PATIENT RESOURCE

5th Edition

Understanding Melanoma

A PATIENT GUIDE TO DIAGNOSIS, TREATMENT, FOLLOW-UP AND PREVENTION

Prevention

Diagnosis

Survivorship

Published in partnership with

AIM AT MELANOMA FOUNDATION

PRP PATIENT RESOURCE PUBLISHING®

AIM AT MELANOMA FOUNDATION

HERE FOR YOU

AIM at Melanoma Foundation is one of the top resources for melanoma patient support, education, research, and advocacy. We strive to provide patients and their caregivers - both the newly diagnosed as well as those looking to gain a greater understanding of their disease - with a full suite of tools to guide them along their treatment journey.

Melanoma Support

Our melanoma medical expert provides accurate answers to a wide range of melanoma questions

Melanoma Education

Our educational symposiums provide patient-friendly information by internationally renowned medical experts

Melanoma Resources

Our extensive virtual library of educational materials covers every aspect of melanoma

Visit the Melanoma Learning Center

AIM at Melanoma knows that a melanoma diagnosis can be confusing, but you don't have to handle it alone.

www.AIMatMelanoma.org

5th Edition

Understanding Melanoma

IN THIS GUIDE

CO-EDITORS-IN-CHIEF

Charles M. Balch,
MD, FACS

John F. Thompson,
MD, FRACS, FACS

➥ ***For more information***
about the Patient Resource Medical Advisory Board, visit ***PatientResource.com/The_Advisory_Board.aspx***

PATIENT RESOURCE

Chief Executive Officer	**Mark A. Uhlig**
Co-Editor-in-Chief	**Charles M. Balch, MD, FACS**
Co-Editor-in-Chief	**John F. Thompson, MD, FRACS, FACS**
Senior Vice President	**Debby Easum**
Vice President, Publications	**Dana Campbell**
Managing Editor	**Colleen Scherer**
Contributing Writer	**Annie Stuart**
Graphic Designer	**Michael St. George**
Medical Illustrator	**Todd Smith**
Circulation & Production Manager	**Sonia Wilson**
Vice Presidents, Business Development	**Amy Galey** **Kathy Hungerford**
National Account Executive	**Billy Dunbar**
Office Address	**8455 Lenexa Drive** **Overland Park, KS 66214**
For Additional Information	**prp@patientresource.com**
Advisory Board	**Visit our website at PatientResource.com to read bios of our Medical and Patient Advisory Board.**

For Additional Copies: To order additional copies of *Patient Resource Cancer Guide: Understanding Melanoma,* visit PatientResource.com, call 913-725-1600, or email orders@patientresource.com.

Editorial Submissions: Editorial submissions should be sent to editor@patientresource.com.

Educate yourself immediately upon diagnosis

Hearing the words, "you have melanoma," is overwhelming. But the more you know about your type of melanoma, the better prepared you will be to have informed discussions with your medical team. Treatment options for all stages have developed at a rapid pace over the past few years. Today, several immunotherapy and targeted therapy treatment regimens continue to be tested in melanoma.

Melanoma is a cancer that starts in skin cells known as melanocytes that produce melanin, the substance that colors the skin and eyes. Damaged DNA can cause the melanocytes to grow abnormally. When melanocytes grow out of control, forming a tumor, they become a melanoma.

Melanomas can develop anywhere on the skin, but they can also occur in the eyes and in mucosal linings, such as in the mouth, genitals and anal area. The neck and face are common sites for melanoma of the skin. Melanocytes may also form moles that can turn into melanoma.

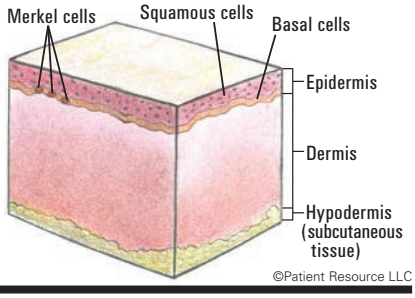
TYPES OF MELANOMA

Although melanoma is a rare type of skin cancer, it is considered the most serious type. It can easily spread into deep layers of skin as well as to lymph nodes and other organs. The skin's layers include the epidermis (outer layer), dermis (inner layer) and hypodermis (subcutaneous tissue). Melanoma typically develops in the epidermis, which contains melanocytes (see Figure 1).

