Just Diagnosed with Melanoma... Now What?
If you are reading this, you have undergone a biopsy (either of a skin lesion or a lymph node) or have had other tests in which the diagnosis of melanoma has been confirmed.

**YOU ARE NOT ALONE.** Melanoma is one of the fastest growing cancers in the United States and can strike men and women of all ages, all races and skin types. With a one in 50 lifetime risk of developing melanoma, nearly 77,000 Americans are expected to be diagnosed with the disease in 2013, resulting in over 9,400 deaths. Melanoma is the most common form of cancer for young adults 25- to 29-years-old and the second most common cancer in adolescents and young adults 15- to 29-years-old. The majority of melanomas occur on the skin; in fact, melanoma is the most serious type of skin cancer. Melanoma can also occur in the eye (ocular, or uveal melanoma), in mucous membranes (mucosal melanoma), or even beneath fingernails or toenails.

So what do you do if you have just been diagnosed with melanoma?

First – take a breath…and read the following…
UNDERSTANDING MELANOMA AS A DISEASE

| 1 | You have been given a diagnosis – not a death sentence. |
| 2 | Melanoma survival statistics describe a group of similar patients… but they may have nothing to do with your chance of survival. |
| 3 | Often for melanoma treatment, there is no single answer. Every case is different. |
| 4 | It is important to be an active participant in your treatment. Be your own advocate. |

The “phases” that many melanoma patients seem to go through are **Discovery, Diagnosis, Treatment** and **Recovery**. These phases are very closely linked to physician visits when the information about melanoma diagnosis and treatment is shared with the patient. While melanoma treatment is fairly straightforward, more advanced stages of melanoma require more physician and patient interaction, especially in the Diagnosis and Treatment phases. You may experience an adjustment period after treatment, whether it is physical, emotional or both.

### IMPORTANT QUESTIONS TO ASK YOUR PHYSICIAN

- Why do you think I have melanoma?
- Has my stage of melanoma been determined?
- Do I need more tests to determine my stage?
- If I need more tests, what tests are they?
- What are my treatment options?
- How will you determine if the cancer has spread?
- Should I get a second opinion?
- What type of follow-up will I need?
- Will my treatment be done here or at another center?
Once diagnosed with melanoma, your dermatologist will need to find out more about your disease. He/She may order additional tests or refer you to a medical or surgical oncologist for further evaluation.

Additional surgery may be required to remove the entire tumor with normal tissue surrounding it. Additionally, depending on the melanoma’s thickness or its level of invasion, lymph nodes may also be evaluated for involvement. The results of all of these tests will determine your stage.

Other tests may also play a role in staging. These include:

**Blood Work:** Non-specific indicator that melanoma may be involved in several organ systems.

**Bone Scan:** Uses radioactive material to find if there is any bone involvement with your melanoma.

**CT Scan:** Looks for melanoma in other organs of the body such as: abdomen (bowel and liver), chest (lungs and lymph nodes), neck and head.

**MRI Scan:** Used primarily to determine if melanoma has spread to the brain.

**PET Scan:** Looks for “metabolically active” areas in the body which may be melanoma.

**Sentinel Lymph Node Biopsy:** Removal and examination of the first lymph node(s) to which cancer cells are likely to spread.
STAGING MELANOMA

Staging is the process used to describe the extent of the disease. Oncologists (doctors who specialize in cancer) consider three things when staging melanoma:

1. The thickness and depth of the tumor. This is referred to as Breslow Thickness and is reported in your pathology report. Thin tumors are often easier to treat than thick tumors.

2. Whether the tumor is ulcerated (cracked or bleeding). Ulcerated tumors tend to be more serious than non-ulcerated tumors.

3. If, and how far, the melanoma has spread. Melanoma that has spread to the lymph nodes or to other parts of the body is more serious than melanoma that has not spread.

Stress from a melanoma diagnosis can be felt physically, mentally and emotionally. At times, this stress can feel unmanageable. You may feel as though you have lost interest in things that you used to enjoy. **It is important that all signs of stress, depression, and anxiety be discussed with your doctor.**

**IMPORTANT TIP #1**

As it is most likely that you have been in some shock given the discovery of melanoma, it is important to bring another person with you to take notes on what is said or suggested during your physician visits. These can then be reviewed after the visit.
WHY DO YOU NEED TO KNOW YOUR MELANOMA STAGE?

Your stage helps the melanoma treatment team develop an appropriate plan for you. Your stage will also help determine your prognosis, or outlook.

IMPORTANT TIP #2

Before starting any surgical or treatment plans (and especially in more advanced cases in which treatments may be more controversial), you need to understand your diagnosis and all the various options for your stage of melanoma. In other words, before you undergo any treatment, you need to do your homework and understand your options before deciding with your physician what the plan for your melanoma treatment will be.
# Staging Classifications

