

R e c u r r e n t R e s p i r a t o r y P a p i l l o m a t o s i s

NEWSLETTER

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P.O. Box 6643, Lawrenceville, NJ 08648-0643
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2011 Spring

In memory we dedicate this Newsletter

We are deeply saddened to report the passing of two members of our network during this past year. Ayrie from Minnesota, was only four years old when his life was cut tragically short due to complications from obstructing respiratory papillomas. Malena Lynn Hamilton developed RRP as a two-year-old child and endured well over 100 surgeries. As an adult she developed tracheal papilloma and extensive scar tissue which required a tracheostomy. Subsequently, Malena developed pulmonary RRP and lung cancer. Despite her own battles she remained very supportive of others in the RRP community until her untimely death last November at the age of 36.

Our thoughts and prayers are with the families of Ayrie and Malena.

Contents

- ❑ Opening Comments - p1
- ❑ RRPF Organization Information - p2
- ❑ RRPF Publication and Subscription Policy - p2
- ❑ RRP Network News & Listserv - p3
- ❑ RRP Patient Survey Stats - p3
- ❑ Patient Support – p3
- ❑ Fundraising – p3
- ❑ RRP Meetings – p4-5
- Adjunct Therapy Update – p5-6
- ❑ RRP Patient Case History – p7-8
- ❑ Science & Research Activities – p9-11
- Pulmonary Papilloma Research Initiative – p9
- Ongoing Studies – p9-11
- ❑ Support/Subscriber Info. – p12

From the RRPF Board and Officers

The RRP Foundation has been supporting and networking the RRP community for over 17 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 RRPF. **The best way to let us know what you are thinking is by email to one of the members of the RRPF Board, i.e., Chris Neuberger, Maura Burke Weiner, Jennifer Woo or Bill Stern,** (see addresses listed in the section on “Organizational Information”).

We are very pleased to announce that Caroline Lang has offered her services to the **RRPF** by taking on the task of **Newsletter Coordinator**. Thank you Caroline!

We hope you find this newsletter issue to be interesting and helpful. **Our best wishes for health and happiness during the rest of 2011.**

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 RRPF home page
(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 RRPF 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 about 900 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 to fill out the **RRP patient survey available online at <http://www.rrpf.org/rrpf/survey>**.

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**. Please make sure to alert us of **changed addresses** by checking the "new address" box. There is also a box that we ask you to check if you do or do **not** want your name and address information to be included in the RRP 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.

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 RRP home page (www.rrpf.org).

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

RRPF Listserve

The RRP "listserv" continues as a valuable resource for the RRP community. As of January 2011, the electronic mailing list has over 750 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 R. Tula
435-773-1627
e-mail: mesifam@hotmail.com

Fundraising Activities

Many Thanks to **Maurissa and Brianna Weiner** who raised nearly \$1000 for the RRP Foundation by asking for donations to the RRPF in lieu of gifts for their respective "sweet 16" celebrations.

Running for RRP

RRPF Director, Bill Stern ran in the 35th **Marine Corp. Marathon** on Sunday 31 October 2010 to raise funds for RRP (and for his own personal insanity). Thanks to all who contributed.

100% of proceeds from these fundraising events go to the RRP Foundation support and research activities

RRP Meetings

Summaries of 2010 RRP Task Force Meetings

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

Highlights of RRP Task Force meeting in conjunction with the COSM/ASPO meeting in Las Vegas, Nevada on April 29, 2010