Cutaneous melanoma has four main types:

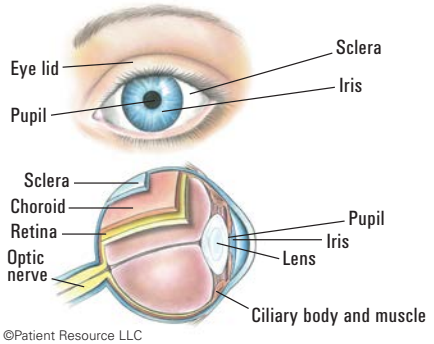
- Superficial spreading melanoma, the most common type, usually develops from an existing mole.
- Nodular melanoma usually appears suddenly as a bump on the skin.
- Lentigo maligna melanoma typically begins on the face, ears, neck and arms that have been exposed to the sun for long periods of time.
- Acral melanoma (ALM) is found on the palms of the hands, soles of the feet or under the nail bed.

FIGURE 1
ANATOMY OF THE SKIN



©Patient Resource LLC

FIGURE 2
ANATOMY OF THE EYE



©Patient Resource LLC

Other subtypes include amelanotic, which lacks pigmentation (color), and desmoplastic, which is distinguished by the presence of certain cell types.

Ocular melanoma, a rare type of melanoma, develops in the eye. No screening tests are available for the disease, but routine eye exams help doctors find most ocular melanomas. Others may be found after they begin to cause symptoms or when the pupil is dilated during an eye exam.

The eye is composed of several layers of tissues, including the iris, ciliary body and choroid (see Figure 2). The iris, which is the colored area at the front of your eye, controls how much light enters the pupil. The ciliary body changes the shape of your lens when you focus on an object and makes the transparent liquid found between the outer layer of the eye and the iris. The choroid provides blood to the retina, which is the light-sensitive ocular tissue at the back of the eye. Rarely, melanoma may also develop in the conjunctiva, the mucous membrane covering the eye, which keeps the eye lubricated.

Mucosal melanoma, which is also rare, develops in the mucosal lining of the body (a membrane that covers many body cavities and passageways). Because it often begins in concealed areas and causes no specific symptoms, many cases are diagnosed only after they have progressed to an advanced stage. These areas in the body have moist mucosal linings:

- The respiratory tract, in areas such as the sinuses, nasal passages and mouth. Head and neck mucosal melanoma is the most common type.
- The gastrointestinal tract, including the anus and rectum (anorectal).
- The female genital tract, including the vagina and vulva.

This guide focuses on cutaneous melanoma, its treatment, side effects and survivorship.

HOW MELANOMA GROWS AND SPREADS

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 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 important.

In the first growth stage, known as the radial growth phase, the melanoma grows horizontally, staying within the upper layer of the skin (epidermis). 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 hypodermis, as well as up into the epidermis, and the risk for metastasis increases. This occurs because the lymphatic vessels are located in the lower dermis and hypodermis, and melanoma cells can use these vessels to spread to lymph nodes. Because of this, the thickness of a melanoma is the most important factor in determining the prognosis.

To predict the risk of spreading, melanomas are classified as thin (less than 1 millimeter, or about the thickness of a credit card), intermediate (1 to 4 mm) or thick (more than 4 mm).

Learn more about how certain types of melanoma are treated so you and your doctor can make an informed treatment decision (see *Treatment Options,* page 8). ■

KEY TAKEAWAYS

- **Melanoma is a type of cancer that can develop anywhere on the skin, but also in the eyes and mucosal linings, such as the mouth, genitals and anal areas.**
- **Melanoma of the skin is known as cutaneous melanoma.**

Survivor chooses to maintain a positive mindset

Laurie Sloan offers this advice to anyone newly diagnosed with melanoma: "Your attitude is crucial. Do not live your life in fear. Trust in your doctor and whatever gives you peace." As a Stage IV melanoma survivor, she follows her own advice and credits her amazing husband and family, her doctor ("the melanoma man") and cancer center, as well as her faith with getting her through.

