Romberg’s Connection 2009 Survey

1. Welcome Page

Welcome to our Romberg’s Connection 2009 Survey

Throughout this survey, when we use the term "Rombergs" or "Romberg" we are referring to: "Parry Romberg", "Parry Rombergs", "Parry Romberg Syndrome" and "PRS".

This is an unscientific survey designed to gather information from those who must deal with Rombergs on a daily basis.

There are four buttons used to navigate through the survey.
They are:
Quit: This button will close the survey and save your location in the survey. When you return at a later time, you will be able to start where you had left off.

Back: This button will return you to the previous page.

Next: This button will take you to the next page in the survey.

Finished: This button is found at the end of the survey and will "End" the survey for you and record your responses.

This survey is made up of eight parts.
I. General Information
II. Rombergs Symptoms History
III. Associated Symptoms of Rombergs
IV. Triggers for Rombergs
V. Treatment for Rombergs
VI. Any Other Affected Family Members
VII. Miscellaneous Questions
VIII. Closing Survey

There are only four questions that are required to be answered.
Those questions are:
1) The country where the person with Rombergs is from.
2) The person who is affected by Rombergs.
2.a.) The gender of this person if it is "Yourself", “Spouse” or if you are "Speaking for someone else".
3.) The age of the person who is affected by Rombergs.

Each part or section will have a menu of options to select from.
Depending upon your selection you may be asked some follow up questions.

This survey has a lot of detail, but remember that after you answer the four required questions, you can click the Next button to skip over any section you do not care to answer.

The survey will leave a "cookie" on your computer. But at no time will your identity be revealed.

Romberg's Connection 2009 Survey

You can Close out of the survey or click the "**Quit**" button at anytime. At a later time, when you come back to the survey, the survey will start where you left off. You can repeat this as many times as you need to. When you click the "**Finished**" button, the survey will be ended for you.

Our thanks go the following people who have contributed to the questions in this survey:
Dr. Foeldvari, Dr. Jon Stone, Kristina, Markus, Margaret H., Margaret L., Pam, Terri and Sally.

If you have any problems or questions about this survey, please contact:

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Webmaster
Romberg's Connection
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3. I. General Information

1. First name only (Optional):

2. Email (Optional):

3. Country (Required):

If other, please enter

Note: The Country is Required. If you do not select a Country you will receive the following message:

5. I. General Information cont.: No Country Selected

The selection of a Country is required.
I will return you to the "General Information" page.
At Question 3, Please select a Country.
Thank you.

8. I. General Information cont.: Who Is Affected

1. Please select who is affected (Required):

	Yourself
	Daughter
	Son
	Mother
	Father
	Sister
	Brother
	Aunt
	Uncle
	Cousin (Female)

	Cousin (Male)
	Granddaughter
	Grandson
	Speaking for a Friend
	Spouse
	Other, Please specify

Note: The Person Affected is Required. If you do not select the Person Affected you will receive the following message:

4. I. General Information cont.: No Selection Was Made

The Person Affected is required.
I will return you to the "Who Is Affected" page.
Please make a selection as to whom is affected with Rombergs Syndrome.
Thank you.

Note: If you would select Yourself, Speaking for a Friend, or Spouse for the Person Affected, you will open this page:

6. I. General Information cont.: Person's Gender

1. Gender (Required):

	Female		Male

Note: The Gender is Required. If you do not select a Gender you will receive the following message:

7. I. General Information cont.: No Selection for Person's Gender

The Gender is required.
I will return you to the "Person's Gender" page.
Please make a selection for the "Person's Gender".
Thank you.

9. I. General Information cont.: Affected Person Medically Diagnosed and Age?

1. Was the affected person medically diagnosed with Rombergs?

	Yes		No

2. Was the affected person medically diagnosed with Linear Scleroderma?

	Yes		No

3. Which diagnosis came first?

	Linear Scleroderma		Rombergs

4. What is the age of the affected person in number of years? (Required)

Note: The person's Age is Required. If you do not enter a person's Age you will receive the following message:

10. I. General Information cont.: Age Not Given

The affected person's Age is required.

I will return you to the "Affected Person Medically Diagnosed and Age" page.
Please enter the Age for the person who is affected with Rombergs Syndrome.
Please enter the years in numbers.
For example:
For a fifty year old person, enter 50.
For a twenty years and six months years old person, enter 20.5 or enter 20.
Thank you.

Note: If you answered Yes to "Was the affected person medically diagnosed with Rombergs" then you will open the following page with questions about the diagnosis:

11. I. General Information cont.: Diagnostic Information

1. At what age was the affected person diagnosed:

2. Please select the type of specialist who made the diagnosis:

	Acupuncturist
	Dentist
	Dermatologist
	Ear, Nose and Throat
	General Practitioner
	Geneticist
	Neurologist
	Opthamologist
	Plastic Surgeon
	Reconstructive Surgeon
	Rheumatologist
	Other (Please Specify)

3. Please select the procedure used to make the diagnosis:

	ANA (Antinuclear Antibody test for level of inflammation)
	Biopsy for bacteria
	Biopsy for sclerotic content
	CAT (computed axial tomography (CAT or CT scan))
	MRI (magnetic resonance imaging)
	Ultrasound
	Visual Diagnosis
	Other (Please Specify)

4. Comments for the Affected person's diagnostic information:

12. II. Rombergs Symptoms History

1. History of symptoms:

Age of the affected person when the symptoms started?