Update of ongoing research studies

- * HPV serology in RRP patients: Dr. Buchinsky reported on the data-collection over 18 months involving 71 RRP patients (8 of which have received the quadrivalent HPV vaccine). For some patients HPV sub-types are known as well. Merck's immunoassay will be applied to these samples to seek to identify anti-HPV 6 and 11 antibody levels (with hope towards identifying a subset of patients who may therapeutically benefit from administration of the vaccine). Further discussion focused on the possibility of potentially avoiding distal spread by early administration of prophylactic vaccine.
- * Genetics Study: Dr. Buchinsky is continuing to enroll RRP patients.
- * Celebrex study: Drs. Pransky and Derkay reported that centers are still recruiting subjects for this adult/pediatric prospective, randomized cross-over study with a yearly investigators meeting scheduled for June 4-5 in NYC.
- * Canadian Registry: Dr. Derkay updated the group on Dr. Campisi's progress in securing participation of all the Canadian academic centers. The project will now go forward with prospective data gathering to see what the effect of a differential uptake of the Gardasil vaccine throughout Canada has on future incidence and prevalence of RRP.
- * Survey on limitations of activity due to RRP: Debra Rosenberg reported to the group on her efforts to design a quality of life (QOL) survey to measure the effect of RRP on family and child activities.
- * Male indication for Gardasil: Dr. Derkay informed the group of Merck's intention to improve communication to patients and providers regarding the potential benefits of male vaccination in light of recent FDA approval. It was noted that, to date, this has been given to less than 1% of age-eligible boys.
- * Propranolol: Dr. Hartnick has proposed an open-label single arm multi-center study of Propranolol for treatment of RRP.
- * Avastin: The group noted observations of benefit in adults with RRP in the recent article published by Dr. Steven Zeitels.
- * Artemisinin: Drs. Inglis and Pransky noted their limited experience (positive and negative) in Seattle and San Diego. Dr. Bastian was not available to discuss his limited pilot study. Difficulties in obtaining "pure" (uniform concentrations) drug was noted to be a barrier to use.
- * EGFR research at Hopkins: Dr. Tunkel informed the group of the research efforts at Johns Hopkins by Sofia Pike's lab on differential expression of EGFR in RRP. The group is also working on a therapeutic DNA vaccine and is utilizing an animal model for RRP using nude mice.

RRP Education Activities

- * ASPO: Dr. Lowy is the Bluestone Lecturer discussing the potential benefits and implications of the commercially available HPV vaccines for patients with RRP.

- * International HPV conference in Montreal July 2010: Dr. Campisi will make a single 15 minute presentation after efforts to coordinate a larger session with Tom Broker and the Patient Advocacy groups fell through.
- * 4th World Voice Conference Seoul, South Korea, September 2010: Drs. Derkay, Campisi, Dekkers and de Alarcon will be presenting a panel on RRP covering surgical treatment, epidemiology, adjuvant therapies and vaccines.
- * ESPO: There will be both a panel discussion on RRP and a European RRP Task Force meeting (Dr. Desmond Nunez from Bristol organizing).
- * AAO-HNS Boston September 2010: Dr. Wiatrak and Derkay's Instructional course was accepted as was Dr. Hartnick's Mini-seminar on Treatment of RRP.

Highlights of meeting in conjunction with the annual AAO meeting Boston held on September 25, 2010

Review of current research studies in RRP

- * Genetics: Dr. Buchinsky updated the group on his ongoing efforts to add patients to this study. He currently has 455 cases with a goal of 540. Interested in continuing to add cases from participating institutions as well as adding new overseas sites including India and China.
- * HPV antibodies: Still awaiting analysis of antibody levels.
- * Celebrex: Dr. Derkay reported that the study is ongoing, enrolling adults and children. Investigators are blinded so nothing to report on results yet.
- * Propranolol and Avastin: Dr. Hartnick relayed that the results have not been overwhelming. He has encountered some issues with the IRB regarding dosage.
- * HPV-11/E6 DNA vaccine: Mouse study at Hopkins showing some promise as a model. HPV 16 therapeutic vaccine being tested in women with vulvar dysplasia with a 50% reduction.
- * Registry updates: Dr. Campisi reported that he has captured virtually all pediatric RRP cases in Canada and will follow incidence and prevalence throughout the country (keeping in mind different uptakes of quadrivalent vaccine). Registries are also being planned in France, Australia and India.
- * Artemisinin: Dr. Bastian presented his results at the mini-seminar showing no visible evidence of response in his small series of patients. He cautioned that this was a small sample who were not being treated simultaneously with surgery and that he could not determine the potency of the product since it is unregulated by the FDA.
- * Other: Discussion ensued about including QOL and voice outcomes in future studies to go along with measures of surgical intervals and severity scores.