▲ ***Walking my daughter down the aisle...***

Having a positron emission tomography (PET) was not the way I planned to spend my 50th birthday. But, that is what happened after a 6-centimeter lump was surgically removed from my chest. What my doctors and I thought was likely a fast-growing cyst was Stage IIIA melanoma.

Six years before, I had a mole removed in the same place, but I'd forgotten about it until the surgeon told me in the recovery room that he didn't like the looks of what he removed. He referred me to a well-known melanoma specialist at a university cancer center about an hour from my small town. I had another PET and a sentinel lymph node biopsy. Both were clear, which meant the melanoma had not spread. However, because of the sheer size of the tumor, my oncologist suggested adjuvant therapy "just in case." He recommended a clinical trial.

I was aware of clinical trials but had no experience with them. I am an X-ray technologist at our small local hospital, but we don't have a research area. I really debated about participating. After all, there wasn't any cancer left. My kids, however, were concerned it might spread and that I'd have regrets if I didn't do all I could now. They reminded me I am a fighter. I agreed to participate.

The clinical trial included an immunotherapy given by infusion about every three weeks for a year. The side effects included a nasty rash. Right before my last treatment, scan results showed a tumor in my small bowel. The melanoma was now Stage IV. Instead of having a celebratory dinner that night, I was thinking about my upcoming bowel resection.

My surgeon removed several inches of my small bowel. My doctor suggested another immunotherapy clinical trial. The treatment involved a shot in the arm three or four times. After, I had a procedure to check for a response but, unfortunately, there wasn't one.

My doctor added a different daily immunotherapy treatment, hoping it would trigger an immune system response. I had to travel an hour each day to the cancer center, but I couldn't drive so I had to rely on my friends and family to take me. I felt like such a burden, but my church organized a prayer list and I was overwhelmed at the response. I had more than enough offers of rides.

The side effects from this immunotherapy were headaches and flu-like symptoms. I worked in the mornings and had treatment in the afternoons. I would feel wiped out the rest of the day, but I was grateful that I felt well enough to work in the mornings.

About two years after my diagnosis, in December 2014, we found a tumor in my left lung. During a wedge resection to remove it, my surgeon found a second tumor. These were the tumors that shook me. While I was in the hospital recovering, my lung collapsed and I struggled. I was scared and anxious. I called out to God that night, and I felt an overwhelming peace that enabled me to put the decision making in my doctor's hands and my healing in God's hands. That was the best therapy I ever had.

In March, an inoperable tumor was discovered in the mesentery of my pelvis. I began taking another immunotherapy. I'd work a full shift, get my treatment once every three weeks at my local hospital then go home. I felt a little washed out the next day, had dry mouth and thinning hair.

At my follow-up two months later, I waited an extraordinarily long time in the waiting room for the imaging results. When I saw my doctor's face, I knew it was bittersweet news. The inoperable tumor was gone but a new tumor was found in a lymph node by my heart. Removing the tumor would require open heart surgery. But because I'd responded to the immunotherapy, it was decided I'd continue treatment and scan again in two months.

My follow-up was July 22, exactly one month before my daughter's wedding, so I was nervous. The results would determine if I needed open heart surgery right before the wedding. The scan was clear, and I was able to walk my daughter down the aisle. It was very special.

I stopped the immunotherapy after two and half years and now have annual follow-ups. My husband and my family keep me laughing. ■

Understanding your staging and pathology results

Once your diagnosis is made, a process called staging is used to determine the extent of the cancer within your body. This section is designed to help you better understand how staging enables your doctor to develop a disease management plan for you.

Melanoma is usually staged twice. First, your doctor considers the results of your physical exam and skin biopsy to assign a clinical stage. During a more extensive procedure, the lesion (or as much of it as possible) is removed along with some healthy tissue surrounding it. In a different procedure, some lymph nodes may be removed (see *Lymph Node Mapping*, page 6). After reviewing these specimens with and without a microscope and noting key characteristics, a pathologist also considers results from lymph node biopsies and other tissue that was examined. Then a pathologic stage is assigned. Because the pathologic stage is based on more details about the melanoma, this staging is the most accurate and is important in determining appropriate treatment options for your diagnosis.

