

Thank you so much for spending the time filling this survey! you are making a difference and helping tremendously other patients with RP!

1. Are you

- Female
- Male

2. How old are you?

3. Are you

- White
- African American
- Indian or Alaskan
- Asian
- Hawaiian or Pacific Islander
- Hispanic
- More than once race

4. What is your country of origin?

5. When were you diagnosed with RP?

Date / Time MM DD YYYY

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6. Who diagnosed you?

- Primary care doctor
- Rheumatologist
- ENT
- Other (please specify)

7. How many doctors did you see seeking for a diagnosis before you were diagnosed?

- The first doctor that I saw diagnosed me
- One doctor
- Two doctors
- Three doctors
- More than three

8. Did you go under cartilage biopsy in order to support your diagnosis?

- Yes
- No

9. What were your primary symptoms before diagnosis (please check all that apply)

- Nose pain/pressure
- Nose redness
- Ear pain
- Changes in your voice/hoarseness
- Shortness of breath
- Breathing pain
- Knee pain
- Ankle pain
- Elbow pain
- Wrist pain
- Finger pain
- Knee swelling
- Ankle swelling
- Elbow swelling
- Wrist swelling
- Finger swelling
- Other joint pain (spine, shoulder, mandibular joint, pelvic joints)
- Costochondritis
- Dizziness
- Hearing loss
- Eye inflammation (episcleritis, iritis, corneal ulcer, uveitis)
- Raynaud's (purple color on hands and/or feet with cold exposure)

Other (please specify)

10. Please check all the symptoms you had before and after diagnosis (please check all that apply)

- Nose pain/pressure
- Nose redness
- Ear pain
- Changes in your voice/hoarseness
- Shortness of breath
- Breathing pain
- Knee pain
- Ankle pain
- Elbow pain
- Wrist pain
- Finger pain
- Knee swelling
- Ankle swelling
- Elbow swelling
- Wrist swelling
- Finger swelling
- Other joint pain (spine, shoulder, mandibular joint, pelvic joints)
- Costochondritis
- Dizziness
- Hearing loss
- Eye inflammation (episcleritis, iritis, corneal ulcer, uveitis)
- Raynaud's (purple color on hands and/or feet with cold exposure)

Other (please specify)

11. How many years after you started to have symptoms were you diagnosed with RP?

- less than a year
- 1-3 years
- 3-5 years
- 5-8 years
- 8-10 years
- more than 10 years

12. Did you go to the emergency room due to RP related symptoms before you had a diagnosis?

- Yes
- No

13. How many times did you go to the ER?

- one time
- two times
- three times
- four times
- five times
- more than five times

14. Please check the symptoms that prompt you to go to the ER. Check all that apply

- Shortness of breath
- Chest pain/costochondritis
- Throat pain
- Difficulty swallowing
- Dizziness
- Ear pain
- Nose pain
- Eye pain
- Pain when you breath

Other (please specify)

15. Were you diagnosed with sinusitis before your were diagnosed with RP?

- Yes
- No
- If you answer yes, how long before you were diagnosed with RP

16. Were you diagnosed with asthma before you were diagnosed with RP?

- Yes
- No
- If you answer yes, how long before you were diagnosed with RP?

17. Were you diagnosed with muscular tension dysphonia you were diagnosed with RP?

- Yes
- No
- If you answer yes, how many months/years before you were diagnosed with RP?

18. Were you diagnosed with fibromyalgia before you were diagnosed with RP?

- Yes
- No
- If you answer yes, how many months/years before you were diagnosed with RP?

19. Were you diagnosed with an ear infection before you were diagnosed with RP?

- Yes
- No
- If you answer yes, how many months/years before you were diagnosed with RP?

20. Is there another blood relative member with the confirmed diagnosis of RP?

- Brother
- Sister
- Mother
- Father
- Not applicable
- Other (please specify)

21. Do you have any other autoimmune disease?

- Yes
- No

22. Please check all that apply

- Not applicable
- Rheumatoid arthritis
- Lupus erythematosus
- Vasculitis
- Thyroiditis
- Common variable immunodeficiency
- Other (please specify)

23. Was the other autoimmune disease diagnosed before RP?

- Yes
- No
- How long before you had the diagnosis of RP?

24. Do you notice worsening of your symptoms 24 hours after eating any of the following foods?

- I do not have any worsening of my symptoms related to food
- Gluten
- Soy
- Red meat
- High sugar content food
- High fat content food
- Alcohol
- If more than one food listed above or other food not listed worsen your symptoms please specify here

25. Do you notice worsening of your symptoms 24-48 hours after any of the following?

- Exhausting Physical activity
- Lack of sleep
- Change in weather
- Bronchoscopy
- Surgery
- Piercing
- Airplane travel
- If more than one activity listed above or other not listed worsen your symptoms please specify here

26. Have you had a flare after any of the following infections? (please check all that apply)

- Any infection
- Cold or upper respiratory infection
- Gastroenteritis
- Urinary tract infection
- Strep throat
- Pneumonia
- Other (please specify)

27. Have you had a flare after any of the following situations? (please check all that apply)

- Change in school or Job
- Serious financial difficulties
- Spouse, partner or close friend death
- Move to a new house
- Loss of Job
- Separation or divorce
- Other (please specify)

28. Did you have a flare after pregnancy?

- Yes
- No
- Non applicable
- If you answer yes how long after delivery?

29. Do you notice any change on your symptoms when you get your period?

- Worsening of the symptoms
- Improving of the symptoms
- Not applicable

30. Which medications do you take for RP now?

- Methotrexate
- Cyclophosphamide/Cytoxan
- Azathioprine (Imuran)
- Dapsone
- Prednisone
- Other (please specify)

31. Which medications have you taken in the past for RP before your current regimen?

- Methotrexate
- Cyclophosphamide
- Azathioprine
- Prednisone
- Methotrexate and prednisone
- Cyclophosphamide and prednisone
- Azathioprine and prednisone
- Other (please specify)

32. What is the highest dose of prednisone that you have taken to control your disease?

33. How many flares did you get per month prior to your diagnosis?

- one
- two
- three
- more than three

34. How many flares do you get per month since you started treatment ?

- One
- Two
- Three
- More than three

35. How long does the longest flare you had lasted?

36. Have you been diagnosed with tracheomalacia/weakness/collapse of the trachea?

- Yes
- No
- If you answer yes, have you had a tracheostomy?

37. Have you had any of the following test done?

- Echocardiogram
- Pulmonary function test
- CT scan of the chest
- CT scan of the neck
- Bronchoscopy
- Audiology evaluation
- Ophthalmology evaluation
- Other (please specify)

38. Have you had pneumonia after your diagnosis of RP ?

- Yes
- No
- If you answer yes, how many times?

39. Have you been intubated?

- Yes
- No
- If you answer yes, please specify why (infection/RP/inflammation of your bronchial three)

40. Are you on disability due to RP?

- Yes
- No

41. Why is the reason you have to go on disability?

42. How long after you were diagnosed with RP did you stop working?

43. Have you gone under body piercing before you were diagnosed with RP?

- Yes
- No
- If you answer yes, which body part and how long prior your diagnosis?

44. Do you rely upon alternative medicine/complimentary medicine interventions for management of your disease?

- Yes
- No
- If you answer yes please specify treatment

45. Do you manage your symptoms by adhering to any particular dietary modifications?

- Yes
- No
- If you answer yes please specify

46. Have you smoke?

- Yes
- No

47. How many years have you smoke?

48. How many packs per day?