2. Are the symptoms still active?

	Yes		No

3. Have the symptoms ever stopped and then started again?

	Yes		No

4. Is the person facially affected on:

	the Left side
	the Right side
	Both sides
	Not affected

5. Where on the affected person's body do the symptoms also appear:

	the Left side
	the Right side
	Both sides
	Not affected

6. Comments for Rombergs Symptoms History:

Note: If you answered Yes to "Are the symptoms still active" then you will open the following page:

13. II. Rombergs Symptoms History cont.: Symptoms Still Active

1. Comments for the symptoms still being active:

Note: If you answered Yes to "Have the symptoms ever stopped and then started again" then you will open the following page:

14. II. Rombergs Symptoms History cont.: Symptoms Reactivated

1. Please comment on why you think that the symptoms were reactivated:

Note: If you answered No to "Are the symptoms still active" then you will open the following page:

15. II. Rombergs Symptoms History cont.: Symptoms Are Not Active

1. At what age did the symptoms appear to become inactive?

2. Please comment as to why you think the symptoms ceased:

16. III. Associated Symptoms of Rombergs (page 1 of 4)

1. Please select all that apply (page 1):

	Abnormal sensation in affected area
	Atrophy (tissue loss)
	Blood pressure affected
	Bone loss
	Brain affected
	Chin affected
	Ear affected

Note: For each item that you select, you will be taken to a page with questions about that item. These pages are as follows:

17. III. Associated Symptoms (page 1 of 4) cont.: Abnormal Sensation

1. Please select any abnormal sensations in the affected area:

	Burning
	Coldness
	Pain
	Tingling
	Other (Please Specify)

2. Comments for Abnormal Sensation:

18. III. Associated Symptoms (page 1 of 4) cont.: Atrophy (tissue loss)

1. Please select the location of Atrophy (tissue loss) on the head:

	Cheek
	Chin
	Ear
	Eye lid
	Forehead
	Lower lip
	Upper lip
	Nose
	Scalp
	Temple

2. Other locations of the body with Atrophy (tissue loss):

	Arm
	Back
	Chest
	Leg
	Neck
	Side
	Stomach
	Other (Please Specify)

3. Please rate the severity of this Atrophy (tissue loss):

	1 (very mild)
	2 (mild)
	3 (moderate)
	4 (severe)
	5 (very severe)

4. Comments for Atrophy (tissue loss):

19. III. Associated Symptoms (page 1 of 4) cont.: Blood pressure

1. Blood pressure is:

	High		Low

2. Other:

20. III. Associated Symptoms (page 1 of 4) cont.: Bone loss

1. Please select any location of bone loss:

	Cheek bone
	Forehead
	Jaw bone
	Temple
	Skull

2. Other locations of bone loss:

	Arm
	Back
	Chest
	Foot
	Hand
	Hip
	Leg
	Ribs
	Spine
	Other (please specify)

3. Comments for Bone loss:

21. III. Associated Symptoms (page 1 of 4) cont.: Brain affected

1. Please select how brain is affected:

	Atrophy of
	Lesions
	Seizures

	Strokes (blood clots)
	White matter abnormality
	Other (Please Specify)

2. Please describe what if any effective treatment was obtained:

3. Comments for Brain affected:

Note: If you selected "Seizures" then the following page will open:

22. III. Associated Symptoms (page 1 of 4) cont.: Seizures

1. Please select the type/types of Seizures:

	Grand mal
	Jacksonian epilepsy (sensory seizures)
	Loss of feeling
	Petit mal
	Tingling sensations
	Other (Please Specify)

2. Please list any medications taken for seizures:

3. Length of time medications were taken:

4. Please explain if these medications were or were not helpful:

5. What were some of the side effects of these medications:

6. Comments for Seizures:

23. III. Associated Symptoms (page 1 of 4) cont.: Chin affected

1. Please select how the chin is affected:

	Discoloration
	En coup de sabre (indentation)
	Thin skin
	Tissue loss
	Other (please specify)

2. Comments for Chin affected:

24. III. Associated Symptoms (page 1 of 4) cont.: Ears affected

1. Please select how the ear is affected:

	Hearing loss
	Some atrophy of the ear canal
	Other (Please Specify)

2. Comments for Ears affected:

25. III. Associated Symptoms of Rombergs (page 2 of 4)

1. Please select all that apply (page 2):

	En coup de sabre (indentation)
	Eye affected
	Face affected
	Fasciculation (muscle twitching)
	Fatigue
	Forehead affected
	Hair affected
	Headaches

Note: For each item that you select, you will be taken to a page with questions about that item. These pages are as follows:

26. III. Associated Symptoms (page 2 of 4) cont.: En coup de sabre (page 1 of 2)

1. Please select the location of En coup de sabre:

	Cheek
	Forehead
	Chin
	From scalp to chin, right side
	From scalp to chin, left side
	Tongue
	Other (please specify)

Please describe the progression.

2. Where did it start:

3. At what age:

4. Where did it progress to:

5. At what age did it appear to stop:

6. Was there any hair loss before or after:

	Before		After		Before and After		None

27. III. Associated Symptoms (page 2 of 4) cont.: En coup de sabre (page 2 of 2)

1. Was there any skin discoloration before or after:

	Before		After		Before and After		None

2. Any medication or procedure that stopped the progression:

3. Please comment on effectiveness of this medication or procedure.

4. Please rate the severity of the En coup de sabre:

	1 (very mild)
	2 (mild)
	3 (moderate)
	4 (severe)
	5 (very severe)

5. Comments for En coup de sabre:

28. III. Associated Symptoms (page 2 of 4) cont.: Eye affected (page 1 of 2)

1. Please select how is the eye affected:

	Blurred vision
	Cataracts
	Corneal scarring
	Corneal transplant
	Detached retina
	Dilated pupil
	Discharge
	Double vision
	Drooping eyelids
	Glasses
	Heterochromia (difference in coloration, usually of the iris)
	Iridocyclitis (type of anterior uveitis)
	Iritis (inflamed iris)
	Keratitis (dry eye)
	Optic nerve damage
	Partial or complete loss of vision
	Receding eye
	Scleritis (primary inflammation of the sclera)
	Uveitis (inflammation)
	Other (Please Specify)

