In the News –

10th International Congress on Peritoneal Surface Malignancies

The 10th International Congress on Peritoneal Surface Malignancies was held on November 17-19th, 2016 and hosted by the PSOGI chair, Dr. Paul Sugarbaker in Washington DC. Faculty Doctors from Belgium, the USA, China, Italy, France, Spain, Sweden, the UK, Australia, India, Germany, Denmark, Greece, the Netherlands, Korea, Isreal and Japan were on hand to collaborate, teach and discuss the latest advances in PMP and Colorectal cancer care and research. In addition, a team from our own PMP Pals Network were on hand as exhibitors as well. Our partners from ACPMP awarded limited scholarships to some attendees that otherwise would not have been unable to attend. The provided training, aimed toward surgical and medical oncologists, surgical oncology nurses, surgical technicians, perfusionists, and other healthcare professionals interested in peritoneal surface oncology, is accredited by the Accreditation Council for Continuing Medical Education (MedStar Washington Hospital)

With the rarity of PMP occurrence, these dedicated medical professionals go a long way to finding the cure we all seek.

Did You Know?

Proper treatment of PMP is not a part-time practice. Specialization is required to do it well. The literature says patients should look for hospitals that perform many HIPEC procedures every year and select a surgeon that has done 130-140 HIPEC surgeries or more.


Our Featured Article:

Are you having problems with your insurance coverage? Don’t give up hope. Meet Laurie Todd, also known as THE INSURANCE WARRIOR. Laurie is also the author of two books on the subject. She has shared some of her own story and also answered a few questions on coverage problems in our “Featured Article”

It's all about the networks
by Laurie Johnson-Todd

Eleven years ago, Laurie Todd was diagnosed with late-stage appendix cancer. Her doctors were against cytoreductive surgery and HIPEC—and her insurer denied it.

Laurie won her appeal in three days. In October 2005, she had a 14-hour cytoreductive surgery and HIPEC. It wasn’t long before other patients found her—and asked her to write their appeals. As of December 2016, Laurie has written two books on how to win an insurance appeal—and she has written and fought 178 lifesaving appeals.

What is the biggest insurance issue for appendix cancer patients in 2016? Networks.

Networks:
Instrument of control

In the early 1970s, insurers put their heads together to figure out how to get doctors to stop ordering so many expensive tests and treatments. They came up with a powerful instrument of control: Networks.

Insurers said to doctors: If you sign a contract with us—you will be "in network." You won't have to build a practice. Patients will be required to go to a doctor who "takes their insurance card."

Your in-network doctor is bound to the insurer by contract. The insurance company gets to decide which treatments they are going to pay for, how much they are going to pay, and when they are going to pay."

But what happens if the most experienced surgeon is out of network?

What if the best surgeon is out of network?

The most important statistical factor in survival for us appendix cancer patients is the completeness of cytoreduction—in other words, the skill and dedication of the surgeon.
What if the in-network surgeon whom the insurer would like to send us to has done six of these surgeries—and he has never trained or worked at any institution where cytoreductive surgery is performed? Plus, he tells us that he hates doing these surgeries?

Eleven years ago—this is what happened to me.

As more new surgeons offer HIPEC—and insurers shrink their networks—this is also likely to happen to you.

**An out-of-network approval is no better than a denial**

Let’s say that your insurer approves the surgery and HIPEC with your out-of-network surgeon. You have a PPO with out-of-network coverage.

Your summary of benefits states that they will pay 70% if the treatment is out of network. And you will pay the rest.

Let’s say that the surgery costs $100,000. Does this mean that your insurer will pay $70,000—and you will pay $30,000?

If you believe that—you just got snookered.

A percentage doesn't mean anything—until you know what figure it is based on. No insurer pays based on the bill. They pay based on their own "allowable amount."

A typical allowable amount for a $100,000 surgery is about $10,000. Your insurer will pay 70% of that, which is $7,000. And you will pay $93,000.

See how it works? An out-of-network approval is no better than a denial. And the insurer believes that you can't appeal it—because they didn't deny it. But you can.

**Appeal it!**

I see posts on the appendix cancer groups which say: "I really wanted to go to Dr. Smith. But my insurer wouldn't let me—so I had to go to Dr. Jones instead."

Please. What the insurance company says is not the law.

My surgery was denied eleven years ago because my surgeon-of-choice was out of network. Most of my appeals these days are not for denials—they are for out-of-network denials and approvals.
You can appeal out-of-network denials—and you can appeal out-of-network approvals. They are no better than a denial.

No insurer gets to dictate where we go for treatment. It is the insurer’s job to keep us in their network. And it is our job to get to the surgeon who will give us the best chance of survival.

Happy and peaceful insurance warrior-ing,

Laurie Todd
www.theinsurancewarrior.com

PMP Trending:

Sponsored by NORD, the National Organization of Rare Disorders, Rare Disease Day® takes place on the last day of February each year. The main objective is to raise awareness with the general public and decision-makers about rare diseases and their impact on patients’ lives. The global theme for Rare Disease Day 2017 is research.

For more information see:
http://rarediseaseday.us/about/history/

Launch of the first “Regional PMP Pals Group”

Are you interested in meeting some of those who share your PMP experiences? A Regional PMP Pals group is a collection of PMP Pals members that meet up locally in an area to support PMP survivors and caregivers. Perhaps a discussion with a fellow caregiver or patient could give you new insights and coping skills. A newly formed Regional PMP Pals Group in the San Francisco Bay Area met recently in Stockton California for lunch and soon became friends and confidants sharing personal stories. The event went so well, more get togethers are planned.

The San Francisco Bay Area Regional PMP Pals group, invites you to join us in celebrating the new year. We will be meeting on Jan 14th in Concord Ca. Renew or make new friendships. Let’s start the year off supporting one another in the best way possible. If you can, please send an email to dawn.haskin56@gmail.com. Give your name, email and city when you reply so we can add you to our email list of PMP Pals in the area.
(Not to worry, we will not give out, share, loan, sell or rent, your e-mail info to anyone)

If you have formed a Regional PMP Pals group, let us know what you’ve been up to at:

newsletter@pmppals.net

Provide us information about your event(s) with a point of contact so we can inform others about your Regional PMP Pals group in upcoming newsletters.
Announcements:

PMP Pals is proud to announce the latest addition to our team. Linda King has advice for your diet after you’ve had HIPEC surgery for Pseudomyxoma Peritonei. Linda is a long term PMP survivor diagnosed in 2002. During her time as a patient she has broken all the rules: having an ostomy for 12 years, which has since been reversed, and having been on TPN twice, each for stretches of nine months at a time. She has also practiced as a dietitian, a physician’s assistant and a family therapist enabling her to support the physical and emotional needs of patients and caregivers fighting PMP. Although Linda is no longer a healthcare professional, and it’s imperative that you formulate your dietary plan with your physicians, she can offer some excellent points to consider.

Email Linda directly at eatlikeaking@pmppals.net with all of your dietary questions. We hope Linda and PMP Pals can help you Eat Like a King. See Linda’s blog (http://pmppals.net/category/eat-like-a-king) for additional Info.

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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/

**ACPMP** – (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://acpmp.org/

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Like us on Facebook
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:

info@pmppals.com