

Finding My Voice

Recurrent Respiratory Papillomatosis

HPV 6/11

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What is Recurrent Respiratory Papillomatosis (RRP)?

- Recurrent Respiratory Papillomatosis (RRP) is a devastating disease in which papilloma of the airway cause airway obstruction, and can become malignant, resulting in sometimes hundreds of surgical interventions over a lifetime.
- RRP is the most common benign neoplasm in children.
- RRP is most often HPV 6, 11.
- The recent introduction of the 9-valent human papillomavirus vaccine offers hope for prevention of transmission of the virus to neonates.



The Cost of Misdiagnosis/Undiagnosed



Neveah stopped breathing at daycare. She lived, but had a MD realized she had RRP, brain damage could have been avoided. Neveah is also a pulmonary patient.



Tyson stopped breathing the day this picture was taken. He went on life-support for three weeks while awaiting diagnosis. Tyson now has pulmonary RRP that has changed to SCLC. He is a teenager.

Hi, I'm Kim, and I Have RRP. Over 250 surgical interventions since the age of five.



Moms make funny faces with their adult sons



RRP doesn't rob you of being fun!



Using my voice to advocate for RRP

Pulmonary RRP



- ◇ In the lower corner of the image, you will see a pulmonary nodule, biopsy confirmed to be squamous cell papilloma HPV type 11, that has cavitation. Current measurement is 2.6 CM.
- ◇ There are no screening protocols in place to monitor RRP patients for pulmonary disease. We would like RRP to be listed a risk factor for lung cancer.

Male, 29 y/o Pulmonary RRP Case (Used with permission)



- ◆ Note the large pulmonary mass. HPV 11 positive. Currently this male is not a candidate for surgery due to the papilloma location and potential risk to his heart. He is under palliative care. How can we work together to get all Pulmonary RRP classified as a “pre-cancer?”

“Tyson” 17 year old male

Pulmonary RRP that is now malignant. First round of chemo failed and SCLC has now spread to right lung.



RRP spread to the lungs can be deadly. Squamous Cell Lung Cancer shouldn't occur in children, yet it does for RRP (and adults).



Systemic Avastin Case Reports

<https://medicine.duke.edu/node/1110019>

<https://www.ncbi.nlm.nih.gov/pubmed/28657692>

<https://www.enttoday.org/article/systemic-bevacizumab-promising-treatment-resistant-recurrent-respiratory-papillomatosis/>

<https://www.sciencedirect.com/science/article/pii/S0923753419593450>

<https://www.atsjournals.org/doi/full/10.1164/rccm.201702-0279LE>

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4186578/>

<https://www.chop.edu/news/finally-lasting-help-patients-recurrent-respiratory-papillomatosis-rrp>

RRP Research Recent/Ongoing

Safe use of systemic bevacizumab for recurrent papillomatosis in children

<https://www.ncbi.nlm.nih.gov/pubmed/30588638>

Systemic bevacizumab for recurrent respiratory papillomatosis: A national survey.

<https://www.ncbi.nlm.nih.gov/pubmed/28657692>

Safety and clinical activity of PD-L1 blockade in patients with aggressive recurrent respiratory papillomatosis

<https://www.ncbi.nlm.nih.gov/pubmed/31053174>

Pembrolizumab for HPV-associated RRP

<https://clinicaltrials.gov/ct2/show/NCT0263234>

“Murine Papillomavirus as a model for Pulmonary Papillomatosis”. The principal investigator for this study is Dr. Simon Best from Johns Hopkins.

This award is part of our Pulmonary Papillomatosis Research Initiative (http://rrpf.org/RRP_research/PPRI_RFP2018.pdf), which is dedicated to funding research efforts that show promise of improved treatments for pulmonary RRP.

Why the HPV Vaccine Matters to the future of RRP

"This is a world-first finding of evidence that the HPV vaccine has actually prevented recurrent respiratory papillomatosis cases,"
said study author Julia Brotherton, M.D., Ph.D., M.P.H., of the Victorian Cytology Service in Melbourne, Australia, in a news
release.(www.idsociety.org) "It's really exciting that we finally have a way to prevent this terrible disease. It adds to the list of strong
reasons why you as a parent should choose to vaccinate your child."

All new JORRP cases were children born to unvaccinated mothers.

<https://academic.oup.com/jid/article/217/2/208/4596529>

Therapeutic Use of the HPV Vaccine on RRP

- ◇ <https://www.ncbi.nlm.nih.gov/pubmed/30358875>
- ◇ Dr. T. Rosenberg, et al, in the Journal for Infectious Disease 2019, continued the data that has indicated that the use of the HPV vaccine as an adjuvant treatment for RRP did show some benefit in some patients.
- ◇ The RRP Task Force encourages the vaccination of all RRP patients, even if outside the CDC 9-45 age range.

The Faces of RRP

In 2018, the RRPF created a video of 50 RRP Warriors highlighting each surgery count for each warrior. The total exceeded 4000 surgical interventions.



- Kim's Ad

RRP

A lifetime diagnosis.

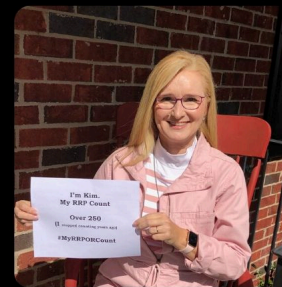
No cure.

No FDA approved pharmaceutical treatment.

Just surgery.

For our pulmonary warriors-the daily worry of “is today the day?”

My story began at the age of five. Over 250 surgeries to date. Pulmonary disease in two lobes.



Have questions? Want to connect?

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National HPV Roundtable Member

Soon To Launch:

RRP Patient Registry (International, HIPAA compliant, IRB reviewed, free to access data-with IRB review)



Finding My Voice, is finding the voice of every RRP Warrior

A seagull is flying in the sky above a sunset over the ocean. The sky is filled with soft, golden light from the setting sun, and the ocean below is dark with gentle waves. The seagull is positioned in the upper center of the frame, flying towards the right.

Believe in the power of
your voice! Be yourself.
Everyone is unique.

Barbra Streisand