

Registration for the RLS Foundation Brain Bank

Contact Information

(All lines must be completed and form must have original signature.)

RLS Foundation Brain Bank Donor Information

| | | |
|-------------------|--------------------|------------------|
| First Name | Middle Name | Last Name |
|-------------------|--------------------|------------------|

Address

| | | |
|-------------|--------------|-----------------|
| City | State | Zip Code |
|-------------|--------------|-----------------|

| | | |
|------------------|------------|---------------|
| Telephone | Fax | E-mail |
|------------------|------------|---------------|

Date of Birth

Donor Signature

Date Form Signed

Legal Next of Kin or Legally Authorized Representative for Donor

| | | |
|-------------------|--------------------|------------------|
| First Name | Middle Name | Last Name |
|-------------------|--------------------|------------------|

| | | | |
|----------------|-------------|--------------|-----------------|
| Address | City | State | Zip Code |
|----------------|-------------|--------------|-----------------|

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| Telephone | Fax | E-mail |
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Relationship to Donor

Required Contact Information Sheet for RLS Foundation Brain Bank
RLS Foundation • 1610 14th St NW Suite 300 • Rochester, MN 55901

Restless Legs Syndrome Questionnaire

Please mark the box denoting your answer with an

Restless Legs Syndrome Questionnaire

**Please answer all questions as completely as you can.
If you cannot answer, write DK or Don't Know, NA or Not Applicable**

| | |
|--|---|
| Your full name: | |
| Today's date (dd/ mm/ yy) | <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> |
| Your date of birth (dd/ mm/ yy) | <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> |
| Age | |
| Your height (Either format) | <input type="checkbox"/> Feet <input type="checkbox"/> <input type="text"/> <input type="text"/> Inches <input type="checkbox"/> <input type="text"/> <input type="text"/> Centimeters |
| Your weight (Either format) | <input type="checkbox"/> <input type="text"/> <input type="text"/> <input type="text"/> Pounds <input type="checkbox"/> <input type="text"/> <input type="text"/> Kg |
| Your gender (Mark the correct box with an <input checked="" type="checkbox"/>) | <input type="checkbox"/> Male <input type="checkbox"/> Female |
| Ethnicity (Mark all boxes that apply with an <input checked="" type="checkbox"/>) | <input type="checkbox"/> African <input type="checkbox"/> Asian <input type="checkbox"/> Arab <input type="checkbox"/> Central or South American <input type="checkbox"/> European <input type="checkbox"/> Russian <input type="checkbox"/> Indian <input type="checkbox"/> Latin American <input type="checkbox"/> Native American (Indian, Eskimo, Aleut) <input type="checkbox"/> Pacific Islander <input type="checkbox"/> Spanish American <input type="checkbox"/> Other: _____ |
| If you have European ancestors, list the primary countries from which you believe your ancestors came: | |

Please answer these questions as completely as you can.

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| What time do you usually go to bed? | |
| What time do you usually get out of bed for the day? | |

| | |
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| Do you now take medications for RLS? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
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If you take medication for RLS, answer the following questions as you feel the situation would be if you were NOT taking this medication to treat your RLS.

| | |
|--|--|
| 1. Have you ever had unpleasant or uncomfortable feelings in your legs that occurred mainly while sitting or lying down ? | <input type="checkbox"/> Yes <input type="checkbox"/> No (if "no", go to #3) |
| 2. Would you describe these feelings as: (please check only one box) | <input type="checkbox"/> Usually painful <input type="checkbox"/> Somewhat painful and uncomfortable <input type="checkbox"/> Not painful but very uncomfortable |

| | |
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| 3. Have you ever had a recurrent need or urge to move your legs that occurred mainly while sitting or lying down ? | <input type="checkbox"/> Yes (if "yes", go to 3a) <input type="checkbox"/> No <ul style="list-style-type: none"> • If you answered "NO" to BOTH questions #1 and #3, then STOP HERE. • If you answered "YES" to either question #1 or #3, continue with 3a below. |
| 3a. Do these feelings in your legs ever become overwhelming to the point that you cannot resist moving your legs? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 3b. If you developed these feelings in your legs and you could not move your legs, or if someone were to hold your legs down, how would this effect the feelings in your legs? (Please indicate your response by checking ONE of the boxes) | <input type="checkbox"/> My legs would feel a lot better <input type="checkbox"/> My legs would feel somewhat better <input type="checkbox"/> There would be no difference <input type="checkbox"/> My legs would feel somewhat worse <input type="checkbox"/> My legs would feel a lot worse |

| | |
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| 4. Do you think these feelings in your legs are due to a charlie-horse or muscle cramp? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 4a. If you answered "yes" to question 4, then are these feelings always due to a charlie-horse or muscle cramp? | <input type="checkbox"/> Yes <input type="checkbox"/> No |