New business

- * RRP grant for research: Speaking to the group over Skype, Bill Stern from the RRP re-iterated the appeal sent out by email for RRP projects to study Pulmonary RRP with an offer of up to \$50,000 available. There was much discussion around the table regarding this. Various suggestions included multi-center trials of IV Cidofovir or pegylated Interferon; Canine or Rabbit in vivo studies of promising agents; studies of aggressive RRP (not necessarily involving the lung papilloma); concentrating a study at one site (St. Jude's?); and performing a targeted, comprehensive survey on adults and children with pulmonary RRP.
- * Patients like me: Dr. Buchinsky informed the group about an

organization that works specifically with patients with “orphan diseases”. They are based in Boston.

Brief Summary of RRP Task Force Spring 2011 meeting April 28th in Chicago just prior to the COSM/ASPO meeting.

There were 16 members attending in person and two called in via Skype.

Current research: Preliminary results from the Merck sponsored **HPV serology** study (SyRRup) includes 70 RRP patients with some interesting implications for selected use of the vaccine for therapeutic purposes. The **RRP genetics** study is continuing to recruit RRP patients (and their parents/family). so far 480 cases have been analyzed with the goal of recruiting at least another 60. There has been some progress in identifying some candidate genes. The **celebrex** trial now involves 39 patients from 5 centers. There appears to be some complete responders, but since the study is double-blind, it cannot be revealed which group(s) the responders are from at this time. No other clinical trials were discussed. One doctor (outside of MGH) mentioned that he has had some success with **Avastin** in two adults and one child, he noted that he also used the KTP laser. However, one preliminary publication appears to show no significant benefit. (See more about the successful use of Avastin at MGH on page 9 of this newsletter issue.) It was noted that there is a published case study of a child with aggressive tracheal RRP benefiting by treatment with **inhaled cidofovir**. Dr. Ian Frazier has been conducting a very early stage limited trial of a **therapeutic HPV vaccine** being used to treat some RRP cases in Australia and China (very preliminary results appear to show no benefit in existing RRP patients).

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 RRPF (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 intralesionally 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).

MMR/Mumps Vaccine – Has been used (off-label) by Nigel Pashley, MD to treat RRP patients for over a decade; 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 Activities** 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 RRPF 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 Activities** in this newsletter for more details).

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

<http://www.rpfwebsite.org/index.cfm/category/389/artemisinin-usage-wmd-guidelines.cfm>

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 intralesional 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 Activities** in this newsletter and the **RRPF Listserve** archived posts on Avastin.

Experimental therapies for which the RRPF 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

Update on BioResponse DIM and Phytosorb Orange Sprinkles for 2011 By Michael Zeligs, MD

We are pleased to continue to offer highly absorbable, microencapsulated DIM (Diindolylmethane) to the RRP community. We continue to produce and study our supplement products, BioResponse DIM (in capsules) and Phytosorb Orange Sprinkles a taste masked flavored powder for those individuals unable to swallow capsules. BioResponse DIM and Phytosorb Orange Sprinkles contain pure DIM which has proven to be very stable.

These supplement products should **not** be refrigerated. We specify that they be stored "in a cool dry place" which means in

a closed kitchen cabinet that is not in direct sunlight. Based on stability testing the shelf life is now over 2 years. The supplement use of BioResponse DIM is proceeding with continued evidence of safety during studies that have lasted from 6 months to 1 year in adults.

BioResponse DIM is the only microencapsulated DIM on the market for proven absorption. Plain DIM is highly insoluble and poorly absorbed.

We are happy to respond to your questions either through our website: www.bioresponse.com or toll-free during business hours (9-5 MST) at 1-877-312-5777. Please let us know you are members of the RRP community when you contact us. Wishing you a healthy 2011, BioResponse, LLC.

For background information about the impact of indole-3-carbinol (I3C) / Diindolymethane (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.

How to get I3C or DIM and how much to take

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
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. If you send an email to 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.

BioResponse-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 Orange 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.

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

zeligsm@bio-response.com

I3C may be purchased from:

Theranaturals Inc.

