

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



MEMORIAL CANCER INSTITUTE

# Patient and Family Advisory Board Newsletter

### From the chair...

The newly formed Patient & Family Advisory Council (PFAC) is a committee consisting of patients, caregivers and hospital personnel who focus on various aspects of the patient & family encounters after having been diagnosed with cancer/ blood disorder. I want to take this opportunity to thank everyone involved in making this committee come to together, particularly since everyone is a volunteer. I also wanted to take this time to share some of my experience as a cancer survivor. In 1999, I was diagnosed with Mantle Cell Lymphoma. I had several chemotherapy protocols and some, such as Rituxin with virtually no impact. The original protocol was to include a peripheral blood stem cell transplant. However, I was willing to try various protocols to avoid or delay the transplant. Finally I accepted the

fact that my only chance was the transplant, which occurred in March 2000. As a newly diagnosed patient you will experience many feelings and have a multitude of questions. This committee was formed to help with some of the issues you will encounter.

Most committee members make themselves available should you have questions concerning your individual situation. I am always available to speak with anyone with questions or to discuss all areas related to transplants and the various phases of recovery.

The battle may seem difficult at times but thinking positive and surrounding yourself with the talent at Memorial, friends, family and your religious beliefs are all factors in achieving a positive goal.

*~ Tom Cappadona  
Patient Advisor*

### Meet An Advisor



Tom Cappadona is a bone marrow transplant survivor, local realtor, and chair of the Patient and Family Advisory Council.

#### Advisory Council Members:

- Tom Cappadona - Chairman
- Liliana Nicholls Grant - Vice-Chair
- Natalie Sands - Co-Secretary
- Terry Zimmerman - Co-Secretary
- Katharine Campbell (MCI Staff)
- Carol Kubetz (Radiation Director)
- Marie Lafortune
- Micrena Lafortune
- Elliot Natale
- Mike Sands
- Howard Zimmerman



#### **Core Principles:**

- Dignity & Respect
- Information Sharing
- Participation
- Collaboration

#### **Inside This Edition:**

- Message from the Chair
- Patient roles & responsibilities
- Physician roles & responsibilities
- The importance of the patient survey



## From a Family Member's Perspective: A Patient's and/or Family Member's Goals and Responsibilities

Just as patients and families have expectations for their physicians and physicians offices, we as patients and families also have goals and responsibilities. As I thought about this I wanted to share what I believe are the goals and responsibilities of a patient and family member includes.

- 1) Become an informed/educated patient or family member.
- 2) Ask questions and express your concerns, no matter how trivial they appear to be.
- 3) Be an active participant in the cancer-care decision making process. You have the right to request and expect full information from your physician regarding your diagnosis, planned course of treatment, available al-

ternatives, risks, and prognosis.

4) As an active participant in the development of your course of treatment you are responsible for following your treatment plan and discussing with your physician any changes in that plan that you might be considering.

5) Learn about and take advantage of all resources and support services that are available at MCI and throughout the community.



6) Expect to be treated in a dignified manner with courtesy and respect by all members of the office and medical staff.

7) Notify your physician regarding any unexpected or expected changes in your condition. Expect to hear from him or her in a reasonable amount of time if this constitutes a medical emergency.

8) Build on your strengths and participate in experiences that enhance control and independence.

*~Elliot Natale  
Family Advisor*

## The Patient Satisfaction Survey...What You Need to Know...



I would like to tell you about the patient satisfaction survey. This survey is very important. This survey is how you can see a lot of changes take place. This survey looks at items such as "team cooperation" and "time taken to see a patient". From these surveys, administration can look at how well you receive services such as when the lab technician understands not to stick you two

times and they ask for another tech who can see the vein. It does not mean that the technician does not know what she or he is doing. But some tech's (maybe they have a calling by God) have the ability to find the vein in a second.

That's really exceptional. That is the importance of the survey. The survey's are personally looked at by managers and staff. I encourage every patient to fill the survey. They really care about what we say.

As for my experience, I don't know how to thank the staff (like the doctor and nurses from suite 170, suite 270, women's imaging, radiology, the surgeon, and staff

of the breast cancer center) at Memorial Cancer Center. All of them did a good job. They made me feel happy and I never thought a second about dying. After God, they do their best to help you fight with that disease. In addition, I had the opportunity to attend the Look good...feel better support group where they make you feel pretty. That's an excellent program to help patient's become another person. With chemo I looked like a zombie and that program made me look like somebody. Anyway, that was an excellent experience.

*~ Marie Lafortune  
Patient Advisor*

## From a Family Member's Perspective: A Physician's Goals and Responsibilities

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- 1) Educate each patient about his/her particular form of cancer and what he or she will be facing. Help your patient understand what must be done to fight his or her cancer.
- 2) Treat every question or concern as extremely important to your patient.
- 3) Inform patients, in an unbiased manner as possible, as to what treatments are available that are most suitable to his or her cancer diagnosis.
- 4) Explain the side effects of each treatment, and how to maintain his or her health and well-being while dealing with any situation that may arise.
- 5) Help your patient prioritize his or her options in selecting a treatment approach. Remember, the informed patient is the most

important member of the decision making team.

- 6) Provide your patient's family (at his or her request) with the information they may need as active participants in the cancer care process.
- 7) Inform your patient when any change being considered in the course of treatment may not have any significant effect on the outcome of his or her treatment.
- 8) Inform your patient when change being considered in the course of treatment will have a significant effect on the outcome of his or her treatment.
- 9) Support any decision your patient makes, if medically feasible.
- 10) Set the example for your office and medical staff regarding the treatment of patients courteously and respectfully. You are their role model.
- 11) Put yourself in the shoes of your patient who is going through a trau-

matic experience.

