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Survey: Loss of a Twin (Consent Form)

(Return this Copy of the Consent Form)

Thank you for participating in this study. The loss of a twin is an experience that deserves considerable professional attention. You are invited to participate in a study of how twin loss affects the surviving twin partner and other family members. Results from this study can teach us a great deal about how counselors and other psychological professionals may assist twins and their families in dealing with such loss. The public also needs to be informed about the unique aspects of twinship. You must be age 18 years, or older, to complete this survey.

If you decide to participate, you will be asked to complete a survey that you will receive by mail—or that you can download from my website (<http://psych.fullerton.edu/nsegal>). It is estimated that 30 minutes will be required for your participation. There are no foreseeable risks associated with this task. I am happy to share results with you when the study is completed, so one benefit to you would be learning more about how the findings impact the question under study.

Your participation is strictly voluntary. All research records will be kept confidential to the extent provided by law. Data are filed in cabinets and kept in a locked office to which only the investigator and assistants have access. In any written reports or publications, no one will be identified or identifiable, and only group data will be presented. The data will serve as the basis for a student project, and will later be used in conference presentations and journal articles. Data will be kept in a locked room indefinitely. Future uses of the ratings may include combining it with larger samples for other data analyses.

Your decision concerning whether or not to participate will not affect your future relations with California State University, or your relations with your current educational institution or place of business in any way. If you decide to participate, you are free to discontinue participation at any time.

If you have questions regarding your rights as a research participant, you may contact the Institutional Review Board (IRB) representative at CSUF, at 714-278-7640 who welcomes any questions. These forms and the data will remain on file indefinitely. You may also contact the investigator, Dr. Nancy L. Segal; please see the contact information in the letterhead.

You will be offered a copy of this form to keep for your records.

Sincerely,

Nancy L. Segal, Ph.D.

Professor of Psychology

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You are making a decision about whether or not to participate. Your signature indicates that you have read the information provided above and have decided to participate. You may withdraw at any time without prejudice after signing this form should you choose to discontinue participation in this study.

Signature of Participant

_____/_____/_____
Month Day Year

Signature of Investigator

Nancy L. Segal, Ph.D.
Professor of Psychology
Director, Twin Studies Center

formdate 13-AUG-07

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Signature of Investigator

Nancy L. Segal, Ph.D.
Professor of Psychology
Director, Twin Studies Center

formdate 26-JUN-09

TWIN SURVEY

Thank you so much for participating in our study of twins. We understand that you are a twin who has lost his, or her, twin partner. We realize the very sensitive nature of this subject, but we would greatly appreciate it if you would take the time to complete the questions that appear on this form -- the information you provide will enable us to better understand this situation, in the hope that we can eventually help other twinless twins. In fact, the idea for this survey came about because twins who had lost their twin brothers and sisters contacted our laboratory for information and assistance. All information you provide is completely confidential. We plan to conduct a telephone follow-up survey wherever possible. Finally, because of our strong interest in this area, we are willing to accept partially completed questionnaires. However, we encourage you to provide as much information as possible. PLEASE PRINT ALL INFORMATION. Please print this and mail it to Dr. Nancy L. Segal (the address appears on the last page—you will be reimbursed for postage.)

NAME _____
 First Middle Last

PHONE _____ e-mail _____

TODAY'S DATE: _____
 Day Month Year

STREET _____

CITY _____

STATE _____ POST CODE _____

COUNTRY _____

YOUR BIRTHDAY: _____
 Day Month Year

SEX: (Circle One) Male Female

YOUR CURRENT AGE IN YEARS _____

YOUR CURRENT OCCUPATION _____

YOUR CURRENT MARITAL/RELATIONSHIP STATUS (Circle One)

Single Married Divorced Separated In a Significant Relationship

Other (Explain): _____

If you need extra space to answer any of the questions that follow, please feel free to use the margins, the back of this form, or to include additional sheets. Please read every question COMPLETELY before answering, or before deciding that a certain item does not apply to you. No question is adequate for every individual. We encourage you to let us know about things we have failed to ask.

