

## ACOR Carcinoid E-Group Archives

The **Carcinoid Cancer Foundation** and **ACOR (Association of Cancer Online Resources)** are pleased to announce that selected archival questions posted on the **ACOR Carcinoid e-group** will now be available on CCF's website. We hope to expand the archives throughout the year. The ACOR Carcinoid e-group has existed since 1997. Its current seven co-list managers have arranged to share the advice and wisdom of its members (now more than 700) on topics that are frequently discussed or are of urgency. **ACOR**, founded by **Gilles Frydman**, is a large collection of cancer-related Internet mailing lists, delivering over 1.5 million e-mail messages weekly to subscribers across the globe.

Anyone interested in joining the Carcinoid e-group may either:

1. Write to [carcinoid-subscribe@listserv.acor.org](mailto:carcinoid-subscribe@listserv.acor.org) and follow the directions to confirm the subscription
2. Go to [www.acor.org](http://www.acor.org) to mailing lists, to c, carcinoid, and follow the instructions there.

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### Communicating with Your Doctors, Suggestions for

Communication - the way to good treatment  
(thanks to Lucy W.)

Sunday, February 13, 2011

Before I go to the doctor, I write up my current meds, symptoms  
And any problems I'm having. I number them and leave white space  
between the problems.

At the top of each page, I put my name and birth date and "Enter this into my records." I make two copies.

I try to be brief as possible. When I get to the doctor's office, I  
Ask that one copy of my document be placed in my file before I see  
The doctor. That way, there's at least a chance he or she will glance at  
it.

When I see the doctor, I get out my copy of the document and make  
Notes under each section. When I am seeing more than one doctor about the same problem, I make  
sure other members of the treatment team get  
copies of my document with my notes on it. For example: "Problem with  
insomnia. Rx Ambien CR - Dr. So-and-so."

That cuts down on tedious repetition and makes for fewer mistakes. I believe 90 percent of the  
problems we have with medical professionals  
Can be traced to poor communication.

There's strength in numbers. When one of our favorite local oncologists moved away, two of us  
drafted a carcinoid patients' manifesto and interviewed two oncs who were interested in treating  
patients with our disease. It was easier for us to do this together than trying to arrange a no-charge  
interview alone. This is a role for local support groups and I hope more groups will try this, if needed.

Life is too short (I think we all know how short) to deal with Doctors who either don't care or don't know and still don't care, about you as a patient. When you find one, make the communication as easy and complete as possible.

Ask if your doctor will communicate via email. Do NOT send them everything that comes your way - just the pertinent info and any questions you might have after the visit. When in doubt, pick up the phone and call them. You probably will not get to speak directly with the doc but a message is likely to get through to them.

Never assume that if your test results were abnormal, "someone" will call you. Follow up on your own. Ask for copies of every test and scan. You never know when they will be important.

### Five E's to Avoid

(thanks to Jan. J., originally from Dr. Eugene Woltering)

November 30, 2009

Like everything else with carcinoid, the five E's also boil down to what the individual can or cannot tolerate.

**Exercise** - please do, but do not "overexercise" which could bring on excessive flushing and other symptoms. Guess this means you need to pace yourself. I like to swim and exercise in the water and do not seem to have a problem with that while Dann the Bear can walk miles and miles with ease.

**Emotion** - Try to keep an even keel - as if. Anger is especially apt to tip one over the edge into symptoms. For me, stress can have me running for the bathroom as fast as possible.

**Ethanol** - that's alcohol. Some of us can still imbibe (though very little); some of us can't. Red wine seems to be a particular culprit in bringing on symptoms.

**Eating** - this is tricky. Check the nutrition section on the Carcinoid Foundation website for foods to avoid. Mostly this is spicy food (unless you are really, really used to it) and "aged foods" like salami, certain cheeses, etc. Here again - for me- it is cooked tomatoes (think spaghetti with red sauce and pizza) and any kind of citrus.

**Epinephrine** - It's the first thing EMTs want to inject if one is having an allergic reaction or a heart problem (guess if there is no other choice one gets epi - but they need to be aware of the effect it could have). At the dentist's, ask for the novacaine without epinephrine. I find that codeine has the same effect on me as epinephrine. In fact, one of the things to be wary about are certain things that end in "ine" - but on the other hand, morphine ends in "ine" and most of us get that after surgery.

Some of these things to avoid may be a matter of "trial and error" - but hopefully, the errors will not be disastrous.

Mostly this is common sense with what our bodies can put up with.

We are each so different from the other.

Carcinoid: Not a one-size-fits-all kind of disease.

## **ACOR Carcinoid E-Group Archives**

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