Restless Legs Syndrome Questionnaire

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| | |
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| 5. When you are awake and you have these feelings in your legs, will your legs ever jump involuntarily ? | <input type="checkbox"/> Yes <input type="checkbox"/> No (If "no", go to #6) |
| 5a. When you are awake and you have these feelings in your legs, how frequently will your legs also jump or jerk? (Check one answer only) | <input type="checkbox"/> Rarely <input type="checkbox"/> Occasionally <input type="checkbox"/> Commonly <input type="checkbox"/> Almost always |
| 6. Are these feelings in your legs worse when you are resting (either sitting or lying down) than when you are physically active? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 7. When present, do these feelings improve or go away when you get up and walk around as long as you are walking? (Please note that you may be aware that these feelings will be bad again if you stop walking, but while you are walking is it less of a problem?) | <input type="checkbox"/> Yes <input type="checkbox"/> No (If "no", go to #8) |
| 7a. Will you get some relief almost immediately when you start walking? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 7b. Will the feelings in your legs return while you continue to walk ? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 8. Are these feelings in your legs much more likely to occur when you are sitting than when you are lying down ? | <input type="checkbox"/> mostly when lying down (go to 9) <input type="checkbox"/> both lying down and sitting (go to 9) <input type="checkbox"/> mostly when sitting (go to 8a) |
| 8a. Would it be true to say that you have these feelings almost exclusively when you are sitting and only rarely, if ever, when lying down? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 9. Are these feelings in your legs worse at night or in the evening than other times of day? | <input type="checkbox"/> Yes (If "yes", go to #10) <input type="checkbox"/> No |
| 9a. Not NOW, but when these feelings first started did they occur predominantly at night or in the evening? | <input type="checkbox"/> Yes <input type="checkbox"/> No |

| | |
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| <p>10. Approximately how old were you when you first noticed these feelings? (Please write in an approximate age)</p> <p>It is very important you make your best estimate for this.</p> <p>Remember important events in your life when you know you were a certain age – high school or marriage or a particular job – and relate the onset of your RLS symptoms to whichever event was closest in time to the onset</p> | <p>_____ years old</p> |
|--|------------------------|

| | |
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| <p>11. Do you still have these feelings in your legs?</p> | <p><input type="checkbox"/> Yes (If YES, go to Note after 12)</p> <p><input type="checkbox"/> No (If NO, go to 12)</p> |
|---|--|

| | |
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| <p>12. Did your feelings stop because you were on RLS medication?</p> | <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> |
|---|--|

NOTE: Please respond to ALL the questions below (13 – 30) the way you think you would feel if you were **not on any RLS treatment at this time.**

For each of the questions below (13 – 15), please write in the time & circle AM or PM

| | |
|---|--|
| <p>13. What time of day would these feelings usually start?</p> | <p>_____ AM / PM</p> |
| <p>14. On any given day, what is the earliest time that these feelings are likely to occur if you were to sit down or rest?</p> | <p>_____ AM / PM</p> |
| <p>15. On a usual day, about what time will these feelings stop occurring for that day?</p> | <p>_____ AM / PM</p> <p><input type="checkbox"/> Never</p> |

Please double-check your times above.
Were the times entered correctly as either AM or PM?

Restless Legs Syndrome Questionnaire

Please mark the box denoting your answer with an

| | |
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| <p>16. How often do you experience these feelings? (Check <u>only one answer</u> that is the best match)</p> | <input type="checkbox"/> Everyday <input type="checkbox"/> 4-5 times per week <input type="checkbox"/> 2-3 times per week <input type="checkbox"/> 1 time per week <input type="checkbox"/> 2 times per month <input type="checkbox"/> 1 time per month <input type="checkbox"/> Less than once a month <input type="checkbox"/> None during the last year |
|--|---|

| | |
|--|--|
| <p>17. Since these feelings first occurred, how many years did it take before they started to occur this frequently?</p> | <p style="text-align: center;">_____years</p> |
| <p>18. Approximately how old were you when you first decided to seek medical help for these feelings in your legs?</p> | <p style="text-align: center;">_____years old</p> <input type="checkbox"/> Never sought help |

