Melanoma
A TREATMENT GUIDE FOR PATIENTS AND THEIR FAMILIES

CONTENT REVIEWED BY A DISTINGUISHED MEDICAL ADVISORY BOARD
# Melanoma

**Fourth Edition**

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**Melanoma Survivor**

*Do whatever you can to keep a positive attitude. You can beat this.*

~ Jennifer Holt, Stage IB melanoma survivor

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For reprint information, email prp@patientresource.com.
Jennifer Holt is a 53-year-old Stage IB melanoma survivor. She spent more than 20 years working in the financial services industry before taking a part-time job at the local senior center. Now taking a leave from work, she lives with her husband, Robert, and dog, Buster, on a small farm in the country. An amateur photographer, she also plants pumpkins every year and enjoys sharing them with friends and family in the fall.

Melanoma Survivor Credits Daughters with Early Diagnosis

Jennifer Holt

I have fair skin, blue eyes, reddish-blond hair, and a lot of moles and freckles. At the urging of my daughters, I scheduled an appointment with a dermatologist for a full-body check to put everyone’s mind at ease. The doctor removed two moles, labeling one more suspect than the other.

Within three days, the nurse called to inform me the mole they’d removed from my left arm was indeed Stage IB melanoma. She advised me that because of my diagnosis, my care would be transferred to a different doctor who would soon be contacting me about the next steps.

I was somewhat stunned. I didn’t think my initial appointment would actually amount to anything. The nurse had cautioned me to be leery of stories on the Internet and told me to not get worked up with all the horror stories out there. I still did a little research, but I restricted myself to reading only from trusted, reputable resources. I also decided not to seek a second opinion because I trusted my medical team and had faith that they were properly trained and knew what was best.

I initially only told close family and friends about my diagnosis. Until I had more information from my next doctor and knew exactly what I was up against, I didn’t feel like answering questions for which I really didn’t have the answers.

As promised, the new doctor called and scheduled a surgery—a wide local excision at the cancer site on my left arm and a sentinel lymph node biopsy to see how far the cancer had spread. Fortunately, there was no residual cancer at the original site, nor was there any indication of cancer in any of the five removed lymph nodes. No further treatment needed. Hallelujah!

The surgery was completed on an outpatient basis, and the length of my incision was about seven inches. I had to be cautious for a few weeks after the surgery, and my doctor told me to not lift anything. The surgical site was a bit sore, but I guess that was to be expected. I also still have some lingering numbness from the sentinel lymph node biopsy, but it continues to improve. Other than that, I had no issues and felt like everything went very well.

I now see the dermatologist every six months and the surgeon every four months for a skin check. I also have regular chest X-rays.

Through everything, I leaned on my family. We’re very close-knit, and I’m thankful for all the support they provided.

These days, it’s not uncommon for people to ask about the scar on my left arm (which is a bit unsightly). When that happens, I’m happy to talk about my cancer experience, but I’m not really one to shout it from the rooftops. I do, however, always remind people of the importance of using sunscreen, especially on babies and children.

I’ll be forever grateful that my melanoma was caught early, before it had a chance to spread. More than anything, this experience taught me that it’s OK to listen and learn from your children, despite the initial difficulty of accepting the role reversal of parent and child. If my daughters hadn’t urged me to schedule that first appointment, who knows where I’d be today?

Humor has always helped me cope and look at things with a more positive attitude. My daughters and I now share a lot of laughs debating whether mom or daughter knows best. With my scar, we also joke about unusual body markings; who needs tattoos anyway?

My best advice to those who’ve been recently diagnosed with melanoma is to take it one day and step at a time. I’d also encourage everyone to take a notebook to all doctor appointments. Even if you think you’ll remember everything, you won’t. So don’t be embarrassed to write it down and look at it later. Most important, do whatever you can to keep a positive attitude. You can beat this.
Learn the basics of melanoma

Receiving a cancer diagnosis often leads to many emotions, unanswered questions and concerns. Knowing what to expect, the resources available and how others have handled the disease can be a valuable asset as you navigate your cancer care options. This guide is designed to help you learn about melanoma so that you can make more informed decisions throughout your journey.

Although a diagnosis of melanoma can be frightening, new treatment options for all stages have been developing at a rapid pace over the past few years and have resulted in substantially improved outcomes. In fact, melanoma has been the focus of several new, innovative approaches in the quickly evolving field of immunotherapy.

WHAT IS MELANOMA?
One of many specific kinds of cancer, most melanomas arise in the skin, but they may also develop in the eye (ocular melanoma) or in the mucosal linings of the body (mucosal melanoma). This guide focuses on melanoma of the skin, also known as cutaneous melanoma.

Melanoma is one of the three most common types of skin cancer. More than three million cases of skin cancer are diagnosed in the United States each year, but most are basal cell carcinomas and squamous cell carcinomas, which grow slowly and rarely spread or threaten life. Melanoma accounts for only a small percentage of skin cancers, with 73,870 estimated new cases in 2015; however, it is much more likely to spread to nearby lymph nodes or other parts of the body, making it potentially more serious. Thankfully, most melanomas are found at an early stage, when the chance of cure is greatest.

Unfortunately, melanoma is on the rise. The number of cases has steadily increased over the past 30 years, especially among males older than 50 years and females 15 to 29 years old. In fact, melanoma has become the most common cancer among young adults 25 to 29 years old. Greater exposure to ultraviolet (UV) radiation from the sun and indoor tanning devices is thought to be the main cause of this increase, and the International Agency for Research on Cancer includes UV tanning devices on its list of the most dangerous cancer-causing substances—a list that also includes cigarettes and asbestos.

DEVELOPMENT OF MELANOMA
Melanoma begins in the outer layer of the skin in cells called melanocytes. These cells produce the pigment melanin, which gives color to the skin, hair and eyes. Melanocytes may also form moles that can turn into melanomas. The four main types of melanoma of the skin are superficial spreading melanoma, nodular melanoma, lentigo maligna melanoma and acral lentiginous melanoma (see Table 1).

In the first growth stage of melanoma, known as the radial growth phase, the melanoma grows horizontally, staying within the upper layer of the skin (epidermis) (see Figure 1). During this phase, melanomas are not likely to metastasize (spread to other areas). In the next phase, the vertical growth phase, the melanoma begins to grow down into deeper layers, such as the dermis and subcutaneous tissue, as well as up into the epidermis, and the risk for metastasis increases. Because of this, the thickness of the melanoma is the most important factor in determining its prognosis. Melanomas are classified as thin (less than 1 millimeter, about the thickness of a credit card), intermediate (1 to 4 mm) and thick (more than 4 mm). About seven of every 10 melanomas are classified as thin at the time of diagnosis, and the prognosis is best for patients with these melanomas.

As they spread, melanoma cells may enter the lymphatic system, a network of vessels that carry lymph (a colorless fluid) throughout the body. Once in this system, melanoma cells can spread to nearby lymph nodes and may also enter the bloodstream and travel to other parts of the body. Early treatment can stop the melanoma before it spreads through the lymphatic system to lymph nodes in the region or to distant organs, which is why early detection and treatment are so important.

In recent times, treatment outcomes have improved overall, with clinical trial research leading to improvements in various types of treatment for all stages of melanoma. For example, less extensive surgery has been proven safe for many patients, providing a better cosmetic result without compromising the outcome. Treatment has also become personalized through the use of lymphatic mapping and sentinel lymph node biopsy, which allow surgery to be tailored for each specific case of melanoma to better identify people who may benefit from having lymph nodes removed. You can learn more about lymphatic mapping and sentinel lymph node biopsy on page 9.

**TABLE 1**

<table>
<thead>
<tr>
<th>Type</th>
<th>Percentage of all melanomas</th>
<th>Most common site on the body</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Superficial spreading melanoma</td>
<td>70%</td>
<td>Trunk and back in men; legs and back in women</td>
<td>Occurs most frequently in Caucasians</td>
</tr>
<tr>
<td>Nodular melanoma</td>
<td>15%</td>
<td>Back in men; back and lower legs in women</td>
<td>More aggressive type of melanoma</td>
</tr>
<tr>
<td>Lentigo maligna melanoma</td>
<td>10%</td>
<td>Sun-damaged, sun-exposed sites (face, neck, arms, back of hands)</td>
<td>Sometimes mistaken for a “sun spot,” usually in older individuals</td>
</tr>
<tr>
<td>Acral lentiginous melanoma</td>
<td>5%</td>
<td>Palms, soles of the feet, underneath the nail beds</td>
<td>Accounts for about half of all melanomas in people with dark skin, such as African American, Asian and Hispanic individuals</td>
</tr>
</tbody>
</table>
Those with Stage III and IV melanoma now have more treatment options, as many new treatments — and one combination of molecular tumor cell inhibitors — have been approved by the U.S. Food and Drug Administration (FDA) since 2011. Three of these new treatments are based on research showing that a genetic mutation (abnormality) is present in some melanomas, and this abnormality can be the target of a new type of drug. This discovery is leading the way for personalized treatment of advanced melanoma, with treatment selected according to the specific characteristics of the melanoma.

While many patients worry about the side effects of melanoma treatment, the good news is that many of these effects are minimal with treatments for thin or early-stage disease. Side effects from treatments for later-stage disease are usually not severe, and can now be managed in many ways. Talk to your doctor about the potential side effects of your treatment options and ask if there are ways to prevent or reduce them. During treatment, tell your doctor or other member of your health care team about any symptoms or side effects so they can be managed before they become severe.

Be sure to ask your doctor about all of your treatment options and talk about your preferences. Also talk about how to properly follow the guidelines to detect a second melanoma (or other skin cancer) and ways to maintain a healthy lifestyle during and after treatment. A diagnosis of melanoma can be overwhelming. By learning about your specific cancer you can make more informed decisions through the course of your cancer journey.

### ADDITIONAL RESOURCES
- American Academy of Dermatology: [Melanoma](http://www.aad.org)
- Cancer Research Institute: [Melanoma](http://www.cancerresearch.org)
- [Cancer Immunotherapy: Melanoma](http://www.aad.org)

### MELANOMA OF THE SKIN INCIDENCE RATES BY STATE

**Does where you live make a difference in your risk for melanoma?**

The map shows the number of melanoma cases reported in each state. Rates are per 100,000 people and are age-adjusted to the U.S. population in the year 2000.