- 12) Encourage your patient to use all the resources and support services available at MCI and throughout the community.
- 13) Respond in a reasonable amount of time to a patient who is reporting expected or unexpected changes in his or her condition that may constitute a medical emergency.
- 14) Coordinate and maintain communication among your patients other doctors.
- 15) Recognize each family members as an active participant in the patient's cancer care team.

*~Elliot Natale  
Family Advisor*

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## The physicians response to their goals and responsibilities:

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Dr. Sundararaman is the Medical Director for Radiology Oncology at Memorial Cancer Institute. He took a look at the above article and added these comments:

- 1) Agree; we all recognize that the delivery of the diagnosis is so important. The facts need to be stated more than once & with someone else in attendance.
- 2) Agree
- 3) Remember when treatment options are reviewed some physicians discuss options outside their specialty which has pros & cons.
- 4) Initial & on-going interactions with all staff should include discussions such as side effects.
- 5) The patient is always part of the treatment team. We must emphasize the patient take charge of things under their control & also

yield to others for factors not in their hands.

- 6) A support system with family & friends is invaluable.
- 7 & 8) Any changes or modifications are discussed with the patient with rationale & implications.
- 9) Patients of sound mind, can make decisions after they are armed with all the necessary data.
- 10) Agree
- 11) It is often possible to sympathize but not everyone can empathize & objectively proceed.
- 12) Agree; Physicians need to have resources name and contact information handy.
- 13) We strive to respond timely. We also recognize if patients are under treatment, they have the opportunity to see a physician the

next day. We need to triage questions & symptoms on the phone. If there is any uncertainty, the patients will be directed to the Emergency Dept. Education at the start & during therapy goes a long way in patients' anticipation of possible side effects & alleviates concerns if side effects occur (probably avoiding the sense of emergency).

- 14) We communicate amongst our own department physicians continuously about patients and referring doctors to ensure continuity of care and have established a Peer Review Process.
- 15) We recognize patients' wishes about what family should know and also vice versa.

*~ Dr. Sundararaman  
Physician Advisor*

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**MEMORIAL CANCER  
INSTITUTE**

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

Katharine Campbell, LCSW  
Kcampbell@mhs.net  
954-430-6880 x9712

Or

Bettye Bradshaw, LCSW  
BBradshaw@mhs.net  
954-987-2020 x5768

## Take advantage of Memorial Cancer Institute's Free Services:

**Oncology Social Worker:** You have recently been diagnosed with cancer. By the time you read this newsletter your anger, shock, denial, and disbelief have been tempered by the many concerns a cancer diagnosis often raises. Memorial Cancer Institute's oncology social workers have received specialized training in working with groups and individuals. They are trained to provide counseling and case management. They are Licensed Clinical Social Workers with specialized training as oncology social workers and have worked in the field of oncology for many years. They have received letters of support which validate their knowledge in this field. They are especially familiar with and understand the needs of oncology patients, including the emotions of getting a cancer diagnosis and how it affects the patient's family, friends, work life and finances. They can be a single source for information, support and guidance in navigating the cancer care system. They recognize that each case is different and therefore

the needs of each person with cancer are different. You may have many questions such as: What will it mean to me to have cancer? How will this affect my family and how will they cope? How can I maintain my emotional well-being during treatment and recovery? What resources can my family and I turn to for help? Remember, an oncology social worker can and will focus on assisting you throughout your treatment. Feel free to contact the oncology social worker for west campus Katharine Campbell via email at KCampbell@mhs.net or by phone at 954-430-6880 x9712 or the oncology social workers for regional and breast cancer center Bettye Bradshaw via email at BBradshaw@mhs.net or by phone at 954-987-2020 x5768 and Sherry Mcmilian via email at SMcmilian@mhs.net or by phone at 954-987-2020 x6471

**Oncology Dietitian:** The dietitian can and should be an invaluable and interactive member of your cancer care team. Maintaining a proper diet before, during, and after your radiation and /or chemotherapy treatment should be an integral part of your complete cancer care. MCI's oncology dietician is a registered and licensed dietician with a BS in nutrition (including a 900-hour dietetic internship) and a Masters in Public Health. She has 3 years of outpatient work experience in the oncology field. Her recommendations are based on the individual patient's diagnosis and some of the nutritional information she provides includes weight loss consultation, healthy living during and after treatment, and how to deal with decreased appetite or weight loss. She is also able to provide information on dietary supplements. She will follow you throughout your treatment. So, please feel free to contact Debi Krieman via email at Dkieman@mhs.net or by phone at 954-987-2020 x3442.

~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 title.
2. Call and leave any suggestions or comments for improvement at 954-430-6880 ext. 9700  
Make sure to leave your name and phone number if you want a return call.
3. Complete the form below to have us send you future newsletters.
4. If you are interested in joining the Patient & Family Advisory Council or serving in other capacities just email [MCI-PFAC@mhs.net](mailto:MCI-PFAC@mhs.net) or call 954-430-6880 ext. 9700 and leave your name, number and that you are inter-

ested in serving. An advisor or staff member will return your call within the week. Or, you can complete the form below and send it to:

Memorial Cancer Institute  
Attn: PFCC/Katharine Campbell  
801 N. Flamingo Road, suite 11  
Pembroke Pines, Florida 33028

*To obtain past issues of the PFAC Newsletters 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*

I am interested in hearing more regarding the Memorial Cancer Institute Patient and Family Advisory Council  
(Please check all that apply):

I am interested in serving as an advisor or in some other capacity of the PFAC

Please send me the quarterly newsletter  Please send to:

Name: \_\_\_\_\_

Address: \_\_\_\_\_