

Frankly Speaking About Cancer: Melanoma



Table of Contents

Overview.....	2
What is Melanoma?.....	4
Diagnosis and Staging.....	8
Coping With a Melanoma Diagnosis.....	12
Treating Melanoma.....	16
Managing Side Effects.....	30
The Empowered Patient.....	32
Resources.....	38
A Bold New Era: A Bright Future.....	42

Overview

“I think, in melanoma, an important part of our role today is explaining all these new approaches, and that we need to take the time with our patients to help them understand the options.” — Lynn Schuchter, MD, University of Pennsylvania

Melanoma is usually, but not always, a cancer of the skin. It begins in melanocytes – the cells that produce the pigment melanin that colors the skin, hair, and eyes. Melanoma affects over 75,000 people in the United States every year. The average age for a melanoma diagnosis is 62, but people of any age, including adolescents and young adults, can get this disease.

The number of people who have received a melanoma diagnosis has been rapidly on the rise in the United States for the last 40 years. This increase is attributed to the use of tanning beds and other unsafe exposure to ultraviolet rays. Although the number of cases is on the rise, deaths from melanoma have actually decreased.

When detected early, melanoma is often highly curable. Unlike other skin cancers, melanoma can spread to other parts of the body. It accounts for about 2% of all skin cancers, but causes the

majority of skin cancer deaths. Until recently, there were few effective treatment options for advanced or metastatic melanoma but recent years have seen the introduction of new and better treatments that are offering new options and hope for many.

Most melanomas arise in moles on the surface of the skin and are first detected by patients themselves. Individuals who are at a higher risk for developing melanoma should be screened regularly by their doctors. People at higher risk are those with sun sensitive skin types that freckle easily, many common moles or dysplastic moles, a history of sun exposure, or a family history of skin cancer or melanoma.

The diagnosis of melanoma is usually made by biopsying the suspicious area. If cancer is found, it is very important to determine how deeply the melanoma has grown into the skin, whether it has spread to nearby lymph

nodes, or to other organs in the body. The depth of the melanoma, the type and its stage help determine the best treatment options.

Early melanomas are treated with outpatient surgery. Melanomas that are deeper or have spread to lymph nodes may require additional treatments after surgery, also called adjuvant therapy, to help reduce the risk that they will recur. There are now more treatment options for people with metastatic melanoma, including targeted therapy and immunotherapy.

People with melanoma and their loved ones need support—both to understand treatment options and to deal with the emotional challenges of a diagnosis. This is a time to talk with your health care team and identify the resources that will help you.

Learning that you have melanoma can be a frightening and life-changing experience. It is important to know, that whatever the stage of your disease, there are treatment options available and resources for emotional and social support.

IF YOU ARE FACING A MELANOMA DIAGNOSIS, OR BEING TREATED FOR THIS DISEASE:

- Learn about your melanoma.
- Talk to your doctors.
- Ask questions.
- Think about getting your treatment in a facility that has expertise and experience in treating melanoma.
- Take care of yourself.
- Talk to your health care team about getting the support you need right from the start.

What is Melanoma?

“Early melanomas are very curable. I recommend that everyone gets naked and looks for things that are changing on their skin.”

—Lynn Schuchter, MD, Penn Medicine

Melanoma is a cancer that begins in cells called melanocytes. Melanocytes make the pigment called melanin, which gives the skin its tan or brown color. Melanin also protects the deeper layers of the skin from the harmful effects of the sun.

Most of the melanin in our bodies is concentrated in the top layer of the skin (epidermis). For that reason, most melanomas develop on the surface of the skin. But, melanoma can arise in any tissue where pigment producing cells are found, including the mucous membranes and the eye.

Melanomas are usually brown or black, but some can appear as tan, pink, or even white. They often arise in moles, or nevi. This can occur in a pre-existing mole that suddenly begins to grow or change, or in a new mole. They are most common on the back, chest, and legs but can be found anywhere on the body. The neck and face are other common sites. In rare instances, melanomas can form in the eyes (ocular

melanoma), mouth, genitals, and anal area (mucosal melanoma).

WHO IS AT RISK FOR MELANOMA?

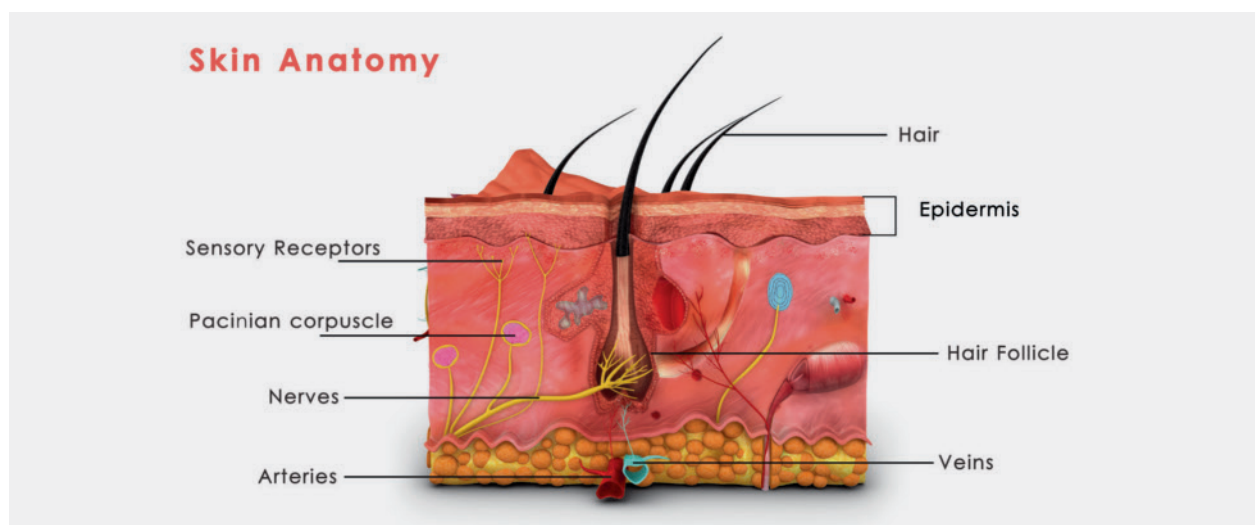
Anyone can get melanoma, but some people are at higher risk of developing this cancer and they include:

- Individuals who have fair skin, lots of freckles, and light hair.
- Anyone who has a first-degree relative who has had melanoma. A first-degree relative means a mother, father, or sibling.
- Anyone who has already had melanoma.
- People with multiple moles (more than 50). This can be hereditary, and is often linked to specific syndromes or conditions.
- People who have a history of blistering sunburns during childhood or adolescence or a history of chronic sun exposure.
- People who have a compromised immune system.

YOUR SKIN

The skin has three layers:

- The epidermis or top layer. This is where melanocytes are found along with several other types of skin cells.
- The dermis or middle layer. This layer contains hair follicles, sweat glands, blood vessels, and nerves held in place by collagen, which gives the skin its elasticity and strength.
- The subcutis or deepest layer is formed by a network of collagen and fat cells. It helps the body conserve heat and acts as a shock absorber.



A LITTLE HISTORY

Melanoma is an ancient disease. The first recorded description of the dark tumor, “melas” and “oma” are found in the writings of Hippocrates in the 5th century B.C. The earliest physical evidence comes from the skeletons of Pre-Columbian mummies estimated to be at least 2,400 years old.

