

## PATIENT INFORMATION

Whether you are a newly diagnosed patient, significant other or spouse of a patient, or parent of a patient, please, let us help you. We are a MN non-profit 501(c)3 organization and a dedicated group of individuals who have walked 'in your shoes' and now strive to spread awareness about this disease.

The Relapsing Polychondritis Awareness and Support Foundation (RPASF) offers information about the disease, helpful contact information, links to our support groups, as well as information about upcoming autoimmune disease events and fundraisers. We are a patient-founded and patient-driven foundation and we extend a warm welcome to you!



For more information you can find us at:

[www.polychondritis.org](http://www.polychondritis.org)

Our Foundation Facebook page can be found at:

<https://www.facebook.com/polychondritisawarenessandsupportfoundationinc>

## SUPPORT GROUPS

### US Based

<https://www.facebook.com/groups/RPAwarenessandSupport>

### UK based

<https://www.facebook.com/groups/relapsingpolychondritisawareness>

### Netherlands Based

<https://www.facebook.com/groups/relapsingpolychondritisnl>

### Australia Based

Relapsing Polychondritis Awareness and Support Australia

### Pediatric

Pediatric Relapsing Polychondritis

### Yahoo

#### Group1

<http://health.groups.yahoo.com/group/RPolychondritis>

#### Group 2

<http://health.groups.yahoo.com/group/relapsingpolychondritisuk>



@RPASFInc (US)

@RPUK\_official (UK)

### **DONATIONS CAN BE MADE TO:**

RPASF, Inc.  
17310 NE45th St #119  
Redmond, WA 98052

### **OR ONLINE AT:**

[www.polychondritis.org](http://www.polychondritis.org)



# Polychondritis Or Relapsing Polychondritis



**RELAPSING  
POLYCHONDritis**

[www.polychondritis.org](http://www.polychondritis.org)

## WHAT IS RELAPSING POLYCHONDRITIS?

Relapsing Polychondritis is a rare autoimmune disease that can be fatal. This systemic condition with a predilection for cartilage can inflame the trachea, distal airways, blood vessels, the heart, brain, nerves, kidneys, nose, eyes, ears and joints, as well as other areas of the body. If Relapsing Polychondritis is not diagnosed early and treated effectively there can be irreversible damage to the cartilage and similar tissues that can lead to tracheal or bronchial collapse, blindness, and deafness.

## INFORMATION FOR PHYSICIANS AND OTHER HEALTH PROFESSIONALS

- Relapsing Polychondritis should be suspected whenever there is a multisystem presentation of inflammation of the cartilage or proteoglycan rich structures.
- This disease requires a multidisciplinary medical team approach for obtaining baseline status of systems, identifying level of damage if there was a delay in diagnosis, as well as for ongoing subspecialty care. Do not wait until problems arise.
- Each patient's presentation of the disease, areas affected, course of the disease, and response to treatment is different. Vigilance is key for all patients.

## SYMPTOMS

- Shortness of breath, wheezing, dry cough, ankle edema
- Joint pain
- Sore throat, anterior neck pain hoarseness, change in voice
- Edema of extremity at joint or near joint
- Inflammation, redness, swelling or pain in outer (cartilaginous portions) or inner ear, nose, or eyes
- Skin rash
- Vision disturbances
- Tinnitus
- Hearing loss (sudden/unusual)
- Rib pain, sternum pain
- Unsteady gait, long or short term memory difficulties, headache
- Cranial nerve palsy, weakness or sensory disturbances, confusion, psychiatric signs
- Abnormal heart rhythms, chest pain
- General malaise, low grade fever, loss of appetite
- GI disturbances

"...I couldn't believe that I could feel so ill and yet my labs would come back normal." - *Ann*

"...I felt relieved that I was finally given a diagnosis." - *Steph*

"I was told that this was 'in my head' and was sent to a psychiatrist. I felt too sick to even argue with her. Six months later I was diagnosed with RP." - *Sue*

"The ear symptoms showed up last." - *Pete*

"I am fortunate to have a great team helping me." - *C. D.*

"It took me over 6 years and 5 physicians to get my diagnosis. By that time my lungs were damaged." - *D. R.*



**"But you don't look sick."  
"You look well and the labs are okay;  
you are fine. You need to relax."  
"But I feel really ill."**