



**We're on the Web:**

[www.pmpals.net](http://www.pmpals.net)

**E-mail us at:**

[info@pmpals.net](mailto:info@pmpals.net)

**Inside this issue:**

*Betty & Shealy's Story* 2

*Get Well Cards* 3

*Bare Bottom Bears* 3

*Welcome New Team Members* 3

*Blog Corner* 3

*Events* 4

*The Monthly Yardstick* 4

*Recently Diagnosed? Find a Specialist!*

If you're recently diagnosed, first we want to extend our regrets to you. We're sorry for this news, but if you're reading this you've found a great resource in PMP Pals. We've been through treatment ourselves, can help you find the specialists that treat PMP and can support you throughout your journey.

Unfortunately, it's common for patients to go misdiagnosed and be treated by local surgeons. Although well-intentioned, these surgeons may not be able to provide optimal care. It is always best to consult with a HIPEC specialist who is familiar with this rare disease and its treatment.

Pseudomyxoma Peritonei, like many cancers, is actually a family of diseases. Despite its rarity the experts have learned how to distinguish between the spectrum of tumor types and the necessary treatments. While some patients need chemotherapy in their treatment regimen, others do not. And in some cases watching and waiting may be the appropriate strategy. The specialists and their teams are trained to understand your particular case and create a personalized treatment plan.

At PMP Pals we do not recommend one surgeon over another, but rather, it's our hope that you'll seek care with a specialist



*Select a hospital and surgeon that have extensive experience in the treatment of PMP.*

trained in treating PMP with HIPEC.

Once you've selected your hospital and surgeon, we're here with advice on preparing for surgery. Reach out to us at [info@pmpals.net](mailto:info@pmpals.net) and we'll be happy to help.

**Did You Know?**

Proper treatment of PMP is *not* a part-time practice. Specialization is required to do it well.

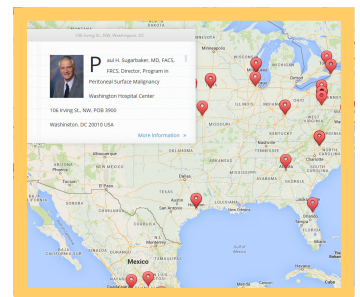
The literature says patients should look for **hospitals** that perform many HIPEC procedures every year<sup>1</sup>, and select a **surgeon** that has done 130-140 HIPEC surgeries or more<sup>2,3</sup>. Citings on p. 4.

*Find a Surgeon*

For help in finding a surgeon experienced in HIPEC, go to [pmpals.net](http://pmpals.net) and under Get Information click Find a Surgeon. There you'll find a global map identifying surgical oncologists that can advise and treat PMP patients.

In the map you can see a listing of the surgeons, filter by country and see their contact information.

PMP Pals' goal is simple: to give you the opportunity to find a specialist, and give you hope for a cure.



*Find specialists in your area or anywhere around the world, online at [pmpals.net](http://pmpals.net)*



## *Betty & Shealy Rely on Faith to Pull Them Through*



Based on the article *Journey of Faith* by **Jessica Brodie**, Originally published in the **South Carolina Advocate**

Pals Betty and Shealy are both living with a rare cancer. Despite the fact that their cancers can be debilitating and even deadly, they've decided to rely on their faith to fight back and choose life no matter the circumstances.

Betty was diagnosed in 2004 with leiomyosarcoma, a rare cancer that develops in the smooth muscles and soft tissues of the body. It was a chance scheduling snafu that led to Betty's diagnosis in 2004. When her high school aged daughter had to miss a doctor's appointment at the last minute, Betty asked if she could take the appointment. That decision may have saved her life, as doctors quickly recommend she have a hysterectomy due to the bleeding she'd been experiencing. But surgery didn't go exactly as planned.

During surgery Betty had an unusual amount of bleeding, and after multiple surgeons were brought in to help they found the leiomyosarcoma hiding behind a large benign tumor inside her uterus. Surgeons understood chemotherapy and radiation weren't effective against her cancer, and they worked quickly to remove it.