| | |
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| <p>For each of the questions that follow, please MARK THE BEST ANSWER.</p> | |
| <p>19. Since these feelings first started, the number of days they occur has:</p> | <input type="checkbox"/> Increased <input type="checkbox"/> Not changed <input type="checkbox"/> Decreased |
| <p>19a. Since these feelings first started, the number of hours in a day when they occur has:</p> | <input type="checkbox"/> Increased <input type="checkbox"/> Not changed <input type="checkbox"/> Decreased |
| <p>19b. Since these feelings first started, the feelings (when they occur) have become</p> | <input type="checkbox"/> More intense <input type="checkbox"/> Not changed in intensity <input type="checkbox"/> Less intense |

For the questions below, please **CHECK ALL ANSWERS THAT APPLY.**

20. When these feelings first started, in what part(s) of the body did you first notice them?

- Lower leg
- Upper leg
- Knee
- Lower arm
- Upper arm
- Other: _____

21. At the present time, in what parts of the body have you experienced these feelings?

- Lower leg
- Upper leg
- Knee
- Lower arm
- Upper arm
- Other: _____
- At present, do not have these feelings

22. Do these feelings occur while you are walking?

- Yes
- No (If "no", go to #23)

22a. Do these feelings sometimes start while you are walking?

- Yes
- No

Restless Legs Syndrome Questionnaire

Please mark the box denoting your answer with an

23. To the right of each of the activities that are listed in the table, please **CHECK** the box that best describes the effect the corresponding activity would have on the feelings in your legs. If you have no experience with the effects of the activity on the feelings in your legs, then just indicate that you **DON'T KNOW**.

| Activities | Very Likely to Cause Feelings | Might Cause Feelings | Neither Cause Nor Relieve Feelings | Might Relieve Feelings | Very Likely to Relieve Feelings | Don't Know |
|------------------------------|-------------------------------|--------------------------|------------------------------------|--------------------------|---------------------------------|--------------------------|
| Walking | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Standing | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Sitting | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Reading | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Lying down | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Rubbing, massage legs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Very hot baths | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Long ride in car or airplane | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Evening at theater/movies | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| | |
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| 24. Are you on dialysis? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 25. Have you been told that you have thin blood or anemia? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 26. Have you ever been told that your body has too little iron? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 27. Have you ever been told that you have damage to the nerves in your feet or legs? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 28. Are you aware of any other medical problems or conditions that might have caused these feelings? | <input type="checkbox"/> Yes <input type="checkbox"/> No |

29 – For any disorder or condition mentioned in questions 25 to 28, please indicate:

- a. How old you were when it began:
- b. How old you were when it stopped:

Continue on back of sheet if there is no room to complete description here

For the questions that follow, please check only one answer.
Indicate how the feelings you deal with affect your ability to:

| | |
|--|---|
| 30a. get to sleep? | <input type="checkbox"/> No effect <input type="checkbox"/> Very little effect <input type="checkbox"/> Mild effect <input type="checkbox"/> Moderate effect <input type="checkbox"/> Severe effect |
| 30b. stay asleep? | <input type="checkbox"/> No effect <input type="checkbox"/> Very little effect <input type="checkbox"/> Mild effect <input type="checkbox"/> Moderate effect <input type="checkbox"/> Severe effect |
| 30c. return to sleep (if awakened during the night)? | <input type="checkbox"/> No effect <input type="checkbox"/> Very little effect <input type="checkbox"/> Mild effect <input type="checkbox"/> Moderate effect <input type="checkbox"/> Severe effect <input type="checkbox"/> Rarely awake during the night |

31. List all medicines that you took in the past for RLS and indicate whether you benefited or not. Indicate the highest dose you took if you remember. If you can't remember the maximum dose or whether you benefited, write Don't KNOW (DK)

| List Medication for RLS | Did it help your RLS | Maximum dose taken |
|-------------------------|----------------------|--------------------|
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| | | |
|------------------|--|--|
| Brother | | |
| Daughter | | |
| Son | | |
| Other (describe) | | |
| Other (describe) | | |
| Other (describe) | | |

Please write below any other information you think would be helpful to us in understanding your RLS condition and treatment. (Use the back of this form if more space is needed.)

Thank you for completing the questionnaire.

Please check to make sure you have answered all of the questions to the best of your ability.