Over the years, physicians and researchers studied these mysterious tumors. They learned that melanomas often originated in moles, yet understood little about how cancers grow and spread, so the only treatment was to cut or burn the mole off and hope that was enough.

It is only in the last decade that new understanding of the relationship between cancer cells and the immune system has resulted in new treatment options for people with advanced melanoma.

The other significant contribution to treating advanced melanoma was the discovery of “driver mutations.” These are changes that occur in tumors and fuel the growth and spread of the cancer cells. These known mutations occur in more than half of all melanoma patients and can now be targeted with agents that either turn off or block their activity.

As with any risk factors, having one or more of these does not mean that you will develop melanoma. But, it does mean you should check your own body once a month and have a yearly skin screening from your dermatologist. Individuals with large numbers of moles should discuss with their dermatologist a technique called “whole body photography” which provides a way of examining and comparing moles over time.

For people with multiple moles doing a full body check may be difficult. Those individuals should try to look for the “ugly duckling,” the mole that appears suddenly, begins to grow or change color or shape.

PREVENTION

Most melanomas are caused by damage from ultraviolet light—either from natural or artificial sources. It is very important for everyone to take precautions to protect themselves. This includes:

- Using sunscreen—at least 30 SPF, broad-spectrum and water resistant. Apply every two hours, and more often if you are swimming or sweating.
- Wearing protective clothing and wide-brimmed hats.
- Taking advantage of the shade as much as possible when you are outdoors. An umbrella or a tree can help protect your skin.
- Saying no to tanning beds. Indoor tanning has been shown to increase the risk of melanoma by up to 75%.

WHEN TO WORRY ABOUT A MOLE

Doctors use what they call the ABCDE system to describe worrisome moles
—the ones that may be or are cancerous.

A IS FOR ASYMMETRY.

Imagine folding the mole in half. If the two halves are not the same size or shape, it is asymmetrical and of more concern.

B IS FOR BORDER.

Melanomas often have irregular borders.

C IS FOR COLOR.

Melanomas are often darker than other moles, and have different colors within their borders.

D IS FOR DIAMETER.

Melanomas are often—but not always—larger than other moles.

E IS FOR EVOLVING OR ELEVATION.

A mole that grows or changes size or appearance or begins to bleed is of more concern.

If you notice any of the above warning signs, see a dermatologist and have the mole or lesion evaluated as soon as possible.

Diagnosis and Staging

“The most challenging time for me was the initial diagnosis. I recommend taking someone with you to the appointments to help digest information, to take notes on different treatments. It tends to be overwhelming and you just don’t hear very much.” —Matt, Melanoma survivor

DIAGNOSIS

Melanomas are usually diagnosed when either the person or the doctor notices a suspicious mole or area on the skin. The next step is a biopsy, a procedure in which the surgeon removes either the entire suspicious area or a sample for examination under the microscope. The exact type of biopsy and its extent depend on the size and appearance of the lesion. Biopsies are generally done under local anesthesia on an outpatient basis. The different types of biopsies include:

- **Shave biopsy**—The doctor shaves off the top layers of the skin, usually just the epidermis and dermis. This is appropriate when the risk of cancer is very low, and is not recommended when there is higher chance of cancer.
- **Punch biopsy**—This involves the use of a tool that resembles a tiny round cookie cutter to remove a deeper sample of skin. This technique may not provide as much tissue to examine the margins as other approaches.

■ **Excisional and incisional biopsies**—These procedures are used to examine lesions that are suspected of having invaded deeper into the skin. The excisional biopsy removes the entire tumor, while the incisional biopsy removes only a portion of the tumor. Both procedures are done with surgical instruments and local anesthesia.

If the biopsy results come back as melanoma, a number of additional tests and procedures are needed to determine how deeply the melanoma has invaded and whether it has spread to other sites in the body. Today, diagnosis also involves lab tests to determine the biological features of the tumor. This helps predict how the cancer will behave and helps the treatment team recommend the best options for you.

Some melanomas are diagnosed after they have spread to lymph nodes or to another organ. This can happen if the original melanoma on the skin is not found or is so small that it goes undetected.

A small number of melanomas arise in mucous membranes or in the palm/sole, fingernail bed or in the eye. Their cause is not known, but they don't necessarily carry a higher risk if caught early and treated properly.

In others cases, the tumor causes symptoms in the areas that are affected. It may also appear as a lump or enlarged lymph node in the neck, groin, or elsewhere. When this happens, the diagnosis is made by biopsying the lump or the mass detected in another organ, such as the lung, liver, or brain. Depending on the location of the tumor, the diagnosis can be done either with a fine needle aspiration, by removing the entire lymph node or by a surgical or endoscopic biopsy.

TYPES OF MELANOMA

There are several types of melanoma, each with unique features related to their shape, color, location, and growth pattern.

- Superficial spreading melanoma resembles a brown or black stain that appears to come out of a mole. This is the most common type of melanoma and tends to occur in skin that has been exposed to ultraviolet light.

- Nodular melanoma is a more pronounced, firm, dome-shaped bump. This type of melanoma tends to spread more rapidly into the dermis.

- Lentigo maligna melanoma looks like a dark stain and is not associated with a mole.

It is the slowest growing type of melanoma.

- Acral lentiginous melanoma occurs on the soles of the feet, palms of the hands, or under the nails. It looks like a dark spot on the skin or under the nail that doesn't go away. It is the most common type of melanoma in African-Americans.

- Ocular melanoma is a rare form of melanoma that begins in the eye. It behaves and is treated differently than melanomas that arise on the skin.

- Mucosal melanoma is a rare form of melanoma that occurs in the mucous membranes of the nasal passages, mouth, and genitals.

THE PATHOLOGY REPORT

The pathology report contains all of the critical information about the tumor and the cells that make it up. It is a very detailed and technical document. Some people want to understand every line in the report and what it means to their treatment and prognosis, while others would prefer to have their doctors explain what is important to them.

Regardless of how you approach the pathology report, it is important to have at least a basic understanding of the diagnosis, its extent, and treatment options available to you.

A guide to the type of information you will find on your pathology report is on page 10.

Guide To Information You Will Find On Your Pathology Report

Diagnosis: The type of melanoma.

Tumor location: Where on the body was the tumor found.

Breslow thickness: How deep the melanoma has grown in the skin. This is measured into millimeters.

Ulceration status: Has the top layer of the tumor begun to break up and pull apart.

Dermal mitotic rate: This measures the number of melanoma cells that are actively growing and dividing.

Clark level: This uses a five-point scale to assess the depth to which the tumor has invaded the skin. Clark Level is different than stage. Clark Level I involves only the epidermis, while a level V has invaded tissue below the skin. Clark Level has been replaced by the Breslow Thickness in many clinics.

Peripheral margin status: Did the surgeon get a clean margin around the edge of the tumor?

Deep margin status: Did the surgeon get a clean margin under the tumor?

Microsatellitosis: Does the tumor have microscopic satellites within two centimeters of the primary tumor? This means there are no cancer cells in the tissue surrounding the tumor.

Tumor infiltrating lymphocytes (TILS): Are any white cells or immune cells found in the tumor? This can be a sign of an immune response. The more TILS, the better.

Radial Growth Phase: The tumor in earliest phase with little chance of metastasis.

