

# Recurrent Respiratory Papillomatosis

## NEWSLETTER

Vol. 17 No. 1

An RRP Foundation Publication  
P.O. Box 6643, Lawrenceville, NJ 08648-0643  
[www.rrpf.org](http://www.rrpf.org)

2009 Spring

This issue of the RRP Newsletter is dedicated to  
**Pulmonary Papillomatosis**  
and all those patients and families who have been affected by  
this most devastating form of RRP.

### In Memory

It is with much sadness that we report the passing of **Kathy Blankenship (age 54), Jackie Howard-Townsend (age 19), Sarah Rosenthal (age 14) and Andrew (age 14)** who all tragically died recently from complications associated with RRP. They all battled pulmonary papillomas for a number of years. Our thoughts and prayers are with their families.

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### From the RRP Board and Officers

We are pleased to announce the election of **Jennifer Woo** as the new **RRP Foundation President** and new member of the **RRPF Board**. Special thanks to Marlene Stern and Susan Woo who, after more than 15 years of dedicated service, have decided to step down as RRP President and RRP Board member respectively. Marlene will continue on as Vice President and

Susan will always be available to provide her insights and advice regarding RRP.

The RRP Foundation has been supporting and networking the RRP community for over 15 years and wants to continue to be responsive to the needs of the RRP community. In this regard we would appreciate any comments you may have regarding the RRP. **The best way to let us know what you are thinking is by email to one of the members of the RRP Board, i.e., Chris Neuberger, Maura Burke Weiner, Jennifer Woo or Bill Stern,** (see addresses listed in the section on "Organizational Information".)

We continue to seek additional help in preparing, editing and coordinating the publication of the **RRP Newsletter**. If you are interested in assisting in any way, please contact **Bill Stern** ([bills@rrpf.org](mailto:bills@rrpf.org)).

We hope you find this newsletter issue to be interesting and helpful. **Our best wishes for health and happiness during 2009.**

We are most grateful to all those individuals, medical professionals and corporations who have supported the **RRPF**. Although it is impossible to publish the names of all who contribute, we extend our sincere thanks to everyone who has supported our efforts. Future donations from individuals, professionals or from the business community will be very much appreciated.

**Tax-deductible contributions may be made to:**

RRP Foundation  
P.O. Box 6643  
Lawrenceville, NJ 08648-0643

Do you donate to the **United Way** through your employer? You can select a "Donor Choice" option, which would allow you to direct a donation to the **RRPF** as the 501 (c) (3) of your choice. Since the RRP Foundation is a 501(c) (3) foundation, you may specify the RRP Foundation directly by writing in the name and address of the foundation as follows: RRP Foundation, P. O. Box 6643, Lawrenceville, NJ 08648. If you should need to add our Fed. ID number, it is 521798693. Thank you for your support.

**Donations accepted online from the RRP home page** ([www.rrpf.org](http://www.rrpf.org)) or go directly to <http://www.rrpf.org/donate.htm>

**To physicians and nurses:** Please distribute copies of this newsletter to your RRP patients. Please register with the RRP or provide updated information about your RRP patient population by completing the online Practitioner Questionnaire at: <http://rrpf.org/practitionersurvey.html>.

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### RRPF Publication and Subscription Policy

The **RRPF** produces two publications, the *RRP Newsletter* and the *RRP medical reference service*. The *RRP Newsletter* focuses mainly on the human and clinical aspects of recurrent respiratory papillomatosis and in this regard targets a broad readership, including patients/families, attending physicians/nurses, as well as researchers and the general public seeking to stay in touch with RRP from a clinical perspective. The *RRP medical reference service* serves those in the community seeking a more comprehensive understanding of this disease. Please help us by supporting these publications and other RRP services including patient outreach, support, advocacy and research.

### Subscription Policy and Suggested Minimum Annual Donations:

**RRP Newsletter**  
**Professional/Corporate - \$25**  
**Individual - \$15**

**RRP Newsletter plus Medical Reference Service**  
**Professional/Corporate - \$40**  
**Individual - \$25**

[Note: Issues of the *RRP Newsletter* and *Medical Reference Service* are available on the website.]

## RRP Network News

Our international support network has grown to over 850 respiratory papilloma families. Patients range in age from about 2 to 92 years. Domestically, patients are located in 48 states plus the District of Columbia. Outside the U.S. there are currently Over 70 patients from over 30 countries.

Our thanks to all who have taken the time in the past to fill out the **RRPF Patient/Therapy Survey**. There is now a **comprehensive RRP patient survey available online at <http://www.rrpf.org/rrpf/survey>**. So even if you have already completed a survey, help us to learn more about this disease by **taking a little time to complete the new survey**. Please make sure to alert us of **changed addresses** by checking the “new address” box. There is also a box which we ask you to check if you do or do **not** want your name and address information to be included in the RRPF Patient Directory. We are requesting the information contained in this survey be made available for RRP research. In this regard there is a place in the beginning of the survey to grant permission.

As our support network has grown, we have become more dependent on the patient questionnaires to maintain our mailing list and keep our database of RRP patient information up to date. If you are providing updated information, you need only identify yourself, and answer only those questions where you have new information to provide. For the online survey, just make sure you specify the **patient’s first and last names and their year of birth**.

**Doctors and nurses** treating RRP patients, please take a few minutes to fill out the online **practitioner survey form**.

**You can find the online “patient survey” and “practitioner survey” respectively on the “patient” and “practitioner” page links from the RRPF home page ([www.rrpf.org](http://www.rrpf.org)).**

We ask that patients and practitioners update their survey at least once a year.

### **RRPF Listserve**

The RRPF "listserv" continues as a valuable resource for the RRP community. As of February 2009, the electronic mailing list has over 600 subscribers that include RRP patients, families, caregivers, researchers and healthcare professionals.