Melanoma is usually staged twice. First, your doctor will consider the results of your physical exam and any imaging tests that were done, and assign a clinical stage. Then, after a biopsy or surgical procedure, a pathologist will examine tissue taken from the tumor (and possibly nearby lymph nodes) and assign a pathologic stage. Because the pathologic stage is based on more details about your specific melanoma, this staging is more precise and is the key to deciding which treatment options may be best, and to more accurately predict the treatment outcome.

Both the clinical and pathologic stages of melanoma are classified according to the tumor, node, metastasis (TNM) system developed by the American Joint Committee on Cancer (AJCC), as shown in Table 1.

The thickness of the primary melanoma is used to classify the melanoma in the T category. Each T classification is further divided into groups according to whether ulceration (a break in the outer layer of skin over the melanoma) is absent (subcategory a) or present (subcategory b). For example, a non-ulcerated melanoma three millimeters thick is classified as T3a, while an ulcerated lesion two mm thick is classified as T2b. Another factor for thin melanomas (those thinner than one mm) is the mitotic rate, which measures how fast the cancer cells are dividing and multiplying.

The node (N) classification is used to describe how many lymph nodes contain melanoma cells. The N category includes subcategories to describe the number of cancer cells in the lymph nodes. If the cancer cells in the nodes can only be found with a microscope, the metastasis (spread) is considered to be microscopic. If there are enough cancer cells in the lymph node that the doctor can feel the mass during a physical exam or can see the mass on an X-ray, it’s said to be “macroscopic” lymph node involvement. Another subcategory indicates whether melanoma

### Table 1
AJCC System for classifying melanoma

<table>
<thead>
<tr>
<th>Tumor (T)</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tx</td>
<td>Primary tumor cannot be assessed.</td>
</tr>
<tr>
<td>T0</td>
<td>No evidence of primary tumor.</td>
</tr>
<tr>
<td>Tis</td>
<td>Also known as “melanoma in situ,” melanoma cells are found only between the outer layer (epidermis) and the inner layer (dermis) of skin and have not yet invaded these layers. This lesion is considered precancerous.</td>
</tr>
<tr>
<td>T1</td>
<td>Melanoma is no more than 1 millimeter thick (about the thickness of a credit card).</td>
</tr>
<tr>
<td>T1a</td>
<td>Melanoma is no more than 1 mm thick, without ulceration and a mitotic rate less than 1/mm².</td>
</tr>
<tr>
<td>T1b</td>
<td>Melanoma is no more than 1 mm thick, either with ulceration or a mitotic rate of 1/mm² or greater.</td>
</tr>
<tr>
<td>T2</td>
<td>Melanoma is thicker than 1 mm but not more than 2 mm thick.</td>
</tr>
<tr>
<td>T2a</td>
<td>Melanoma is thicker than 1 mm but not more than 2 mm thick, without ulceration.</td>
</tr>
<tr>
<td>T2b</td>
<td>Melanoma is thicker than 1 mm but not more than 2 mm thick, with ulceration.</td>
</tr>
<tr>
<td>T3</td>
<td>Melanoma is thicker than 2 mm but not more than 4 mm (about one-tenth of an inch) thick.</td>
</tr>
<tr>
<td>T3a</td>
<td>Melanoma is thicker than 2 mm but not more than 4 mm, without ulceration.</td>
</tr>
<tr>
<td>T3b</td>
<td>Melanoma is thicker than 2 mm but not more than 4 mm, with ulceration.</td>
</tr>
<tr>
<td>T4</td>
<td>Melanoma is thicker than 4 mm.</td>
</tr>
<tr>
<td>T4a</td>
<td>Melanoma is thicker than 4 mm, without ulceration.</td>
</tr>
<tr>
<td>T4b</td>
<td>Melanoma is thicker than 4 mm, with ulceration.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Node (N)</th>
<th>Description</th>
</tr>
</thead>
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<tr>
<td>Nx</td>
<td>Regional lymph node cannot be assessed.</td>
</tr>
<tr>
<td>N0</td>
<td>No melanoma found in regional lymph nodes.</td>
</tr>
<tr>
<td>N1</td>
<td>Melanoma found in one lymph node.</td>
</tr>
<tr>
<td>N1a</td>
<td>Microscopic metastasis found in one lymph node.</td>
</tr>
<tr>
<td>N1b</td>
<td>Macroscopic metastasis found in one lymph node.</td>
</tr>
<tr>
<td>N2</td>
<td>Melanoma found in two to three lymph nodes.</td>
</tr>
<tr>
<td>N2a</td>
<td>Microscopic metastasis found in two to three lymph nodes.</td>
</tr>
<tr>
<td>N2b</td>
<td>Macroscopic metastasis found in two to three lymph nodes.</td>
</tr>
<tr>
<td>N2c</td>
<td>In-transit melanoma or satellite lesions are found, without metastasis to lymph nodes.</td>
</tr>
<tr>
<td>N3</td>
<td>Melanoma is found in four or more lymph nodes, or in two or more lymph nodes that appear to be joined together (known as matted lymph nodes). Or, melanoma is found as in-transit lesions or as satellite lesions that have spread to the lymph nodes.</td>
</tr>
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<table>
<thead>
<tr>
<th>Metastasis (M)</th>
<th>Description</th>
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<tbody>
<tr>
<td>Mx</td>
<td>Metastasis cannot be assessed.</td>
</tr>
<tr>
<td>M0</td>
<td>No metastasis.</td>
</tr>
<tr>
<td>M1a</td>
<td>Metastasis to skin, subcutaneous tissues or distant lymph nodes.</td>
</tr>
<tr>
<td>M1b</td>
<td>Metastasis to lung.</td>
</tr>
<tr>
<td>M1c</td>
<td>Metastasis to any other distant organs.</td>
</tr>
</tbody>
</table>

### Table 2
Stages of melanoma

<table>
<thead>
<tr>
<th>Stage</th>
<th>T</th>
<th>N</th>
<th>M</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Tis</td>
<td>N0</td>
<td>M0</td>
</tr>
<tr>
<td>IA</td>
<td>T1a</td>
<td>N0</td>
<td>M0</td>
</tr>
<tr>
<td>IB</td>
<td>T1b</td>
<td>T2a</td>
<td>N0</td>
</tr>
<tr>
<td>IIA</td>
<td>T2b</td>
<td>T3a</td>
<td>N0</td>
</tr>
<tr>
<td>IIB</td>
<td>T3b</td>
<td>T4a</td>
<td>N0</td>
</tr>
<tr>
<td>IIC</td>
<td>T4b</td>
<td>N0</td>
<td>M0</td>
</tr>
<tr>
<td>IIIA</td>
<td>T1a</td>
<td>T4a</td>
<td>N1a</td>
</tr>
<tr>
<td>IIIB</td>
<td>T1a</td>
<td>T4b</td>
<td>N1a</td>
</tr>
<tr>
<td>IIIIC</td>
<td>T1a</td>
<td>T4b</td>
<td>N1b</td>
</tr>
<tr>
<td>IV</td>
<td>Any</td>
<td>Any</td>
<td>N0</td>
</tr>
</tbody>
</table>
STAGES OF MELANOMA

Stage 0
Melanoma only in outer layer of skin

Stage IA
Melanoma no more than 1 mm thick

Stage IB
Melanoma between 1 mm and 2 mm and no ulcer

Stage IIA
Melanoma between 2 mm and 4 mm and no ulcer

Stage IIB
Melanoma larger than 4 mm and no ulcer

Stage IIC
Melanoma is larger than 4 mm with ulcer

Stage IIIA
Micrometastases to no more than 3 lymph nodes

Stage IIIB
Macrometastases to no more than 3 lymph nodes or in-transit melanoma; metastatic deposits in lymph vessels, but not in lymph node

Stage IIV
Cancer has spread to other parts of the body:
- Metastases in lymph nodes and vessels
- Metastases in bloodstream travel to other parts of the body

Stage IV
Cancer has spread to other parts of the body:
- Metastases in lymph nodes and vessels
- Metastases in bloodstream travel to other parts of the body

Primary melanoma

Brain
Lung
Liver
Lymph nodes
Intestine
Bone

While the stage of melanoma is the main factor in determining your prognosis, it's important to remember that prognosis by stage is based on groups of people with similar risk factors, so the prognosis for one individual may differ from that for others. Talk to your doctor about prediction tools that can help estimate your prognosis according to your specific situation. One such tool is available at http://melanomaprognosis.org.
To learn more about your specific melanoma, your doctor will rely on your pathology report. It provides important information about the characteristics of your melanoma and serves as a guide to plan the treatment most likely to be effective. The details in this report are also important for helping your doctor determine the prognosis (likely outcome).

Pathology reports may look different at different cancer centers and hospitals, but most include the same details. The descriptions may be difficult to read because they include unfamiliar terms, but learning more about what each element means can help you better understand your diagnosis and allow you to more clearly discuss your treatment options with your doctor.

Your diagnosis is based on the careful examination of tissue taken during a biopsy or surgical procedure to remove the melanoma (and possibly lymph nodes). A pathology report is provided by a pathologist after he or she has examined the specimen with and without a microscope, measuring its thickness, describing its location and appearance and performing special tests (see Table 1).

For people with localized disease (Stage I and II), the three most important features for predicting outcome are the tumor thickness, the presence or absence of ulceration and the mitotic rate (how fast the melanoma cells are dividing). For the few melanomas that are metastatic at the time of diagnosis, molecular testing on a sample of the melanoma is recommended to check for a mutation (abnormality) in the BRAF gene (see page 12 for additional information). Other genetic mutations are currently being evaluated in clinical trials, and routine testing for these mutations may be done in the future.

Accurate pathologic assessment and interpretation of results is necessary, and a second opinion from another pathologist with extensive expertise in interpreting melanoma tissue can be helpful, especially if the pathology report does not contain a definite diagnosis or if it’s likely the melanoma has already spread.

The pathology report also indicates the stage of the melanoma. Learn more about how melanoma is staged on page 5. Always ask for a copy of your pathology report, and ask your doctor to explain how the results will influence treatment options. Also, ask what the pathology results mean in terms of your prognosis.