PO. Box 344

Orem UT 84059-0344

e-mail: 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

RRP Patient Case History

Focus Feature on RRP Patient, Caroline Lang

By Caroline Lang

Many of you reading this newsletter will probably remember me from the RRP listserve, on which, from time to time, I've been quite active. My name is Caroline Lang and like you or your loved one, I have RRP. I am now 34 years old and had my first surgery, of what would be many more to follow, at six years old. I believe I've had about 136 surgeries on my larynx and trachea since then, but as you know, it sometimes gets difficult to keep track. That is not counting other surgeries or procedures I've had that are also related to the RRP either, which I think would put me much closer to about 150. Although my RRP, did effect my life (and my family's) from the time I had my very first symptoms, I always tried my hardest not to let it stand in my way from living my life to the fullest I could. I managed to finish nursing school and really enjoyed taking care of my patients. It really fulfilled me being able to reach out to help others in this way. I think because of my own challenges with dealing with RRP, it enabled me to relate to them in a way I never would have been able to otherwise. I understood that when a person's health and wellness was disrupted, (no matter what the cause), that a person isn't just effected physically, but emotionally, socially, and spiritually, as well. It was my endeavor to try and assist patients in a holistic manner that attended to all their unique, individual needs. For many years, I worked taking care of persons in the community, from babies to older adults, (though mostly children), who had chronic multiple disabilities. Working with these special individuals really gave me a lot of insight. It helped me to understand a lot better what really was important in life. After my husband and I started dating, we knew very quickly that we wanted to marry and start a family. My husband was already a single father then to a five-year-old son, his ex-wife having passed away just before his son turned three. Since then, we have added two more boys to our family. The boys are now 13, 7, and 3 and they are a handful, but very, very, loved. Our family has dealt with the same challenges that most deal with, but a few more were added to our list over the years.

In October 2006 we became aware of several changes occurring within my lungs. Although a secondary infection of methicillin-resistant staphylococcus aureus was identified soon after and treated, it wasn't until March 2008 (and after a pregnancy that was very complicated by very aggressive RRP necessitating an early delivery) that it was established that I had pulmonary papillomatosis. I had begun some preliminary research (and didn't find very much back then) into pulmonary papillomatosis and wasn't at all encouraged by my findings. It seemed that basically it was a death sentence despite whatever interventions I might take. I came across one report of a woman treated with IV cidofovir that seemed to stabilize her disease. Since that was all that I had to go on, (and also the only thing any of my doctors came up with), that was what I started. I had done the injections to the vocal cords for several years, but the IV cidofovir was much more difficult to tolerate given the toxicities involved. I managed with that for eight months, after I had a mediport placed in my chest for the treatment in April 2008. I was literally coughing up pieces of tumor at times (as much as an inch long), and blood at times, but the growth on my vocal cords had completely stopped while I was on it. I had

begun to get suspicious though. As I did a little more research, I found that there were quite a few cases where people with pulmonary papillomatosis developed lung cancer and I was worried about it. I finally got them to test one of the tumor pieces I'd been coughing up and the results came back inconclusive on whether it was cancer or not. I ended up getting pneumonia again (I'd had several episodes since my initial lung problems had turned up that were MRSA related) and my CT showed a lot of new growth in my right lower lobe. I went in for another bronchoscopy in March 2009 and the results were highly suspicious for cancer. When I started coughing up gross amounts of blood the next week, the pulmonologist told me bluntly that in his opinion, I was going to need the right lower lobe removed and that I may have several lymph nodes involved as well that will need to be removed. I had an emergent lobectomy done the next day in Detroit. I went go into the details of that recovery in this newsletter, other than to say it wasn't easy, and was quite complicated. I ended up needing another surgery to save my life about 12 days later. It was a very scary time.