To subscribe to the list simply access:

**<http://health.groups.yahoo.com/group/rrpf/>** from your Internet browser.

## RRP Patient Survey Stats

Please complete or update the comprehensive RRP patient survey available online at: <http://www.rrpf.org/rrpf/survey>

**NOTE: If you have received Gardasil vaccinations whether by standard protocol or in any other manner, please indicate this on your survey via the “other” entry category.**

Very preliminary statistics may be viewed at:

<http://www.rrpf.org/rrpf/survey/update/admin/>  
user = “rrpf”

password = “Foundation” (case sensitive)

(Caution: These are “raw” stats and in some cases may not make sense.)

## Patient Support

**[For support of new RRP research initiatives, please see section on “Science and Research Activities”]**

### **Support for RRP patient related travel expenses:**

The RRPF has dedicated a limited amount of funds to provide indirect support of some travel expenses to obtain treatment for RRP families truly in need. We are doing this by providing small grants to two charity travel organizations, i.e., **Miracle Flights for Kids** and **Angel Flights**. If you would like more information please contact:

Geni Mesi  
(801) 358-9351  
e-mail: [mesifam@hotmail.com](mailto:mesifam@hotmail.com)

## Fundraising Activities

Many Thanks to **Ed and Maura Weiner** for once again sponsoring the (7<sup>th</sup> annual)

### **RRP HOCKEY NIGHT**

at the Verizon Center, Washington, D.C.

on Friday, March 27, 2009

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## **Running for RRP**

**RRPF Director, Bill Stern** will run in the 113<sup>th</sup> **Boston Marathon** on Monday April 20, 2009 to raise funds for RRP (and for his own personal insanity).

**Pledges** may be emailed to [marathon@rrpf.org](mailto:marathon@rrpf.org)

**Donations** should be mailed to RRPF, P.O. Box 6643, Lawrenceville, NJ 08648 or may be made online at:

<http://www.rrpf.org/donate.htm>

**100% of proceeds from these fundraising events go to the RRP Foundation**

## RRP Meetings

### Highlights of Sept. 2008 RRP Task Force Meeting

Minutes prepared by Craig Derkay, MD  
summarized below by Bill Stern

The Fall Task Force meeting took place in September, in conjunction with the AAO annual meeting that was held in Chicago on September 22, 2008.

**Teleconferencing future meetings** – Dr. Farrel Buchinsky proposed using the program **Skype** on a laptop to teleconference future meetings so those members unable to attend in person have an opportunity to participate. It should be quite cost effective, providing both audio and video teleconferencing for the cost of a wireless internet connection. This approach was supported by the group attending and the goal is to have this in place for the May meeting in Seattle, Washington.

#### Reviews of ongoing studies -

1. **Serology in RRP (SyRRyP)** - Dr. Buchinsky related his progress (about 25 current patients enrolled) and the steps needed to become either a participating site or to directly enroll patients through his institution. He will distribute google document links to Task Force centers to help them get started.

2. **PDL multi-site study** - Dr. Brigger related the progress of this study with concerns with slow patient enrollment and the possibility of the sites having to return the PDL lasers to Kay Pentax.

3. **RRP Genetics Study** - Dr. Buchinsky gave an update on his progress (310 probands with a goal of around 300 more) and received advice regarding comparisons with a control group for making genetic comparisons.

4. **Celebrex** - Information prepared by Dr. Bettie Steinberg regarding the LIJ and NIH sponsored Celebrex study was distributed. Dr. Seth Pransky, from one of study's participating centers (Children's of San Diego encouraged the group to refer their adult and pediatric patients to regional centers or to contact Dr. Steinberg to become a participating center. Dr. Klein announced that Emory has recently finished submitting the necessary IRB paperwork to begin enrolling patients.

5. **Merck-sponsored Incidence and prevalence study:** Dr. Derkay announced that Merck is working with a private research group to update the national estimates of RRP incidence and prevalence.

#### New business

1. **Artemisinin** - A letter was distributed to the group from the International RRP ISA center and the RRP Foundation (via Michael Green and Bill Stern) requesting that the Task Force publicly recommend that research into the use of Artemisinin and its analogues be moved toward the top of any short list of RRP research initiatives. The group decided to arrange to have Dr. Richard Schlegel address the Task Force on his work with Artemisinin and defer any action to the May 2009 meeting regarding his work in this area. Additionally, Dr. Wiatrak volunteered to try and put Dr. Schlegel in touch with Dr. Tom Broker to review the available data and suggest further applications for translational research involving RRP.

2. **Additional possible adjuvant therapies** - Dr. Brian Wiatrak in a brief presentation to the group discussed two new therapies that could possibly have a future role in treating RRP:

**Pegasy** (a new formulation of interferon alpha that is being widely used to treat Hepatitis C and **cms100** (an anti-smallpox DS DNA experimental drug that is a lipid derivative of Cidofovir and could be administered orally).

3. **HPV sub-typing** - The commercially available Roche Linear array test is now slated for becoming available in 2009.

4. **RRP surgical tools** - There was discussion among the members present regarding innovations in surgical instruments and lasers for use in RRP patients. This included a few "tricks of the trade" with respect to the coblator, flexible CO2 laser, PDL and KTP-PDL lasers.

5. **Therapeutic use of Gardasil** - The pros and cons of administering Gardasil to RRP patients outside of a clinical protocol was discussed and it was decided to try and hold off on this approach until after preliminary data from the SyRRyP study becomes available.

#### Upcoming meetings

1. **RRP Task Force Spring meeting** – In conjunction with the AAO-ASPO meeting in Seattle on Friday May 22, 2009 at the Seattle Marriott Waterfront Hotel. Executive Board Room from 2 PM – 3 PM.