### TABLE 1

<table>
<thead>
<tr>
<th>ELEMENTS OF A MELANOMA PATHOLOGY REPORT</th>
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<tbody>
<tr>
<td><strong>Descriptor</strong></td>
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<tr>
<td>---</td>
</tr>
<tr>
<td><strong>Type</strong></td>
</tr>
<tr>
<td><strong>Thickness</strong></td>
</tr>
<tr>
<td><strong>Ulceration</strong></td>
</tr>
<tr>
<td><strong>Location (site)</strong></td>
</tr>
<tr>
<td><strong>Growth phase</strong></td>
</tr>
<tr>
<td><strong>Deep margin</strong></td>
</tr>
<tr>
<td><strong>Surgical margins</strong></td>
</tr>
<tr>
<td><strong>Lymph node status</strong></td>
</tr>
<tr>
<td><strong>Mitotic rate (or count)</strong></td>
</tr>
<tr>
<td><strong>Regression</strong></td>
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<tr>
<td><strong>Blood vessel/lymphatic invasion</strong></td>
</tr>
<tr>
<td><strong>Satellite lesions (or satellitosis)</strong></td>
</tr>
<tr>
<td><strong>Molecular testing</strong></td>
</tr>
</tbody>
</table>

*Molecular testing is now recommended for all non-localized melanomas.*

### QUESTIONS YOU MAY WANT TO ASK YOUR MEDICAL TEAM

- May I have a copy of my pathology report?
- What is my exact type of melanoma?
- Has the cancer spread to my lymph nodes or other organs?
- What is the stage of cancer, and what is my prognosis? What does this mean?
- Would testing for genetic abnormalities be helpful?
- What is the risk that my melanoma will come back five, 10 or more years from now?
Surgery is usually the primary treatment option for melanoma and may be the only treatment necessary in certain cases, including some early-stage tumors. Surgery as initial treatment is done with the intent to cure the cancer or prolong life, and the goal of surgery is to remove all malignant tissue and reduce the risk of recurrence (reappearance) of the melanoma. Other treatments, such as targeted therapy, immunotherapy, radiation therapy or chemotherapy, may be given in addition to surgery as part of the overall treatment regimen.

In addition to removing the primary melanoma, the surgeon may remove nearby lymph nodes. A procedure known as a sentinel lymph node (SLN) biopsy may be performed to find out if melanoma has spread to nearby lymph nodes. A skin graft — a section of skin from another area of the body — may be needed after the removal of a large melanoma or multiple melanomas in one area to ensure that the surgical wound is adequately covered.

SURGICAL REMOVAL OF THE MELANOMA

In most cases, the recommended surgical procedure to remove a primary melanoma is a procedure known as a wide local excision. With this procedure, the melanoma is removed along with a measured area of normal skin and underlying fatty tissue around and below the melanoma. The normal tissue is removed as a precaution; if any melanoma cells have started to spread beyond the original site, they will likely be removed with the normal tissue. This normal tissue is called the surgical margin, and the width of the margin depends on the thickness of the melanoma (see Table 1, Figure 1). It was once thought that an even wider excision was necessary, but research has shown that the currently recommended surgical margins offer a better cosmetic result while still providing the same level of safety and effectiveness.

**TABLE 1**

<table>
<thead>
<tr>
<th>Melanoma thickness</th>
<th>Recommended excision margin</th>
</tr>
</thead>
<tbody>
<tr>
<td>In situ</td>
<td>0.5 cm</td>
</tr>
<tr>
<td>≤1.0 mm</td>
<td>1.0 cm</td>
</tr>
<tr>
<td>1.01-2 mm</td>
<td>1-2 cm</td>
</tr>
<tr>
<td>2.01-4 mm</td>
<td>2 cm</td>
</tr>
<tr>
<td>&gt;4 mm</td>
<td>2 cm</td>
</tr>
</tbody>
</table>

The two most common side effects of lymph node dissection are wound complications (such as infection) and lymphedema. Lymphedema is a buildup of lymph fluid in an area that occurs because lymph fluid cannot drain properly if lymph nodes are removed (see Figure 2). This causes swelling in a limb (arm or leg), which can be uncomfortable and restrict activity. You can learn more about lymphedema on page 15.

**ADDITIONAL RESOURCES**

- American Cancer Society: [www.cancer.org](http://www.cancer.org)
- Melanoma Skin Cancer
- National Comprehensive Cancer Network: [www.nccn.org](http://www.nccn.org)
- NCCN Guidelines for Patients: Melanoma
A procedure known as sentinel lymph node mapping is recommended when there is an increased risk the melanoma may have spread to nearby lymph nodes. Also known as lymphoscintigraphy, this procedure tracks the exact path of lymph (the bodily fluid that carries white blood cells) as it drains from the skin surrounding the melanoma to the nearest lymph node. The draining lymph node closest to the melanoma is called the sentinel lymph node (SLN). Identifying which lymph node is the SLN is important because the decision to remove lymph nodes often depends on whether melanoma has spread to an SLN.

**WHAT IS AN SLN BIOPSY?**
In the operating room, the surgeon will inject a blue dye into the skin around the site of the melanoma to visually identify the SLN (see Figure 1). The surgeon will then make a small incision in the area of the lymph nodes and remove the SLN, which can be identified by the blue dye and the presence of the radioactive tracer as detected by a hand-held device. This procedure is called an SLN biopsy. The node is then carefully examined by a pathologist for the presence of melanoma cells. Because the SLN is the first place to which lymph drains from the site of the melanoma, it's highly unlikely the melanoma has spread to any other lymph nodes if no cancer cells are found in the SLN.

This procedure involves a team of experienced physicians: A radiologist who specializes in nuclear medicine imaging reviews the images; a surgeon who injects the blue dye and performs the biopsy; and a pathologist who evaluates tissue from the SLN to see if melanoma cells are present.

**WHAT ARE THE BENEFITS AND RISKS?**
The primary benefit of lymph node mapping and SLN biopsy is that they accurately identify people at low risk for recurrent disease; these patients can then be spared a lymph node dissection and additional treatment after surgery. Additionally, recent evidence has shown a substantial survival benefit for patients with intermediate-thickness melanomas (1.2 to 3.5 mm thick) with a positive SLN biopsy who then had a complete regional lymph node dissection. The rate of complications associated with the procedure alone is low, especially compared with the rate of complications after a lymph node dissection. An SLN biopsy should also be considered as part of the staging of thicker melanomas (more than four mm) if the information will help guide additional surgery and other treatments, and the risks of the procedure are acceptable.

**WHAT IS LYMPH NODE MAPPING DONE?**
Lymphoscintigraphy is a special type of imaging technique done in a hospital’s nuclear medicine department on the day before or the day of surgery to remove the melanoma. A radioactive tracer is injected into the skin around the site of the melanoma, and an imaging device that detects radioactivity makes a series of images that show the path of the radioactive material as it travels to the nearest group of lymph nodes.

**WHO SHOULD HAVE LYMPH NODE MAPPING AND SLN BIOPSY?**
Two major organizations of cancer experts – the American Society of Clinical Oncology (ASCO) and the Society of Surgical Oncology (SSO) – both recommend that the procedure be performed for all people who have a melanoma of the skin (at any place on the body) that is one to four millimeters thick.

Although there’s not enough evidence of treatment benefit for an SLN biopsy for melanomas less than one mm thick, the procedure should be considered if a thin melanoma has certain aggressive features, such as:

- Positive deep surgical margins (making the true thickness uncertain)
- Ulceration (the melanoma has broken the skin covering it)
- Lymphovascular invasion (melanoma cells are found in lymph vessels)
- Mitotic rate of 1/mm² or more and a thickness of 0.7 mm or greater

**ADDITIONAL RESOURCES**
- AIM at Melanoma Foundation: www.aimatmelanoma.org
- American Society of Clinical Oncology: www.cancer.org
- Sentinel Lymph Node Biopsy for Melanoma
- Skin Cancer Foundation: www.skincancer.org

**FIGURE 1**
Injection of blue dye and radioactive tracer around primary melanoma
Sentinel lymph node is removed and tested for cancer cells

©Patient Resource LLC
The most important factor in selecting the best treatment plan is the stage of your melanoma. More than 80 percent of melanomas are considered early-stage (Stage I or II) at the time of diagnosis, and the cure rate is highest for these melanomas. For many early-stage melanomas, surgical removal of the melanoma is the only treatment needed.

STAGE IA, IB AND IIA
Surgery (a wide surgical excision) is the initial treatment for Stage I-IIA melanomas. Lymphatic mapping and a sentinel lymph node (SLN) biopsy are recommended for melanomas that are one millimeter or thicker, or less than one mm thick with aggressive features. If the SLN is positive (contains melanoma cells), the stage will be reclassified as Stage III and a complete lymph node dissection is recommended. Additional treatment after surgery, such as chemotherapy or radiation, has not been found beneficial for early-stage disease. Surgery alone leads to an excellent outcome for most people with these stages of disease.

STAGE IIB AND IIC
A wide surgical excision is also recommended for Stage IIB and IIC melanomas. Because these melanomas are thicker than earlier-stage melanomas, the width of the surgical margin is greater. An SLN biopsy is also recommended, and a complete lymph node dissection should be done if an SLN is positive. Immunotherapy with high-dose interferon alfa (Intron A) may be recommended after surgery for ulcerated melanomas more than four mm thick, even after a negative sentinel node biopsy. Side effects are common with interferon alfa and include chills, fever, aches and fatigue. Talk to your doctor about whether this treatment option is right for you, including your risk for recurrence and the benefits and risks of interferon after surgery for your specific diagnosis.

Patients and their loved ones play an important role in detecting melanoma. Unlike other cancers, melanoma of the skin can often be seen as it grows and has many defining traits. And because melanoma is the most aggressive form of skin cancer, early detection is critical.

A skin self-examination once a month is a great way to check for melanoma at home. And be sure you’re encouraging your family and friends to check themselves as well! To conduct a self-exam, use a mirror to examine your head, face, neck, chest and torso. If you have a lot of hair, use a blow dryer to move your hair while you check your scalp. Use a hand mirror to inspect the back of your neck, shoulders, upper arms, back, buttocks and legs. Don’t forget your hands, palms, feet, soles and nails. If you notice any moles or spots that change shape, size or color, make an appointment with a dermatologist. For more information on melanoma abnormalities, see the ABCD chart on page 18.