1. I was born a: (Circle one) Twin Triplet Quadruplet

Birth Order: I was the (circle): 1st-BORN 2nd-BORN Uncertain OTHER: _____

Birth Weight: I was (circle): HEAVIER at birth LIGHTER at birth Uncertain OTHER: _____

THE WORD "TWIN" WILL BE USED FROM THIS POINT ON, EVEN IF YOU WERE BORN A TRIPLET OR A QUADRUPLET.

2. If you were to rate your feelings of CLOSENESS toward your twin, which of the choices listed below would be most true for you? (Please circle a number)

- 1... much closer than any best friend.
- 2... generally closer than any best friend.
- 3... as close as any best friend.
- 4... not as close as best friends, but closer than casual friends.
- 5... as close as casual friends.
- 6... generally less close than casual friends.
- 7... much less close than casual friends.

3. If you were to rate how COMPETITIVE you felt toward your twin, which of the choices listed below would be most true for you? (Please circle an answer).

- 1... often competitive
- 2... generally competitive
- 3... competitive only occasionally
- 4... rarely, or never, competitive

4. This section will ask HOW MUCH TIME you used to spend with your twin. Please answer ALL parts of question 4.

A. Have you ever lived apart (in different homes) from your twin? (Circle one) YES NO

If YES, indicate the dates that you lived apart, and the distance (in km or miles) that separated you. (Add additional lines, if needed)

DATES LIVING APART

DISTANCE LIVING APART

From	To	(Circle one)	
_____ month _____ year	_____ month _____ year	_____ km	_____ mi
_____ month _____ year	_____ month _____ year	_____ km	_____ mi
_____ month _____ year	_____ month _____ year	_____ km	_____ mi
_____ month _____ year	_____ month _____ year	_____ km	_____ mi

B . Were you living together at the time of your twin's death? (Circle one)

YES NO

C. On the average, when living TOGETHER (in the same home) with your twin, how much time did you spend together? (Circle one number)

1. . . every day

2. . . 2-3 times per week

3. . . 1 time per week

4. . . 2-3 times per month

5. . . 1 time per month

6. . . 2-3 times per year

7. . . 1 time per year

8. . . never

9. . . other (EXPLAIN): _____

D. On the average, when living APART FROM your twin (in different homes), how much time did you spend together? (Circle one number)

1. . . every day

2. . . 2-3 times per week

3. . . 1 time per week

4. . . 2-3 times per month

5. . . 1 time per month

6. . . 2-3 times per year

7. . . 1 time per year

8. . . never

9. . . other (EXPLAIN): _____

5. We are interested in knowing how you felt when seeing or meeting other twin pairs BEFORE YOUR TWIN'S DEATH. (Circle one number)

1. . . Very happy

2. . . Generally happy

3. . . Neutral; I did not really react when I saw other twin pairs

4. . . Generally unhappy

5. . . Very unhappy

6. . . Does not apply

6. Answer both A and B

A. My twin and I were raised in the same home by our biological parents. (Circle one)

YES NO OTHER (Explain): _____

B. Were you and your twin adopted or living in the same foster home? (Circle one)

YES NO OTHER (Explain): _____

If YES, please describe the circumstances briefly:

C. Were you and your twin adopted separately or living in different foster homes? (Circle one)

YES NO OTHER (Explain): _____

If YES, please describe the circumstances briefly:

7. We know only too well that questions concerning the loss of one's twin may be difficult to answer. We would, however, greatly appreciate any information you are willing to provide, as it will help us to understand this experience and, therefore, be of greater service to others.