The pathology from my lobectomy confirmed a combination of papilloma and squamous cell cancer. In the beginning, I don't think I really took in the full ramifications of what this meant to me. I knew lung cancer was bad, but I just didn't know how *bad*. After getting out of the hospital, I threw myself into research – research on lung cancer, research on pulmonary papilloma, and research on cancer linked to HPV. I gathered dozens and dozens of articles, from medical journals all over the world. I clung to anything that looked remotely helpful, since the general prognosis that I was finding on both conditions was so incredibly poor and discouraging. It's been a whirlwind of trying different treatments to see what – if anything, would help. I've tried (in order- more or less) artemisinin derivatives, more IV cidofovir, subcutaneous interferon, high frequency radiowave ablation therapy (RFA), embolization of my bronchial artery in the left lower lobe, artemisinin derivatives, chemotherapy (carboplatin and taxol), IV Avastin, more RFA, IV Avastin, RFA again, more chemotherapy (Nexavar), and most recently another embolization procedure this time on the bronchial artery in what is now the right lower lobe (used to be the medial lobe before the lobectomy). Of these interventions, I feel that the RFA has been quite successful (so far) in killing the cancerous tumors that have been treated with it. I also feel the IV Avastin really slowed down the growth of the papilloma and most likely the cancer. I went from having surgeries on my vocal cords at an average of 4 or more a year to 15 months between surgeries on the vocal cords and 13 months between surgeries on the trachea. Unfortunately, I still had the continued growth in the lungs, necessitating the repeated RFA procedures, those areas all confirmed cancerous. Of late, (I've been off the IV Avastin since the fall) I've needed much more frequent surgical interventions on my airways. The latest pathology results show that my right main stem bronchus, trachea, and vocal cords all are now showing high-grade dysplasia – just a step down from cancer.

All of this treatment has taken a toll on me, as have the symptoms of my disease itself. I'm not sure if it was from growths on my trachea on bronchi, or from pneumonia, or both, but I've had to deal with horrible coughing fits all last fall, winter, and going into the spring that were occurring several times a day. I would cough and cough, triggering my gag reflex and then I would be throwing up. My sides would ache from all the coughing and the only thing that would settle the episodes down were taking narcotics that would sedate me. I also had

been dealing with chronic pain from my arthritis. I had come to believe that one of the things that had contributed to the progression of my RRP disease was the use of immunosuppressive steroids to control my RA (and my pregnancies). While the steroid dose I was on was a low one, I was completely dependent on it. I tried multiple times to go off of it following my lobectomy, and each time, was overwhelmed with severe joint pain to a point where I was completely crippled and so miserable that life wouldn't have even been worth living in that shape. I was forced to make a horrible decision: take a drug that I know will ease my pain and suffering and make life livable again, but also one that will likely make my RRP and cancer worsen, ultimately shortening my life and disabling the fight I was trying to make for my life, or not take it and have more of a fighting chance to "beat" my cancer, but be so overwhelmed with pain that I had no quality of life at all. The choice was Quantity vs. Quality. I chose quality. I don't regret it. I still have had to deal with joint pain and am limited with my treatment options, but it hasn't gotten to the severity it was without the steroids, so I'm grateful for that much.

One thing that has kept me going through all of this is counting my blessings – what I'm grateful for, each and everyday. There are so many things we take for granted that we can't even begin to realize – that is one thing I learned from working with my special needs patients. I'm grateful for each and everyday and count it as a blessing. I know that I have already defied the odds. I've had 5 separate cancerous tumors in 4 different lobes over the last 2 years and I'm still here. I know I'm blessed. I count my children as one of my greatest blessings – they definitely give me the drive to keep on fighting. I want to be here for them as long as I possibly can be. I used to have a lot of fears regarding how much time I had left, wondering if my kids would remember me, and how they would fare without me around. Through my faith, (I'm a Christian), I've been able to let go of so many of those fears and find peace in the midst of crises after crises. Sometimes, even I'm amazed by it. I pray a lot. I know there are a lot of other people praying for me too. I trust that God has a plan and purpose for me, and that whatever His plan is, I know that it is better than any I could've come up with, and that it will ultimately prevail, and because I can trust that I'm able to calm down and find the serenity. I'd be completely lost without my faith. I don't know how I'd hang on through all of this otherwise; thankfully, I don't have to go through this alone. I have God on my side, my family, my friends, and also this community of others fighting RRP disease. I know that my story is different from yours. All of our stories are different, but they are the same in at least one way – we're all fighting RRP and we're all here for each other through support groups like the RPPF and the RRP-ISA. I only found these networks just before my lobectomy, just over two years ago. I would especially like to thank the RPPF for their generous donation to help me financially with meeting the high cost of my COBRA payment. I've been unable to work since February 2009 and my husband has to help out at home with our young children, since that also is sometimes too much for me to do alone. Without the donations made by the RPPF and other individuals and charities, I simply wouldn't have any health insurance right now, when I have needed it more than ever. I'm exceedingly grateful. When the RPPF asked me to help out with the Newsletter, as a Coordinator, in return, I was thrilled at the opportunity to do so. I can only hope that I will be able to do justice to what needs to be done.

