RRPF-RRP PATIENT REGISTRY

Two of the most important decisions any patient can make is to be with a skilled RRP care team and to be enrolled in the RRPF-RRP Patient Registry. The International Registry is IRB reviewed and HIPAA/GDPR compliant (i.e., secure and safe). This is patient driven data and updatable as new procedures / treatments take place. The registry will greatly assist RRP researchers, who are able to access data via an IRB approval process, as they consider the patient experience crucial to research towards non-surgical treatments and a cure.

Enroll at the Sanford CoRDS Health portal. All subsequent visits are via the patient portal.

RRP Patient Support

Recurrent Respiratory Papillomatosis Foundation
P.O Box 6643
Lawrenceville, NJ 08648-5557

@rrpforg
Closed Private Support Group
@rrpforg

Bill Stern,
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RRPF Affiliations:

√ RRP Task Force
√ National HPV Roundtable
√ National Organization of Rare Disorders

Researchers, please access data request application via the “Download Access Form.”
WHAT IS RRP?
Recurrent Respiratory Papillomatosis (RRP) is a disease in which benign (noncancerous) tumors, caused by human papilloma virus (HPV), grow in the air passages leading from the nose and mouth into the lungs (respiratory tract). Although the tumors can grow anywhere in the respiratory tract, they most commonly grow in the larynx (voice box)—a condition called laryngeal papillomatosis. The papillomas (typically HPV6 or HPV11) may vary in size and can grow at different rates. They often grow back after they have been removed.

JORRP-Juvenile Onset RRP is disease diagnosed typically by the age of 12.
AORRP-Adult onset is disease diagnosed as an adult, and is thought to be acquired differently than JORRP.

IS RRP CONTAGIOUS?
No, RRP is not contagious (although some non-respiratory HPV infections may be).

CAN RRP BECOME MALIGNANT?
While rare, RRP can become malignant, especially when it has spread to the lungs (pulmonary papillomatosis).

HOW IS RRP TREATED?
Current methods of treatments include:

Surgical methods:
- Laser – (KTP, CO2)
- Microdebrider
- Cold Steel

Currently Used Adjunctive therapies:
- Avastin (intra-lesional, systemic - IV)
- Cidofovir (intralesional, systemic - IV)
- Immunotherapy (systemic - IV)

Nutritional Supplements:
- DIM (Diindolylmethane)
- I3C (Indole-3-carbinol)
- Artemisinin
- AHCC (mushroom compound)

Gardasil Vaccine Series
(see clinicaltrials.gov for more info)

RRP Resource Book (for in-depth info)
Recurrent Respiratory Papillomatosis
Paolo Campisi, Editor. Springer, 2018

WAYS TO HELP THE RRP

Join the RRPF Facebook Support Group via rrpf.org
Tag and follow on social media
Facebook: @rrpforg

Conduct a Facebook fundraiser via Network for Good, Recurrent Respiratory Papillomatosis Foundation
Enrollment in the RRPF-RRP Patient Registry: research.sanfordhealth.org/rare-disease-registry

DONATIONS
RRPF.ORG/DONATE

For additional ways to support the RRP Foundation go to: RRPF.ORG

The RRPF is a 501(c)(3) non-profit corporation as determined by the Internal Revenue Service. Fed. ID# 521798693