Vertical growth phase: The direction of the tumor's growth into the skin. The report will indicate whether this is present or absent.

Regression: Means that the tumor has actually disappeared, perhaps because of destruction by the immune system. It is listed as either present or absent. If present, the extent of the regression is described.

Angiolymphatic invasion: Has the tumor invaded blood cells?

Histologic subtype: This groups cancer cells by certain qualities or characteristics.

All of this information comes together to form a profile of your cancer. Your doctors use this information to recommend treatments for your situation. You can always ask for a copy of your pathology report and to discuss it with your doctor.

STAGING

Melanoma is staged from 0 to IV, with stage 0 being the earliest and stage IV the most advanced. As with most cancers, melanomas are staged using the TNM system:

- T refers to the tumor—its size, thickness, and depth
- N refers to nodal status—the presence or absence of positive lymph nodes
- M refers to metastases—whether the tumor has spread to other organs

Staging takes into account many factors. The stage of the melanoma guides the treatment and generally predicts the prognosis. Most early stage melanomas can be treated with surgery and have a good prognosis.

Melanomas that are thicker, ulcerated, have certain biologic features, or have spread to the lymph nodes are at higher risk for recurrence and require more extensive treatment, as do those that arise in the head and neck area. Melanomas that have spread to other sites in the body are treated with a number of therapies, including targeted agents and immunotherapy.

OTHER TESTS AFTER A DIAGNOSIS

Blood tests are not used to diagnose melanoma. They may be used to monitor melanoma once it has spread to another part of the body.

For patients with newly diagnosed melanomas, imaging may be used to determine if the cancer has spread to another organ or part of the body. Most patients will have a CT scan as part of their diagnostic workup. Doctors may also use MRI, PET scans, or ultrasound for this purpose.

People with melanoma that has spread have regular imaging tests to see how their tumors are responding to therapy.

EARLY MELANOMA

Anne was 32 years old, the mother of two very young children, when she noticed a mole on her back that was “darker and uglier” than the few others she had. Her doctor was concerned as soon as he saw it and sent the punch biopsy for rush pathology. The diagnosis was melanoma.

“It turned my life upside down,” she says. “For weeks, it consumed all my thoughts. I was so stressed out.” Anne had a wide excision and a sentinel node biopsy, which showed that her nodes were clear of cancer. Her husband, although very supportive, at first did not understand the potential seriousness of her disease. Anne recalls his shocked look when she discussed survival rates with him. “You have a survival rate?” he said. Today, Anne now has four children and is actively working to raise awareness and funding for melanoma. “I feel braver than I was before this happened, and more of an advocate.” she says, “It has been very helpful to reach out and talk to others.”

Coping With a Melanoma Diagnosis

“I was very involved in coaching lacrosse for my kids. I never stopped during my treatment. For me, that was my escape mechanism, my support.” —Steve, Metastatic Melanoma Survivor

Any diagnosis of cancer is a life changing event. From the day you hear those words, you enter a world in which you have to learn a new language, make decisions, and deal with issues you never imagined would be part of your life.

You are suddenly faced with multiple doctor's appointments, tests, procedures, and possibly treatment sessions. Your family life, your friends, your job, your financial situation—everything may be impacted. It can seem overwhelming—and that is normal.

You are not alone. You are not powerless.

There are people there to support you, and steps you can take to help navigate this new world and to make your journey more manageable.

THE BENEFITS OF TAKING CARE OF YOURSELF

There are positive benefits to taking an active approach to living with your cancer. Many people do better physically when they take care of their emotional and social needs. You may experience less fatigue, anxiety or depression, or be better able to tolerate your therapies.

Taking care of your emotional needs also provides you with more control over your life, regardless of where you are in your treatment. It is not unusual for people with cancer to discover new meaning in their lives, or to develop deeper appreciation for the people and things that are important to them.

Many people find that connecting with other people with cancer helps both in what you receive in those interactions, and what you give.

What You Can Do

- Learn about your cancer. Melanoma is a complicated disease. Your experience and your treatment will depend on the stage of your melanoma.
- Communicate. Good, open communication with your health care team is key. It is important to try to find a doctor and treatment center experienced in treating melanoma. It is also key to find a team who will answer your questions and address your issues. Don't be afraid to ask questions or let your team know if you are experiencing

side effects or struggling with the emotional impact of your cancer. Make a list before your appointment of the issues you want to discuss. Take someone with you to your appointments to help listen and respond to what you learn.

■ Be your own best advocate. Some people want to know everything about their cancer and its treatment. They pour over their pathology report and research new developments in the field. Others are more comfortable knowing the basics and relying on their doctors to tell them what they need to know. Even if you only want to know the basics, consider getting a second opinion from another doctor. A second opinion can help reconfirm your diagnosis and treatment options. It can also give you the chance to see if there is another health care team that you would like to work with.

There is no right way to approach your situation, but it is very helpful to understand enough about your disease so you can be an informed, active participant in your treatment. Knowing the stage of your disease and the treatment options available to you will help assure that your life and your goals are part of the discussion. Never hesitate to ask questions or raise issues with your team. You are the expert on your life and your body—and your own best advocate.

COST CONCERNS

Unfortunately, the cost of cancer care is an issue for many people. It can add more stress to an already stressful time. Costs can be direct—bills that result from treatment such as copays, or indirect—losing work, paying for childcare, gas money, parking for treatment. Questions about what your insurance covers or how to get insurance coverage may also come up. Whatever your situation, there are resources and organizations that can help. Ask to sit down with the financial or insurance counselor at your cancer center. They can work with you to understand what the costs may be and develop a plan to pay for it.

GETTING SUPPORT, BEING AN ADVOCATE

After Ken's surgery for ocular melanoma, he knew he needed some help. "But I had no idea what help I needed. My significant other, Ruth, found the Cancer Support Community Philadelphia. I checked it out and liked very much what I saw. In the outside world, you may have a lot of support from your friends and family, but they don't get it like a room full of cancer patients do. You don't have to explain things. You don't have to explain feelings or fears," he says.

Ruth found that "Caregivers need to be advocates. Sometimes the caregiver is the one with the clear head. The person going through the cancer can be overwhelmed with just that—the physical and emotional experience of having cancer. They can't always see the next step." Through her experience as a caregiver, she also realized that she was often the one searching for information to help guide Ken to resources. She believes "caregivers can also help medical people do their job by helping them understand how the person with cancer is really doing."





Treating Melanoma

“We have seen a firestorm of progress in understanding and treating melanoma.” — Meenhard Herlyn, PhD, The Wistar Institute

The treatment for melanoma depends on the stage of the cancer, the person’s overall health, and other factors such as genetic changes or characteristics of the tumor that may make it more aggressive or at higher risk of recurring.

Today, treatment and care recommendations are made by a team working together, for you and with you. For melanoma, that team includes the dermatologist, pathologist, surgeon, imaging specialists, and possibly a medical oncologist and radiation therapist, nurses, social worker, and other support staff.

EARLY STAGE MELANOMA

Almost all people with localized or regional melanomas, stage 0-III, will have surgery to remove the primary tumor. The vast majority of melanomas, about 84%, are diagnosed at an early stage, when they are localized and highly curable. For these people, surgery is often the only treatment required.

People whose melanomas are later stage may also need to have surgery but often need

additional treatment to reduce the risk of recurrence or disease progression.