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). This system uses the size and extent of the tumor (T), whether cancer cells are found in nearby lymph nodes (N) and whether the cancer has metastasized, or spread, to other parts of the body (M). The thickness of the primary melanoma is used to classify the melanoma in the T category. Additionally, 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). The node (N) classification is used to describe how many lymph nodes contain melanoma cells and includes subcategories to describe the extent of cancer cells in the lymph nodes.

The results of the TNM analysis are then used to determine the overall stage of melanoma for each individual. Stages range from 0 to IV (see Tables 1 and 2 and Figure 1).

TABLE 1
AJCC TNM SYSTEM FOR CLASSIFYING MELANOMA OF THE SKIN

Classification	Definition	
Tumor (T)		
T Category	**Thickness**	**Ulceration status**
TX	Primary tumor thickness cannot be assessed.	Not applicable
T0	No evidence of primary tumor.	Not applicable
Tis	Melanoma in situ.	Not applicable
T1 **T1a** **T1b**	≤ (not more than) 1.0 mm. < (less than) 0.8 mm. < (less than) 0.8 mm. 0.8 – 1.0 mm.	Unknown or unspecified Without ulceration With ulceration With or without ulceration
T2 **T2a** **T2b**	> (more than) 1.0 – 2.0 mm. > (more than) 1.0 – 2.0 mm. > (more than) 1.0 – 2.0 mm.	Unknown or unspecified Without ulceration With ulceration
T3 **T3a** **T3b**	> (more than) 2.0 – 4.0 mm. > (more than) 2.0 – 4.0 mm. > (more than) 2.0 – 4.0 mm.	Unknown or unspecified Without ulceration With ulceration
T4 **T4a** **T4b**	> (more than) 4.0 mm. > (more than) 4.0 mm. > (more than) 4.0 mm.	Unknown or unspecified Without ulceration With ulceration
Node (N)		
N Category	**Number of tumor-involved regional lymph nodes**	**Metastases status***
NX	Regional nodes not assessed.	No
N0	No regional metastases detected.	No
N1 **N1a** **N1b** **N1c**	One tumor-involved node or in-transit, satellite, and/or microsatellite metastases with no tumor-involved nodes. One clinically occult. One clinically detected. No regional lymph node disease.	 No No Yes
N2 **N2a** **N2b** **N2c**	Two or three tumor-involved nodes or in-transit, satellite, and/or microsatellite metastases with one tumor-involved node. Two or three clinically occult. Two or three, at least one of which was clinically detected. One clinically occult or clinically detected.	 No No Yes
N3 **N3a** **N3b** **N3c**	Four or more tumor-involved nodes or in-transit, satellite, and/or microsatellite metastases with two or more tumor-involved nodes, or any number of matted nodes without or with in-transit, satellite, and/or microsatellite metastases. Four or more clinically occult. Four or more, at least one of which was clinically detected, or presence of any number of matted nodes. Two or more clinically occult or clinically detected and/or presence of any number of matted nodes.	 No No Yes
* In-transit metastases occur more than 2 cm from the primary melanoma (both on the surface of the skin or below the surface of the skin) to the regional lymph nodes. Satellite metastases occur on or below the skin within 2 cm of the primary melanoma. Microsatellite metastases in the skin or in the deeper layer of the dermis near or deep within the skin of the primary melanoma is detected upon microscopic examination.		
Metastasis (M)		
M Category*	**Anatomic site**	**LDH level**
M0	No evidence of distant metastasis.	Not applicable
M1 **M1a** **M1a(0)** **M1a(1)** **M1b** **M1b(0)** **M1b(1)** **M1c** **M1c(0)** **M1c(1)** **M1d** **M1d(0)** **M1d(1)**	Evidence of distant metastasis. Distant metastasis to skin, soft tissue including muscle, and/or nonregional lymph node. Distant metastasis to lung with or without M1a sites of disease. Distant metastasis to non-CNS visceral sites with or without M1a or M1b sites of disease. Distant metastasis to CNS with or without M1a, M1b, or M1c sites of disease. 	See below Not recorded or unspecified Not elevated Elevated Not recorded or unspecified Not elevated Elevated Not recorded or unspecified Not elevated Elevated Not recorded or unspecified Normal Elevated
*Suffixes for M category: (0) LDH not elevated, (1) LDH elevated. No suffix is used if LDH is not recorded or is unspecified.		

