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Cartoon Contest

Oh Well. Some ideas work out and some don't. Due to lack of interest, the Cartoon Contest was cancelled

PMP Pals October Conference, Monterey CA



Chris Piekarski-PMP Pals President in conversation with Dr. Laura Lambert, MD UMASS



Attendees had plenty of extra time to visit and form lasting friendships

On October 7-8, we saw many PMP Pals gather in Monterey CA at the 2017 PMP Pals conference. Attendees met for Dinner Saturday night to meet and greet this year's speakers:

- **Dr. Laura Lambert**, well known for treating pseudomyxoma peritonei and other abdominal cancers, spoke of the types and strains of appendix cancer.
- **Dr. Tessa Sugarbaker**, MFT, OB-GYN and Daughter of Dr. Paul, Sugarbaker, spoke about PMP
- **Reverend Dr. Michael Barry**, author, spoke about forgiveness
- **Dr. Samuel Jamieson**, DC, ACN, spoke of holistic integrative medicine with nutrition and mental health
- **Brendon Ayanbadejo**, *Super Bowl Champion from the Baltimore Ravens*, spoke about the importance of physical exercise as part of emotional health

The theme this year concentrated on the mental health aspect of waging a cancer fight but we also heard updates to ongoing research and continuing studies. A surprise was an announcement from Dr. Laura

Lambert will be leaving UMASS and moving to Salt Lake to work in a newly built state of the art cancer facility. This facility will certainly be welcoming news to those on the west coast with a facility and expert closer to home. Attendees met Saturday evening for dinner where they got to rub elbows with the guests and speak one on one with each one. As is always the case, plenty of time over this weekend is allowed to forge lasting relationship, fellowship, and comradery for PMP warriors and caregivers. It is safe to say, the 2017 was by far large success. For those that didn't make this event, save the early part of OCT 2018 for next year's events. If you did not attend this year, look for links to the conference videos on the PMP Pals Network Facebook page.



Dr. Tessa Sugarbaker



Adele Jasion-PMP Pals Treasurer and Superbowl Champion Brandon Ayanbadejo





A Poem

By

PMP Pal and Survivor, Judy Thompson

We gather round the table
Some with increasing girth
Jelly Beans with convex side facing forwards
That's why they call it jelly belly
Peculiar shapes and sizes
Doesn't mean we're peculiar people though
We go through reshaping, therapies, whatever comes our way
Find support in the group; our PMP buddies
As we care for others so they care for us
Tales and laughter; joy and tears
Every day finds something that makes us glad to be alive
And tomorrow is a blessing
So for now, live, laugh and love.

Our Featured Article:

Cancer Treatment Side Effect: Chemobrain

BY MEAGAN RAEKE

In the late 1990s, doctors began to pay attention to chemobrain, a term used by an increasing number of patients to describe mental symptoms and side effects. Since that time, chemobrain has become accepted as a legitimate, diagnosable condition experienced by many cancer patients. We sat down with Jeffrey Wefel, Ph.D., associate professor of Neuro-Oncology and chief of Neuropsychology, to learn more.

What is chemobrain?

Chemobrain is a term used by patients to describe changes in their thinking, or cognitive function. Depending on the person, "chemobrain" may refer to forgetfulness, slower thinking, difficulty concentrating or periods of mental confusion or "fogginess." It's difficult to pinpoint an exact definition, but it generally describes a feeling that "my brain is not working quite the same as it was before cancer."

What causes chemobrain?

When we look at cognitive changes in cancer patients, there are two distinct groups. In the first, patients with brain tumors can have changes in cognitive function due to the location of their brain tumor and treatments that directly affect brain tissue.

However, "chemobrain" is often used to refer to cognitive changes experienced by patients in the other group: those without cancer in the brain. While the term "chemobrain" seems to directly blame the problem on chemotherapy, we've actually found that cognitive problems can appear before any treatment begins. Even if cancer is not growing in the brain, it can still disrupt systems in the body that end up affecting mental function. Some treatment, including certain forms of chemotherapy, hormonal therapy and immunotherapy, can also cause cognitive dysfunction, meaning they can directly or indirectly disrupt, damage or alter normal brain function.



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Does chemobrain get better with time?

For many patients, the symptoms of chemobrain improve over time, though they may not go away completely. Some people may continue to experience chemobrain symptoms long after they've completed their cancer treatment.

How is chemobrain diagnosed?