WIDE EXCISION SURGERY

Once the diagnosis is established through the biopsy, additional surgery is usually required to remove all of the cancer cells from the original site. This is called a wide excision—meaning that the surgeon removes not only the tumor but an area around it. The goal is to remove all of the cancerous cells with a “clean margin” of normal tissue both at the edges and below the tumor.

The amount of tissue removed depends on the size of the melanoma, its thickness, and the area in which it occurs. Thicker melanomas need wider margins, as do those which have spread more on the skin’s surface.

A wide excision is a surgical procedure. In some instances, the wide excision may also require a skin graft from another part of the body to close the wound and minimize scarring.

SENTINEL NODE BIOPSY

Research has shown that it is possible to find and map the lymph nodes that are likely to be the first place the tumor spreads, and biopsy only one or two nodes. These are known as sentinel nodes. If the sentinel node is free of cancer, then it is not necessary to do the full lymph node dissection. This spares the patient from the more major surgery and informs the treatment decision-making process.

Today, it is more common to do a sentinel lymph node biopsy. This is usually done for melanomas that are more than 1.0 mm thick, have ulceration, a high rate of cell division, or other features that increase the risk that they will recur or spread. The sentinel lymph node biopsy should be performed before the wide excision surgery.

To do a sentinel node biopsy, the nuclear medicine doctor injects a small amount of radioactive substance into the area around the melanoma, and then uses a special camera to see if the substance collects in one or more sentinel nodes. The patient then goes to surgery where a blue dye is injected into the same place as the radioactive substance. The lymph nodes that are blue, the sentinel nodes, are removed for biopsy.

Some people will not need a sentinel node biopsy because their melanomas are thin and have not invaded the layers of the

skin deeply. Others will have an obviously enlarged lymph node near the site of the tumor, which requires a full lymph node dissection.

Full lymph node dissections often involve major surgery and contribute to the development of lymphedema. There are now studies underway to determine if full lymph node dissections are ever indicated—but more and more centers are now using the sentinel node biopsy for patients at all stages.

HIGH RISK MELANOMAS

“The goal of treating melanomas is to minimize their risk of recurrence without causing unnecessary side effects or expense to our patients. We don’t want to overtreat people who can be cured with surgery. The key is finding ways to identify those patients who really will benefit from adjuvant or neoadjuvant therapies.”

—April Salama, MD, Duke University

Adjuvant Therapy

People with deeper or more extensive melanomas are at higher risk for having their cancers recur or spread after the primary tumor has been removed. These are usually stage III or IV melanomas that can be removed surgically, or stage II melanomas with high-risk features.

Your health care team may recommend treatment after surgery, called adjuvant therapy. The past several years have been an exciting time for melanoma research.

LYMPH NODE DISSECTION

Lymph node dissections are surgical procedures to remove all the lymph nodes next to the primary cancer to determine if the cancer has spread to them. Although lymph node dissections have been part of melanoma treatment for many years, it is not clear whether this procedure improves the cure rate or extends survival for melanoma patients.

LYMPHEDEMA

Lymphedema occurs when the lymphatic channels that drain fluid from the tissues are damaged by surgery or radiation therapy. People whose melanomas occur in their arms or legs, especially those who have lymph node dissections, are at risk of developing lymphedema after treatment.

The symptoms of lymphedema are swelling and distortion of the affected limb. Some people also experience pain or loss of feeling. Lymphedema can be a very serious, disabling condition and should be treated right away.

It is less common with the increased use of sentinel node biopsies but remains a real concern for anyone who has had surgery or radiation therapy that affects lymph nodes in their arms or legs. Treatment for lymphedema is done by physicians trained in rehabilitation medicine or physical therapists with special training in caring for this condition.

In the past, the only adjuvant therapy that demonstrated an improvement in survival was interferon, an agent that boosts the overall immune response.

In 2015, the Food and Drug Administration approved the immunotherapy ipilimumab (Yervoy®) as an adjuvant therapy for stage III melanoma. This drug has been used as a treatment for metastatic melanoma since 2011, and is described on page 25.

Other drugs may be available through a clinical trial. Ask your health care team if adjuvant therapy is an option for you. Also, be sure to ask about the possible side effects associated with any drugs you consider. More information on stage III melanoma can be found in CSC's Frankly Speaking About Cancer: Putting the Focus on Stage III Melanoma.

ADVANCED AND METASTATIC MELANOMAS

“You have to be careful when you look for information about advanced melanoma online. You are going to get a lot of outdated information if you don't go to the right place.”

— Matt, Melanoma Survivor

Understanding the Diagnosis

Some people are diagnosed with melanoma that has already spread to other organs of the body. Others have melanomas that recur after surgery, sometimes years after the primary treatment. This is known as stage IV, advanced, or metastatic melanoma.

HOW MELANOMA SPREADS

Cancer cells have the ability to invade neighboring tissues and organs and spread from the primary site to other sites in the body. This is called metastasis. Once a melanoma has grown into the second layer of skin, the dermis, the cells have access to the lymphatic system and to blood vessels.

When a large number of cancer cells form a mass, or tumor, it can be detected with imaging techniques such as CT, PET or MRI scans. Small numbers of cells can be present in the lymphatic or blood systems, in tissue near the primary tumor, or in a distant organ that cannot be found with these imaging methods. These are called micrometastases.

It is important to know that melanomas cannot spread to distant organs until the cells have access to the lymphatic or blood systems. This is why it is so important to have accurate pathology and staging to help determine the appropriate treatment.

EMOTIONAL SUPPORT

Donna was diagnosed with stage III B melanoma. While her family and friends were very supportive she heard from others that a cancer diagnosis can be really hard on everyone. Family and friends may not always know how to respond or be supportive. Donna says, “I went to counseling for some time just to talk to someone that wasn’t related to my family just so I could really let my hair down so to speak and tell him exactly how I was feeling.” While one-on-one counseling may not be for everyone, Donna also found online communities to be very helpful. She says, “There are closed groups out there that you can get into. One woman I met she encouraged me when I was going through a really difficult time during my treatment and I had the chance to meet her in person recently at a melanoma walk in Houston, which was incredible.”





Once a melanoma has spread in this way, it can no longer be cured with surgery. Additional systemic treatments are needed to try to control the tumor for as long as possible.

In the recent past, the diagnosis of metastatic melanoma meant the prognosis was poor. However, today there are more treatment options for advanced melanoma. While it remains a very serious disease, one that requires ongoing treatment, there is real hope today for people facing metastatic melanoma.

This progress is exciting, but it brings new challenges for both patients and their health care teams. The diagnosis of advanced melanoma is frightening. It is normal to feel anxiety and uncertainty about the future. This is a critical time to educate yourself about your treatment options and work closely with your entire treatment team to develop a plan you understand and meets your life goals. Being able to talk openly with your health care team is essential to managing your cancer.

The treatment for advanced melanoma is complicated and is rapidly changing. Some emerging treatments may be available only through participation in clinical trials. There are multiple settings in which you can receive excellent treatment for your cancer.

Talk to your doctor about the full range of new and developing therapies. You can always get a second opinion.

V

RESEARCH DRIVES PROGRESS

“Clinical trials are essential to advancing any new treatment. Patients are our partners in these efforts.”