2. **RRP Focus Session 2009** – Possibly to be held in conjunction with the AAO spring ASPO meeting in Seattle on May 23 and sponsored by the International RRP ISA center. Arrangements for this meeting are not firm.

3. Dr. Seth Pransky announced his intention to put on "**Endoscopy Day**" in San Diego the Friday prior to the AAO\_HNS 2009 meeting in October with a section theme of updates on RRP treatment.

## Adjunct Therapy Update

In addition to surgical management, a number of therapies are being used by RRP patients to help slow regrowth of papillomas. Here is a list of some of the more widely used adjunct treatments as reported to the RRP (in descending order of number of users):

**I3C/DIM** – Nutritional supplements, largest number of users reporting; easy to take on your own; virtually no side effects; about 60% efficacy. (See following section for more details)

**Interferon** – One of the earliest adjunct treatments for RRP; administered via subcutaneous injections usually 3-5 times/week; often accompanied by flu-like symptoms (occasionally elevated liver enzymes); about 60% efficacy but very few complete remissions.

**Cidofovir** – Powerful anti-viral that has been used (off-label) to effectively treat RRP patients since the late 1990s; administered intravesically mostly in conjunction with surgical excision of papillomas but sometimes without removing the papillomas; some side effects have been reported, including post-op edema, throat soreness and a case of webbing; in high doses it can be toxic to the kidneys and there are indications that it can be carcinogenic in rats; reported efficacy is close to 80%; please read cautionary guidelines from the RRP Task Force before using ([http://www.rpf.org/RRP\\_Task\\_Cidofovir.html](http://www.rpf.org/RRP_Task_Cidofovir.html)).

**MMR/Mumps Vaccine** – Has been used (off-label) by Nigel Pashley, MD to treat RRP patients for over a decade;

## How to get I3C or DIM and how much to take

intralesional injections to sites where papilloma have been removed; few side effects reported with most common being some post-op edema; patient/parent reports indicate about 65% efficacy.

**Celebrex** (Cox-2 inhibitor) – Is a commonly used anti-inflammatory currently being used experimentally to treat RRP patients as part of a multi-center clinical trial being coordinated by Long Island Jewish Medical Center. For more details see the article in the section on **Science and Research Activites** in this newsletter.

**Artemisinin** – Is a (plant extract) drug approved for treating Malaria. Dr. Richard Schlegel, from Georgetown, has shown via research studies, a therapeutic impact of artemisinin on papilloma in dogs. (In addition to inducing apoptosis, artemisinin derivatives show some anti-angiogenic activity.) Researchers from the University of Washington are working with Artemisinin as a cancer therapy (for more info see <http://www.uwnews.org/article.asp?articleID=44335>)

Between the RRP Listserve and the RRP ISA Forum, there have been approx. 12 positive anecdotal reports from RRP patients using Artemisinin plus derivatives (ART). Dr. Robert Bastian is now conducting a pilot study using Artemisinin as part of a treatment protocol for RRP patients (see the article in the section on **Science and Research Activites** in this newsletter for more details).

The RRP ISA Center has posted some anecdotal dosing suggestions at:

[http://www.rrpwebsite.org/index.cfm/fuseaction/category.display/category\\_ID/348%5C/](http://www.rrpwebsite.org/index.cfm/fuseaction/category.display/category_ID/348%5C/)

**Avastin** – Is a anti-angiogenesis drug used extensively for ophthalmological applications. Dr. Steven Zeitels from the Voice Center at Massachusetts General Hospital, has been conducting a pilot study involving a number of adult RRP patients combining KTP laser removal of papilloma with intra-lesional injections of Avastin. Early results thus far from Dr. Zeitels and a number of his patients have been quite positive. For more details see the article in the section on **Science and Research Activites** in this newsletter and the **RRPF Listserve** archived posts on Avastin.

### Experimental therapies for which the RRP has very little or no documented patient supplied statistics:

HPV Vaccines including Gardasil

Omega-3 Fatty Acids (Fish Oil)

Cimetidine (Tagamet)

Tarceva (for pulmonary, possibly in combination with Celebrex – see <http://www.bio-medicine.org/biology-news/Combination-therapy-shows-promising-results-in-patients-with-advanced-lung-cancer-3627-1/>)

### I3C/DIM

For background information about the impact of indole-3-carbinol (I3C) / Diinolymethane (DIM) on estrogen metabolism and how this subsequently may act to reduce the growth rate of respiratory papillomas, see the *RRP Newsletters* Fall 93 through Fall 94 and Fall 97, Winter 2000-01 for **DIM**, as well as Bradlow et al., 1996 *J. of Endocrinology* **150**, S259-S265; Newfield et al., 1993, *Anticancer Research* **13**, 337-342.

Phytosorb-DIM™ products containing DIM are available from:

BioResponse

L.L.C. at P.O. Box 288

Boulder, CO 80306

Email at [etzeligs@bio-response.com](mailto:etzeligs@bio-response.com)

877-312-5777 or 303-447-3841 - phone; 303-938-8003 - Fax

Credit card orders (Visa and MasterCard) are being accepted

**Internet ordering:** You can now order the Phytosorb products on the Internet at [www.hormonalbalance.com](http://www.hormonalbalance.com). If you send an email to [support@hormonalbalance.com](mailto:support@hormonalbalance.com) they will set an account up for you in the Phytosorb group to purchase on the Internet. There are additional discounts available when you order on line. Please let BioResponse know if you are an existing customer. If you are a new customer, please send them your phone number so they can contact you to set up an account.

Phytosorb-DIM is available in two forms:

1. Phytosorb-DIM Capsules; 150 mg; 60 capsules per bottle or 75 mg; 90 capsules per bottle.

Estimated dosages; BioResponse recommends that individuals with RRP choose a daily dose which is close to 8 mg/kg/day (see BioResponse article on next page for recent updates on their Phytosorb-DIM product). A typical man weighing 70-85 kg (where kg. = 2.2 lbs.) would take approximately 500 to 700 mg per day. A typical woman weighing 60-70 kg would take from 450 to 600 mg per day.