If your family is considered at high risk for familial melanoma, a regular examination by a dermatologist is typically recommended for each family member. Familial melanoma affects families with two or more first-degree relatives diagnosed with melanoma, and accounts for 5 to 10 percent of all melanoma cases. Other inherited factors such as skin, hair and eye color can also increase a person’s risk for melanoma. Children who are considered at high risk should start performing examinations at 10 to 12 years of age.

Free skin cancer screenings are offered in many areas through the American Academy of Dermatology’s SPOTme program. To find a free screening site near you, visit www.aad.org/spot-skin-cancer.
Stage III and IV melanoma

An advanced melanoma diagnosis of Stage III or Stage IV disease indicates that the primary tumor cells have spread beyond the original site to lymph nodes in the region (known as regional disease) or to distant sites in the body (known as advanced disease). The type of treatment your doctor recommends will depend primarily on the specific stage and location of the melanoma, as well as your overall health. Your treatment regimen may include surgery, targeted therapy, immunotherapy, chemotherapy, radiation therapy or a combination of treatments.

Talk to your doctor about the risks and benefits of each treatment option to select the most appropriate treatment for you, based on your diagnosis. Many of the treatments used for Stage III and IV melanoma require specialized knowledge and should be managed by an appropriately trained medical oncologist, surgical oncologist, dermatologist or other specialized physician. Talk to your team about who will be delivering your treatments, the possible side effects you may experience and how they can be managed.

TREATMENT OF STAGE IIIA, IIIB AND IIIC MELANOMAS

Surgery is the initial treatment for Stage III melanoma and usually involves the removal of involved lymph nodes. Additional treatment after surgery, which is called adjuvant therapy, is often recommended, especially in high-risk patients. The goal of adjuvant therapy is to kill any remaining melanoma cells to decrease the chance that the melanoma will return and to improve survival rates. Adjuvant treatment usually includes a form of interferon (high-dose or pegylated). Adjuvant therapy may also include targeted therapy or immunotherapy drugs. Radiation therapy to the area where the lymph nodes were removed may be given if melanoma cells have spread outside the lymph node or are found in many lymph nodes, or if the tumors are very large or have invaded surrounding tissues.

For Stage III in-transit melanoma, the preferred primary treatment is the surgical removal of all melanoma metastases (when only a few lesions are present), and an SLN biopsy, if it has not already been performed. For locally advanced or recurrent melanoma on an arm or leg, procedures known as hyperthermic isolated limb perfusion and isolated limb infusion may be options when multiple, large or recurrent lesions are present. These involve isolating the blood flow to the limb and treating it directly with high-dose chemotherapy.

If surgical removal of all melanoma metastases is not possible, other treatment options include injections of the bacillus Calmette-Guerin vaccine to stimulate an immune response; radiation therapy; laser treatment using a carbon dioxide laser to remove the melanoma; or systemic therapy. Targeted therapy or immunotherapy (explained on page 12) may also be options for you.

TREATMENT OF STAGE IV MELANOMA

Management of Stage IV melanoma typically includes targeted therapy, immunotherapy and chemotherapy. Until 2011, only two immunotherapy drugs and one chemotherapy drug were approved in the United States for treating melanoma. Options for systemic therapy (treatment that travels through the body via the bloodstream), however, have greatly expanded with the subsequent approval of several new drugs (see Table 1).

Combinations of treatments, such as surgery with radiation therapy, or chemotherapy with immunotherapy (called biochemotherapy), are often used. Radiation therapy may also be included to treat symptoms of metastatic cancer, primarily to the brain or bones.

Surgical removal of melanoma metastases is usually done when possible, especially if the tumor is limited in size and confined to one organ, if the person has symptoms and if the risk of surgery-related complications is acceptable. When melanoma has spread to the brain, radiation therapy or surgery sometimes can relieve symptoms or prevent future symptoms.

If surgery is not possible, immunotherapy may be used as first-line treatment, and second-line immunotherapy treatment options are available if the first-line drugs are not effective. Targeted therapy may be another option for people with Stage IV melanoma with the BRAF gene mutation. Combinations of immunotherapies and targeted therapies are also under evaluation in clinical trials. Talk to your doctor to see if volunteering for a clinical trial is right for you.

SURVIVOR VOICE | Heather Snyder | Stage IV melanoma survivor

"Patients with advanced cancer should know that it does get better, and you can have a busy, active and healthy life both during and after cancer treatment."

Read about her journey on page 14.
TARGETED THERAPY

Targeted therapy is treatment with drugs or other substances that block the growth and progression of cancer. They do so by interfering with specific molecules involved in tumor growth and progression. The targeted therapy agents block or modify the molecules on or inside cancer cells that alter signaling pathways, which are complex systems that direct basic cell functions, such as cell division and cell death.

The development of certain targeted therapy drugs used to treat melanoma began after researchers identified a specific genetic mutation, called BRAF V600, in about half of all people with metastatic melanoma. The mutation affects the BRAF gene and causes tumor cells to grow and divide more quickly. Drugs known as BRAF inhibitors specifically attack the mutated form of BRAF and are approved for use only in people who have melanoma with the BRAF mutation. Because the attack is so targeted, molecular testing must be done on a sample of melanoma tissue before treatment begins to see if the mutation is present.

The identification of the BRAF and MEK mutations and the development of drugs to target these two mutations is a significant advancement in the treatment of Stage IV melanoma. Clinical studies have shown that using the combination of a BRAF plus a MEK inhibitor resulted in higher response rates and improved progression-free and overall survival compared to either drugs as a single agent or standard chemotherapy. And the side effects are more manageable. Thus, the combination is generally used together in patients with BRAF mutated metastatic melanoma.

Because targeted drugs are meant to attack only the cancer cells and not normal cells (unlike traditional chemotherapy), side effects are typically more manageable.

IMMUNOTHERAPY

While advanced melanoma can be difficult to treat using standard therapies, it’s been one of the most responsive cancers to newly developed immunotherapy treatments. Immunotherapy is a type of cancer treatment that seeks to stimulate your own immune system to fight cancer.

The use of immunotherapy to treat melanoma began in the 1990s with interferon alfa (Intron A) and interleukin-2 (Proleukin), which are both types of cytokine treatment. Cytokines are the messengers of the immune system, aiding in communication between immune cells to induce an immune response. Cytokine immunotherapy treatments involve introducing large amounts of manufactured cytokines to the immune system to stimulate it to respond, including boosting certain cells’ abilities to attack cancer. When used alone, both interferon alfa and interleukin-2 have been shown to shrink advanced melanoma tumors in some patients. They are often combined with additional treatments such as other immunotherapy or chemotherapy drugs. In 2011, another type of cytokine therapy was approved to prevent malignant melanoma from recurring after surgery. Peginterferon alfa-2b (Sylatron) is a pegylated drug, which stays in the blood longer than non-pegylated cytokines. Because it stays in the blood longer, peginterferon alfa-2b can be taken less often than other cytokines and still be as or more effective than they are.

Cytokines have the potential to cause substantial immune-related side effects especially when given in high doses. Because of this, certain patients must receive treatment in a hospital so they can be monitored closely by their physician.

Recent advancements in immunotherapy treatment for melanoma include drugs known as checkpoint inhibitors. Immune cells communicate with other cells (including tumor cells) through several proteins on the surface of each cell that connect to one another. Immune checkpoints are specific connections between cells that help regulate the immune response, specifically when to shut down the response once it’s no longer necessary. Immune checkpoint inhibitors are drugs that block the checkpoint from being engaged (see Figure 1), which essentially turns the immune system back on so it can fight the melanoma. These types of drugs have shown significant promise, with the approval of three checkpoint inhibitor drugs to treat melanoma since 2011: ipilimumab (Yervoy), pembrolizumab (Keytruda) and nivolumab (Opdivo). New immunotherapy treatments are quickly becoming first-line and second-line therapy options, above other treatment types that have long been considered standard therapy.

Another type of immunotherapy treatment for advanced melanoma is oncolytic virus immunotherapy. In this treatment, an oncolytic virus (a virus that infects and kills cancer cells) is injected into tumors. Talimogene laherparepvec (Imlygic), often called T-VEC, is the first FDA-approved oncolytic virus immunotherapy to treat melanomas that cannot be removed with surgery.
Immunotherapy is commonly associated with side effects such as flu-like symptoms (chills, fever, muscle and joint aches and fatigue), nausea, vomiting, rash and diarrhea, but may also cause serious, immune-related side effects. Talk to your doctor about how to prevent, monitor and manage side effects during and after treatment with immunotherapy.

**CHEMOTHERAPY**

Chemotherapy involves the use of drugs to kill rapidly multiplying cells, including cancer cells. This type of treatment has not been as effective for melanoma as for other types of cancer, and studies have shown that chemotherapy has no benefit after surgery for Stage III melanoma. Thus, chemotherapy is primarily used to relieve symptoms related to Stage IV melanoma, and may help shrink melanomas in a small percentage of patients with Stage IV disease.

Chemotherapy is often associated with side effects such as nausea, vomiting and a decrease in the number of healthy blood cells, but these effects are usually temporary and manageable.

**RADIATION THERAPY**

Radiation therapy uses high-energy X-rays or other forms of radiation to destroy cancer cells. Radiation has been shown to reduce the risk of relapse when multiple lymph nodes are involved with the tumor, when a tumor is very large, or if it has invaded surrounding tissues, but it has not shown benefit in overall survival. It can, however, shrink tumors and reduce symptoms of metastatic melanoma in the bones, brain, skin and underlying tissues.

Radiation can be delivered in multiple ways. External-beam radiation is delivered from a source outside the body; it may cause sunburn-like skin changes in the area being treated, and can also cause swelling, a feeling of heaviness in the irradiated area, and overall fatigue. Stereotactic radiation is the use of focused radiation delivered through a device (e.g., Gamma Knife, CyberKnife). This type of treatment has been highly effective in controlling limited numbers of brain metastases where surgery may be difficult. Stereotactic radiation may also be used to relieve symptoms related to metastatic disease in bone.

**QUESTIONS TO ASK YOUR MEDICAL TEAM WHEN DISCUSSING TREATMENT OPTIONS**

- Will you be my only doctor or will I have a team of oncologists?
- What are my treatment options?
- What are the possible side effects of each treatment?
- How common are these side effects?
- When are these side effects most likely to occur and how long will they likely last?
- Is there a way to prevent or manage my side effects?
- When should I contact a member of my health care team about a side effect?
- How long will my treatment plan last? Where will my treatments be done?
- Will I need to make any lifestyle changes before, during or after treatment?
- How do the benefits of the recommended cancer treatment compare with the risks?