2. Please comment if the affected person had any surgeries that caused problems with their eyes:

3. If the affected person had cataract surgery, please comment on the results:

4. If the affected person had any loss of vision, please comment:

29. III. Associated Symptoms (page 2 of 4) cont.: Eye affected (page 2 of 2)

1. Please give the results if the affected person had surgery to correct a receding eye:

2. Please describe any factors that caused dilation of the eye:

3. How long did the dilation last?

4. What measures did the affected person take to correct problems with dry eyes:

5. Comments concerning how the eye is affected:

30. III. Associated Symptoms (page 2 of 4) cont.: Face Affected

1. Please select how the face is affected:

	Facial pain
	Facial paralysis or weakness

Note: For each item that you select, you will be taken to a page with questions about that item. These pages are as follows:

31. III. Associated Symptoms (page 2 of 4) cont.: Facial Pain

1. Describe the location of this Facial pain:

2. Is the pain triggered from the trigeminal nerve?

	Yes		No

3. Any medication or procedure that stopped this facial pain:

4. Please comment on effectiveness of this medication or procedure.

5. Rate the severity of this facial pain:

	1 (very mild)
	2 (mild)
	3 (moderate)
	4 (severe)
	5 (very severe)

6. Comments for Facial Pain:

32. III. Associated Symptoms (page 2 of 4) cont.: Facial paralysis or weakness

1. Do you feel this facial paralysis or weakness is related to Rombergs?

	Yes		No

2. Comments for facial paralysis or weakness:

33. III. Associated Symptoms (page 2 of 4) cont.: Fasciculation (muscle twitching)

1. Can it be linked to the start of progression:

	Yes		No

2. How long did it last:

3. Can it be linked to a stage of activity:

4. Comments for Fasciculation (muscle twitching):

34. III. Associated Symptoms (page 2 of 4) cont.: Forehead affected

1. Please select how the Forehead is affected:

	Bone loss
	Discoloration
	En coup de sabre (indentation)
	Protruding bone
	Thin skin
	Other (Please Specify)

2. Comments for Forehead affected:

35. III. Associated Symptoms (page 2 of 4) cont.: Hair affected

1. Please select how is the Hair affected:

	Alopecia (hair loss)
	Excessive hair
	Eyebrow (missing all or part of)
	Eyelashes (missing all or part of)
	Loss of body hair
	Thinning
	Other (Please Specify)

2. Comments for Hair affected:

36. III. Associated Symptoms (page 2 of 4) cont.: Headaches

1. Please select the type/types of Headaches:

	Fatigue
	Migraines
	Muscle weakness
	Nausea
	Slurred speech
	Vomiting
	Other (Please Specify)

2. Comments for Headaches:

37. III. Associated Symptoms of Rombergs (page 3 of 4)

1. Please select all that apply (page 3):

	Heart affected
	Jaw affected
	Joint affected
	Morphea
	Mouth affected
	Muscle loss
	Nose affected
	Numbness
	Problems with balance

Note: For each item that you select, you will be taken to a page with questions about that item. These pages are as follows:

38. III. Associated Symptoms (page 3 of 4) cont.: Heart affected

1. Please select how the Heart is affected:

	Ailments
	Mitral valve prolapse with regurgitation
	Murmur
	Other (Please Specify)

2. Comments for Heart affected:

39. III. Associated Symptoms (page 3 of 4) cont.: Jaw affected

1. Please select how the Jaw is affected:

	Atrophy of the jaw bone
	Bite that feels uncomfortable
	Biting of the tongue or cheek
	Inability to open comfortably
	Grinding teeth
	Jaw clicks
	Jaw locking
	Jaw spasms
	Limited opening
	Misalignment between upper and lower jaw
	Overbite
	Pain in the jaw joint
	TMJ disorder (Temporomandibular Joint in Jaw)
	Other (Please Specify)

2. Please describe the steps that were taken to resolve any of these problems:

3. Please describe if any of these steps were successful:

4. Comments for Jaw affected:

40. III. Associated Symptoms (page 3 of 4) cont.: Joint affected

1. Which joint(s) is/are affected:

2. Please rate the joint impairment:

	1 (very mild)
	2 (mild)
	3 (moderate)
	4 (severe)
	5 (very severe)

3. Comments for Joint affected:

41. III. Associated Symptoms (page 3 of 4) cont.: Morphea

1. Please select the location of Morphea on the head:

	Cheek
	Chin
	Ear
	Eye lid
	Forehead
	Lower lip
	Upper lip
	Nose
	Scalp
	Temple

2. Comments for Morphea on the head:

3. Other locations of the body with Morphea:

	Arm
	Back
	Chest
	Leg
	Neck
	Side
	Stomach
	Other (Please Specify)

4. Comments for Morphea on other locations of the body:

5. General comments about Morphea:

42. III. Associated Symptoms (page 3 of 4) cont.: Mouth affected

1. Please select how the Mouth is affected:

	Asymmetrical
	Palette
	Thinning lip
	Tongue
	Other (Please Specify)

2. Comments for Mouth affected:

43. III. Associated Symptoms (page 3 of 4) cont.: Muscle loss

1. Select the location of muscle loss:

	Abdominal
	Arm
	Back
	Chest
	Eye
	Jaw
	Leg
	Neck
	Other (Please Specify)

2. Comments for Muscle loss:

44. III. Associated Symptoms (page 3 of 4) cont.: Nose affected

1. Please select how the Nose is affected:

	Asymmetrical
	Deviated septum
	Loss of tissue
	Pulled to one side
	Sinus cavity is thinning
	Other (Please Specify)

2. Comments for Nose affected:

45. III. Associated Symptoms (page 3 of 4) cont.: Numbness

1. Please select the location of Numbness on the Head:

	Cheek
	Chin
	Ear
	Eye lid
	Forehead
	Lower lip
	Upper lip
	Nose
	Scalp
	Temple

2. Other locations of the body with numbness:

	Arm
	Back
	Chest
	Leg
	Neck
	Side

	Stomach
	Other (Please Specify)