<table>
<thead>
<tr>
<th>Stage</th>
<th>What It Means</th>
<th>Treatment</th>
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</thead>
<tbody>
<tr>
<td>IA</td>
<td>The tumor is less than 1 millimeter thick. The outer layer of skin does not look cracked or scraped (ulcerated). It has not spread to any lymph nodes or other organs.</td>
<td>The tumor and some surrounding tissue are removed surgically. Usually no other treatment is necessary.</td>
</tr>
<tr>
<td>IB</td>
<td>The tumor is either less than 1 millimeter thick and ulcerated, or 1–2 millimeters thick and not ulcerated. It has not spread to any lymph nodes or other organs.</td>
<td>The tumor and some surrounding tissue are removed surgically. Usually no other treatment is necessary.</td>
</tr>
<tr>
<td>IIA</td>
<td>The tumor is either 1–2 millimeters thick and ulcerated, or 2–4 millimeters thick and not ulcerated. It has not spread to any lymph nodes or other organs.</td>
<td>The tumor and some surrounding tissue are removed surgically. Usually no other treatment is necessary.</td>
</tr>
<tr>
<td>IIB</td>
<td>The tumor is either 2–4 millimeters thick and ulcerated, or more than 4 millimeters thick and not ulcerated. It has not spread to any lymph nodes or other organs.</td>
<td>The tumor and some surrounding tissue are removed surgically. Additional treatment(s) may be recommended.</td>
</tr>
<tr>
<td>IIC</td>
<td>The tumor is more than 4 millimeters thick and is ulcerated.</td>
<td>The tumor and some surrounding tissue are removed surgically. Additional treatment(s) may be recommended.</td>
</tr>
<tr>
<td>IIIA</td>
<td>The tumor may be any thickness. It may or may not be ulcerated.</td>
<td>The tumor and lymph nodes that have cancer cells are removed surgically. Additional treatment(s) may be recommended.</td>
</tr>
<tr>
<td>IIIB</td>
<td>The tumor and lymph nodes that have cancer cells are removed surgically. Additional treatment(s) may be recommended.</td>
<td></td>
</tr>
<tr>
<td>IIIC</td>
<td>The cancer cells have spread to the lymph nodes, other organs in the body, or areas far from the original site of the tumor.</td>
<td>The tumor and lymph nodes that have cancer cells are removed surgically. Additional treatment(s) may be recommended.</td>
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Note: 1 millimeter = 1/25 of an inch
**MELANOMA TREATMENT OPTIONS**

**Adjuvant Therapy**
The use of chemotherapy or radiotherapy, in addition to surgical resection, in the treatment of cancer.

**Clinical Trials**
Research studies to test promising new or experimental cancer treatments, new ways to detect melanoma, or new ways to monitor melanoma. Clinical trials are often considered the best treatment option for Stage IV melanoma patients.

**Surgery**
Surgery is the mainstay of therapy for early stage melanoma and for resection of an isolated metastatic melanoma site. Types of surgery include: Simple Excision, Mohs Surgery, Wide Local Excision and Sentinel Lymph Node Biopsy.

**Radiation Therapy**
Radiation Therapy is used to prevent a local recurrence of the melanoma. This therapy is often used when clear margins are not obtainable, when there are matted lymph nodes or extracapsular extension in the affected lymph nodes. Types of radiation therapy include: Gamma Knife and Cyber Knife.

**Immunotherapy**
Immunotherapy is treatment designed to activate a person's immune system so that it will destroy melanoma cells within the body.

**Chemotherapy**
Chemotherapy is a type of treatment that destroys melanoma cells by impeding their growth and reproduction. It can be delivered intravenously, by injection or by mouth, and is often used as an adjuvant treatment in melanoma.

**Targeted Therapy**
Targeted Therapy is a type of treatment designed to interfere with specific molecular abnormalities that are driving the growth and spread of the melanoma. This therapy attempts to target those pathways while leaving normal cells intact.

Please visit www.melanoma.org to learn more about melanoma treatment options.
How to approach and organize the information you obtain

• Make a list of the various treatment options for your stage of melanoma.

• Compare/contrast how the large melanoma centers treat your stage of disease.

• Look for consensus in their treatment options.

• Determine how the various treatment options could affect your life (i.e., determine side effects of treatment, the effect on family, work, lifestyle you are used to).

• Make a “wish list” based on the information and decisions you have reviewed and made:

<table>
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<th>YOUR WISH LIST</th>
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<tr>
<td>1 Your ideal treatment plan (medical/surgical and length)</td>
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<tr>
<td>2 Your ideal place the treatment will take place</td>
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<tr>
<td>3 Your ideal followup</td>
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<tr>
<td>4 Your ideal outcome</td>
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Prepare this and your list of questions for your doctor and take them to the appointment with you. As this appointment may require more time than a normal routine visit, be sure the doctor has allowed ample time for the consultation.
POSSIBLE OUTCOMES FROM YOUR DOCTOR VISITS

• Agree on treatment and plan for your therapy.
• Disagree on treatment and plan.
• Ask about second opinions.
• Obtain information from your physician about other resources or major melanoma centers.

FINALLY...

This is not an all-inclusive method for determining your stage of melanoma or the “right” treatment. However, this information can be helpful for the newly diagnosed “now what?” patient. Our hope is that by giving overwhelmed and frightened melanoma patients an approach to finding information about their disease and treatment options, they will become empowered and active participants in their diagnosis and treatment.
FREE PATIENT RESOURCES

Melanoma Patient Information Page (MPIP)
The oldest and most lively online community for melanoma patients.
www.mpip.org

Ask the MRF Nurse
The MRF Nurse provides free, personalized answers to melanoma questions.
askanurse@melanoma.org

Toll-Free Helpline
Our helpline is staffed by trained oncology social workers at CancerCare.
1 (877) 673-6460

MRF Clinical Trial Finder
A free, confidential, personalized service to help patients navigate clinical trials.
1 (800) 517-2218 or www.emergingmed.com/networks/MRF

MRF has set up email addresses to handle various specific functions:
education@melanoma.org
To learn about educational programs.
info@melanoma.org
For general information about melanoma and its treatment.
voluteer@melanoma.org
To learn about volunteer activities.