**VETERAN NEWS ANCHOR SURVIVES MELANOMA**

Sam Donaldson is widely known for his 46-year career at ABC News and his distinctive broadcasting style. In 1995, Sam became known for another reason—a diagnosis of Stage III melanoma at age 61. He was inducted into what he calls the Melanoma Club. “You’re drafted and you suddenly find yourself in a club you don’t want to join.”

→ Like many melanoma experiences, Sam’s began when he noticed a changing mole. One of his moles changed colors, so he had it removed. The pathology reports on the mole and surrounding tissues came back negative for melanoma. With no reason to doubt the results, Sam carried on.

Seven years later, as he was showering, Sam discovered an egg-sized lump in his groin. Immediately he knew something was wrong. He saw a doctor and told him about the mole that wasn’t melanoma. The doctor wanted to take a biopsy right away.

This time, the results came back positive for melanoma. After several appointments, Sam and his health care team decided he would have surgery to remove the lump. Sam met with a renowned oncology surgeon at the National Cancer Institute. “The doctor was very congenial. He examined me physically, looked at the CT scan result and the data on my biopsy and said, ‘I think you have a good chance to lead a long and normal life.’ I blurted out, ‘I don’t believe you!’”

Fortunately, his surgeon was right. The surgery was successful. Only one lymph node was involved, and there was no metastasis. As a survivor, Sam wants to do what he can to bolster the hope of other survivors. “I want to encourage people who have been diagnosed with cancer. That’s something every cancer survivor can do—be a living witness to others similarly situated.”

Sam Donaldson is a member of the Patient Resource Cancer Guide Advisory Board.
Throughout treatment I always did my best to stay active, and I feel like I’m the healthiest I’ve ever been right now. I exercised regularly and still ran during chemo, which I believe alleviated some of my side effects and kept my mind right as I dealt with this disease. Joint pain was a problem, but the more I kept moving, the better I felt—thus my desire to work out almost every day.

I’ve run in several half marathons over the past few years, I recently completed a marathon, and I have a triathlon coming up. I didn’t let cancer cramp my style.

You’re going to need plenty of support to help you through this, and I was lucky enough to have it from every direction. My husband, parents, siblings and in-laws pulled together and helped me tremendously, as did our church community who sent over food and set up a fundraiser for us. I’m eternally grateful to everyone who reached out, and I couldn’t have survived without them.

Today, I try and return the favor so that other patients with advanced cancer realize you don’t have to live life feeling like death is breathing down your neck. It does get better, and you can have a busy, active and healthy life both during and after cancer treatment.

I struggled at times but have used this opportunity to teach my kids that you have to be tough to make it in this world—and that their mommy is tougher than cancer!

Seven years after being diagnosed, I’m eternally grateful that I’ve been able to watch my children grow up while enjoying a healthy, active and cancer-free life! To say I’ve been humbled is an understatement; I’m eternally thankful for every single waking moment.

Cancer doesn’t care if you’re young, busy or if you have family that’s depending on you. No one is safe, and it took a while to accept my reality: Not only did I have cancer; I had the worst kind possible—the kind that kills.

The disease had already spread to my lymph nodes, and I was told I only had six months to live. Hearing that my life had an official expiration date was devastating, especially with a two-year-old son and a six-month-old daughter at the time.

I cried hysterically but quickly realized that I needed to pull myself together and face this disease head on. It was time to suck it up and find a way to survive—for myself and my family.

A surgeon immediately removed the affected areas and I began taking interferon (Intron A), but six months later the cancer returned.

I began aggressive biochemotherapy, which consisted of a combination of interleukin 2 (IL-2), cisplatin, vinblastine and dacarbazine (DTIC-Dome). Cancer and chemo became our new “normal,” but only because we didn’t have any other choice.

Because I still had two tumors left on my butt (God has a funny sense of humor), doctors operated again, but five months later the cancer was back. I cried all weekend until my doctor said he knew of a new drug I could try, but it was still in a clinical trial.

After traveling to the facility where the clinical trial was offered, I was tested for the BRAF mutation and was thrilled that I qualified. The trial drug, vemurafenib (Zelboraf), has kept the cancer at bay for the past five years. Most patients only take it an average of eight months, but my body responded extremely well so for now I continue to take this medication twice daily. Although there have been random (and concerning) side effects, I’ve managed to keep them under control with the help of several doctors (whom I’m lucky enough to have on speed dial).

As a busy young mother caring for a toddler and a baby, Heather Snyder regretfully neglected a suspicious-looking spot on her left calf. By the time her dermatologist got a look, he knew immediately that they were dealing with melanoma, and tests soon confirmed the unthinkable. At barely 30 years old, Heather was diagnosed with Stage IV melanoma and given less than a year to live.

IT’S OK TO BE DEVASTATED AS LONG AS YOU GET MOTIVATED
A melanoma diagnosis is likely to lead to many changes in your daily life. Once treatment starts, this may include not only an adjustment to your schedule but also the prevention or management of disease-related symptoms and treatment-related side effects.

MANAGING SIDE EFFECTS

The possibility of pain is often one of the leading fears for many people with cancer. However, melanoma patients do not usually have pain related to the disease and if they do, there are ways to manage it effectively. Pain may occur temporarily after surgery or can result from metastatic melanoma after it has spread to other tissues or organs. If you experience pain, don’t hesitate to talk to your doctor or another member of your treatment team about how it can be managed and any fears you may have about pain medication.

Mild pain can usually be managed with over-the-counter pain relievers, and more severe pain is often treated and controlled with prescription drugs, such as opioids (narcotics). It’s important to take pain-relieving drugs exactly as your doctor prescribes, including at the intervals suggested rather than on an “as needed” basis. Pain medication is more effective when taken this way because it can help stop pain before it develops or worsens.

People with cancer may also fear the side effects related to treatment. However, it’s now possible to prevent or manage most of the common side effects associated with melanoma treatment. This is extremely important because when side effects are managed well, patients feel better and are generally more likely to finish their treatment regimen.

Not all people will have the same side effects or any side effects at all, even when taking the same medications or receiving similar treatments. Side effects also vary in severity and differ according to the type of treatment (see Table 1).

Some of the common side effects associated with melanoma and its treatments include:

- **Lymphedema**: The most common side effect of surgery for melanoma is lymphedema, a buildup of fluid in body tissues that causes some enlargement of an arm or leg. Lymphedema is most likely to occur after the removal of certain lymph nodes. Without the nodes, lymph fluid may not flow normally, causing the fluid to build up. The amount of swelling can range from mild to extreme, and many patients have no swelling.

Management of lymphedema focuses on ways to reduce swelling and control discomfort. Your doctor may suggest wearing a compression stocking or sleeve, or elevating the limb to a point higher than your heart to help increase the flow of lymph fluid to decrease swelling. Your doctor may also suggest treatment by a physical therapist or other professional with special training in lymphedema.

- **Nausea and vomiting**: Nausea and vomiting are the most common side effects of traditional chemotherapy, and they can also result from immunotherapy and targeted therapy treatments, although less often. Because nausea and vomiting are easier to prevent than to manage once they occur, your doctor may prescribe medication that you take before the start of each treatment.

- **Low blood cell counts**: Cancer treatments such as chemotherapy and immunotherapy are known to lower the number of certain blood cells in your body. Low white blood cell counts can increase the risk of infection; low red blood cell counts can make you feel tired and weak; and low platelet counts can increase your risk of bleeding and cause you to bruise easily. Your doctor will monitor your blood counts during treatment to make sure levels are well-maintained. If the counts are too low, your doctor may prescribe medication to stimulate blood cell growth or delay cancer treatment until your blood cell counts increase. Be sure to talk to your doctor about when to notify your treatment team about symptoms related to these side effects.

<table>
<thead>
<tr>
<th>TABLE 1</th>
<th>MOST COMMON SIDE EFFECTS OF TREATMENT FOR METASTATIC MELANOMA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of treatment</td>
<td>Side effects</td>
</tr>
<tr>
<td>Surgical removal</td>
<td>Pain, swelling, scar</td>
</tr>
<tr>
<td>Lymph node dissection</td>
<td>Lymphedema, numbness, restricted movement of limb</td>
</tr>
<tr>
<td>Systemic therapy</td>
<td>Fever, chills, aches; fatigue; injection-site reaction; low blood pressure; heart and liver damage (interleukin-2); skin, liver, colon and glandular inflammation</td>
</tr>
<tr>
<td>Immunotherapy</td>
<td>Nausea and vomiting, hair loss, mouth sores, increased risk of infection and bleeding, easy bruising, fatigue, loss of appetite</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>Rash, joint pain, liver-function abnormalities, sensitivity to the sun, cutaneous squamous cell carcinoma (skin cancer)</td>
</tr>
<tr>
<td>Targeted therapy</td>
<td>Swelling, skin changes (similar to a sunburn), fatigue</td>
</tr>
</tbody>
</table>
Nearly every type of cancer — and melanoma in particular — has benefited from scientific advancements in recent years. In fact, virtually all of the cancer-fighting drugs and devices currently available exist only because they were thoroughly tested beforehand. These tests, known as clinical trials, are research studies designed to evaluate the safety and effectiveness of new drugs and other types of therapies. Many of these trials have led to remarkable successes in the advancement of melanoma treatment in recent years.

Trials are led by physicians and other research professionals and are usually sponsored by government agencies (such as the National Cancer Institute), by groups of doctors and health care institutions or by the pharmaceutical or biotechnology companies that develop the new treatments.

The primary benefit of a clinical trial is access to the highest quality of cancer treatment, with the possibility of receiving a new treatment before it is widely available. People who have participated in a clinical trial have identified several perceived advantages to participation, including having access to the best available care, receiving newer and better treatments, receiving increased medical attention, playing an active role in their own health care, and making a valuable contribution to cancer research.

If you consider participating in a trial, it is important to know that all clinical trials are developed according to strict scientific and ethical principles and are conducted under the supervision of physicians and expert research professionals. Every clinical trial follows a set of rules called a protocol. The protocol defines the eligibility criteria, specifies the tests to be done and the procedures to be used, describes the medications and their doses and establishes the duration of the study. Several safeguards are in place and regulated to ensure the safety of all participants.