We would like you to share with us the causes and circumstances surrounding the death of your twin. Please tell us how he or she died. Please be as specific or as general as you like. Feel free to write on the back of this sheet, if necessary:

8. How old were you when you lost your twin?

AGE IN YEARS _____ Twin's Name _____

Date of Twin's Loss: _____
 Day Month Year

9. How old were you when you first learned of your twin's death?

AGE IN YEARS _____

a. Your MARITAL/RELATIONSHIP STATUS at the Time of Your Twin's Loss (Circle One):

Single Married Divorced Separated In a Significant Relationship

Other (Explain): _____

10. The next set of statements is concerned with the experience of grief.

The statements listed below represent thoughts and feelings commonly expressed by people who have suffered the loss of a relative. Please read each statement and then try to determine how well it described you during your period of bereavement for your twin. If you are still experiencing some of these thoughts and feelings, please respond in the same manner. If the statement is true or mostly true as applied to you, circle the letter T (TRUE) at the end of the question. If the statement is false or mostly false, circle the F (FALSE) at the end of the question. If a certain statement does not apply to you at all, circle the number of that question (question numbers are at the LEFT of each question). Please try to answer as many questions as possible.

1. Immediately after the death I felt exhaustedT F
2. I tend to be more irritable with others.....T F
3. I am strongly preoccupied with the image of my deceased twin.....T F
4. I frequently experience angry feelings.....T F
5. It is not difficult to maintain social relationships with friendsT F
6. My arms and legs feel very heavyT F
7. I am unusually aware of things related to deathT F
8. It seems to me that more could have been done for my deceased twinT F
9. I showed little emotion at the funeralT F
10. I felt a strong necessity for maintaining the morale of others after the death.....T F
11. I feel cut-off and isolatedT F
12. I rarely take aspirins.....T F
13. I feel reluctant to attend social gatheringsT F
14. I was unable to cry at the announcement of the deathT F
15. I have feelings of guilt because I was spared and my twin was taken.....T F
16. I have a special need to be near others.....T F
17. I often experience confusionT F
18. I feel lost and helpless.....T F
19. I am comforted by believing that my deceased twin is in heavenT F
20. I have had frequent headaches since the deathT F

21. It was difficult to part with the clothing and personal articles
of my deceased twin.....T F
22. It was necessary to take sleeping pills after the deathT F
23. The yearning for my deceased twin is so intense that I sometimes feel physical
pain in my chestT F
24. I cry easilyT F
25. I have taken tranquilizers since the deathT F
26. I experience a dryness of the mouth and throatT F
27. I feel restlessT F
28. Upon first learning of the death I had a dazed feelingT F
29. Concentrating upon things is difficult.....T F
30. I have feelings of apathyT F
31. I experienced a feeling when the death occurred that
"something died within me"T F
32. Aches and pains seldom bother me.....T F
33. I find I am often irritated with othersT F
34. I could not cry until after the funeralT F
35. I feel that I may in some way have contributed to the deathT F
36. I find myself performing certain acts which are similar to
ones performed by my deceased twinT F
37. I made the funeral arrangementsT F
38. I lack the energy to enjoy physical exerciseT F
39. I rarely feel enthusiastic about anythingT F
40. I feel that grief has aged meT F
41. I have never dreamed of my deceased twin as still being aliveT F
42. I find myself frequently asking "why did the death have to happen
in this way?"T F
43. I sometimes have difficulty believing the death has actually occurredT F

44. I feel a strong desire to complete certain unfinished tasks that my deceased twin had begunT F
45. I have often dreamed of times when my deceased twin was living.....T F
46. I am often irritableT F
47. I have dreamed of my deceased twin as being deadT F
48. I feel extremely anxious and unsettled.....T F
49. I feel tenseness in my neck and shouldersT F
50. Sometimes I have a strong desire to screamT F
51. I am so busy that I hardly have time to mournT F
52. I feel anger toward GodT F
53. I have the urge to curl up in a small ball when I have attacks of crying.....T F
54. I feel the need to be alone a great deal.....T F
55. I rarely think of my own death.....T F
56. I find it difficult to cryT F
57. Looking at photographs of my deceased twin is too painfulT F
58. Life has lost its meaning for me.....T F
59. I have no difficulty with digestionT F
60. I have had brief moments when I actually felt anger at having been leftT F
61. I have no trouble sleeping since the deathT F
62. I have a hearty appetiteT F
63. I feel healthyT F
64. It comforts me to talk with others who have had a similar loss.....T F
65. I yearn for my deceased twinT F
66. I seldom feel depressedT F
67. I have the feeling that I am watching myself go through the motions of livingT F
68. Life seems empty and barrenT F