TABLE 2
STAGES OF MELANOMA OF THE SKIN

Stage	T	N	M
0	Tis	N0	M0
IA	T1a T1b	N0 N0	M0 M0
IB	T2a	N0	M0
IIA	T2b T3a	N0 N0	M0 M0
IIB	T3b T4a	N0 N0	M0 M0
IIC	T4b	N0	M0
IIIA	T1a/b-T2a	N1a or N2a	M0
IIIB	T0 T1a/b-T2a T2b/T3a	N1b, N1c N1b/c or N2b N1a-N2b	M0 M0 M0
IIIC	T0 T1a-T3a T3b/T4a T4b	N2b, N2c, N3b or N3c N2c or N3a/b/c Any N ≥ N1 N1a-N2c	M0 M0 M0 M0
IIID	T4b	N3a/b/c	M0
IV	Any T, Tis	Any N	M1

Used with permission of the American Joint Committee on Cancer (AJCC), Chicago, Illinois. The original and primary source for this information is the AJCC Cancer Staging Manual, Eighth Edition (2017) published by Springer Science+Business Media.

MORE ABOUT YOUR PATHOLOGY REPORT

Pathology report results, which may include genomic or molecular abnormalities, can provide important information on your prognosis and disease management plan (see *Understanding Your Diagnosis,* page 6). Doctors can use genetic mutations to consider whether certain therapies may be appropriate, but they can only be used if they are confirmed with genomic or molecular testing.

Along with your diagnosis and histologic subtype (classification based on the melanoma's microscopic features), your pathology report may include some or all of the following:

Thickness: how deep the tumor has grown into the skin

Ulceration status: whether the tumor's top skin layer is present and intact (not ulcerated) or broken or missing (ulcerated)

Dermal mitotic rate: how many melanoma cells are actively growing and dividing

Peripheral margin status: the presence or absence of cancer cells in the normal-looking tissue that was removed from around the tumor

Deep margin status: the presence or absence of cancer cells in the normal-looking tissue that was removed from underneath the tumor

Microsatellitosis: the presence of tiny satellite tumors that have spread to skin near the first melanoma tumor. These can only be seen with a microscope.

Regression: the presence of lymphocytes (a type of white blood cell) and scar-like changes that suggest a person's immune system is attacking the melanoma

Location: where the tumor is found

Tumor-infiltrating lymphocytes: the presence of white blood cells that may be present in a primary melanoma