Many people recognize the possible benefits of a clinical trial but are afraid of the risks. Participation is always voluntary, and you can choose not to participate for personal reasons. Also, you can agree to enter a clinical trial and then decide to withdraw if it doesn't meet your expectations. Your decision about whether to participate has no effect on your routine medical care.

Because clinical trials do carry a risk of the unknown, such as the possibility of unanticipated side effects, the potential risks and benefits of each trial are explained to every participant using clear and concise language in a manner that is easily understood. After this explanation, participants must sign an agreement to say that they understand the potential risks and benefits.

Through trials, physicians have been able to confirm the potential benefits of new therapies, such as improved survival rates, reduced complications and lessened side effects. They can also identify characteristics of the patients who are most likely to receive maximum benefit from specific treatments. Thanks to clinical trials, more treatment options are now becoming available for people with all cancer types, including melanoma.

Thousands of cancer clinical trials are taking place throughout the world, so it can be difficult to know what is available and what trials you may qualify for. Networking and communication among doctors is helpful, so be sure to ask your care team about any clinical trials you may qualify for within a reasonable traveling distance for you. In addition to talking to your doctor, an increasing number of websites are becoming available where patients can find out about available clinical trials (see above).

Anyone with a cancer diagnosis should consider participating in a clinical trial. There are varying levels of involvement, from simply allowing your medical information to be used for research to receiving new treatments. Knowing all of your treatment options, including what clinical trials are available, allows you to make more informed treatment decisions.
After your melanoma treatment has been completed, you must be careful to monitor for recurrence and second cancers. Because of your history of melanoma, you’re at an increased risk for developing a new melanoma or skin cancer, so follow-up care and skin cancer prevention are especially important.

MONITORING FOR RECURRENT OR A SECOND PRIMARY MELANOMA
Most recurrences of melanoma develop within the first five years after treatment, so your follow-up visits will be more frequent within that time period. However, late recurrence, even after 10 years, is also possible. How often your doctor will see you for follow-up visits depends on several factors, including the stage of the melanoma and your particular risk factors (see Table 1). Your check-ups will include a thorough physical exam with particular attention to your skin and lymph nodes.

Tests on blood samples and regular X-rays and imaging scans have not been found to be useful for follow-up, but they may be done if you have symptoms or clinical signs that suggest recurrence. For anyone at a high risk for recurrence, imaging studies may include computed tomography (CT), positron emission tomography (PET) or combined PET/CT to look for melanoma in the organs and lymph nodes. Magnetic resonance imaging (MRI) may be used to look for the spread of melanoma to the brain, and a bone scan may be performed to look for the spread of melanoma to the bones.

Your doctor will ask you to participate in your follow-up care with a monthly self-examination of your skin for potential melanoma. During these skin checks, you should also look for any abnormal lumps, especially where the surgery was done and in nearby lymph nodes. The “ABCDE” rule will help

PROTECTING YOURSELF FROM ULTRAVIOLET (UV) LIGHT EXPOSURE

IMPORTANT PROTECTION MEASURES
- Wear protective clothing. Consider UPF-rated clothes if you sunburn easily.
- Wear a broad-brimmed hat.
- Wear sunglasses that protect against UV rays.
- Minimize your exposure to the sun during its highest intensity (10 a.m. to 4 p.m.).
- Use lip balm with an SPF of at least 30; petroleum jelly does not provide protection against the sun.
- Do not use indoor tanning facilities.

USE SUNSCREEN APPROPRIATELY
- Choose a sunscreen with a sun protection factor (SPF) of at least 30. For some individuals, a sunscreen with an even higher SPF may be necessary to avoid burning.
- Select a sunscreen that protects against both UVA and UVB rays. Look for labels with the words “broad spectrum” or “multispectrum” or that list ingredients such as titanium dioxide or zinc oxide. (Try to avoid sunscreens with oxybenzone or retinyl palmitate, which may be dangerous for certain groups of people.)
- Expand the use of sunscreen beyond the summer. Remember that snow reflects up to 80 percent of the sun’s rays.
- Use sunscreen anytime you plan to be in the sun for more than 20 minutes, even when it’s cloudy.
- Apply sunscreen at least 30 minutes before going out in the sun.
- Use sunscreen even if wearing makeup that contains SPF. (Apply sunscreen underneath makeup.)
- Apply sunscreen liberally and reapply at least every two hours (sooner if swimming or sweating). Adults need at least a shot glass full of sunscreen lotion per application. If you use a spray sunscreen, be sure to coat all of your exposed skin.
- Make sure to use sunscreen on often-forgotten areas, such as ears, scalp (if bald) and back of neck.
- Check the expiration date on the bottle of sunscreen; expired products may not be effective.

<table>
<thead>
<tr>
<th>Clinical/pathologic stage</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 0 (in situ)</td>
<td>Annual skin examination.</td>
</tr>
<tr>
<td>Stage IA-IIA</td>
<td>History and physical examination (with emphasis on lymph nodes and skin) every six to 12 months for five years, then every year as needed; annual chest X-ray. Routine blood work or imaging is not recommended.</td>
</tr>
<tr>
<td>Stage IIB-IV</td>
<td>History and physical examination (with emphasis on lymph nodes and skin) every three to six months for two years, every three to 12 months for three years, then every year as needed. Imaging studies (chest X-ray, CT, PET/CT and/or MRI) may be done every four to 12 months for people who are at high risk for recurrent or metastatic disease.</td>
</tr>
</tbody>
</table>
you know the difference between a melanoma and a benign (not malignant) mole (see Figure 1). Because family history plays an important role in melanoma and other skin cancers, your family members should also have regular skin screenings.

**THE IMPORTANCE OF SKIN CANCER PREVENTION**

As the risk of recurrence decreases, the risk of developing a second melanoma or other type of skin cancer increases. This means you must continue skin cancer prevention practices, even when your follow-up visits become further apart. Be prepared to practice skin cancer prevention for your entire life!

The most important preventive measure is to avoid excessive exposure to ultraviolet (UV) rays. The sun is the primary source of UV rays, and you and your family should follow national guidelines to protect yourself (see Helpful Tips, page 17). Protection from UV rays is especially important for people with a fair complexion, light-colored eyes, blond or red hair, and a tendency to burn or freckle with exposure to the sun. Another dangerous source of UV rays is indoor tanning facilities. Studies have shown the risk of melanoma is three times higher for people who regularly use such facilities.

Sun exposure and indoor tanning should never be used for the purpose of increasing your levels of vitamin D. If required, oral supplements are an excellent way to boost your vitamin D levels safely and effectively. To be sure you are getting enough vitamin D, your doctor will likely check your blood levels and may suggest a vitamin D supplement.

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**FIGURE 1**

<table>
<thead>
<tr>
<th>ABCDE Rule</th>
<th>Benign tumors</th>
<th>Melanomas</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A</strong></td>
<td>Symmetric (both halves are the same)</td>
<td>Asymmetric (one half is different from the other half)</td>
</tr>
<tr>
<td><strong>B</strong></td>
<td>Clear-cut, distinct border</td>
<td>Irregular border (has notches, is uneven or is blurred)</td>
</tr>
<tr>
<td><strong>C</strong></td>
<td>Uniform light or dark color</td>
<td>Uneven (shades of brown, tan and black)</td>
</tr>
<tr>
<td><strong>D</strong></td>
<td>Less than 6 mm (usually)</td>
<td>More than 6 mm (about a quarter of an inch)</td>
</tr>
<tr>
<td><strong>E</strong></td>
<td>No change over time</td>
<td>Change in size, shape, surface, shades of color, or symptoms</td>
</tr>
</tbody>
</table>

---

**THINK BEFORE YOU INK**

> Monitoring your body for signs of melanoma is a tedious yet necessary task if you want to avoid the most dangerous form of skin cancer. Doctors say this is especially true if you cover your skin with tattoos, as they can delay your diagnosis and put you in more danger than people who are ink-free.

It’s important to watch new and existing moles — along with birthmarks — that change color, shape or size. When ink (or laser tattoo removal) alters the skin’s pigment, these signs are harder to detect, which is why many doctors strongly advise against covering existing skin problems with tattoos.

If you are fair-skinned, have several moles or have relatives with melanoma, think before you ink. If you can’t resist, doctors advise opting for a lighter and smaller tattoo that still allows you to easily survey your skin. Most tattoo artists will steer clear of moles for the very same reason and agree that it’s smart to get clearance from a dermatologist before you decide to decorate any part of your body.

The same consideration applies when you choose to lose your tattoos with the help of laser treatments. Lasers should never come in contact with moles or birthmarks, so make sure that the procedure can be performed safely before you begin.

While there’s no connection between tattoos and cancer, there is a realistic concern that they may prevent you from finding and fixing skin problems early, when a cure is more likely.
Transitioning into a post-treatment schedule

Early screening tests, new developments in treatment and better side effect management are all credited with increasing cancer survival rates, especially in the field of melanoma. More than one million of the estimated 14.5 million cancer survivors in the U.S. today are melanoma survivors. The cancer community is realizing now that with more and more survivors comes the responsibility to continue care beyond treatment. Recovery — both physical and mental — takes time, resources, education and patience.

DEFINING CANCER SURVIVORSHIP
Cancer survivorship is often defined in two ways: completing treatment and having no remaining signs of disease; or living with, through and beyond cancer. According to the second definition, survivorship begins at diagnosis, continues through treatment and persists past it—including those who are living disease-free and those who are managing cancer as a chronic condition.

As you transition into survivorship, you may experience some unexpected difficulty. You may begin to realize that unfortunately the issues related to your cancer do not end when treatment stops. Your history of disease will affect both your health care needs and your lifestyle every day from here on. Knowing what to expect and the resources available can be valuable assets as you continue your own journey into life after cancer.

WHAT TO EXPECT
Cancer and its treatment can affect your body long after it ends—for days, months or even years. Many cancer survivors must manage continuing and late effects of treatment, such as cognitive changes, fatigue, lymphedema and neuropathy. There are ways to alleviate and manage these effects, so maintaining an open dialogue with your health care team even after treatment has ended is vital. Your quality of life after cancer should be a continuing, lifelong focus as you move forward from your diagnosis.