—Lynn Schuchter, MD,
University of Pennsylvania

The key to effectively treating, and possibly preventing melanoma, is in understanding what actually happens when a melanocyte becomes a cancer cell. As scientists discover more, they turn that knowledge into new treatments through clinical trials. These studies often compare the existing standard of care to the new drug or approach. Clinical trials are critical in advancing treatment and are playing a crucial role in the progress made against melanoma. To learn more about clinical trials or to find a clinical trial see the Resources section.

TREATMENTS FOR ADVANCED MELANOMA

“Therapies for metastatic melanoma are rapidly evolving. Since 2011 at least six new drugs have been approved that have substantially improved the five-year survival rates for people with stage IV disease.”

—Richard Joseph, MD, Mayo Clinic

Targeted Therapy

One of the great discoveries of the last two decades is that cancer growth and spread is controlled by specific characteristics of the tumor. In many cases, these are genes that have undergone a change, losing their normal function. They are part of intricate molecular pathways responsible for controlling the growth, reproduction and death of all the cells in our body. Genes that fuel cancer growth are called “driver genes,” and are very important because they can be targeted with agents that block their activity.

Researchers have identified several molecular pathways and mutated genes that are abnormal or activated in melanoma. These discoveries have led to the development of a new category of agents known as targeted therapies that have changed the outlook for many people with advanced melanoma.

Any person with a diagnosis of advanced melanoma should have the tumor genetically profiled to identify potentially targetable genetic mutations. This can be done in virtually all major cancer centers and in many community oncology practices. Genetic profiles can help identify who will

benefit from the available treatments, and those who will not.

Targeted therapies only work for the individuals who have the specific gene mutation or tumor characteristic targeted by the drug or agent.

■ **BRAF Inhibitors:** Approximately 50% of all melanomas have a mutated or activated BRAF gene. This discovery led to the development of three drugs:

- dabrafenib (Tafinlar®)
- trametinib (Mekinist®)
- vemurafenib (Zelboraf®)

These have been approved for stage IV and some stage III melanomas that cannot be surgically removed. These agents produce high response rates in people who have the BRAF mutation, often resulting in significant shrinkage of the tumors and reduction of symptoms.

They have been demonstrated to prolong life and improve quality of life, but they are, not by themselves, a cure for advanced melanoma. In virtually every case, the cancer returns after a period of months, or sometimes years.

Researchers now know there are multiple variations of the BRAF mutation and that tumors respond differently to therapy. Treatments will continue to become more precise and individualized as the ways in which these different mutations influence cancer growth are understood.

■ **MEK Inhibitors:** MEK is a protein involved in cancer growth and survival. It is abnormally activated in patients who have a BRAFV600E or V600K mutation—a specific type of BRAF mutation. The Food and Drug Administra-

tion (FDA) has approved two drugs that target MEK. They are used to treat people with unresectable stage III or stage IV melanomas that test positive for BRAF V600E or V600K mutations. Trametinib (Mekinist®) is used in combination with dabrafenib (Tafinlar®). Cobimetinib (Cotellic®) is used in combination with vemurafenib (Zelboraf®).

■ **KIT Inhibitors:** KIT is another gene that is sometimes mutated in certain types of melanoma, including lentigo maligna melanoma, mucosal melanoma, and acral lentiginous melanoma. There are a number of drugs being tested in clinical trials for patients with stage IV melanoma.

■ **Targeted Therapies In Clinical Trials:** Identifying targets for therapy is an area of enormous interest and activity in cancer research and treatment. It is important that people with advanced melanoma be aware of ongoing clinical trials. If you are interested in a clinical trial, talk with your doctor or see the Resources section.

Immunotherapy

Immunotherapy uses the body's own natural defense system to fight the cancer. This sounds like an obvious way to treat cancers, but for many years the efforts to develop effective immunotherapy led to disappointment and poor results.

This was particularly frustrating in melanoma because researchers knew that this is an “immunogenic” disease—one in which the immune system mounts a response. They observed the occasional case in which an advanced melanoma would disappear. They

found evidence of an immune response in melanoma tumors. Interferon, an agent that boosts the immune response produced very positive results in a small group of patients and helped others.

The question was—why did the response fall short or fail in so many instances?

The persistence and ingenuity of cancer researchers has opened the doors to a remarkable new era in which immunotherapy is emerging as an innovative, important tool to fight cancer. Since 2011, a number of new immunotherapy drugs have been approved to treat melanoma—with more studies in progress.

There are a number of approaches to immunotherapy. These include:

■ **Interferon:** High-dose interferon alfa-2B has been shown to delay recurrences in some patients after surgery. Interferon has substantial side effects, including severe flu-like symptoms, nausea, vomiting, and depression. With the introduction of new treatment approaches, interferon is now used much less often.

■ **Anti-CTLA 4 Antibody:** The 2011 introduction of ipilimumab (Yervoy®), a new kind of immunotherapy, to treat advanced melanoma had a huge impact on the field. Ipilimumab (Ipi) is a human monoclonal antibody that targets the cytotoxic T-lymphocyte (CTLA-4) associated molecule, a component that helps turn off your immune system.

Ipi works by unblocking or taking the brakes off the immune system. Approximately 10-

15% of people respond to ipi. Ipi is now a first-line treatment for people whose melanomas have recurred or spread.

Ipi has been shown to prolong survival in people who respond to it. While most patients do not respond to ipi, those that do typically benefit for years, but their melanomas usually recur at some point. A small percentage of people have complete disappearance of their tumors, which appears to be long-lasting and may be permanent. Current data indicate that patients who are free of disease after three years of treatment are unlikely to have their melanomas return.

Ipi and new drugs like it have side effects, which can be serious. The drug can trigger an autoimmune response. This can cause colitis, liver inflammation, skin reactions, as well as hormone and nerve problems. The severity of side effects is related to the dose. This has led to a number of studies designed to try to increase the effectiveness of anti-CTLA 4 antibodies while reducing the side effects.

■ Anti-PD-1/PDL-1 (PD-1/PD-L1 Antibodies): We now know many cancers are able to deactivate or block the natural immune response. PD-1/ PD-L1 inhibitors stop the cancer from blocking the ability of T-cells to identify and destroy tumor cells.

The Food and Drug Administration (FDA) has approved pembrolizumab (Keytruda®) and Nivolumab (Opdivo®) to treat people with unresectable stage III or stage IV melanomas. Nivolumab (Opdivo®) may be given in combination with ipilimumab (Yervoy®).



NEW TREATMENTS MEAN NEW HOPE

Steve was 44 years old, a husband and father of four children when he was diagnosed in 2011 with metastatic melanoma. “At first, it was like, will I be around? Will I see my kids graduate? If I’m not, how will my wife take care of the family?” he says. When Steve started reading on the internet about his diagnosis, he stopped because what he was finding wasn’t positive. So Steve says, “I relied on my doctor to set the course. I wanted to get started on treatment right away. I was all in. I liked the idea of immunotherapy because my body was going to fight the cancer. It worked for me. I always say that my story is unique and anyone who has been through this would tell you the same thing. I would ask anyone—what’s your goal? I felt this trial and this treatment were the best thing for me.”

New studies provide evidence that PD-1 antibodies have higher response rates than ipi alone. Approximately 33% of patients who have not received any prior treatment respond to a single agent PD-1 antibody and as many as 60% respond when it is combined with ipi, although side effects may be significant when these agents are used in combination.