Betty didn't focus on the fact that her cancer was rare, but rather, focused on important milestones in her future. "I never had a fear of dying—I just wanted to see my youngest graduate from high school," Betty said. Betty's daughter is now in her late twenties and has graduated from high school, college and graduate school.

Seven years after Betty's diagnosis, it became Shealy's turn to fight a rare cancer. Shealy was afraid he had eaten bad food when he became violently ill after a familiar celebration on a Saturday afternoon. By Tuesday Shealy was in agony and was rushed to the hospital for surgery, where he was diagnosed with stage 4 cancer of the appendix.

Shealy sought care from a specialist and had HIPEC at Wake Forest in Winston-Salem, NC with Dr Votanopoulos. His 13 hour surgery was a scary experience for him. "When you're younger, you don't think about your mortality," Shealy said, "but then it's right there in front of your face".

The Shealys relied on their faith to help them through both their surgeries. "The theme for our lives is how our faith carries us. You have challenges, and you get through the lowest lows, and you either live in that moment or you start dying slowly, not just physically but spiritually," Shealy said. "You just have to trust and pray yourself through," Betty said. "You don't know the whys and hows. You just have to accept it. You just struggle sometimes with the purpose in all this."

"Perhaps the purpose is for people to realize, through your struggles and your relationship with God, you can overcome a lot of things," Shealy said. "You rally to get past it or just fall. You accept your own mortality, you know this may eventually take your life, but you're choosing to live." Betty adds "Sometimes the news takes a hard toll, but you buck up and you pray and you rearrange your mindset and you find humor."

Sitting on their couch in their living room with their dog between them, the two finish each others sentences and tease one another about how their memories have gone fuzzy from all their treatments. "We hope we'll get a good report at the next appointment," Betty says, smiling at her husband. "But if not, we'll just reassess," Shealy says smiling back.

## Get Well Cards: [getwellcards@pmppals.net](mailto:getwellcards@pmppals.net)



Sending Get Well Cards to Pals is a time-honored tradition that enables us to stay connected. Whether you're a patient recovering from surgery or a caregiver celebrating a wedding anniversary, it would be our pleasure to send cards to you.

Know someone needing cards? Send your request to [getwell-cards@pmppals.net](mailto:getwell-cards@pmppals.net)

with a brief description of the occasion, and we'll mobilize the card writing Pals.

Want to write Cards? Send an email to [getwell-cards@pmppals.net](mailto:getwell-cards@pmppals.net) and let them know you want to help.

Here's How It Works: Around

the first of the month Card Writers receive an email containing a list of cards that are needed. They write cards appropriate for the occasion and mail them to the PMP Pals mailing address:

225 Crossroads Blvd.  
Suite 390  
Carmel, CA 93923

The Get Well Cards Team then mails the cards they've received to the best location by the 15th of the month.

Get plugged into the Pals and participate in the Get Well Cards program today!

## Bare Bottom Bears: [barebottombears@pmppals.net](mailto:barebottombears@pmppals.net)

**"Send us an email at [barebottombears@pmppals.net](mailto:barebottombears@pmppals.net) and we'll be happy to send you your very own bear."**

Since its earliest days, PMP Pals has strived to remind patients they're not alone, even with a rare disease. Many Pals remember receiving their Bare Bottom Bear with a note reminding them PMP Pals was there to lend a hand.

We're proud to once again offer this program, run by the

same faithful Pals that have been doing it for years.

If you know someone headed for surgery, send us an email at [barebottombears@pmppals.net](mailto:barebottombears@pmppals.net) and we'll be happy to send them their very own bear. That way they won't be the only one wearing those embarrassing gowns!



*Email us today to receive your bear free of charge*

### **Welcome new team members!**

The PMP Pals Leadership Team wants to extend a special thanks to the following new volunteers working behind the scenes:

- Pat O—Get Well Cards Coordinator
- Misty P—Blog Program Coordinator
- Peter B—Blog Program Contributor
- Linda A—Bear Bottom Bears Coordinator

PMP Pals is a volunteer run organization. Volunteers are patients and caregivers from around the world who want to help support PMP patients. Want to help? Email [info@pmppals.net](mailto:info@pmppals.net) today.

### Blog Corner

Check out our recent blog posts:

- ◆ Post Operative Nausea and Vomiting
- ◆ Is Appendix Cancer Hereditary?  
By Dr. Brian Loggie
- ◆ Tips for Returning to Work After Appendix Cancer Surgery

Go to [www.pmppals.net/blog](http://www.pmppals.net/blog) for these and other articles of interest!

## PMP Pals' Network

225 Crossroads Boulevard  
Suite 390  
Carmel, CA 93923



**E-mail us at:**  
**info@pmppals.net**

*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 mentor program. If you or someone you know is affected by this rare cancer, please contact us today so we can provide HOPE to YOU!*



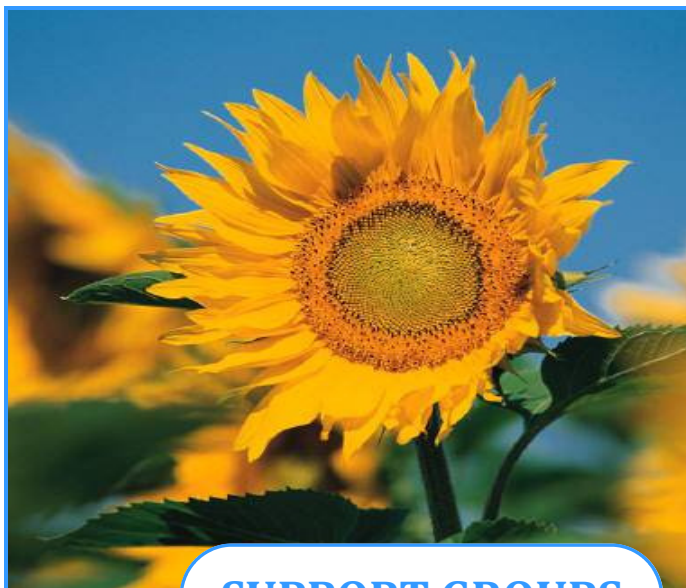
Like us on  
**Facebook**

## Events

Consider attending these upcoming events to meet patients, raise funds and learn.

Aug 9	Appendix Cancer Survivor Summer Celebration	Froedtert WCM Milwaukee, WI
Sep 12	Symposium: Advances in Treatment & Research	UCSD Moores La Jolla, CA
Oct 4	Heat It To Beat It	Mercy Baltimore, MD

Go to [www.pmppals.net/events](http://www.pmppals.net/events) for more information.



## SUPPORT GROUPS

Your local hospital is likely to host support groups for cancer patients. No one knows what it's like to go through cancer like another patient. Consider joining yours today.

**Donate**

At [www.pmppals.net](http://www.pmppals.net)

## THE MONTHLY YARDSTICK

PMP Pals strives to provide support for patients with a rare disease. We see our impact by measuring what we do.

- Information Requests Completed: 27
- Mentor Matches Made: 9
- Patients Receiving Get Well Cards: 7
- Bare Bottom Bears Sent: 2

Citing's from page 1

1. *Multicentre study of the learning curve and surgical performance of cytoreductive surgery with intraperitoneal chemotherapy for Pseudomyxoma peritonei* by Drs. Kusamura, Moran, Sugarbaker, Levine, Elias, Baratti, Morris, Sardi, Gleben and Deraco. *British Journal of Surgery*, Volume 101, pps. 1758-65, Oct. 2014
2. *Multidimensional Analysis of the Learning Curve for Cytoreductive Surgery and Hyperthermic Intraperitoneal Chemotherapy in Peritoneal Surface Malignancies* by Drs. Kusamura, Baratti and Deraco. *Annals of Surgery*, Volume 255, Number 2, February 2012
3. *Learning curve of combined modality treatment in peritoneal surface disease* by Drs. Smeenk, Verwaal & Zoetmulder, *British Journal of Surgery*, Volume 94, pps. 1408-1414, Jul. 2007