The effects of cancer and its treatments also include psychosocial and emotional changes. Surviving cancer can stir up a lot of feelings, which will be different for everyone. Survivors often experience a mixture of emotions, from relief and joy to stress, depression, guilt or fear. It’s important to be aware that these emotions and many others may arise so you can be prepared to acknowledge, accept and move past them—and seek the appropriate help if you have trouble doing so.

CREATING A SURVIVORSHIP PLAN
Once you’re past primary treatment, it’s important to take the time to create a survivorship plan. Similar to the way your treatment plan helped you navigate treatment, a survivorship plan is like a life wellness plan—a roadmap that helps you figure out where you’re going and how to get there. No single plan applies to every patient, but certain aspects of a plan may be similar.

Your survivorship plan should include everything from comprehensive information about the treatments you received to a follow-up care schedule and more. While you may be able to compile most of the necessary information on your own, be sure to thoroughly discuss each component of your survivorship plan with your doctor.

WHAT TO INCLUDE
A well-documented medical history record and summary of your cancer treatments can help any doctors you see in the future provide you with the best possible care. Your records should contain your entire history of medical care, including your exact cancer diagnosis (date of diagnosis, specific cancer type, stage and location of the cancer), symptoms, diagnostic tests, procedures, treatments (including drug names and dosages), dates, side effects and any supportive care you received. It’s also important to include information about your family’s medical history, including any history of cancer. And if you haven’t already, create a contact log for your entire health care team. List names, titles, phone numbers and addresses; also describe the role each person played (or plays) in your care.

Late effects are those that develop weeks, months or even years after your treatment ends. Because of this, your survivorship plan should include information about your risk for developing certain late effects based on your specific type of cancer and treatment plan. Be sure to ask your doctor about the signs and symptoms you should watch for so that you can detect and manage them early on. Your survivorship plan should also discuss the risk that your cancer may come back as a local recurrence (where it originally developed) or as a distant recurrence in the form of metastatic disease.

In addition to your medical history and treatment summary, your survivorship plan should include plans for follow-up care. At the end of your treatment plan, your doctor should provide you with a follow up care schedule. This schedule will detail the information regarding future appointments, diagnostic tests and exams. Ask about how often you will have checkups for the first year, second year, etc. Also record any medications you’ll be taking, including maintenance therapy drugs.

Staying healthy and active is perhaps as important as sticking to your follow-up schedule so you and your doctor may choose to add healthy goals and recommendations to your survivorship plan. This can include things such as working with a dietitian to establish healthier eating, maintaining or starting an exercise regimen, quitting smoking if you are a smoker and vowing to wear sunscreen every time you go outside.

In your survivorship plan, you might also want to include your estate plan. This usually involves completing advance directives, naming a power of attorney, developing a will and possibly establishing trusts.

Your survivorship plan is only useful if you actually understand and use it. If you have questions about any of the elements in your plan, don’t hesitate to ask your doctor.

ADDITIONAL RESOURCES
- American Cancer Society: www.cancer.org
- American Society of Clinical Oncology: www.cancer.org

Journey Forward: www.journeyforward.org
About Survivorship Care Planning
ADVOCACY & ASSISTANCE RESOURCES

CANCER EDUCATION

Academy of Oncology Nurse Navigators .............................................. www.aononline.org
American Cancer Society ................................................................. www.cancer.org
American Society of Clinical Oncology (patient website) ................. www.cancer.net
Association of Community Cancer Centers ..................................... www.accc-cancer.org
CANCER101 .................................................................................. www.cancer101.org
CancerCare .................................................................................. www.cancercare.org
CancerGuide ................................................................................ www.cancerguide.org
CancerQuest ................................................................................ www.cancerquest.org
Centers for Disease Control and Prevention (CDC) ......................... www.cdc.gov
The Gathering Place, A Caring Community for Those Touched by Cancer ...................................................... www.touchedyourcancer.org
Get Palliative Care ........................................................................ www.getpalliativecare.org
Global Resource for Advancing Cancer Education (GRACE) .............. www.cancergrace.org
The Hope Light Foundation .............................................................. www.hopelightproject.com
LIVESTRONG Foundation ............................................................... www.livestrong.org
National Cancer Institute ................................................................. www.cancer.gov
National Comprehensive Cancer Network (NCCN) ......................... www.nccn.org
National LGBT Cancer Network .................................................... http://cancer-network.org
OncoLink ..................................................................................... www.oncolink.org
Oncology Nursing Society ............................................................... www.onrs.org
PearlPoint Cancer Support ............................................................ www.pearlpoint.org
Pine Street Foundation ................................................................... www.pinestreetfoundation.org
R.A. Bloch Cancer Foundation, Inc. ...................................................... www.blochcancer.org
Scott Hamilton CARES Initiative ..................................................... www.scottcares.org
Union for International Cancer Control ............................................. www.uicc.org

CAREGIVERS & SUPPORT

4th Angel Mentoring Program .......................................................... www.4thangel.org
Bloom Cancer Hotline .................................................................... 800-433-0464
Buddy Kemp Cancer Support Center .................................................. www.novanthealth.org/home/services/cancer/support--advocacy/buddy-kemp-cancer-support-center.aspx
CANCER101 .................................................................................. www.cancer101.org
Cancer Action ................................................................................ www.canceractinicke.com
Cancer and Careers ....................................................................... www.cancerandcareers.org
CancerCare .................................................................................. www.cancercare.org
Cancer Connection ........................................................................ www.thecancerconnection.org
Cancer Hope Network .................................................................... www.cancerhope.com
Cancer Information and Counseling Line ....................................... 800-525-3777
Cancer Really Sucks! ....................................................................... www.cancerreallysucks.com
Cancer Support Community ........................................................... www.cancersupportcommunity.org
Cancer Support Community Open to Options counseling program ........ 888-793-9355
Cancer Survivors Network ............................................................... http://csn.cancer.org
CancerWellness Center ................................................................... www.cancerwellness.org
Caregiver Action Network ............................................................... www.caregiveraction.org
CaringBridge ................................................................................ www.caringbridge.org
Center to Advance Palliative Care .................................................... www.capc.org
Cleaning For A Reason ..................................................................... www.cleaningforreason.org
Cooking with Cancer ..................................................................... www.cookingwithcancer.org
Cuddle My Kids ............................................................................. www.cuddlemykids.org
Family Caregiver Alliance ............................................................... www.caregiver.org
Fighting Chance ............................................................................. www.fightincancer.org
The Gathering Place, A Caring Community for Those Touched by Cancer ...................................................... www.touchedyourcancer.org
Guam Cancer Care .......................................................................... http://guamcancercare.org
Guide Posts of Strength Inc ................................................................ www.guideposts.org
The Hope Light Foundation .............................................................. www.hopelightproject.com
Immanuel Angels ............................................................................ www.immanuelangels.org
The LGBT Cancer Project - Out With Cancer .................................. www.lgbtcancer.org
LIVESTRONG Foundation ............................................................... www.livestrong.org
LivingWell Cancer Resource Center .................................................. www.livingwelllrc.org
Lotsa Helping Hands ........................................................................ www.lotsahelpinghands.com
MyLifeline Cancer Foundation ........................................................... www.mylifeline.org
SHARE Caregiver Circle for Family and Friends ............................... www.shares Carson/CaregiverCircle.org/shares-new/supportfor_partners_and_caregivers

CLINICAL TRIALS

ACT (About Clinical Trials) ................................................................. www.actaboutclinicaltrials.org
Center for Information and Study on Clinical Research Participation ...... www.ciscr.org
CenterWatch ............................................................ www.centerwatch.com
Coalition of Cancer Cooperative Groups ........................................ www.cancertrialshelp.org
MyClinicalTrialsLocator.com .......................................................... www.myclinicaltrialslocator.com
National Cancer Institute ............................................................... www.cancer.gov
National Institutes of Health .......................................................... www.nih.gov
TrialCheck .................................................................................... www.trialcheck.org

COMPLEMENTARY PROGRAMS & ALTERNATIVE MEDICINE

Believe Big ..................................................................................... www.believebig.org
The Center for Mind-Body Medicine ................................................. www.cmbm.org
Kansas City Healing Touch .............................................................. www.kansascityhealingproject.org
National Center for Complementary and Alternative Medicine ........ www.nccam.nih.gov
Office of Cancer Complementary and Alternative Medicine ........... www.cancer.gov/ocam
Society for Oncology Massage ....................................................... www.s4om.org
Stewart’s Caring Place: Cancer Wellness Center ................................. www.stewartsacaringplace.org
Touch, Caring and Cancer .............................................................. www.partnersinhealing.net

IMMUNOTHERAPY

The Answer to Cancer ..................................................................... www.theanswerscancer.org
Cancer Research Institute ............................................................... www.cancerresearch.org
Immun-Oncology .......................................................................... www.immunoncology.com
Society for Immunotherapy of Cancer ............................................. www.sitcancer.org

MELANOMA & OTHER SKIN CANCERS

A Cure in Sight (ocular melanoma) ..................................................... http://acureinsight.org
AIM at Melanoma ........................................................................... www.aimatmelanoma.org
American Academy of Dermatology ................................................. www.aad.org
Basal Cell Carcinoma Nevada Syndrome Life Support Network ........... www.bccsn.org
Joanna M. Nicolay Melanoma Foundation ......................................... www.melanoman.com
Melanoma Hope Network ............................................................... www.melanomahopenetwork.org
Melanoma International Foundation ............................................... www.melanomainternational.org
Melanoma International Foundation Forum .................................... www.melanomaforum.org
Melanoma Patients Information Page ............................................. www.melanoma.org/community/mpp/melanoma-patients-information-page
Melanoma Research Alliance .......................................................... www.curemelanoma.com
The Melanoma Research Foundation ............................................. www.melanoma.org
Mollie’s Fund ................................................................................ www.molliesfund.org
Ocular Melanoma Foundation ........................................................ www.creamelanoma.org
Outrun the Sun ............................................................................... www.outrunthesun.org
The Skin Cancer Foundation .......................................................... www.sklcancer.org
Skin of Steel .................................................................................... www.skinfoxsteel.org
SunWise School Program ............................................................... www.epa.gov/sunwise

PAIN MANAGEMENT

American Chronic Pain Association .................................................. www.theacpa.org
Cancer Pain Research Consortium ................................................... http://cancerpainresearchcouncil.org
LIVESTRONG Foundation ............................................................... www.livestrong.org
The Resource Center of the Alliance of State Pain Initiatives .......... www.rts.wisc.edu
U.S. Pain Foundation ....................................................................... www.uspainfoundation.org