2. Phytosorb-DIM Flavored\* Sprinkles; 9.0 grams per bottle with directions indicating dosage per teaspoon.

At the suggested dosing below, 1 bottle should provide a two-to-four month supply for a child about 50 lbs.

\* Available in orange as well as chocolate flavors.

Shipping : US priority mail , UPS, or global priority. Call or e-mail for product pricing

BioResponse has reformulated its "Sprinkles". These new formulations require lesser amounts of the powder to deliver the increased suggested dose. Detailed dosing instructions are included on the bottle label. Guidelines for children are as follows:

Weight in Pounds (lbs)

Amount of Sprinkles in Teaspoons (tsp.) up to 25 lbs. 1/8 tsp 25 to 50 lbs 1/4 tsp, 50 to 75 lbs 3/8 tsp, 75 to 100 lbs 1/2 tsp 100 to 150 lbs 3/4 tsp

**(Please consult your doctor, especially for young children.)**

Special Note: Unlike I3C, Phytosorb-DIM does not require activation by stomach acid. Individuals who use antacids or H2 blockers like Zantac can take Phytosorb-DIM.

For scientific inquiries contact Michael Zeligs, MD at [zeligsmd@bio-response.com](mailto:zeligsmd@bio-response.com)

I3C may be purchased from:

**Theranaturals Inc.**

PO. Box 344

Orem UT 84059-0344

e-mail: [theranat@fiber.net](mailto:theranat@fiber.net)

(801)224-8893 - Telephone; (801) 226-6064 - Fax  
 www.theranaturals.com  
 [Credit card orders may be placed by phone, fax, web or e-mail]

Theranaturals I3C and B3IM product pricing as of Oct 2006  
 (includes shipping via USPS priority mail within US):  
 1 bottle - 100 capsules @ 100 mg - \$20  
 3 bottles - 100 capsules @ 100 mg - \$55  
 add \$16.00 to above prices for Fed X shipping.

Approximate dosing information is based on preliminary results of Dr. Leon Bradlow's estrogen metabolism studies, as follows:

Estimated dosages - Adults approx. 400 mg, Children (under 50 lbs.) 100 - 200 mg

### Additional I3C Notes

The digestive process is **important** to properly break down I3C (see *RRP Newsletter* - Spring 94 ). In this regard, try to avoid taking antacids and it is probably best to take I3C at mealtime. It has also been suggested that taking ascorbic acid (vitamin C) along with I3C will produce ascorbigen, which some investigators (Preobrazhenskaya, et al., 1993, *Food Chemistry*, 48,48-52) speculate may be an even more important anti-carcinogen than I3C.

If you do not appear to be responding to I3C, you might want to give DIM a try.

Finally, no matter what product one is using the best way to extend the shelf life is to keep them in a cool dark location such as the refrigerator.

### I3C/DIM reported side effects:

- Occasional gastro-intestinal upset
- A couple of instances of dizziness
- A few anecdotal instances of lowered bone density

### Pulmonary Papillomatosis Case Histories

It is estimated that the incidence of papillomas in the lungs in RRP patients is about 5%, yet complications associated with pulmonary papillomas account for about 95% of the mortality among RRP patients. Both surgical and adjunctive approaches have generally been ineffective in controlling papillomas in the lungs. Furthermore, usually pulmonary papillomas will undergo malignant transformation to lung cancer.

For many with RRP the disease ranges from an occasional inconvenience to a significant annoyance, however, for those with pulmonary papillomas it often presents as a constant battle and many times a life threatening struggle.

The following are personal/parental accounts of some pulmonary papilloma patients.

#### **BOBBY, 12-YEAR-OLD-MALE**

Bobby is 12 years old and was diagnosed with RRP as an infant. He underwent a tracheostomy at the age of 10 months.

At 2 years old, Bobby experienced an anoxic incident on the way home from the hospital following one of his routine surgeries, and underwent extensive deep suctioning after the incident. Two months later, he was diagnosed with pulmonary papillomatosis.

Bobby was subsequently treated with interferon and cidofovir. He also received intravenous cidofovir for a year and a half. His pulmonary papillomas grew slowly over the next several years. Bobby's doctor advised withdrawing cidofovir treatment after five years due to concerns regarding prolonged use in the absence of evidence of positive outcome.

A year ago, Bobby started MMR treatments in Denver. He has since had numerous surgeries with MMR treatment, as well as reconstructive surgery on his upper airway. For several months, his trach was removed, but had to be reinserted after his lower airway collapsed.

Bobby's last CT scan, in May 2008, showed massive papilloma growth in both lungs. His most recent two surgeries revealed a papilloma-free airway. Currently, Bobby is able to cough up his own secretions without suctioning, and his lungs sound strong and clear. He does not have any major breathing complications. His physician has performed surgery to open up his lower airway, and treating it with mitomycin.

#### **DARNELL, 42-YEAR-OLD FEMALE**

Darnell is a 42-year-old mother of two. She was diagnosed with RRP at the age of 18 months. Darnell underwent a tracheostomy two weeks after her diagnosis, and retained the trach until she was 4 years old. Surgical excision of papillomas occurred using cold steel.

From age 12-16, she received routine laser surgery treatment for her RRP. Her disease regressed as she entered adulthood. In 1994, she took the homeopathic remedy thuj and reported going a year without any surgery. That same year, she underwent colposcopy for HPV infection.

In 2002, Darnell received 2 shots of intralesional cidofovir. Three years later, in 2005, she suffered a lung abscess, but there was no evidence of pulmonary papillomatosis at that time.