PD-1 antibodies do have side effects. They include fatigue, itching, joint pain, and nausea.

There are many clinical trials to determine which patients benefit from this kind of

immunotherapy and when to give this treatment. These are being done using a variety of PD-1 antibodies often in combination with other therapies.

Other types of immunotherapy were used to treat melanoma before checkpoint inhibitors were developed. These include peginterferon alpha 2-b (Sylatron®) and interleukin-2 (IL-2; Proleukin®).

■ **Oncolytic viral therapy:** Viral therapy works by adapting a virus so that it spreads to and destroys cancer cells. In 2015, the FDA approved the viral therapy talimogene laherparepvec (Imlygic®) (commonly

COMBINING THERAPIES FOR BETTER OUTCOMES

Recent studies treating metastatic melanoma are looking at combinations of two or more drugs to improve response rates and overall survival. For example, in 2015, the FDA granted accelerated approval of nivolumab (Opdivo®) in combination with ipilimumab (Yervoy®), for the treatment of patients with unresectable or metastatic melanoma who have the BRAF V600 mutation. This drug combination was later given full approval for unresectable or stage IV melanomas more broadly.

Be sure to ask about the side effects of any and all recommended drugs, when given on their own or in combination. More information on the side effects of immunotherapy can be found in CSC's Frankly Speaking About Cancer: Immunotherapy & Melanoma booklet.

called T-VEC) to treat unresectable stage III and stage IV melanoma. The drug is injected into the tumor. Thus, it is only used for local treatment of unresectable cutaneous, subcutaneous, and nodal lesions, in melanomas that return after surgery.

■ **Interleukin:** A small percentage of people with advanced melanoma have good responses to high dose interleukin. However, there can be serious side effects so interleukin must be given in a hospital at specialized centers.

Chemotherapy

For years, chemotherapy was used for the treatment of advanced melanoma. Overall, the

results were disappointing. The response rate was low and responses generally lasted for only a few months. Today, doctors often favor targeted therapies and immunotherapies, though chemotherapy may be used in some instances. Dacarbazine (DTIC-Dome®) is the only form of chemotherapy approved for the treatment of advanced melanoma. Temozolomide (Temodar®), an oral form of the same drug, is not FDA-approved but sometimes used to treat metastatic melanoma with similar results.

Chemotherapies include:

- Carboplatin and Cisplatin
- Dacarbazine
- Nab-Paclitaxel/Paclitaxel
- Temozolomide

SCANXIETY

“Scanxiety” is a term coined by Bruce Feller to describe the anxiety and fear he felt when he had to have a scan to determine if his cancer, a bone tumor, had spread. While there is no antidote to this common experience, there are ways to help reduce your level of anxiety:

- Try to have a short waiting period between the time you schedule the scan or tests and when you actually have them.
- Talk to your doctors and let them know you want the results of the scan as soon as possible, the same day if they can make it happen.
- Take a family member or friend with you to the scan and the appointment in which you learn the results.
- Even though it may be hard, do something to distract yourself from thinking about the scan both before you get it, and while you wait for the results.
- Know that your feelings are normal.

THE DELAYED RESPONSE TO TREATMENT

“I went into the hospital to find out the cause of some internal bleeding I was having and the pathology came back as melanoma. I had always been healthy and active, so getting the diagnosis was shocking. The surgeon said, ‘I want you to see an oncologist...tomorrow,’ and that’s when I started to understand how serious the situation was,” says Robert. Robert has metastatic melanoma and is on an immunotherapy clinical trial. “For weeks, it didn’t seem like anything was happening. My oncologist said, ‘let’s do one more scan and then we will change treatments’—and on that scan, the tumors had regressed significantly. I was one of the people who had the delayed response. It was tough going that long without knowing if I was responding, but I realize that’s part of what you get with this kind therapy,” he says.

When people with cancer are treated with most standard therapies, it is possible to measure whether it is working or not fairly quickly—usually within a week or so of beginning treatment. It often doesn’t work that way with immunotherapy. It can take weeks or even several months to know whether the treatment is working. The tumor may even appear to grow or progress on a scan. This is the result of an inflammatory reaction—the body attacking the tumor cells and those cells reacting.

This can be very challenging and cause anxiety for people going through this therapy. The wait can be very difficult to handle. This is an issue to discuss with your treatment team so that you understand in advance what to expect.





Managing Side Effects

“The cancer diagnosis is such a roller coaster. Talking to the team—the oncologist, the nurse practitioners, the nurse, the physician assistant to get information can really help the process.”

— Suzanne McGettigan, Nurse Practitioner, PennMedicinta

The side effects of specific treatment approaches are noted in each of those sections. It is important to realize every treatment has some side effects. The exact nature of those side effects and their severity depend on the specific treatments you receive, and your individual responses.

It is also important to know many treatments actually decrease the symptoms of the disease so people feel better and their quality of life improves.

Here are some tips on how to manage side effects.

- Talk to your doctor and treatment team before you start a therapy. Let them know what is important to you, what scares you, and what you want to be able to do during therapy.
- Know that there are many ways to ease or eliminate side effects. Let your team know immediately if you develop side effects or they become worse. This is true for all treatments, but especially for immunotherapy. More information on the

side effects of immunotherapy can be found in CSC’s Frankly Speaking About Cancer: Immunotherapy & Melanoma booklet.

- Don’t forget the emotional side. Not all side effects are physical.
- Take care of yourself. You are the expert in what you can handle, what kind of activities you can engage in, and how much you can and want to do on any day.
- Let family and friends help you. Give people specific suggestions for what will be helpful: a meal, childcare, a ride, an afternoon to yourself, or a walk together in the park.
- Most of all communicate—with your health care team and your family.

YOUR VALUES AND SIDE EFFECTS

When you make decisions about treatment, it’s important to think about potential benefits of that therapy and balance those with the things in your life that are important. That means having an open, honest, two-way conversation with your health care team. You

need to have a good understanding of the goals of your treatment, just as your doctors and nurses need to understand your goals.

Your willingness to deal with side effects may be influenced by what can be realistically achieved with the approach being offered, or by your personal situation. You may decide a treatment that offers a potential cure or a significant extension of your life is worth tolerating more serious side effects, or side effects that last for months or years.

If you have already been through a number of treatments, the treatment offers only a short response time, or you have other serious health conditions, those same side effects may not be justified for you. These are very individual decisions. One person may focus solely on living as long as possible. Another's focus may be to see his or her child graduate from college, while someone else will choose to stop or reduce treatment. Your values matter. Talk to your doctor and treatment team about what is important in your life.

“The issues that people bring up vary over time. The questions someone has at diagnosis are different from those that come up after a person has been on treatment for a while. People want to know how their treatment is going to affect their lives.”

—Ryan Nipp, MD, Dana-Farber Cancer Institute



LIVING LIFE

“I live a relatively normal life with two young kids and a wife and we do what people without stage IV cancer do,” says Matt. Matt was originally diagnosed with melanoma in 2003, but recurred in 2013. “I had a good result with the targeted therapy, but it didn’t last forever. The cancer finds a way around it. So, we switched to immunotherapy. I was on one of the FDA-approved drugs. After the second treatment, I started to notice some GI symptoms, and that developed into full-blown colitis. Thanks to my doctor and a wonderful nurse, I was able to manage these side effects. I know some patients end up in the hospital with colitis, but because my problems were handled so well through doctor-patient communication, I was able to avoid that. Generally speaking, I feel good and have worked full time throughout my treatments,” he says.