YOUNG ADULTS

Critical Mass: The Young Adult Cancer Alliance ............................... http://criticalmass.org
Hope for Young Adults With Cancer ................................................ www.hope4ywac.org
I’m Too Young For This! Cancer Foundation ................................... www.stupidcancer.org
National Collegiate Cancer Foundation .......................................... www.collegiatecancer.org
Planet Cancer ................................................................................ www.planetcancer.org
The SAMFund for Young Adult Survivors of Cancer ......................... www.samfund.org
Teens Living With Cancer .............................................................. www.teenslivingwithcancer.org
The Ulman Cancer Fund for Young Adults ........................................ www.ulmanfund.org
Young Adult Cancer Canada .......................................................... www.youngadultcancer.ca
Young Survival Coalition .............................................................. www.youngsurvivor.org
FINANCIAL RESOURCES

BASIC LIVING EXPENSES
Brenda Melting Cancer Fund (patients 18-40)........www.bmcf.net, 661-310-7940
Bringing Hope Home........................................www.bringinghopehome.org, 484-580-8395
The CHAIN Fund Inc........................................www.thechainfund.com, 203-530-3439
Cleaning for a Reason (free house cleaning service)........www.cleaningforareason.org, 877-337-3348
Family Reach Foundation................................www.familyreach.org, 973-394-1411
Hugs and Kisses.............................................www.hugsandkissesinc.org, 661-819-9471
Life Beyond Cancer Foundation.........................www.lifebeyondcancer.org, 281-791-7549
Rise Above It (youth, young adults).........................www.railbenefit.org
The Simple Doctor........................................www.thesimpledoctor.com/category/insurance
Stupid Cancer................................................www.stupidcancer.org, 877-735-4673
Team Continuum........................................www.teamcontinuum.net, 646-589-5619

CHILD CARE EXPENSES
Brenda Melting Cancer Fund (patients 18-40)........www.bmcf.net, 661-310-7940
CancerCare..................................................www.cancercare.org, 800-813-HOPE
Family Reach Foundation.................................www.familyreach.org, 973-394-1411

FINANCIAL ASSISTANCE
American Cancer Society................................www.cancer.org
BeneFitCheckUp..........................................www.benefitcheckup.org
Bringing Hope Home......................................http://www.bringinghopehome.org
CancerCare..................................................www.cancercare.org
Cancer Financial Assistance Coalition................www.cancerfac.org
The CHAIN Fund Inc.......................................www.thechainfund.com
HealthWell Foundation................................www.healthwellfoundation.org
LIVESTRONG Foundation.............................www.livestrong.org
Medicare......................................................www.medicare.gov
NeedyMeds..................................................www.needymeds.com
Partnership for Prescription Assistance..............www.pparx.org
Patient Access Network Foundation...............www.panfoundation.org
Patient Advocate Foundation........................www.patientadvocate.org
Patient Services Inc....................................www.patientservicesinc.org
RxAssist......................................................www.rxassist.org
RxHope......................................................www.rxhope.com
Social Security Administration.......................www.ssa.gov
Social Security Disability Resource Center...........www.ssdrc.org
State Health Insurance Assistance Programs........www.shiptacenter.org
Stupid Cancer................................................www.stupidcancer.org

GOVERNMENT ON AGING
Administration on Aging........................................www.aoa.gov, 202-401-4634
Benefits.gov................................................www.benefits.gov, 800-FED-FIND
Centers for Medicare & Medicaid Services........www.cms.gov, 800-MEDICARE
Hill-Burton Program.......................................www.hrsa.gov/gethealthcare/affordable/hillburton, 800-638-0742
Legal Services Corporation............................www.lsc.gov, 212-295-1500
Medicare Rights Center................................www.medicarights.org, 800-333-4114
Social Security Administration.......................www.ssa.gov, 800-772-1213
Social Security Disability Resource Center..........www.ssdrc.org
State Health Insurance Assistance Programs ........www.shiptacenter.org
U.S. Department of Veterans Affairs....................www.va.gov/health/index.asp

HOME HEALTH CARE EXPENSES
Brenda Melting Cancer Fund (patients 18-40)........www.bmcf.net, 661-310-7940
CancerCare..................................................www.cancercare.org, 800-813-HOPE
NeedyMeds (links to assistance programs)...........www.needymeds.com
Stupid Cancer................................................www.stupidcancer.org, 877-735-4673

HOUSING DURING TREATMENT EXPENSES
American Cancer Society (Hope Lodges)................www.cancer.org, 800-ACS-2345
Brenda Melting Cancer Fund (patients 18-40)........www.bmcf.net, 661-310-7940
Fisher House (military families).........................www.fish erhouse.org, 888-294-8560
Hope Lodge................................................www.cancer.org/treatment/supportprogramsservices/hopelodge/index, 800-227-2345
Hospitality Homes........................................www.hosp.org, 888-595-4678
Joe’s House..................................................www.joesshouse.org
National Association of Hospital Hospitality Houses Inc.................800-542-9730
Stupid Cancer................................................www.stupidcancer.org, 877-735-4673

LEGAL ISSUES
Administration on Aging (search for “legal assistance”)........www.aoa.gov, 800-204-4634
American Bar Association........................................www.americanbar.org, 800-285-2221
Cancer and Careers........................................www.cancerandcareers.org
Disability Rights Legal Center.........................www.disabilityrightsspeciallegalcenter.org, 888-999-3752
LawHelp.org................................................www.lawhelp.org
Legal Services Corporation............................www.lsc.gov, 202-295-1500
National Coalition for Cancer Survivorship........www.canceradvocacy.org, 877-NCCS-YES
National Health Law Program (links to assistance programs)........www.healthlawhelp.org, 202-289-7861
Patient Advocate Foundation.........................www.patientadvocate.org, 800-532-5274
Social Security Disability Resource Center..........www.ssdrc.com

MEDICAL CARE EXPENSES
American Cancer Society (local chapters)........www.cancer.org, 800-ACS-2345
Brenda Melting Cancer Fund (patients 18-40)........www.bmcf.net, 661-310-7940
CancerCare..................................................www.cancercare.org, 800-813-HOPE
Cancer Survivors’ Fund (young adults, children)....www.cancersurvivorsfund.org, 261-437-7142
Cancer Warrior Inc........................................www.cancerwarriorinc.org
Foundation for Health Coverage Education..........www.coverageforall.org
Patient Advocate Foundation (links to assistance programs)........www.patientadvocate.org, 800-532-5274
Rise Above It (youth, young adults)...................www.railbenefit.org
Stupid Cancer................................................www.stupidcancer.org, 877-735-4673
Verna’s Purse...............................................www.vernaspurse.org, 888-489-8944
Zichron Shlome Refund Fund...........................www.zsrf.org, 718-GET-WELL

PRESCRIPTION EXPENSES
American Cancer Society................................www.cancer.org, 800-ACS-2345
Brenda Melting Cancer Fund (patients 18-40)........www.bmcf.net, 661-310-7940
CancerCare Co-payment Assistance Foundation........www.cancercarecopay.org, 866-552-6729
Cancer Financial Assistance Coalition................www.cancerfac.org
The CHAIN Fund Inc.......................................www.thechainfund.com, 203-691-5955
Foundation for Health Coverage Education..........www.coverageforall.org
Good Days...................................................www.gooddaysformcfl.org, 877-968-7233
HealthWell Foundation................................www.healthwellfoundation.org, 800-675-8416
National Organization for Rare Disorders.............www.rarediseases.org, 800-744-0100
NeedyMeds (links to assistance programs)...........www.needymeds.org, 800-503-6997
Partnership for Prescription Assistance..............www.pparx.org, 888-PPA-NOW
Patient Access Network Foundation...............www.panfoundation.org, 866-316-PANF
Patient Advocate Foundation Co-Pay Relief..........www.copays.org, 888-512-3861
Patient Services Inc......................................www.patientservicesinc.org, 800-368-7741
Rise Above It (youth, young adults)...................www.railbenefit.org
RxAssist......................................................www.rxassist.org
RxHope......................................................www.rxhope.com
RxOutreach................................................www.rxoutreach.com, 888-796-1234
Stupid Cancer................................................www.stupidcancer.org, 877-735-4673
Together Rx Access......................................www.togetherrxaccess.org, 800-444-4106

REIMBURSEMENT & PATIENT ASSISTANCE PROGRAMS
Amen Assist................................................www.amenassist.com, 888-427-7478
Bayer Healthcare Pharmaceuticals......................www.bayer.com, 866-575-5002
Bristol-Myers Squibb.................................www.bms.com/products/Pages/programs.aspx, 866-801-0408
Indigent Patient Assistance Program................www.738-6903
Genetech Access Solutions.............................www.gene.com/patients/patient-access, 866-249-4918
Merck Access Program................................www.merckaccessprogram.com
Merck Helps (Patient Assistance Program).............www.merckhelps.com, 877-524-5000
Novartis Patient Assistance Now......................www.patientassistancenow.com, 866-245-5356
Proleukin Patient Assistance Program................www.proleukin.com/resources.aspx, 877-778-5385
Tafinlar + Mekinist Patient Support....................www.us.tafinlarmekinist.com, 800-262-7630

TRANSPORTATION & TRAVEL RESOURCES
The Air Care Alliance.......................................www.aircareall.org, 888-260-9707
Air Charity Network........................................www.aircharitynetwork.org, 877-621-7177
Angel Airline Samaritans...............................www.angela airlinepartners.org, 800-296-6127
Angel Airlines for Cancer Patients.................www.angelairlinesforcancerpatients.org, 800-296-6127
Angel Flight Central........................................www.angelflightcentral.org, 888-569-9464
Corporate Angel Network...........................www.corporateangelnetwork.com, 866-328-1313
Lifeline Pilots................................................www.lifelinepilots.org, 800-822-7972
Mercy Medical Angels.................................www.mercymedical.org
Miracle Flights for Kids...............................www.miracleflights.com, 800-FLY-1711
Operation Liftoff..........................................www.operationliftoff.com
Patient Airlift Services.....................................www.palservices.org, 631-694-7257
Veterans Airlift Command.............................www.veteransairlift.org, 952-582-2911

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