3. Comments for Numbness:

46. III. Associated Symptoms (page 3 of 4) cont.: Problems with balance

1. Has any therapy been tried to improve this problem?

	Yes		No

2. Comments concerning problems with balance:

Note: If you answered Yes to this question, you will be taken to a page with questions about therapy to improve this problem with balance.
This page is as follows:

47. III. Associated Symptoms (page 3 of 4) cont.: Problems with balance - therapy

1. Please describe the therapy:

2. Please describe how successful it was:

3. Comments concerning problems with therapy:

48. III. Associated Symptoms of Rombergs (page 4 of 4)

1. Please select all that apply (page 4):

	Scalp affected
	Sensitivity to extreme temperatures
	Skin, absence of pores
	Skin is discolored
	Stress
	Teeth affected
	Thin skin
	Other medical conditions not listed above

Note: For each item that you select, you will be taken to a page with questions about that item.
These pages are as follows:

49. III. Associated Symptoms (page 4 of 4) cont.: Scalp affected

1. Please select how the Scalp is affected:

	En coup de sabre (indentation)
	Indentations
	Tenderness (Occipital neuralgia)
	Thin skin

	Tissue loss
	Other (Please Specify)

2. Comments for Scalp affected:

50. III. Associated Symptoms (page 4 of 4) cont.: Sensitivity to temperatures

1. Please describe Sensitivity to extreme temperatures:

	Hands sensitive to cold
	Hands sensitive to heat
	Feet sensitive to cold
	Feet sensitive to heat
	Other (please specify)

2. Comments for Sensitivity to temperatures:

51. III. Associated Symptoms (page 4 of 4) cont.: Skin is discolored

1. Please select the location of discoloration on the head:

	Cheek
	Chin
	Ear
	Eye lid
	Forehead
	Lower lip
	Upper lip
	Nose
	Scalp
	Temple

2. Other locations of the body with discoloration:

	Arm
	Back
	Chest
	Leg
	Neck
	Side
	Stomach
	Other (Please Specify)

3. Please rate the severity of this discoloration:

	1 (very mild)
	2 (mild)
	3 (moderate)
	4 (severe)
	5 (very severe)

4. Comments for Discoloration:

52. III. Associated Symptoms (page 4 of 4) cont.: Stress

1. Please select how stress affects the person with Rombergs:

	Anxiety
	Daily life struggles
	Depression
	Difficulty in relationships
	Difficulty with job opportunities
	Panic attacks
	Self esteem issues
	Other (Please Specify)

2. Do you feel stress has a negative impact on Rombergs?

	Yes		No

3. Comments for Stress:

53. III. Associated Symptoms (page 4 of 4) cont.: Teeth affected

1. Please select how the Teeth are affected:

	Braces
	Delayed eruption
	Loose
	Loss of
	Misaligned
	Missing
	No permanent teeth
	Overbite
	Overcrowding
	Receding gums
	Resorbed roots
	Root decay
	Other (Please Specify)

2. Comments for Teeth affected:

54. III. Associated Symptoms (page 4 of 4) cont.: Thin skin

1. Please select the location of Thin skin:

	Cheek
	Chin
	Ear
	Eye lid
	Forehead
	Lower lip

	Upper lip
	Nose
	Scalp
	Temple
	Other (Please Specify)

2. Comments for Thin skin:

55. III. Associated Symptoms (page 4 of 4) cont.: Other medical conditions

1. Please describe other medical conditions not listed above:

2. Comments for Other medical conditions:

56. IV. Triggers for Rombergs (page 1 of 2)

1. What possibly could have triggered Rombergs? (page 1):

	Affected person has an autoimmune disorder
	Affected person was breast fed
	Dental work or tooth extractions prior to onset
	Experienced head trauma of any kind prior to onset
	Live near a polluted area or any factories prior to onset
	Lyme disease
	Miscarriage prior to onset
	Serious infection of any kind prior to onset

Note: For each item that you select, you will be taken to a page with questions about that item. These pages are as follows:

57. IV. Triggers (page 1 of 2) cont.: Autoimmune disorders

1. Please select any Autoimmune disorders that the affected person has:

	Addison's disease (adrenal)
	Ankylosing spondylitis
	Autoimmune Thyroid disease
	Arthritis
	Celiac disease
	Chiari Malformation
	Chronic Fatigue Syndrome
	Crohn's disease
	Fibromyalgia
	Goodpasture's Syndrome (lungs, kidneys)
	Graves' disease (thyroid)
	Guillain-Barre Syndrome (nervous system)
	Hashimoto's thyroiditis
	Hughes Syndrome (antiphospholipid)

	Inflammatory bowel disease
	Lupus (SLE)
	Mixed Corrective Tissue disease
	Multiple Sclerosis (MS)
	Polymyalgia Rheumatica (large muscle groups)
	Raynauds Phenomenon
	Scleroderma (skin, intestine, less commonly lung)
	Scleroderma, linear
	Scleroderma, localized
	Sjogren's Syndrome
	Systemic sclerosis
	Temporal Arteritis / Giant Cell Arteritis (arteries of the head and neck)
	Thyroid problems
	Type 1 Diabetes Mellitus
	Ulcerative colitis
	Vitiligo
	Other (please specify)

2. Comments for Autoimmune disorders:

58. IV. Triggers (page 1 of 2) cont.: Breast fed

1. How long breast fed:

2. Comments for Breast fed:

59. IV. Triggers (page 1 of 2) cont.: Dental work

1. Comments for Dental work:

60. IV. Triggers (page 1 of 2) cont.: Experienced head trauma

1. Please rate this trauma as:

	Major trauma
	Minor trauma

2. Describe the location of this trauma:

3. Comments for Experienced head trauma:

61. IV. Triggers (page 1 of 2) cont.: Live near a polluted area

1. Please comment on living near a polluted area:

62. IV. Triggers (page 1 of 2) cont.: Lyme disease

1. Please comment on Lyme disease:

[ ]