I'm so glad to have had the contact with other patients, especially ones going through similar experiences to mine.

Malena Hamilton was the first person I started corresponding with through the listserve. Like me, she was dealing with lung cancer caused by RRP. She had a young son, just as I had young children. We were the same age. We both worked in human service related fields. I related with her on so many different levels. Her death last year was disheartening, except that I know she is no longer suffering, but has found the peace she so greatly deserves and that gives me comfort. I miss her dearly. As for me, I'm still fighting. Recently, I had a molecular analysis done on my newest cancerous tumor and from that they were able to come up with a list of targeted treatments that they believe will be the most helpful in treating my cancer (and hopefully my RRP too, though time will tell on that). I started the number one recommendation, Nexavar, for a few days and ran into complications with bleeding around my RFA site that may or may not have been related to the drug. My latest embolization will, hopefully, prevent future episodes of bleeding in that lobe. I will be starting up again next week with the Nexavar and am hoping for the very best. I know that is the hope of each and everyone of you reading this also, and that gives me so much strength, so thank you and I promise I will keep you posted.

You can visit my carepage for updates at www.carepages.com/CarolineLang. I've been writing there for over two years, since just after my lobectomy. I'm hoping to use the material there in addition to much more to put together a book. I want this book to serve multi purposes and audiences. First off, I think it should be known that it would be a reflection of my faith, because as I've said before, without that, I wouldn't be here at all, anyway. Secondly, I would like for it to be a resource and guide for patients with RRP and their families. Thirdly, I would like to advocate for the prevention and treatment of all HPV related diseases, especially concerning getting as much of the appropriate population as is possible vaccinated with Gardasil. Finally, I would hope that it might be inspirational to anyone facing adversity in his or her life. I have a lot of work, yet to do on it. The most challenging aspect will be the research and technical components, but I think that such material (even if it ends up getting published as a separate work) would be of tremendous value to patients and even doctors. The title of my main work will be: *While I Breathe, I Hope*. I will continue to keep busy as a mother to three young boys. For those of you who are parents, you know that is enough of a job right there. It is my hope that at some point I will be able to return to (paid) work. If my book is successful, (and my health would cooperate) I would love to visit schools to educate and promote vaccination of Gardasil to young persons, especially. Right now, I take things one day at a time and am always grateful for each day. Whatever it may bring, good or bad, it is still another day, and for that alone, I will be grateful.

Science & Research Activities

Support for promising RRP research

The RRP Foundation is pleased to announce the first **PULMONARY PAPILLOMATOSIS RESEARCH INITIATIVE (PPRI)** grant award.

It has been awarded to:

Sofia Lyford-Pike, MD

Senior Resident in Otolaryngology
Department of Otolaryngology/Head and Neck Surgery
Johns Hopkins University School of Medicine

Research Topic:

Therapeutic DNA Vaccine for Recurrent Respiratory Papillomatosis

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UPDATES of ONGOING RRP/HPV RESEARCH STUDIES

Avastin and Angiolytic KTP-Laser Treatment of Recurrent Respiratory Papillomatosis of the Larynx: A Decade of Advances that Evolved from the Past Two Centuries

By

Steven M. Zeitels, M.D., F.A.C.S. and Eugene B. Casey, Professor of Laryngeal Surgery

Introduction

Laryngeal recurrent respiratory papillomatosis (RRP) has been recognized as an omnitemporal clinical problem since the origin of Laryngology as a specialty 150 years ago. Nineteenth century treatment was comprised of mirror-guided cold-instrument removal of the lesions. [1, 2] Remarkably, Franklin Hooper [3] of the Massachusetts General Hospital (MGH) noted in 1882 that *“papilloma is the most frequent morbid growth found in the larynx”* and that *“the vascularity of the growth (papillomatosis) is perhaps the most important factor in determining the rapidity of its reappearance”*. This brilliant observation 130 years ago is the foundation of our current 21st century state-of-the-art treatment at the MGH Voice Center (<http://www.massgeneral.org/voicecenter/>).