69. There are times when I have the feeling that my deceased twin is presentT F
70. I often take sedatives.....T F
71. I have frequent mood changesT F
72. The actions of some people make me resentfulT F
73. My feelings are not easily hurt.....T F
74. I am losing weight.....T F
75. Small problems seem overwhelmingT F
76. I sometimes feel guilty at being able to enjoy myselfT F
77. I frequently have diarrheaT F
78. I often wish I could have been the one to die insteadT F
79. I have lost my appetiteT F
80. I sometimes talk with the picture of my deceased twinT F
81. I am not interested in sexual activitiesT F
82. At times I wish I were deadT F
83. It is hard to maintain my religious faith in light of all the
pain and suffering caused by the deathT F
84. I seem to have lost my energy.....T F
85. I dread viewing a body at the funeral home.....T F
86. I find myself idealizing my deceased twinT F
87. I have problems with constipationT F
88. I frequently take long walks by myself.....T F
89. I avoid meeting old friendsT F
90. I have a special need for someone to talk toT F
91. It often feels as if I have a lump in my throatT F
92. I sometimes find myself unconsciously looking for my deceased twin
in a crowd.....T F

93. I seem to have lost my self-confidenceT F
94. I drink more alcohol now than before the deathT F
95. After the announcement of the death I thought, "This could not be happening to me"T F
96. I have nightmaresT F
97. The thought of death seldom enters my mind.....T F
98. I have never worried about having a painful diseaseT F
99. Funerals sometimes upset meT F
100. I would not feel uneasy visiting someone who was dying.....T F
101. I often worry over the way time flies by so rapidlyT F
102. I have no fear of failure.....T F
103. I am close with only a few personsT F
104. The sight of a dead person is horrifying to meT F
105. I always know what to say to a grieving personT F
106. I often seek advice from othersT F
107. It does not bother me when people talk about death.....T F
108. I cannot remember a time when my parents were angry with meT F
109. I do not think people in today's society know how to react to a person who is grieving.....T F
110. I never have an emotional reaction at funeralsT F
111. I often think about how short life isT F
112. I am not afraid of dying of cancer.....T F
113. I do not mind going to the doctor for check-ups.....T F
114. I shudder at the thought of nuclear warT F
115. The idea of dying holds no fears for meT F
116. I never lose my temper.....T F

117. I have always been completely sure I would be successful when I tried something for the first timeT F
118. I am not usually happyT F
119. I feel that the future holds little for me to fearT F
120. I cannot ever remember feeling ill at ease in a social situationT F
121. I find myself sighing more now than than before the death of my twinT F
122. I spent a great deal of time with my deceased twin before the deathT F
123. I find that comforting others helps meT F
124. My family seems close to me.....T F
125. I feel that I did all that could have been done for my deceased twin.....T F
126. My religious faith is a source of inner strength and comfortT F
127. I am smoking more these daysT F
128. I am not a realistic personT F
129. I am awake most of the nightT F
130. I feel exhausted when I go to bed but lie awake for several hoursT F
131. I lose sleep over worryT F
132. I often wake in the middle of the night and cannot get back to sleepT F
133. I sleep well most nights.....T F
134. Things seemed blackest when I am awake in the middle of the night.....T F
135. I can sleep during the day but not at nightT F
136. One to two months after my twin's loss, I considered suicideT F
137. One to two months after my twin's loss, I attempted suicideT F
138. The spirit of my twin is with meT F

11. People may learn of this unfortunate event in different ways. We would like for you to share with us how you FIRST LEARNED of your twin's loss. Please describe this below: