

## Patient & Family Advisory Council: Working for you!

### Ahoy there! Where is the Port? What is a Port? A Patient's Perspective

Similar to a shipping port which facilitates receiving ships and transferring cargo to and from them, the implantable port (sometimes called portacaths or subcutaneous ports) is used to transfer medication into your vein and to take samples of your blood from your vein for testing. The port is the means by which you will receive your chemotherapy treatment. This makes it possible for you to have your treatment without having to have needles frequently put into your veins. Don't get me wrong, you will still feel like a pin cushion, just not look like one.

I remember when I first got to the hospital to have the port put in me, I was so naïve, afraid and confused that I never even thought to ask to see one.

If you have not had your port put in yet, make sure you are shown one first.

Let me give you an idea of what it looks like. The tube is long, thin, hollow and known as a catheter. The port is a disc the size of a quarter. The catheter is usually inserted (tunnelled) under the skin of your chest. The tip of the catheter lies in a large vein just above your heart and the other end connects with the port which sits under the skin on your upper chest.

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MEMORIAL CANCER INSTITUTE

# Patient and Family Advisory Board Newsletter

### Meet An Advisor



Liliana Nicholls Grant is a breast cancer survivor, business owner & advisor who works to ensure you receive the best care possible.

#### Advisory Council Members:

- Tom Cappadona - Chairman
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- Elliot Natale
- Deborah Polink
- Michael Sands
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#### Core Principles:

- Dignity & Respect
- Information Sharing
- Participation
- Collaboration

#### Inside This Edition:

- Understanding a port
- Understanding a bone marrow biopsy
- Your first chemo



## Ahoy there! (Continued...)

The port will show as a small bump underneath your skin, and can be felt. Your port will be put in at the hospital or outpatient center by a surgeon or a radiologist on an outpatient basis. It can be put in either under a general anesthetic or a local anesthetic. Your port will stay in at least for the duration of your chemotherapy treatment. In my case I had it in for more than a year.

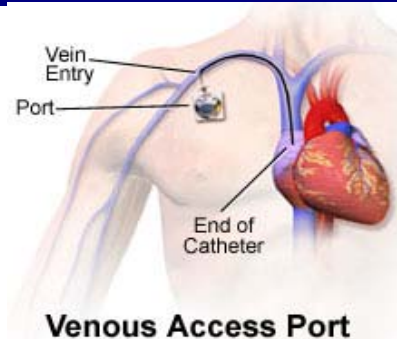
I was receiving weekly treatments and having the port already there was the best way for me to receive my medication. After I was done with my medication, I was surprised to hear from my doctor that he wanted me to keep it in for another 6 months. I couldn't believe it. I still had to walk around with this bump on my chest. Needless to say, the spaghetti strap shirts and dresses were out.

The good news is that since I did not wear them for about 1 ½ years, it felt like I had new clothes to wear once the port was removed.

Once you are given the go ahead to have the port removed, you will receive a prescription for the removal and schedule the removal procedure, which will also need to be done at the hospital or outpatient center—most likely by the same doctor who put it in. A word of advice. Make sure that the doctor does a good job at stitching you up. You will have a scar so make sure that at least it is a neat one.

~Liliana Nicholls Grant

*Patient Advisor*



## Bone Marrow Biopsy: A Patient's Perspective

So the Doctor says you need a bone marrow biopsy. The thought of it brings almost as much fear as a cancer diagnosis. A bone marrow biopsy is simply taking a sample of the marrow. By looking at the cells in your bone marrow, your doctor can get a good idea what is happening with your cancer. Blood is produced in the bone marrow – the center of your bones, and works its way out of the bones into the blood vessels. The largest bones produce the most marrow. Even if the blood is clean, often the answer is in the marrow.

Here's how my experience was: The procedure took about 10 minutes from first needle to finish bandage. The lab technician was there to make sure the sample was good – you don't want to have to do it over. The biopsy is usually taken from the pelvis, just above your back pocket. The Doctor located the 'spot' by feeling with his fingers and then marked it. Which side doesn't really make a difference. Yes it can be painful. Oral sedation is sometimes available to make it more tolerable. I don't like the hangover from the drugs, so I go without them. The first step was a good cleaning. Next an injection of lidocaine (similar to the novacaine your dentist uses) will numb the area. It was just a quick stick and then burning pain for a few seconds. Now the lidocaine was injected directly into the bone to numb it. Your bones have lots of nerves and it takes a lot to numb them. Just try to relax and hold on tightly, that is what those handlebars are for! Once numb the doctor inserted another needle into the bone and with a twisting motion he slowly pushed it all the way through to the marrow. This was not painful but feels like it would be. It took a quite a bit of pressure. You may even notice that you are rocking as the Doctor works it. Once 'in' the aspiration (sucking the marrow out) occurs. It felt like my toes was being sucked into my leg and coming out my pelvis. A couple of quick pulls and it was done. Of course if you have signed up for a study or two, they would like a sample so you get an extra pull. Often a bone core is taken at the same time. This time it feels like he is turning a screw into the bone. Once in, take a deep breath and pop - a core of the bone is taken.