Vertical growth phase: evidence of tumor growth down into the skin

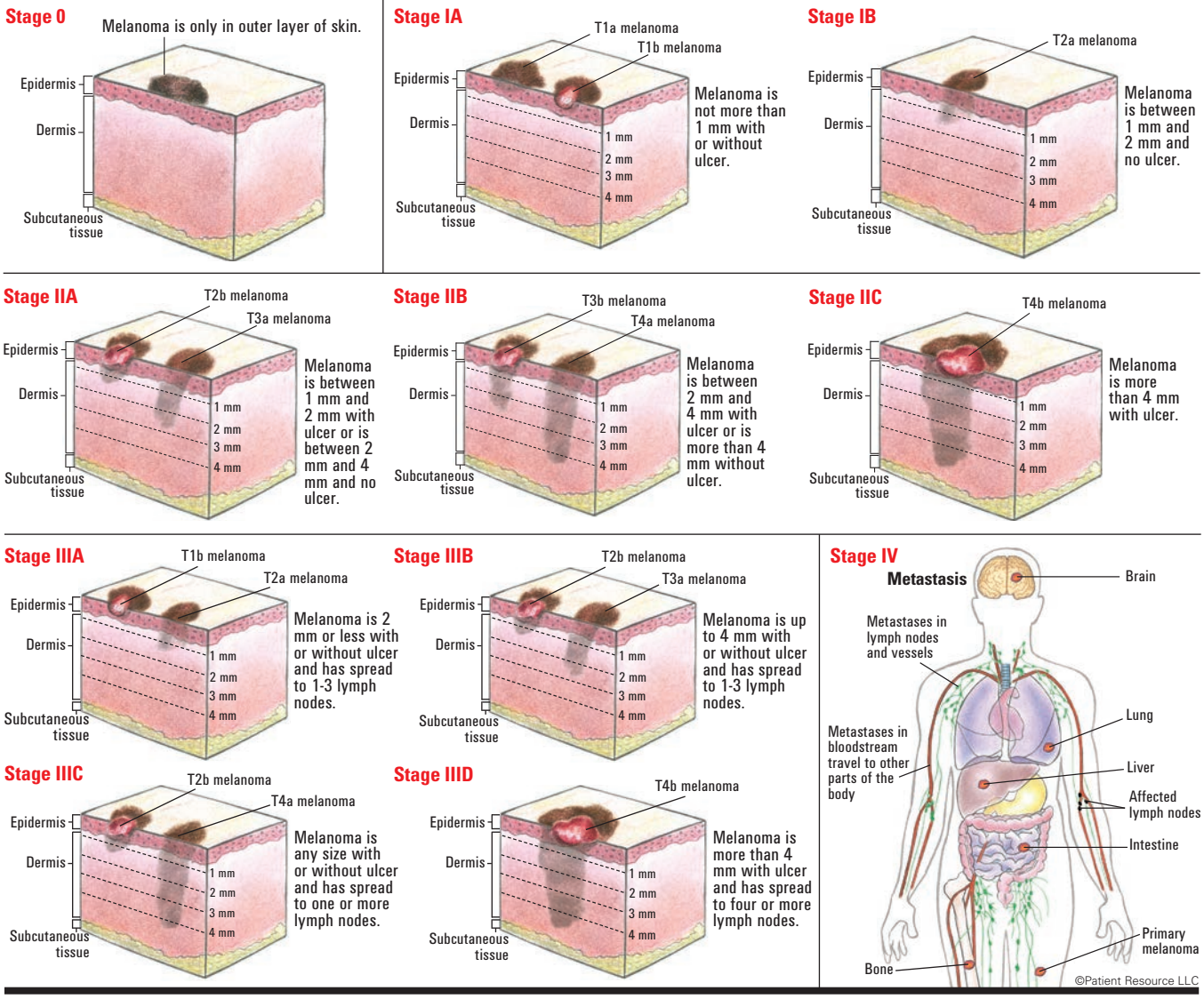
Angiolymphatic invasion: whether melanoma has grown into blood or lymph vessels

Neurotropism: the presence of melanoma cells in or around the nerves in the skin

Ask your doctor to explain how these findings affect your disease management plan. You can also request a copy of your pathology report. ■

FIGURE 1

STAGES OF MELANOMA OF THE SKIN



Knowledge leads to empowered decision making

After you are diagnosed with melanoma, your medical team will introduce you to a lot of new information and unfamiliar words. Learning everything you can about your diagnosis will help you feel more empowered. The more you know about melanoma, the better prepared you will be to actively participate in your disease management plan with your doctors. Consulting with your patient/nurse navigator, oncology nurse and other members of your health care team may also offer valuable insights. Understanding the medical terms, the types of tests and how to read your pathology report are the first steps to understanding your diagnosis.

Although several tests are used to diagnose melanoma, a biopsy is required for confirmation of the diagnosis. The biopsy will provide your doctor with the information needed to confirm your diagnosis and plan treatment.

Depending on the size and location of the melanoma, one of the following types of biopsy may be used.

- An excisional biopsy removes an entire lump or suspicious area.
- An incisional biopsy removes a portion of a lump or suspicious area.
- A punch biopsy removes a small round piece of tissue about the size of a pencil eraser using a sharp, hollow, circular instrument.
- A shave biopsy removes a skin abnormality and a thin layer of surrounding skin with a small blade for examination under a microscope.

After the biopsy sample is removed, your doctor will send it to a laboratory where a pathologist will examine it for specific characteristics, including the following.

- The type and subtype of melanoma
- The depth of the melanoma
- Whether the top skin layer is intact or broken (ulcerated)
- How fast the melanoma cells are growing (mitotic rate)
- Whether the melanoma has spread to lymph vessels, blood vessels, lymph nodes or other organs

Other factors may also be tested for and, in some cases, another biopsy may be needed. The information obtained from your biopsy tests will be in a pathology report, which is the description of cells and tissues made by a pathologist based on microscopic evidence. A pathologist is a doctor who has special training in identifying diseases by studying cells and tissues under a microscope.