In the early 20th century, direct laryngoscopic treatment was initiated in the office but migrated to the operating room due to the enhanced precision provided by improved surgical instrumentation and anesthesia. In the latter 20th century, the introduction of the surgical microscope [4] and the carbon dioxide (CO₂) laser [5-7] greatly enhanced management by improving visualization and controlling minor bleeding. It is likely that CO₂ laser treatment of laryngeal papillomatosis was the first example of removing soft tissue from a human with a laser in the history of surgery. Although the CO₂ laser was initially a groundbreaking laser technology (1970s-1990s) including selected benign lesions [8], the angiolytic lasers such as the pulsed-KTP laser eclipsed other lasers during the past

decade (for those who could afford it) for treating phonatory mucosa. [9-11]

Anderson [12, 13], conceived selective photothermolysis for the treatment of benign vascular malformations of the skin (e.g. port wine stains) by using specialized lasers that target destruction of the abnormal small blood vessels (angiolysis) in the vascular skin lesions. From our close collaboration with Anderson, we initially perfected angiolytic pulsed-dye (yellow light) laser treatment of laryngeal papillomatosis [14, 15] and subsequently abandoned the PDL for the much more effective pulsed-KTP (green light) laser. [9-11]

Both of these angiolytic lasers target small blood vessels within papilloma lesions, however, it is the effectiveness and versatility of pulsed-KTP laser [10, 16] that has revolutionized the current treatment of RRP. We also created office-based angiolytic laser treatment with topical local anesthesia [9, 10, 15] a decade ago so that presently, *it is rare for our adult RRP patients to require ongoing treatment in the operating room with general anesthesia.*

However, regardless of the surgical technique to remove the papillomatosis lesions, no surgical intervention has provided reliable long-term resolution of the disease. Therefore, it is logical to employ an adjuvant medical management to diminish the severity and frequency of recurrence. We do not use Cidofovir because of our observations of patients from other institutions who developed permanent severe hoarseness and vocal cord scarring as well as our great concern for patients developing subsequent malignant transformation to cancer.

Consequently, we sought a different pharmacological prevention strategy consistent with our angiolytic-laser treatment philosophy. This resulted in our identifying Avastin (Bevacizumab) as an effective drug known to inhibit angiogenic blood vessel growth. Based on great success and safety in injecting Avastin for a number of eye disorders, in 2009 we introduced local laryngeal injection of Avastin as a breakthrough prevention treatment to enhance the results of pulsed-KTP laser removal of laryngeal RRP. [17] Sublesional intramucosal injection of an antiangiogenic drug such as Avastin at the time of angiolytic laser removal of laryngeal papillomatosis is a clinically-attractive model because it is based on more than 2 decades of basic science and clinical research funded by the National Institute of Health and the National Cancer Institute as well as extensive private sector investment by the pharmaceutical industry.

After the encouraging and dramatic results that were noted in all 10 patients of the initial RRP study published in 2009 [17], we followed with a new prospective open-label clinical trial investigation, which was done in 2010 with FDA Investigational New Drug approval. The details of this study will be presented in the near future. However, great success was again noted including the fact that all patients had substantial improvement while 25% did not require laser treatment in the vocal cords that were treated with Avastin by the end of the study. This exciting finding was consistent with the experience of Mike Niemann who remains free of RRP for 2.5 years. Mr. Niemann was interviewed by Bill Stern for the Spring 2009 issue of the **RRP newsletter** and his RRP treatment 2 years ago was featured on Good Morning America (<http://abcnews.go.com/GMA/OnCall/opera-singers-lost-voice-returns-devastating-diagnosis/story?id=9364014>) and ABC World News (<http://abcnews.go.com/WN/story?id=7700000&page=1>).