63. IV. Triggers (page 1 of 2) cont.: Miscarriage prior

1. Please comment on miscarriage prior to Rombergs:

[ ]

64. IV. Triggers (page 1 of 2) cont.: Serious infection

1. Please describe serious infections of any kind prior to onset:

[ ]

65. IV. Triggers for Rombergs (page 2 of 2)

1. What possibly could have triggered Rombergs? (page 2):

	Symptoms start during puberty (both male and female)
	Symptoms accelerated during puberty (both male and female)
	Symptoms start during pregnancy
	Symptoms accelerated during pregnancy
	Changes in symptoms after child birth
	Symptoms start during menopause
	Symptoms accelerated during menopause
	Vitamin D deficiency
	My ideas for Other Triggers

Note: For each item that you select, you will be taken to a page with questions about that item. These pages are as follows:

66. IV. Triggers (page 2 of 2) cont.: Start during puberty

1. Please comment on the symptoms starting during puberty:

[ ]

67. IV. Triggers (page 2 of 2) cont.: Accelerated during puberty

1. Please comment on the symptoms accelerating during puberty:

[ ]

68. IV. Triggers (page 2 of 2) cont.: Start during pregnancy

1. Please comment on the symptoms starting during pregnancy:

[ ]

69. IV. Triggers (page 2 of 2) cont.: Accelerated during pregnancy

1. Please comment on the symptoms accelerating during pregnancy:

[ ]

70. IV. Triggers (page 2 of 2) cont.: Changes in symptoms after child birth

1. Please comment on the changes in symptoms after child birth:

[ ]

71. IV. Triggers (page 2 of 2) cont.: Start during menopause

1. Please comment on the symptoms starting during menopause:

72. IV. Triggers (page 2 of 2) cont.: Accelerated during menopause

1. Please comment on the symptoms accelerating during menopause:

73. IV. Triggers (page 2 of 2) cont.: Vitamin D deficiency

1. Please comment on a Vitamin D deficiency:

74. IV. Triggers (page 2 of 2) cont.: Other Triggers

1. Please comment on your "Other" ideas for Romberg Triggers:

75. V. Treatment for Rombergs

1. Please select any treatments that have been used:

	Medications
	Other types of treatment
	Surgery

Note: For each item that you select, you will be taken to a page with questions about that item. These pages are as follows:

76. V. Treatment for Rombergs cont.: Medications Used (page 1 of 13)

1. Select any medications used:

	Aspirin
	Diprosone
	Doryx
	Dovonex
	Doxycycline
	Gabapentin
	Intravenous Gamma Globulin (IVIG)
	Methotrexate
	Methylprednisolone
	Monocycline
	Oral Calcitriol
	Penicillamine
	Plaquenil
	Prednisolone
	Prednisone
	Quinacrine
	Topical antibiotics (Bacitricin - Neosporin)
	Vitamin B-12

2. For "Other" medications, please enter:

Other Med 1	
Other Med 2	
Other Med 3	
Other Med 4	
Other Med 5	

You can add up to five "Other" medications taken for Rombergs symptoms. Through the rest of this section on medication, the drugs that you entered would be considered.

As an example, I use a medication called "Blue Pills". I will enter "Blue Pills" in the box beside "Other Med 1". When I answer any questions for "Other Med 1" I will be referring to the "Blue Pills". This can be done five times with five different medications.

Suggestion: If you have more than One "Other" medication, you may want to make a list to help you to remember these "Other" medications as you complete the rest of this section on medications.
Example of a List:
Med 1 = Blue Pills
Med 2 = White Pills
Med 3 = Black Pills
etc.

77. V. Treatment for Rombergs cont.: Medications Used (page 2 of 13)

1. Is the affected person taking this medication orally or by injection?

	Orally	Injection	(IV) Intravenous
Aspirin			
Diprosone			
Doryx			
Dovonex			
Doxycycline			
Gabapentin			
Intravenous Gamma Globulin (IVIG)			
Methotrexate			
Methylprednisolone			
Monocycline			
Oral Calcitriol			
Penicillamine			
Plaquenil			
Prednisolone			
Prednisone			
Quinacrine			
Topical antibiotics			
Vitamin B-12			
Other Med 1			
Other Med 2			

Other Med 3			
Other Med 4			
Other Med 5			

78. V. Treatment for Rombergs cont.: Medications Used (page 3 of 13)

1. At what age was this medication started?

Aspirin	
Diprosone	
Doryx	
Dovonex	
Doxycycline	
Gabapentin	
Intravenous Gamma Globulin (IVIG)	
Methotrexate	
Methylprednisolone	
Monocycline	
Oral Calcitriol	
Penicillamine	
Plaquenil	
Prednisolone	
Prednisone	
Quinacrine	
Topical antibiotics	
Vitamin B-12	
Other Med 1	
Other Med 2	
Other Med 3	
Other Med 4	
Other Med 5	

79. V. Treatment for Rombergs cont.: Medications Used (page 4 of 13)

1. If the medication has been stopped, what was the age of the person?

Aspirin	
Diprosone	
Doryx	
Dovonex	
Doxycycline	
Gabapentin	
Intravenous Gamma Globulin (IVIG)	
Methotrexate	
Methylprednisolone	
Monocycline	
Oral Calcitriol	

Penicillamine	
Plaquenil	
Prednisolone	
Prednisone	
Quinacrine	
Topical antibiotics	
Vitamin B-12	
Other Med 1	
Other Med 2	
Other Med 3	
Other Med 4	
Other Med 5	

80. V. Treatment for Rombergs cont.: Medications Used (page 5 of 13)

1. Did this medication stop the atrophy, reverse the atrophy or have no change for the atrophy:

(**Note:** The Reset option allows you to Undo your selection.)

