ Shortness of breath __ Lightheadedness __ Autism
__ Seizures/epilepsy __ Webbed toes (or fingers) __ Seizure-like movements __ Problems with GI (gastrointestinal) system
__ Consistent/unusual chest pain or shortness of breath during exercise
__ A child, parent, or sibling who is diagnosed with SADS
__ An extended family member who is diagnosed with SADS
__ A child, sibling, or parent who had a SADS-related death
__ An extended family member who had a SADS-related death
__ A family member who died in a single car accident, hunting accident, swimming, or hunting alone etc.
__ Anyone in your family who died of heart problems before the age of 40
__ Family history of unexpected, unexplained sudden death in a young person < 40

5. What, if any, of the following screening procedures have you had and which type of doctor conducted the screening?

__ None __ EKG resting __ stress test (treadmill) __ loop recorder/internal cardiac monitor
__ Holter/event monitor __ Genetic testing __ Epinephrine study __ Procainamide study
__ Catecholamine study

__ Family practice __ Pediatrician __ Pediatric electrophysiologist
__ Pediatric cardiologist __ Internist __Adult cardiologist __ Adult electrophysiologist

Who is your doctor? _____ City, State_____ Facility_____

6. What were the results of your screening? (Check all that apply)
__ A diagnosis was made
__ I have not been screened for SADS
__ The results indicated you did not have a SADS diagnosis
__ The EKG did not conclusively show a SADS condition
__ The results were "borderline" or "the high end of normal"
__ Genetic testing was recommended

7. Please indicate if any family members have experienced any of the following:

__fainting (syncope) __ SIDS __deafness at birth __palpitations __ seizures or a seizure disorder __ Sudden death

Who has these symptoms? __children __parents __self __other relative – who?_____

8. Have you been genetically tested? __ No __Yes If so, did they find your mutation? __ No __Yes
What is your mutation?_____

<u>Questions?</u>: Contact Marcia Baker, Program Director, at Marcia@SADS.org or 214.675.5577

<u>Send this form to</u>: SADS Foundation, 4527 South 2300 East, Suite 104, Salt Lake City, UT 84117
Fax to: 801-505-0282; or scan and email to Marcia@SADS.org.