It is important for patients and their families to know that while the 2010 Avastin/KTP-laser investigation was being done, the MGH Voice Center group could not treat other patients outside the clinical trial. We have now been cleared to treat all adult patients and selected pediatric patients due to the great clinical success of Avastin and the KTP laser over the past 2 years, and the fact that we have had no complications associated with greater than 200 Avastin injections.

Summary

Our greater than two-year experience with combined use of Avastin and KTP laser treatment for laryngeal papillomatosis has been an outstanding success. We have achieved our best results to date controlling RRP of the larynx and restoring voice quality. Furthermore, there have been no complications associated with over 200 Avastin injections. Coupling the antiangiogenesis agent Avastin with pulsed-KTP laser photoangiolytic is conceptually attractive and scientifically sound since the mechanisms of action are complimentary.

MGH VOICE CENTER INQUIRIES:

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<p>Patients Treated with Avastin and Angiolytic KTP-Laser Treatment For Recurrent Respiratory Papillomatosis of the Larynx</p>

The patients who have been treated at the MGH Voice Center with Avastin and the KTP Laser live in a variety of locations. These individuals comprise the overwhelming majority who had Avastin treatment and they are enthusiastic about helping other patients and their families with this difficult disease. They have unique insights to past and current treatments for RRP. Please feel free to contact them as they have kindly agreed to share their experiences with the readership of the RRP Newsletter.

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

A multi-center study using celecoxib (Celebrex) as an adjunct to surgery for the treatment of moderate to severe recurrent respiratory papillomatosis is progressing. We now have 24 patients who are enrolled in the study and early results are promising.

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.

**Genetic Susceptibility to Papilloma-induced Voice
Disturbance**

By
Farrel Buchinsky, MD, Allegheny General Hospital

We continue to enroll cases and their available parents. Thus far 467 people with recurrent respiratory papillomatosis have enrolled along with 587 parents. 120 of the cases were recruited through the RRP and the RRP ISA support groups. The majority of cases have been enrolled through the 31 satellite sites in the USA (vast majority) and 5 other countries. Our goal is 540 cases and as many parents as possible but we also enroll people with no available parents. We have been very busy in the laboratory over the last few months. We have genotyped (determined the genetic code) 310 subjects at 1.1 million

locations across their entire genome. The task is expensive and takes time but given the capabilities of the Center for Genomic Sciences (CGS) in the Allegheny-Singer Research Institute the process is a relatively cheap and fast compared to what it would have been a few years ago. I and Dr. Jurg Ott, of the Rockefeller University and the Beijing Institute of Genomics are currently analyzing the data. We still need to genotype many more people but our strategy will be informed by the results from the current analysis.

For more info contact:

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**HPV 6 and 11 Serology Status of Patients with Recurrent
Respiratory Papillomatosis (SyRRuP)**

By
Farrel Buchinsky, MD, Allegheny General Hospital

Enrollment is closed. 70 subjects provided blood specimens which have all been assayed to determine the concentrations of antibodies against HPV 6 and 11. We are busy analyzing the data and comparing it to the HPV type that caused the particular persons recurrent respiratory papillomatosis. We are also comparing the data to the thousands of people who participated in Merck's trials of their HPV vaccine. Data will be submitted for presentation within the next couple of months.

RRP and HIV in Zambia

[Via e-mail and phone communications between
Tom Broker, PhD., UAB and Bill Stern]

Tom Broker recently visited Luska, Zambia with the intent of initiating a multidisciplinary project to explore Head and Neck associated viral diseases via a Zambian-UAB research network. An interesting observation is that the clinicians in Zambia are reporting a lot of laryngeal papillomas and especially that this is primarily occurring in HIV-positive patients. In the US, at least according to best available but nonetheless anecdotal reports, RRP occurrence has not been linked to HIV-AIDS. This apparent lack of correlation in the U.S. is hard to explain, since other latent, subclinical HPV infections (such as at ano-genital sites) are activated in proportion to immunosuppression, especially in HIV+ patients.

**For Information about Recurrent Respiratory Papillomatosis
RRPF Local Support Network Coordinators**

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RRPF Subscriber Form – 5/11

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