In May 2008, Darnell noticed a sharp pain in her left side, which she described as similar to the symptoms she experienced when she had her lung abscess. A CT scan revealed a mass in the same spot where her lung abscess had occurred, plus other masses in both lungs. A July 2008 PET scan tested positive for benign squamous papilloma in both lungs. This finding was confirmed shortly thereafter by guided CT biopsy.

Over the next several months, further CT scans every three months showed no further pulmonary papilloma growth, though Darnell reported a new symptom of burning in her chest.

In October 2008, Darnell began a regimen of Celebrex, Gardasil, and artemisinin. Her pulmonologist advised against cancer treatments because there was no evidence of cancer in her airway, and the side effects of cancer treatment would be undesirable.

Darnell also reports seeing a natural health doctor, who has advised her to take N-acetyl L-cysteine and DHEA-5 supplements. Darnell is borderline diabetic, and has also

eliminated sugar from her diet. Her most recent papilloma surgery was November 14.

## **MALENA'S STORY**

My name is Malena Hamilton. I am 32 years old. I am working toward my Master's Degree in Rehabilitation Counseling, working full-time as a Rehabilitation Counselor of the Blind and Visually Impaired, and have a wonderful family.

I was first diagnosed with laryngeal papilloma when I was 2 years old. I have had over 150 surgeries for this since that time. The papilloma started out on my larynx as a child. They spread under my larynx as a young adult. In my mid 20's they began growing in my trachea. I had to have a tracheostomy put in because of the scar tissue from the multiple laser surgeries about 8 years ago.

This year I began to have strange chest pain. It felt like a sharp pain and a dull ache that occurred over different parts of my lungs for varying lengths of time. It would come and go. I asked my ENT to do a chest CT to make sure that I didn't have papilloma growing in my lungs. My ENT did not believe I had much of a chance because the papilloma had not begun to grow in my bronchial area. I asked him to do it anyway. In May of 2008 I found out I had lung papilloma. Both lungs had soft tissue masses and cystic areas. There was one large mass in my upper right lobe that was approximately 4 x 2.6 cm. The pulmonologist was concerned about this mass because of the chance for papilloma to spontaneously change to cancer. I went through 2 biopsies that were inconclusive due to the location of the tumor. I had a PET scan done. It showed up as a neoplasm. In June 2008 I decided to go ahead and have a thoracotomy biopsy and possible upper right lobectomy. The surgeon confirmed that the large mass was squamous cell carcinoma. He also found two other cancer tumors in the middle and lower lobes which were both also confirmed as squamous cell carcinoma. I had my tissue samples sent to Memorial Sloan-Kettering Cancer Center for a second opinion. They confirmed that all three specimens were cancer.

The surgeon left the large mass because it was his opinion that I have Stage IV disease and that systemic chemotherapy would be needed. After consulting with an Oncologist at Sloan-Kettering they confirmed that there was no way to determine whether the two smaller tumors were primary or locally metastatic because squamous cell carcinoma all looks the same and they would have started the same type of therapy.

I began Taxol/Carboplatin chemotherapy in July 2008. The hope is to stop the spread of the disease, but as my doctor has explained I will never be cancer free. I have gone through 4 treatments. My doctor has put me on a break because there has been no change in the tumor size. He feels I have gotten the most out of this combination. Now I just wait and see. Future treatment will determine how fast it begins to grow again. Unfortunately now my voice is worse than it has been since I was young. I fear that while I have controlled the growth of the cancer, the papillomas are now growing stronger. I have surgery scheduled soon and I am hesitant to know the results.

When I was young I had known about the possible risks of this disease spreading to my lungs, although had been told that it was a rare occurrence. It had always been something I thought about in the back of my mind, but ignored so that I could move on with life. There have been several years in my life that I could actually forget that I was in a constant battle with this disease. I even allowed myself to have a family knowing the risks. I sit here typing now with my bald head wondering what I could have done differently to prevent this. I know the partying and high amount of stress in college caused my disease to begin growing out of control again in my twenties. I know that I did smoke for a couple years in college. I know I didn't avoid smoky bars and restaurants as I got older. I don't keep my tracheostomy properly moisturized and I don't wear a filter. The very things that have allowed me to move beyond my chronic lifelong disease...to feel "normal"...could they have caused this progression? I know it hasn't helped. There is no reason to try to place blame on this tragedy because the end result will not change. I have lung papilloma and I have lung cancer. The only thing that matters is figuring out where I go from here.

I have done as much research as humanly possible about my options. I have talked to several hospitals and doctors throughout the United States. They all say the same thing. That it's really rare and there is no known effective treatment for this progression. My only option is to "treat and see". I have to weigh the benefits of the treatment against the side effects. I am so scared. Scared of suffering...scared for my son and husband who will be left behind...scared about an uncertain future. But...no matter how scared I am I keep moving. I keep working at my job and raising my son. The truth is that I will never know the cause of the progression of my disease or what the future holds for me. I do know that I am not ready to give up. Life is too precious and I have too much to live for. I have been fighting for life...a good life...since the age of 2. This is just one more hurdle.

## **Jaquelynn Howard-Townsend 5/10/89-2/6/09**

Jackie had over 350 surgeries to remove RRP from her airway. Her first surgery was at 12 months of age, at 24 months of age she got her tracheostomy. She never let the trache stop her from enjoying life to the fullest. She knew sign language and could whisper in a low voice. At 6 years old she had part of her lung removed to get rid of the RRP that had gone into that lobe and became infected. She was determined to fight this disease. Jackie had been on all of the past and current treatments known throughout the world. She passed away from squamous cell cancer of the lung with the underlying cause of RRP, the cancer was everywhere even in her lymphnodes. She has left a huge whole in our hearts but she taught us many things about; life, patience, love, determination, strength, faith, and gratitude. She was clearly on this earth to give to others and she did.