The Empowered Patient

“I’m thankful I have a great support system with my family and friends. But, I feel like I have more support with the community that I’m connected with online. Their experience with melanoma may not be exactly the same, but they understand.” —Donna

The Cancer Support Community, originally The Wellness Community and Gilda’s Club, was founded to provide support to people and their loved ones impacted by cancer and to empower them to become active partners in their care. In the 1980s, that was a visionary concept. Today, it is an integral part of cancer care.

As you move through the experience of having melanoma, you will find your own path and develop your own strategies to manage your treatment, and your life, but here are some tips that can help:

- Don’t try to do everything at once. Stay in the moment, as much as possible, and focus on what is happening now, and what you need to do to address that situation.
- Ask for support. Many of your family and friends will want to be there for you. Be open about what they can do to support you. It is useful to be specific. Ask someone for a meal, to watch your children, give you

a ride, or just be there on a tough day. For some people, religion and spirituality are a very important source of strength and support while going through cancer. That support may come from a person’s faith or relationship with a god, as well as from the wonderful bonds that often exist among those in the same faith community.

- Take someone with you to medical appointments and procedures. This is important because an extra set of eyes and ears often helps to remember and interpret the information you are given.
- Acknowledge and express your feelings. There are many ways to do this. Talk to a friend or family member, pastor, or a counselor. Write, paint, or play music. Many people benefit from joining a support group and sharing their experiences with other members of the community pastor, or counselor.
- Make time for yourself and the things you enjoy. Being a cancer patient can be very

time consuming and mentally exhausting. It is important to continue to do what you love as much as possible. For some people, that is as simple as taking a walk or planting some flowers. For others, it may mean continuing to work. You may have to adjust your activities to fit your energy level and physical condition, but don't lose sight of the importance of continuing to do what you like to do in your life.

■ **Learn to relax.** For most people, living with cancer involves at least some level of anxiety and emotional distress. It can be very helpful to learn how to give yourself moments in which you feel calm and controlled. Many people benefit from mindfulness or meditation classes, or from practicing yoga. For others, those moments might come from a walk in the woods or from playing the piano. Learning to relax is actually a skill you have to learn but it can help with many aspects of life.

■ **Develop a plan.** Having a treatment plan—one that is developed and shared with your team—is very important. You can coordinate your care and make sure that your emotional as well as your physical needs are addressed. You can also identify resources to help with the various aspects of your care. Your plan will likely change as you progress through treatment. For people whose treatment ends, the emphasis

will be on moving forward and receiving the proper follow-up care. For those who are continuing with their treatment, it is important to talk about your specific goals to ensure your voice is heard in the decision-making process.

■ **Hold onto hope.** There are many ways to hope. You can hope for the big things—that the cancer is successfully treated and you can return to your life, or, depending on your circumstances, you can focus on smaller goals. You might hope for a good result on a scan or a positive report from your doctor. Or, you might hope that tomorrow will be a sunny day and you can get out in your garden, or that you will spend time with your friends and family doing something you all enjoy. The main thing is not to let go of hope, to keep setting goals, and to keep finding things in your life that matter and bring you happiness.

WHAT ABOUT WORK?

“A cancer diagnosis often raises huge issues surrounding work and career. People want to know if they can continue to work, or how it will affect their relationships. It is a very real and often overlooked area of concern.”

—Hester Hill Schnipper, LICSW, OCW-C,
Beth Israel Deaconess Medical Center

TOOLS TO HELP COMMUNICATE YOUR WISHES

Advance directives are legal documents, such as a living will and durable power of attorney for health care, which you put in place to inform your doctors and family what you want to do in terms of end-of-life treatment. Most of these documents can be prepared without the use of a lawyer and without any cost to you or your family.

While it can be difficult to have this discussion, most people find that they and those who love them benefit from talking about the issues and making decisions beforehand so wishes are clearly understood. Anyone can have an advance directive, but it becomes more important when you are facing a cancer diagnosis, especially when the prognosis is uncertain and unfavorable. Your health care team can help you think about your wishes and refer you to someone experienced to help prepare these documents.

For many people, a cancer diagnosis involves serious concerns about the impact of illness and treatment on work. These concerns may include lost time, earnings, and opportunities; the possibility of losing health insurance; or the fear of not being able to support yourself or your family.

Your ability to continue to work throughout your cancer experience will depend on the stage of your disease, the treatment and your response to it, and, in many instances, on your personal priorities and needs. Employers also differ greatly in their willingness and ability to provide support and accommodate your needs during treatment.

There is no single approach to dealing with your work situation and cancer. There are steps you can take to help assess your situation and make decisions about how to manage your work life during this time.

- Think about what you need to do, and what you want to do. Can you take time off? Do you want to do that?
- Find out what your employer offers and what you are entitled to in terms of insurance coverage, disability insurance, sick leave, and reduced hours.
- Let your colleagues and friends support you as much as possible.
- Explore the possibility of working part time or cutting back during the most difficult times.
- Reach out to organizations like Cancer and Careers (www.cancerandcareers.org) or

try contacting Cancer Legal Resource Center (www.disabilityrightslegalcenter.org) to learn more about your rights and the resources available to you.

WHAT IS QUALITY OF LIFE?

“People with serious illnesses have stress in different ways. We need to understand what individuals are going through and focus on the physical, emotional, and spiritual quality of life our patients want.”

—Hunter Groninger, MD,
MedStar Georgetown Washington Hospital Center

Quality of life is an expression that comes up frequently when people are talking about cancer treatment. In medical terms, it is usually defined as maximizing the ability to function normally, while minimizing the negative effects of the disease or its treatment. But there is no single definition.

Each person can define what quality means, and that definition will depend on who you are, what is happening in your life, and how your cancer impacts the things that are important to you. Each person can define what quality means, and that definition will depend on who you are, what is happening in your life, and how your cancer impacts the things that are important to you—whether that is your job, your ability to care for your children, taking care of your home, or going on the trip you planned.

No matter how you define it, quality of life is very important in treating cancer, at all stages of the journey. Talk to your treatment team about what matters to you. Let them know if you are having problems. Share your goals and values with them, so that they can help you achieve the best possible quality for your life.

BE CAREFUL ABOUT THE INTERNET

Just about everyone searches for health-related information on the internet. But, when you research melanoma, be careful about what you read and how you interpret it. Any information you get about the treatment of advanced melanoma that was written before 2011 is completely out of date, and even materials from the last year may no longer be current. If you choose to search for melanoma information on the internet:

- check the date
- stay with credible organizations that update their sites frequently
- and most importantly, discuss what you find with your doctor





LIVING LIFE

Shelley has faced cancer twice. The first time, she was diagnosed with breast cancer. The second time, it was melanoma. In both instances, she used the energy and determination she demonstrated in her years as a high school physical education teacher to make sure her experience had meaning, for herself and others.