	Stop	Reverse	No change	Reset
Aspirin				
Diprosone				
Doryx				
Dovonex				
Doxycycline				
Gabapentin				
Intravenous Gamma Globulin (IVIG)				
Methotrexate				
Methylprednisolone				
Monocycline				
Oral Calcitriol				
Penicillamine				
Plaquenil				
Prednisolone				
Prednisone				
Quinacrine				
Topical antibiotics				
Vitamin B-12				
Other Med 1				
Other Med 2				
Other Med 3				
Other Med 4				
Other Med 5				

81. V. Treatment for Rombergs cont.: Medications Used (page 6 of 13)

1. If there were any improvements, how long before you noticed them?

Aspirin	
Diprosone	
Doryx	
Dovonex	
Doxycycline	
Gabapentin	
Intravenous Gamma Globulin (IVIG)	
Methotrexate	
Methylprednisolone	
Monocycline	
Oral Calcitriol	
Penicillamine	
Plaquenil	
Prednisolone	
Prednisone	
Quinacrine	
Topical antibiotics	
Vitamin B-12	
Other Med 1	
Other Med 2	
Other Med 3	
Other Med 4	
Other Med 5	

82. V. Treatment for Rombergs cont.: Medications Used (page 7 of 13)

1. If there are or were any side affects, please list them:

Aspirin	
Diprosone	
Doryx	
Dovonex	
Doxycycline	
Gabapentin	
Intravenous Gamma Globulin (IVIG)	
Methotrexate	
Methylprednisolone	
Monocycline	
Oral Calcitriol	
Penicillamine	
Plaquenil	
Prednisolone	
Prednisone	
Quinacrine	

Topical antibiotics	
Vitamin B-12	
Other Med 1	
Other Med 2	
Other Med 3	
Other Med 4	
Other Med 5	

83. V. Treatment for Rombergs cont.: Medications Used (page 8 of 13)

1. If there are or were side affects, how debilitating are or were they?

Aspirin	
Diprosone	
Doryx	
Dovonex	
Doxycycline	
Gabapentin	
Intravenous Gamma Globulin (IVIG)	
Methotrexate	
Methylprednisolone	
Monocycline	
Oral Calcitriol	
Penicillamine	
Plaquenil	
Prednisolone	
Prednisone	
Quinacrine	
Topical antibiotics	
Vitamin B-12	
Other Med 1	
Other Med 2	
Other Med 3	
Other Med 4	
Other Med 5	

84. V. Treatment for Rombergs cont.: Medications Used (page 9 of 13)

1. If any testing was advised while on this medication, please list these tests:

Aspirin	
Diprosone	
Doryx	
Dovonex	
Doxycycline	
Gabapentin	
Intravenous Gamma Globulin (IVIG)	

Methotrexate	
Methylprednisolone	
Monocycline	
Oral Calcitriol	
Penicillamine	
Plaquenil	
Prednisolone	
Prednisone	
Quinacrine	
Topical antibiotics	
Vitamin B-12	
Other Med 1	
Other Med 2	
Other Med 3	
Other Med 4	
Other Med 5	

85. V. Treatment for Rombergs cont.: Medications Used (page 10 of 13)

1. If the medication was stopped, please explain why it was stopped:

Aspirin	
Diprosone	
Doryx	
Dovonex	
Doxycycline	
Gabapentin	
Intravenous Gamma Globulin (IVIG)	
Methotrexate	
Methylprednisolone	
Monocycline	
Oral Calcitriol	
Penicillamine	
Plaquenil	
Prednisolone	
Prednisone	
Quinacrine	
Topical antibiotics	
Vitamin B-12	
Other Med 1	
Other Med 2	
Other Med 3	
Other Med 4	
Other Med 5	

86. V. Treatment for Rombergs cont.: Medications Used (page 11 of 13)

1. If the medication was stopped, did any of the symptoms return after a period of time?
(**Note:** The Reset option allows you to Undo your selection.)

	Yes	No	Undecided	Reset
Aspirin				
Diprosone				
Doryx				
Dovonex				
Doxycycline				
Gabapentin				
Intravenous Gamma Globulin (IVIG)				
Methotrexate				
Methylprednisolone				
Monocycline				
Oral Calcitriol				
Penicillamine				
Plaquenil				
Prednisolone				
Prednisone				
Quinacrine				
Topical antibiotics				
Vitamin B-12				
Other Med 1				
Other Med 2				
Other Med 3				
Other Med 4				
Other Med 5				

87. V. Treatment for Rombergs cont.: Medications Used (page 12 of 13)

1. Please rate how effective this medication is or was:
(**Note:** The Reset option allows you to Undo your selection.)

	1) No Change	2) Some Improvement	3) Good Improvement	4) Great Improvement	5) Total Improvement	Reset
Aspirin						
Diprosone						
Doryx						
Dovonex						
Doxycycline						
Gabapentin						
Intravenous Gamma Globulin (IVIG)						
Methotrexate						
Methylprednisolone						

Monocycline						
Oral Calcitriol						
Penicillamine						
Plaquenil						
Prednisolone						
Prednisone						
Quinacrine						
Topical antibiotics						
Vitamin B-12						
Other Med 1						
Other Med 2						
Other Med 3						
Other Med 4						
Other Med 5						

88. V. Treatment for Rombergs cont.: Medications Used (page 13 of 13)

1. Do you feel taking this medication was worth the effort?

(**Note:** The Reset option allows you to Undo your selection.)