## **Kim Howard**

## Science & Research Activities

### Support for promising RRP research

The RRP Foundation is asking the RRP research community to **apply for support of RRP related research projects**. These studies may involve (but are not limited to): **Immunology and RRP, genetics and RRP, RRP quality of life/public health issues and new treatment approaches for RRP**.

We are particularly interested in studies that may lead to new approaches to treat pulmonary papillomas and are introducing a new research support program:

**Recurrent Respiratory Papillomatosis Foundation  
PULMONARY PAPILLOMATOSIS RESEARCH  
INITIATIVE (PPRI)  
Young Investigator Research Grant**

#### Goals:

1. To foster research into pulmonary papillomatosis by providing funds to young investigators in the field of pulmonology, otolaryngology, and thoracic surgery
2. To fund a pilot project which may lead to long-term research support from other granting agencies.

Interested researchers should address inquiries and proposals to:

**Jennifer Woo, RRPF President and Director**

[jennifer.woo@post.harvard.edu](mailto:jennifer.woo@post.harvard.edu)

or

**Bill Stern, RRPF Director**

[bills@rrpf.org](mailto:bills@rrpf.org)

#### RRP Foundation

P.O. Box 6643

Lawrenceville, NJ 08648-0643

**PPRI Grant Application will be available shortly for download as a link from [rrpf.org](http://rrpf.org)**

### NEW RRP/HPV RESEARCH STUDIES

#### HPV Drug Discovery Research

By Tom Broker, PhD. and Louise Chow, PhD.

Tom Broker and Louise Chose have continued to develop a raft culture system that uses primary human skin cells in vitro. In earlier studies Drs Broker and Chow demonstrated that HPV replication (including RRP) in the raft culture system is quite similar to human in vivo viral replication. They have further developed this system to test a variety of drugs for their therapeutic potential against existing HPV infection as well as their ability to prevent new infection.

The current focus is to test drugs that are naturally based including I3C, DIM, artemisinin/artesunate. This research is very much work in progress. Some encouraging preliminary results show that some agents have the potential to block the HPV infection cycle while some others potentially kill infected

cells. More details are available in Wang et al., *Genes and Development*, January 2009. It is hoped that this research will lead to more effective treatments for HPV and RRP along with a better understanding of their mechanisms of action.

#### Anti-Angiogenesis Therapy for treating RRP

by

Bill Stern

[based on a phone interview with Steven Zeitels, MD, extensive input from one of his RRP patients, Mike, plus other informative RRPF Listserve posts]

I recently received a phone call from an RRP patient of Dr. Steven Zeitels. I was amazed at his voice quality without any hint of hoarseness. Mike told me that he was a classical singer who was diagnosed with adult onset RRP on the vocal cords two years ago. After much consulting and researching, he decided to undergo treatment with Dr. Zeitels in Boston (Voice Center at Massachusetts General Hospital: aka MGH).

After each of two surgeries using KTP laser, Mike's voice quality was excellent but then deteriorated to the point where normal speaking was difficult, as the papilloma reappeared within 2-3 months. Dr. Zeitels then suggested trying a drug that has been used extensively for Ophthalmological applications, **Avastin**. During the next procedure lesions were removed, as before with the KTP, but this time Avastin was injected in the vocal cord region. The next three months were notably different – there was no voice deterioration and no new papillomas had appeared, only residual left from the previous surgery. His last surgery was in August 2008. Avastin injections were continued every few months through December 2008. As of March 2009, this classical singer/ RRP patient is once again singing professionally. In Mike's own words, "In fact my voice is as good as ever! It's as if I've never been afflicted by RRP. In addition to Mike, approximately 10 other RRP patients of Dr. Zeitels have had similar positive experiences with this treatment approach combining Avastin and KTP laser, several who have reported on this website.

So why should this treatment approach work? In a recent conversation with Dr. Zeitels, he attributed much of the credit to Dr. Judah Folkman, who pioneered research into the angiogenesis dependency of cancer tumors. Folkman hypothesized that if a tumor could be prevented from growing its own blood supply, it would die. Dr. Zeitels has applied this concept to the treatment of RRP and other laryngeal tumors (including vocal cord cancer). In this regard, he worked closely with Dr. Richard Rox Anderson, who was one of first surgeons to use laser light of specific wavelengths to target blood vessels (photoangiolytic lasers). Dr. Zeitels initially used the 585 nm pulsed dye laser (PDL), but for the past 4 years he is using the green-light 532 nm pulsed KTP (potassium titanyl phosphate) laser. He explained that it has technical advantages which include: much better control of the laser parameters resulting in less trauma to the tissue being treated, solid state electronics which make it more reliable, delivery through a smaller fiber which improves its use in the outpatient setting – overall it provides enhanced precision. Dr Zeitels feels the main

advantages these lasers provide, as compared to CO2 laser, are greater precision, lack of heat trauma injury and superiority in preserving normal vocal cord tissue. Furthermore, the procedures can often be done in the office using only local anesthesia.

Although the pulsed-KTP laser appears to be very effective at removing active papilloma growths in a minimally invasive way while preserving voice quality, there still is the issue of how to suppress new growth after surgery. To address this, Dr. Zeitels decided to try the angiogenesis inhibitor Avastin (also called Bevacizumab) in a pilot study involving informed-consent RRP patient volunteers. Some side effects have been reported with systemic use of Avastin in large doses, however, in these cases much smaller doses were injected intralesionally in the vocal cord region. This pilot investigation demonstrating the value of Avastin in the management of RRP of the larynx is completed and will be presented at the American Laryngological Association meeting in May, and a new trial will be initiated in the near future. Avastin is not considered a "cure" for RRP, but it may provide a way to significantly reduce the need for potentially damaging surgeries to the vocal cords so RRP patients can maintain optimal function until a better treatment is available.