For Shelley, one way of sharing her experience is to organize a dragon boat program for cancer survivors in her area. Dragon boating is the essence of a team activity. It takes 20 people to paddle the boat, along with a drummer to set the pace and a steersperson. The more in sync the paddlers are, the faster the boat moves. Dragon boating has become a popular sport for people who face cancer because of its strong sense of community, shared experience, and purpose. “We go out once a week,” says Shelley. “There’s nothing like getting a group out there on a beautiful morning. People will come to me, especially the ones who are there for the first time and are so excited about the fact they can do this, and they can do it with other individuals who have all faced cancer. We celebrate each other, support each other, and sometimes, we grieve together for the ones who aren’t with us anymore. It’s very empowering. They thank me, but really, they are giving me and each other so much. I just think it is so important for all of us who have been through the cancer experience to find each other and to do things that make us feel good about life.”

Cancer Support Community Resources

The Cancer Support Community's (CSC) resources and programs are available free of charge.

To access any of these resources below call 1-888-793-9355 or visit

www.CancerSupportCommunity.org

CANCER SUPPORT HELPLINE®

Whether you are newly diagnosed with cancer, a longtime cancer survivor, caring for someone with cancer, or a health care professional looking for resources, CSC's toll-free Cancer Support Helpline (888-793-9355) is staffed by licensed CSC Helpline Counselors available to assist you Mon-Fri 9am - 9pm ET.

OPEN TO OPTIONS®

If you are facing a cancer treatment decision, this research-proven program can help you. In less than an hour, our trained specialists can help you create a written list of specific questions about your concerns for your doctor. Appointments can be made by calling 888-793-9355, visiting www.CancerSupportCommunity.org or by contacting your local CSC or Gilda's Club providing this service.

CANCER EXPERIENCE REGISTRY®

The Registry is a community of people touched by cancer. The Registry works to collect, analyze, and share information about the experience and needs of patients and their families. To join, go to www.CancerExperienceRegistry.org.

FRANKLY SPEAKING ABOUT CANCER®

CSC's landmark cancer education series provides trusted information for cancer patients and their loved ones. Information is available through publications, online, and in-person programs.

SERVICES AT LOCAL CSCS AND GILDA'S CLUBS

Almost 50 locations plus 120 satellite locations around the country offer on-site support groups, educational workshops, and healthy lifestyle programs specifically designed for people affected by cancer at no cost to the member.

THE LIVING ROOM, ONLINE

Here you will find support and connection with others.

Acknowledgements

A special thanks to our contributors and reviewers:

AIM at Melanoma, Melanoma International Foundation, Melanoma Research Alliance,
Melanoma Research Foundation, Erin McAllister, MSW, LSW, OSW-C,
Gilda's Club South Jersey; April K.S. Salama, MD, Duke University

The Cancer Support Community provides this information as a service. This publication does not take the place of medical care or the advice of your doctor. Talk to your doctor or other health care professional to answer your questions and learn more.

Other Resources

MELANOMA INFORMATION & SUPPORT

AIM AT MELANOMA

1-877-246-2635

www.aimatmelanoma.org

CANCERCARE

1-800-813-4673

www.cancercare.org

CANCER SUPPORT COMMUNITY

1-888-793-9355

www.CancerSupportCommunity.org/Melanoma

MELANOMA INTERNATIONAL FOUNDATION

1-866-463-6663

www.melanomainternational.org

MELANOMA RESEARCH ALLIANCE

www.curemelanoma.org

MELANOMA RESEARCH FOUNDATION

1-800-673-1290

www.melanoma.org

NATIONAL CANCER INSTITUTE

1-800-422-6237

www.cancer.gov

FINANCIAL, INSURANCE AND LEGAL HELP

CANCER AND CAREERS

646-929-8023

www.cancerandcareers.org/en

CANCERCARE

1-800-813-4673

www.cancercare.org

CORPORATE ANGELS NETWORK

www.corpangelnetwork.org

1-866-328-1313

CANCER LEGAL RESOURCE CENTER

1-866-843-2572

www.disabilityrightslegalcenter.org

HEALTH INSURANCE MARKETPLACE

1-800-318-2596

www.healthcare.gov

NEEDYMEDS

1-800-503-6897

www.needymeds.org

PARTNERSHIP FOR PRESCRIPTION ASSISTANCE

1-888-477-2669

www.pparx.org

PATIENT ACCESS NETWORK FOUNDATION

1-866-316-7263

www.panfoundation.org

PATIENT ADVOCATE FOUNDATION

1-800-532-5274

www.patientadvocate.org

PATIENT ADVOCATE FOUNDATION CO-PAY RELIEF

1-866-512-3861

www.copays.org

UNITED WAY

211

www.unitedway.org

CLINICAL TRIALS

AIM AT MELANOMA

1-877-246-2635

www.aimatmelanoma.org

CANCER SUPPORT COMMUNITY

888-793-9355

www.CancerSupportCommunity.org/ClinicalTrials

MELANOMA INTERNATIONAL FOUNDATION

1- 866-463-6663

www.melanomainternational.org

MELANOMA RESEARCH ALLIANCE

www.curemelanoma.org

MELANOMA RESEARCH FOUNDATION

1-800-673-1290

www.melanoma.org

NATIONAL CANCER INSTITUTE

1-800-422-6237

www.cancer.gov

CAREGIVERS

CANCER SUPPORT COMMUNITY

1-888-793-9355

www.CancerSupportCommunity.org/Caregiver

CAREGIVER ACTION NETWORK

202-454-3970

www.caregiveraction.org

CARING FROM A DISTANCE

www.cfad.org

FAMILY CAREGIVER ALLIANCE

1-800-445-8106

www.caregiver.org

A Bold New Era: A Bright Future

“This is the first time I have seen responses this durable, and most of these people had no side effects. These were patients who had weeks to live. Their immune systems were primed to attack the tumor but were turned off by the tumor.”

—Antoni Ribas, MD, University of California at Los Angeles

Ten years ago, even the most seasoned and optimistic melanoma doctors and researchers would not have predicted the progress that has been made in understanding and treating this disease. There has truly been an explosion of knowledge, new drugs, approaches, and wisdom about how to use these new tools. For the first time, a percentage of people with advanced melanoma are achieving remissions so complete and long lasting that they are now considered cured.

That’s very exciting but there is still a great deal of work to be done. The goal now is to continue to deepen and broaden the understanding of what causes melanoma and allows it to spread and grow, and to apply that knowledge to treatment that will benefit every individual affected by this disease.

That goal is in sight.

As the largest professionally led nonprofit network of cancer support worldwide, the Cancer Support Community (CSC), including its Gilda's Club affiliates, is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community. CSC achieves its mission through three areas: direct service delivery, research and advocacy. The organization includes an international network of Affiliates that offer the highest quality social and emotional support for people impacted by cancer, as well as a community of support available online and over the phone. The Research and Training Institute conducts cutting-edge psychosocial, behavioral and survivorship research. CSC furthers its focus on patient advocacy through its Cancer Policy Institute, informing public policy in Washington, D.C. and across the nation. For more information, please call the toll-free Cancer Support Helpline at 888-793-9355, or visit www.CancerSupportCommunity.org. So that no one faces cancer alone®

**FRANKLY SPEAKING ABOUT CANCER: MELANOMA
PROGRAM PARTNERS**



**THIS PUBLICATION WAS MADE POSSIBLE THROUGH AN
EDUCATIONAL GRANT FROM**



Design by Yolanda Cuomo Design, NYC

Photographs © Ed Cunicelli



www.CancerSupportCommunity.org
888-793-9355

© NOVEMBER 2017
CANCER SUPPORT COMMUNITY.
ALL RIGHTS RESERVED.