	Yes	No	Undecided	Reset
Aspirin				
Diprosone				
Doryx				
Dovonex				
Doxycycline				
Gabapentin				
Intravenous Gamma Globulin (IVIG)				
Methotrexate				
Methylprednisolone				
Monocycline				
Oral Calcitriol				
Penicillamine				
Plaquenil				
Prednisolone				
Prednisone				
Quinacrine				
Topical antibiotics				
Vitamin B-12				
Other Med 1				
Other Med 2				
Other Med 3				
Other Med 4				
Other Med 5				

89. V. Treatment for Rombergs cont.: Other Types of Treatments (page 1 of 3)

1. Select any treatments used:

	Acupuncture
	Hormones
	Light therapy
	Massage
	Naturopathic medicine
	Topical vitamin D

2. For "Other" treatments, please enter:

Other Treat 1	
Other Treat 2	
Other Treat 3	
Other Treat 4	
Other Treat 5	

You can add up to five "Other" treatments taken for Rombergs symptoms. Through the rest of this section on treatments, the treatments that you entered would be considered.
As an example, I use a treatment called "Running In Place". I will enter "Running In Place" in the box beside "Other Treat 1". When I answer any questions for "Other Treat 1" I will be referring to "Running In Place". This can be done five times with five different treatments.

Suggestion: If you have more than One "Other" treatment, you may want to make a list to help you to remember these "Other" treatments as you complete the rest of this section on treatments.
Example of a List:
Other Treat 1 = Running In Place
Other Treat 2 = Rowing
Other Treat 3 = Swimming
etc.

90. V. Treatment for Rombergs cont.: Other Types of Treatments (page 2 of 3)

1. How long was this treatment used:

Acupuncture	
Hormones	
Light therapy	
Massage	
Naturopathic medicine	
Topical vitamin D	
Other Treat 1	
Other Treat 2	
Other Treat 3	
Other Treat 4	
Other Treat 5	

2. Please list any side effects with this treatment:

Acupuncture	

Hormones	
Light therapy	
Massage	
Naturopathic medicine	
Topical vitamin D	
Other Treat 1	
Other Treat 2	
Other Treat 3	
Other Treat 4	
Other Treat 5	

91. V. Treatment for Rombergs cont.: Other Types of Treatments (page 3 of 3)

1. When treatment ended, did the symptoms reappear after a period of time:

Note: The Reset option allows you to Undo your selection.

	Yes	No	Undecided	Reset
Acupuncture				
Hormones				
Light therapy				
Massage				
Naturopathic medicine				
Topical vitamin D				
Other Treat 1				
Other Treat 2				
Other Treat 3				
Other Treat 4				
Other Treat 5				

2. Please rate how effective you think this treatment was:

Note: The Reset option allows you to Undo your selection.

	1) No Change	2) Some Improvement	3) Good Improvement	4) Great Improvement	5) Total Improvement	Reset
Acupuncture						
Hormones						
Light therapy						
Massage						
Naturopathic medicine						
Topical vitamin D						
Other Treat 1						
Other Treat 2						
Other Treat 3						
Other Treat 4						
Other Treat 5						

3. Comments for Other Types of Treatments:

92. V. Treatment for Rombergs cont.: Surgery (page 1 of 7)

1. Please select the type of surgery that the affected person has had:

	Artificial implants
	Bone implant
	Eye
	Fat graph
	Fat injections
	Free flap or flap procedure
	Free flap or flap procedure with microvascular surgery
	Injection of artificial material
	Jaw reconstruction
	Nose
	Revision surgery

2. For "Other" surgeries, please enter:

Other Surgery 1	
Other Surgery 2	
Other Surgery 3	
Other Surgery 4	
Other Surgery 5	

You can add up to five "Other" surgeries for Rombergs symptoms. Through the rest of this section on surgeries, the surgeries that you entered would be considered.

As an example, I had a surgery called "My Surgery". I will enter "My Surgery" in the box beside "Other Surgery 1". When I answer any questions for "Other Surgery 1" I will be referring to "My Surgery". This can be done five times with five different surgeries.

Suggestion: If you have more than One "Other" surgery, you may want to make a list to help you to remember these "Other" surgeries as you complete the rest of this section on surgeries.
Example of a List:
Other Surgery 1 = My Surgery
Other Surgery 2 = Second Surgery
Other Surgery 3 = Third Surgery
etc.

93. V. Treatment for Rombergs cont.: Surgery (page 2 of 7)

1. Please select the number of surgeries:

Note: The Reset option allows you to Undo your selection.

	1	2	3	4	5	6	7	8	9	10	More than 10	Reset
Artificial implants												
Bone implant												

Eye												
Fat graph												
Fat injections												
Free flap or flap procedure												
Free flap or flap procedure with microvascular surgery												
Injection of artificial material												
Jaw reconstruction												
Nose												
Revision surgery												
Other Surgery 1												
Other Surgery 2												
Other Surgery 3												
Other Surgery 4												
Other Surgery 5												

94. V. Treatment for Rombergs cont.: Surgery (page 3 of 7)

1. Please enter the number of surgeries if the number of surgeries is more than 10:

	Surgeries more than 10
Artificial implants	
Bone implant	
Eye	
Fat graph	
Fat injections	
Free flap or flap procedure	
Free flap or flap procedure with microvascular surgery	
Injection of artificial material	
Jaw reconstruction	
Nose	
Revision surgery	
Other Surgery 1	
Other Surgery 2	
Other Surgery 3	
Other Surgery 4	
Other Surgery 5	

95. V. Treatment for Rombergs cont.: Surgery (page 4 of 7)

1. Please enter the age of the person when this surgery was performed:
   Note: If more than one of each surgery, please separate the age for each surgery with a comma (i.e.: 24, 28, 30).

Artificial implants	
Bone implant	
Eye	
Fat graph	
Fat injections	
Free flap or flap procedure	
Free flap or flap procedure with microvascular surgery	
Injection of artificial material	
Jaw reconstruction	
Nose	
Revision surgery	
Other Surgery 1	
Other Surgery 2	
Other Surgery 3	
Other Surgery 4	
Other Surgery 5	

96. V. Treatment for Rombergs cont.: Surgery (page 5 of 7)

1. Please provide a brief description of the surgery:

Artificial implants	
Bone implant	
Eye	
Fat graph	
Fat injections	
Free flap or flap procedure	
Free flap or flap procedure with microvascular surgery	
Injection of artificial material	
Jaw reconstruction	
Nose	
Revision surgery	
Other Surgery 1	
Other Surgery 2	
Other Surgery 3	
Other Surgery 4	
Other Surgery 5	

97. V. Treatment for Rombergs cont.: Surgery (page 6 of 7)

1. Please rate the outcome of this surgery:

Note: The Reset option allows you to Undo your selection.