#### **Artemisinin – A Pilot Study**

By Robert Bastian, MD

[Ed. Note: *In this article Dr. Bastian goes beyond the Artemisinin study by delving into the motivation, expectations, concerns and caveats associated with pilot studies of potential RRP treatments.*]

Our interest in Artemisinin and related compounds for treatment of RRP derives partly from the overarching desire to find treatment better than serial surgical removal. A second but also important impetus is the need to find out if the major benefit reported with its use by some can be demonstrated more generally. In short, is this an exciting new direction, or a rabbit trail?

The ideal first step in the process of validating (or not) any new treatment would be to document regression of visible lesions in the absence of any other variable, such as surgery, that might also explain the regression. (Many laryngologists across the country who have worked with large RRP populations know that "advanced technique" surgery can yield superior voice results, much longer intervals between surgeries, etc. If those laryngologists also use some sort of adjuvant treatment such as Cidofovir, I-3-C, etc. etc. then is it that surgery or the adjuvant treatment that is responsible, or in what proportion?) The strategy for a limited "pilot" might be to obtain highly magnified, textbook-quality photographs of the larynx, then administer Artemisinin and relatives, and then obtain post-treatment photographs of equivalent magnification and resolution. It seems to me that this might be a reasonable "pilot" even when the proposed mechanism of action would not seem to be directed at regression (e.g. Gardasil, Avastin, etc.).

If regression is shown, this does not prove anything, due to the need for a placebo-controlled study, large numbers to overcome the variable behavior of RRP over time, and reproducibility in other clinics. Yet, compelling before and after images made

available prudently to, for example, the RRP Taskforce, might attract attention and interest by researchers with the resources to do robust placebo-controlled study of the particular approach.

If regression were not shown in a few persons, compelling images showing this would again not prove anything definitive, but might stimulate a louder and possibly justified chorus of skepticism—even that these compounds should be put aside and other treatment ideas be moved higher on the list. Alternatively, in the case of Artemisinin compounds, a negative result might call for an adjustment in treatment strategy such as to increase dose or shorten the dosing interval. (Recommendations for use of this medication seem to vary all over the place.) With a negative regression result, still others might propose that the question should change away from "do these compounds single-handedly cause RRP lesions to regress?" and move onward to "Might these compounds be directed at prolongation of surgery interval rather than to regression?" The latter question, by the way, is a much more challenging and complex question to answer, because of the added variables involved. Without very large numbers and single-surgeon studies, it is extremely difficult to tease out the natural variability of the disease process, the effect of surgical meticulousness, the tendency of the virus to be slowly cleared in some over time, etc.

It is entirely appropriate to criticize the above sort of purely observational (no measurement) regression question for a long list of reasons, only a few of which have been mentioned above. Still, this sort of exploratory approach would seem the fastest way to sort through new ideas. The alternative, a more robust and "scientific" approach, adds dramatically to the time and resources required to provoke even a "tickle" of interest.

It is of course evident that a simple, straightforward search for an agent that causes regression will likely happen most rapidly in the "special circumstances" population of RRP patients: those with a short surgery interval, high-risk HPV subtype, tracheo-bronchial involvement, moderate or severe dysplasia accompanying papillomas, the occasional passionately committed person, and so forth. Such individuals are often good candidates because the seriousness of their circumstance and/or personality type has motivated them to seek alternatives, to work through a strenuous informed consent process, and to return for followup that might permit meaningful observation on the part of their physician.

I mentioned above that no clear dosing regimen seems to have emerged. So at this time we have simply chosen to start at 7 mg per kilogram per day for Artemisinin, and 4 mg per kilogram per day for artesunate. We tend to "round up" in that the medications tend to come in 50 mg increments. Hence, for an 80 kg (~180 pound) man, we might use 150 mg of Artemisinin plus 100 mg of artesunate before breakfast, lunch, dinner, and bedtime, for a total of 600 mg of Artemisinin and 400 mg of artesunate per day. Currently there are 9 adult RRP patients participating in this study.

## UPDATES of ONGOING RRP/HPV RESEARCH STUDIES

### Efficacy of Celebrex in Treating RRP By Bettie Steinberg, PhD.

The study of celecoxib (Celebrex) as an adjunct to surgery for the treatment of moderate to severe recurrent respiratory papillomatosis is progressing. We have enrolled 9 patients at LII to date, and are continuing to enroll more. Three of the participating sites are almost ready as well, and should be actively enrolling patients by January. These are: Eastern Virginia Medical Center in Norfolk, VA; University of Alabama, Birmingham; and University of Iowa, Iowa City. The University of California at San Francisco is just slightly behind, and should be enrolling patients by spring.

We have continued to follow the three patients who participated in the original pilot study, all of whom achieved remission while on the study. One patient remains in remission. The other two have had tiny recurrences of papilloma about a year after finishing the study, but nothing like the severe disease they previously had that required surgery every 2-3 months with lots of papilloma growth. The recurrences have been so minor that the patients have not chosen to take celecoxib now that they have finished the study.

As a reminder to interested patients and parents, this is a double-blind, placebo controlled study. Each participant will participate for 2 1/2 years. In addition to surgery to remove the papillomas, 6 months after enrollment patients will be given Celebrex for one year and a placebo for 1 year, the order in which they are taken will be determined randomly.

To be eligible, patients must be at least 2 years old and must have had at least 3 surgeries in the past year to remove papillomas or have tracheal/bronchial disease. To learn more, contact Ginny Mullooly, RN at 718-470-7974. Travel reimbursement to a participating site will be provided.