At MD Anderson, chemobrain diagnosis begins with a referral to our Neuropsychology team for evaluation. A neuropsychologist will talk to the patient and the family to get a full picture of the symptoms, including specific situations where the symptoms get better or worse. The patient also takes a series of standardized tests to measure their thinking skills.

The evaluation shows both strengths and weaknesses in thinking skills. It also rules out (or may reveal) other diagnoses, such as dementia, anxiety, depression or fatigue, all of which can also affect mental function. The neuropsychologist then works with the patient to develop a treatment plan tailored to address their symptoms and goals.

What treatments are available for chemobrain?

Stimulants or brain training may help some patients. Cognitive strategies or healthy lifestyle changes, like improved sleep quality and exercise, can also help. Because symptoms and personal priorities vary from person to person, our treatment plans are highly personalized as well. Read tips for coping with chemobrain.

How has chemobrain research changed in recent years?

Over the last 10 years, the number of publications on cognition and chemobrain has tripled. We have confirmed that chemobrain is real. Now we're trying to better understand which patients have the highest risk for developing chemobrain, what's causing it and the most effective treatment approaches to maintain brain health and maximize cognitive function.

We're currently recruiting breast cancer patients for an NIH-funded observational study that will follow patients over several years. Our goal is to find biomarkers to understand who's at risk for chemobrain.

Measures of cognitive function are also being incorporated into clinical trials more often. In addition to studying how well a particular therapy controls the cancer, we're also monitoring how that therapy affects a patient's thinking skills, both in the short term and into survivorship. One example of this is a study that showed that we can help maintain cognitive function in patients receiving whole brain radiation by adding a medication to their treatment.

In the lab, we're studying regenerative medicine and other approaches to treat brain damage and restore cognitive function after the brain has been damaged by cancer or cancer treatment.

What advice do you have for caregivers when a loved one feels like they have chemobrain?

Sometimes caregivers aren't sure why their loved one is experiencing changes in thinking or behavior, how best to manage these changes and if they will improve or worsen with time. It's important for our patients and their loved ones to know there are experts who can help them understand these changes and provide treatment recommendations.

Ask your loved one's MD Anderson physician for a referral to Neuropsychology for evaluation of chemobrain symptoms. This is the first step to diagnosing and treating cancer-related cognitive changes.

In the News:

Ireland:

The Mater Hospital in Dublin is the only centre on the island of Ireland offering cytoreductive surgery and heated intraperitoneal chemotherapy (HIPEC) for certain cancers such as appendix tumours, advanced colorectal cancers,



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and other rare intra-abdominal cancers. HIPEC is a highly concentrated, heated chemotherapy treatment that is delivered directly to the abdomen during surgery.



New PMP Liaison Staff join the team

James Caldwell in the Ireland

Michael Healy in the UK

I'm delighted to be part of PMP pals in the UK, and with Michael Healy looking after the Republic of Ireland, we've got this neck of the woods covered! While I'm interested in lending support to all of our members, I'm particularly interested in encouraging other men to join the and seek support, rather than through their wives / partners.

I was diagnosed with a high grade appendiceal mucinous adenocarcinoma in 2014. I had surgery in my local hospital and was then referred to the peritoneal malignancy centre in Basingstoke, England who specialise in appendiceal cancers and PMP. I then had eight cycles of systemic chemotherapy. At the time of diagnosis, the cancer had spread to my right ureter, so I had to have a reconstruction. A year later, between chemo and urinary surgery, my kidney function tailed off so I now have Stage 3 kidney failure. Luckily however, since treatment I've been NED. I hope to be kicking around for a while longer, so fingers crossed!

Apart from the physical trauma induced by surgery and chemo, I also suffered mentally and had a bit of a breakdown one year after. I was treated for that, so now in a much better place. Unfortunately, many of our PMP family have to endure bad times, I find "a day at a time" works for me, and over time I've become more philosophical about this disease and how things might pan-out.

I live in Belfast, Northern Ireland. I am a Chartered Accountant (the equivalent of the US CPA), and previous to that I was an RN in a large regional hospital in Belfast – a bit of a mix I know! I work four days a week in a public accountancy and audit practice, and my business partner and I operate a private care home for the frail elderly and those with dementia. It's a busy but enjoyable life. At weekends, I like to visit my holiday home in North Donegal – it's quiet and remote, with fabulous views out over the Atlantic Ocean.