Gauze was applied to the wound along with plenty of pressure to stop any bleeding. Then a large bandage is placed over it. Roll over and let your weight put some pressure on it. It won't hurt. As the lidocaine wears off, it may feel sore. I found that sitting with a small pillow to put pressure on the bandage helps, so does walking. If you thought the biopsy was painful, wait until you pull off the bandage!!! Once I had one that must have been put on with Superglue. After at least 24 hours, a warm shower will help to loosen the bandage.

~Michael Sands

*Patient Advisor*

## **Patient Experience: What to expect from your first chemotherapy session.**

I was terrified, so I highly recommend that you have someone with you. I had heard so many stories about how people would get so sick, that the thought scared the hell out of me. Once I was called to the treatment room, the nurse explained everything to me. I finally remembered to ask to see the actual foreign object (my port) I had implanted in my chest. Much to my surprise it seemed much bigger than the size of the bump I had on my chest.

When the nurse explained to me that she would be inserting the needle in the middle of the bump to access my port, I cringed. She did offer to put a spray on me that numbs the area by making it cold enough that you won't feel the pinch. I decided I was going to be tough as nails, so I turned her down. The truth is that I really don't like the cold.

The process seemed to take forever to get started, but we had to wait for the pharmacist to work up the medicinal cocktail I was going to receive. Like a good bartender, the pharmacist has to make sure I was getting the exact dosage necessary for my weight. Oh yes, I forgot to tell you. You will be weighed each time you receive treatment. The dosage of your treatment is based on your weight. So not only do I have to feel bad about getting treatment, but now someone else knows how much I weigh. There goes one of my best kept secrets.

I finally started getting my treatment as I watched a movie. I kept waiting to feel sick, but nothing really happened. After the session, I was sent home, where I was prepared to feel sick - after all I had all the nausea medicine, vomiting medicine and diarrhea medicine on hand.

That evening I felt great. No effects at all. So I decided I really didn't need my medicine. I guess I am one of those people who feels "why take more stuff when I don't need to". The second day went by without any event. I could not believe it. I felt great. No nausea, vomiting or diarrhea. I was in heaven. Well, maybe not in heaven but you know what I mean. The third day I was great too, until it finally hit me right after dinner. I started feeling a little nauseous, so I decided maybe it was finally time to take my medicine. Well, it was too late. I got so very sick that I did not know which end to keep in the toilet. Between the shivering and the sweating, the toilet and the bucket, I was a complete mess.

So the moral of the story is, even if you feel great or even fine, **take your medicine.** You may be sorry you didn't - just like I was.

*~Liliana Nicholls Grant  
Patient Advisor*

## **Possible Delays in chemotherapy treatment: (cont. from vol 1, issue 3)**

- 1) The preparation of each therapy regimen is done on an individual basis and is checked by 2 oncology nurses prior to its administration.
- 2) Your physician has requested to see you before you begin therapy that day, but is delayed by an emergency or extra time that was required by a previous patient.
- 3) The above applies to a patient who is scheduled for his/her therapy before you. Patients treatment scheduled before you have been delayed, as a result your treatment is delayed.
- 4) There are additional patients schedules for therapy that day because the office was closed the prior day for a holiday.

*~ Elliot Natale  
Family Advisor*

**MEMORIAL CANCER  
INSTITUTE**

For More Information on the  
Memorial Cancer Institute's  
Patient and Family Advisory Council  
contact

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## When Calling Your Doctor's Office: expressing urgency of your call?

Let the person you are speaking to know if:

- 1) Your condition is expected result/side effect of your therapy?
- 2) Your condition is unexpected result/side effect of your therapy?
- 3) Your condition is a result of a pre-existing condition?

Know the answer to these questions:

What is your temperature?

How long have you had this temperature?

What are your symptoms?

How long have you had these symptoms?

Do you have a prescription for antibiotics or any other medication the  
doctor may have prescribed for such an emergency?

Have you filled that prescription?

**Don't panic.** Your physician strives to reply in a timely manner. Your physician's medical staff will triage questions and symptoms on the phone, and if there is any uncertainty, you will be directed to the emergency department.

Remember, education at the start of and throughout treatment goes a long way in your anticipation of possible side effects, and helps alleviate many concerns.

*~ Elliot Natale  
Family Advisor*

## Can't Get Enough...Want More Information?

**The Patient & Family Advisory Council  
wants to open the lines of communication.**

**There are several ways this can be done:**

1. Add your name to our email list to receive quarterly newsletters. Just send an email to  
[MCI-PFAC@mhs.net](mailto:MCI-PFAC@mhs.net)

Make sure to note "Add me to the PFAC  
newsletter list" in the subject line.

2. Call and leave any suggestions or comments for improvement at 954-430-6880 x9700

Make sure to leave your name and phone  
number if you want a return call.

3. If you are interested in joining the Patient & Family Advisory Council or serving in other capacities just call 954-430-6880 x 9700. Your message should include your name, phone number and that fact that you are interested in serving on the council. An advisor or staff member will return your call within the week.

***To obtain past issues of the PFAC Newsletter please call or email Katharine Campbell.***

*Past Issues Include:*

*PFAC Vol 1, Issue 2*

*What is the Advisory Board*

*PFAC Vol 1, Issue 3*

*Billing & Insurance concerns*

*The Medical Assistant role*

*The caregiver experience*