	1) No Change	2) Some Improvement	3) Good Improvement	4) Great Improvement	5) Total Improvement	Reset
Artificial implants						
Bone implant						
Eye						
Fat graph						
Fat injections						
Free flap or flap procedure						
Free flap or flap procedure with microvascular surgery						
Injection of artificial material						
Jaw reconstruction						
Nose						
Revision surgery						
Other Surgery 1						
Other Surgery 2						
Other Surgery 3						
Other Surgery 4						
Other Surgery 5						

98. V. Treatment for Rombergs cont.: Surgery (page 7 of 7)

1. Any suggestions that you would like to pass on:

2. Comments for Surgery:

99. VI. Any Other Affected Family Members

1. Are there any other family members with facial and/or optical asymmetry?

	Yes		No

2. Are there any other family members with neurological symptoms?

	Yes		No

Note: If you answer Yes to either or both of these questions, the following pages will be shown.

100. VI. Any Other Affected Family Members cont.: Describe Family Member

1. Please provide information about this other family member:

Relationship	
Current Age	
Age of onset	

2. Has this person been medically diagnosed with Rombergs?

	Yes		No

3. Is the person facially affected on:

	the Left side
	the Right side
	Both sides
	Not affected

4. Where on the affected person's body do the symptoms also appear:

	the Left side
	the Right side
	Both sides
	Not affected

If more than one other family member is affected, please provide the details in the Comments box below.

5. Comments

Note: If you answered Yes to: "Has this person been medically diagnosed with Rombergs", then the following page will ask more questions about the diagnosis.

101. VI. Any Other Affected Family Members cont.: Diagnostic Information

1. At what age was the affected person diagnosed:

2. Please select the type of specialist who made the diagnosis:

	Acupuncturist
	Dentist
	Dermatologist
	Ear, Nose and Throat
	General Practitioner
	Geneticist
	Neurologist
	Opthamologist
	Plastic Surgeon
	Reconstructive Surgeon
	Rheumatologist

	Other (Please Specify)

3. Please select the procedure used to make the diagnosis:

	ANA (Antinuclear Antibody test)
	Biopsy for bacteria
	Biopsy for sclerotic content
	CAT (computed axial tomography (CAT or CT scan))
	MRI (magnetic resonance imaging)
	Ultrasound
	Visual Diagnosis
	Other (Please Specify)

4. Comments for Diagnostic Information:

102. VI. Any Other Affected Family Members cont.: Comments for facial and/or optical asymmetry

1. Please enter any comments for other family members with facial and/or optical asymmetry:

103. VI. Any Other Affected Family Members cont.: Comments for neurological symptoms

1. Please enter any comments for other family members with neurological symptoms:

104. VII. Miscellaneous Questions (page 1 of 2)

1. Are there any non-Romberg family members who have an autoimmune disorder?

	Yes		No

2. Are there any other family members who have headaches or neurological symptoms limited to one side of the head?

	Yes		No

3. Has the affected person tried any diets (e.g. anti-inflammatory) to help with the Rombergs symptoms?

	Yes		No

Note: If you answer Yes to any of these questions, the following pages will be shown:

105. VII. Miscellaneous Questions cont.: Others with an autoimmune disorder

1. Please select any Autoimmune disorders for non-Romberg family members:

	Addison's disease (adrenal)
	Ankylosing spondylitis
	Autoimmune Thyroid disease
	Arthritis

	Celiac disease
	Chiari Malformation
	Chronic Fatigue Syndrome
	Crohn's disease
	Fibromyalgia
	Goodpasture's Syndrome (lungs, kidneys)
	Graves' disease (thyroid)
	Guillain-Barre Syndrome (nervous system)
	Hashimoto's thyroiditis
	Hughes Syndrome (antiphospholipid)
	Inflammatory bowel disease
	Lupus (SLE)
	Mixed Corrective Tissue disease
	Multiple Sclerosis (MS)
	Polymyalgia Rheumatica (large muscle groups)
	Raynauds Phenomenon
	Scleroderma (skin, intestine, less commonly lung)
	Scleroderma, linear
	Scleroderma, localized
	Sjogren's Syndrome
	Systemic sclerosis
	Temporal Arteritis / Giant Cell Arteritis (arteries of the head and neck)
	Thyroid problems
	Type 1 Diabetes Mellitus
	Ulcerative colitis
	Vitiligo
	Other (please specify)

2. Comments for Others with an autoimmune disorder:

106. VII. Miscellaneous Questions cont.: Others with neurological symptoms

1. Please comment on other family members with neurological symptoms limited to one side of the head:

107. VII. Miscellaneous Questions cont.: Tried any Diets (e.g. anti-inflammatory)

1. Please give a general description of this diet:

2. Please comment on the results of this diet:

108. VII. Miscellaneous Questions (page 2 of 2)

1. Has the affected person seen any improvements of the Rombergs symptoms with lifestyle changes?

	Yes		No

2. Have any health professionals that you have consulted suggested any theories of what they believe may cause Rombergs?

	Yes		No

Note: If you answer Yes to any of these questions, the following pages will be shown:

109. VII. Miscellaneous Questions cont.: Lifestyle Changes

1. What if any life style changes have been helpful:

110. VII. Miscellaneous Questions cont.: Believe May Cause Rombergs

1. Please comment on the health professional's theory for the cause of Rombergs:

111. VIII. Closing Survey

Thank you for taking part in our Romberg's Connection 2009 survey.

1. Any closing comments:

2. This window will close when you click the "Finished" button.

3. If you had any problems, questions or comments concerning this survey, please contact:

Gerri Neal
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