Much love to you all

James Caldwell



Survivor Happenings: From Syracuse, New York

On July 8, 2017 at Onondaga Lake Park , Bob Worden, an Appendix Cancer survivor and his family held their second annual Appendix Cancer Awareness Walk. Friends, families and other survivors enjoyed awesome raffles, a DJ, food, face painting and an enjoyable 3 mile walk to help increase awareness and raise research money. Last year, they raised **\$7,692** and topped it this year by raising an additional **\$8,300** towards education and research for Appendix Cancer.



Hosting this walk every year has become very important to Bob and his family. Bob was diagnosed with Appendix Cancer on July 9th, 2014 and has been courageously battling this disease ever since. With the rarity of this cancer, more education and awareness needs to be done. It is his mission and the goal in his community to increase the publics awareness of Appendix Cancer and help raise valuable research dollars to be put toward a search for a cure.

From San Jose, California PMP CARE Angels "Hair Today - Gone Tomorrow"

"Hair Today – Gone Tomorrow" was a fundraiser primarily to raise money for The ACPMP Research Foundation, and secondly for **PMP Pals**, said Dawn Haskin, Fundraising Chair, " My goal was to raise \$10,000 by August 1, 2017. The original plan after reaching my goal was to shave my head and donate the hair to wigs for cancer patients. But some donors offered to make additional donation if I kept my hair just short and not shaved. Well, the dilemma was put to a vote of all donors to my cause and the result were as shown in the before and after photos."



We celebrated our success on Saturday, August 12, in Sunnyvale, CA in the Parish Hall of St. Mark Lutheran Church. There were raffle prizes, a silent auction, and 50/50 drawing as well as refreshments. At the end of the day, total raised was just over \$19,000. But the sale of handmade item continues on my ETSY site, (CAREAngelsCreations) with all proceeds going to **PMP Pals Network**.

SF Bay Area PMP Pal Survivors –

Our next gathering for Survivors and Caregivers is Saturday, Jan 20th, 2018. If you live near the SF Bay area and would like to join us, email Dawn Haskin at dawn.haskin56@gmail.com

1) *Are you interested in meeting some of those who share your PMP experiences? Have you started a Regional PMP Pals Survivors Group in your area. Perhaps a discussion with a fellow caregiver or patient*



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could give you new insights and coping skills. If you belong or have started a Survivors Group, please let us know what you're up to so that we can feature your event(s) in our Newsletter. Just e-mail us at:

newsletter@pmppals.net

2) *Are you hosting a Fundraiser Run, Walk-a-thon or other event? Let us know so we can share your story.*

Just email us at: newsletter@pmppals.net

Information for the Newly Diagnosed

PMP Pals- Simply by reading this newsletter you are well on your way to staying informed. We believe knowledge is power and hope follows close behind. Did you know that PMP Pals has both a Facebook page as well as a Website where lots more information can be found.

<http://www.pmppals.net>

PMP Appendix Cancer Support Group – On this Facebook page, you'll be able to connect with fellow patients and caregiver throughout the globe. This private (closed) group is ONLY for individuals and their caregivers/advocates, who have, or have had, Pseudomyxoma Peritonei (PMP) and/or any other form of Appendix Cancer, including Adenocarcinoma, Goblet Cell, Signet Ring Cell and others. To join, just navigate to the "ADD MEMBERS" column of the homepage.

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

ACMP – (Appendix Cancer Pseudomyxoma Peritonei-Research Foundation) is dedicated to:

- **Funding research to find a cure** for (PMP), Appendix Cancer, and related Peritoneal Surface Malignancies (PSM),
- **Funding educational programs** to educate physicians and patients about these diseases.

<https://acmp.org/>

Donations: *To contribute to our ongoing efforts, please visit our donor page at:*

<http://pmppals.net/become-a-donor-2/>

We do **NOT** want patients or their families donating—they have more than enough on their plates and must concentrate on getting better. But we are open to donations from past patients and their families if they've found us to be helpful and would like to help us continue this work. Businesses or organizations are also welcome to donate to help us defray cost.

PMP Pals is a global volunteer-run organization that gives hope to patients and caregivers fighting appendix cancer, also known as Pseudomyxoma Peritonei or PMP, and other cancers of the abdominal cavity. We provide information through our web site and personalized support through our programs.

We want to hear how PMP Pals' Network has helped you and your family. Write to us and share your story of hope with new patients as well as long-time PMP Pals. We look forward to hearing from you! E-mail:



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