### Research Study Using PDL and DIM to treat RRP

By Mary Zoccoli, M.D. Boston University Medical Center

Our trial here at Boston Medical Center is utilizing the 585nm pulsed dye laser (PDL) to remove recurrent respiratory papillomas coupled with a 3 month oral administration of the dietary supplement diindolymethane (DIM) and an additional 12 month follow-up with no treatment.

The PDL can remove lesions while causing less damage to the mucosa and submucosal tissues than the carbon dioxide laser by targeting the small vessels that supply blood to the papillomas. This serves to eliminate scarring thereby preserving voice quality. DIM's ability to slow papilloma growth is believed to be a result of the hormonal sensitivity of these lesions; most specifically estrogen. There are two pathways for the metabolism of estrogen (16 alpha-hydroxylation versus 2-hydroxylation). DIM has been shown to directly decrease the amount of 16 alpha-hydroxysterone (which has been shown to promote growth of these lesions) and increase the production of 2-hydroxyestron (which has an antiproliferative effect i.e. the "better" pathway).

Prior to treatment, we assess this ratio in the child as a baseline from urine metabolites and monitor throughout treatment. This is the first study to attack the papillomas via concomitant microvascular and hormonal mechanisms in hopes

to develop a new, voice-preserving and long term effective method of managing laryngeal RRP in children.

Enrollment criteria:

- 1) Be between the ages of 10-21
- 2) Any number of prior surgeries requiring papilloma removal and at the time of enrollment must require surgery

For those interested in enrolling they can contact me at [mary.zoccoli@bmc.org](mailto:mary.zoccoli@bmc.org) or Dr. Pieter Noordzij ([pieter.noordzij@bmc.org](mailto:pieter.noordzij@bmc.org)).

### A Multicenter Randomized Controlled Trial of the Pulsed Dye Laser for Children with Severe Juvenile Onset Recurrent Respiratory Papillomatosis

Enrollment is still taking place for a multicenter randomized clinical trial to determine whether the promise provided by the initial investigations of the pulsed dye laser can be realized in terms of truly improving quality of life in children affected with RRP.

The 585 nm Pulsed Dye laser and 532 nm pulsed KTP lasers are "angiolytic" lasers that allows treatment of JRRP without injury or scar to important structures such as the vocal cords and the anterior commissure. Preliminary studies using the pulsed dye laser in children in addition to standard surgical removal of papillomas have shown promising results (Hartnick et al., Arch Otolaryngol Head Neck Surg. 2007 Feb;133(2):127-30.). Therefore a more complete removal with less scarring and a potentially better voice should be possible. Ultimately, we hope to significantly decrease the number of surgeries needed by achieving a more complete removal of papillomas. **Close study of the vocal quality after conventional therapy versus after pulsed dye laser therapy is one of the chief outcome measures of this study.**

We are seeking patients and parents interested in becoming part of this promising study. Eligible children will be aged 12 or under and have severe RRP requiring four or more surgical procedure per year.

Each child will randomly receive either standard surgical excision or standard surgical excision plus the removal of remaining papillomas with the pulsed dye laser. No child will be treated with placebo. The same procedure will be performed for each surgery needed during the course of a year. We will be monitoring each child's voice with a questionnaire before and after each surgery. We will be looking to see if the pulsed dye laser proves to decrease the number of needed surgeries and provide an improved voice between surgeries.

The study involves four major medical centers and will be based out of the Massachusetts Eye and Ear Infirmary in Boston, MA under the direction of Dr. Christopher Hartnick. Additional sites where children can be seen, enrolled, and treated will be located in Cincinnati, OH; Birmingham AL; and San Diego CA.

If you have any questions or are interested in more information regarding enrollment please contact Dr. Hartnick at 617-573-4206 or [Christopher.Hartnick@meei.harvard.edu](mailto:Christopher.Hartnick@meei.harvard.edu).

### Genetic Study of RRP

Dr. Farrel Buchinsky, a pediatric otolaryngologist, in Pittsburgh, Pennsylvania at Allegheny General Hospital is studying genetic susceptibility to RRP (both adult-onset and juvenile-onset). He is backed by a research grant from the National Institutes of Health (NIH), the state-of-the-art

capabilities of the Center for Genomic Sciences (CGS) at the Allegheny-Singer Research Institute and by the collective clinical experience of the doctors of the RRP Task Force. Two patient-support groups are assisting in publicizing the study: the Recurrent Respiratory Papillomatosis Foundation in Lawrenceville, NJ and the International RRP Information, Support and Advocacy (ISA) Center based in Bellingham, WA.

For more info contact:

Center for Genomic Sciences  
Allegheny-Singer Research Institute  
320 East North Avenue  
Pittsburgh, PA 15212  
Phone: 412- 567-7870  
Email: [fjbuch@gmail.com](mailto:fjbuch@gmail.com)

### **RRP Serology**

Principal investigator, Farrel Buchinsky, MD, is coordinating a multi-center study to investigate whether the immune systems of RRP patients are able to make antibodies in response to HPV infections.

For more information please contact Dr. Buchinsky at: 412-567-7870 or [fjbuch@gmail.com](mailto:fjbuch@gmail.com).

### **Possible Future Study**

**Efficacy of MMR for treating RRP** – The RRP Foundation would like to **encourage and support** a controlled, multi-center trial to scientifically test the efficacy of MMR as a treatment for RRP. The basis for this proposal is the excellent results reported by Dr. Nigel Pashley, who has treated a number of RRP patients with mumps and/or MMR. Backing up Dr. Pashley’s positive results are anecdotal patient/parent responses reported to the RRPF, which are indicating very positive patient responses to MMR/mumps. Given the lack of safe effective treatments for RRP, the RRPF believes this type of anecdotal evidence warrants more attention from RRP practitioners. A first step could be a coordinated multi-center off-label treatment approach.

**For Information about Recurrent Respiratory Papillomatosis  
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