The results of the pathology report will be used to diagnose and stage your melanoma, and it will help your doctor select the treatment options appropriate for you. You may request a copy of the pathology report for your records.

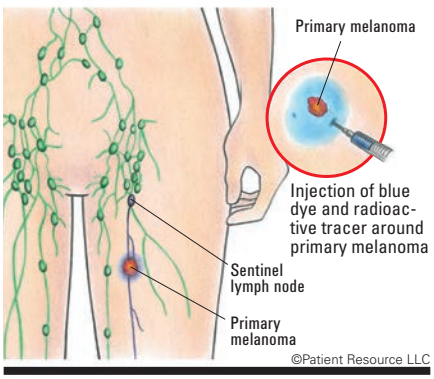
To better understand your pathology report, go to *More About Your Pathology Report* on page 5.

LYMPH NODE MAPPING

A procedure known as sentinel lymph node mapping is recommended when there is an increased risk the primary melanoma may have spread to nearby lymph nodes. 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). Accurately 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. This helps determine the stage as well as the need for genomic testing, which in turn, guides treatment.

Lymph node mapping (lymphoscintigraphy) is a special type of imaging technique done in a hospital's nuclear medicine department ideally at the same time as 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.

FIGURE 1
SENTINEL LYMPH NODE BIOPSY



During an SLN biopsy, the surgeon will inject a special 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 dye and the presence of the radioactive tracer as detected by a handheld device. The node(s) are 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 will have spread to any other lymph nodes if no cancer cells are found in the SLN.

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

GENOMIC TESTING

While examining your biopsy sample under a microscope, the pathologist may also perform molecular testing that checks certain genes, proteins or other molecules for mutations, which are changes that occur in DNA. Many cancers are caused by genetic mutations. Recent research has revealed that melanoma can be classified into subtypes based on mutations in certain genes.

Genomic testing examines a cancer's genes, which may reveal mutations that could indicate the cancer's behavior, how aggressive it might be and if it will metastasize (spread). This information helps doctors choose treatment options. In certain cancers, mutations have been discovered that can be treated with targeted therapy, which is designed for a specific mutation.

Mutations

Several mutations have been discovered that allow melanoma to be classified into distinct subtypes. These include mutations in the genes *BRAF* (pronounced BEE-raff), *NRAS* (pronounced EN-rass), *NF-1* and *KIT*. Around half of all melanomas have *BRAF* mutations. Changes in the gene that makes

the *MEK1* and *MEK2* (pronounced meck) proteins increase the growth of cancer cells.

Several targeted therapies are approved by the U.S. Food and Drug Administration to treat some mutations, most specifically *BRAF* and *MEK* mutations. Targeted therapies known as *BRAF* and *MEK* inhibitors are approved to treat those mutations. Mutations in the *NTRK* (pronounced EN-track) gene have also been found in some melanomas, which qualifies them for tumor-agnostic therapies (see *Treatment Options*, page 8).

Researchers in clinical trials are working to find treatments that target other mutations. However, not all melanomas have these mutations.

Biomarkers

Genomic testing may also be used to detect biomarkers such as genes or molecules that can be measured in the blood, plasma, urine, cerebrospinal fluid or other body fluids or tissues. They are produced by cancer cells or other cells of the body in response to cancer. Also known as tumor markers, biological markers or molecular biomarkers, they are routinely tested for in certain cancers.

Biomarkers may be prognostic, predictive or diagnostic. A prognostic biomarker provides information about a person's overall cancer outcome, regardless of therapy, while a predictive biomarker gives information about whether a certain treatment approach may be appropriate. Diagnostic biomarkers help determine the type of tumor. Some biomarkers may also help determine how aggressive (fast growing) a tumor is and may predict long-term survival.

Some of the following biomarkers may be tested.

- Lactate dehydrogenase (LDH) is the only accepted serum biomarker for melanoma, and it is measured to determine if a person has an elevated risk for metastasis. A decrease in LDH has been associated with response to immunotherapy. It is a prognostic biomarker that may be elevated if the cancer has progressed. It is released when melanoma cells are damaged or die.
- PD-L1 expression may be measured to determine if the tumor cells or immune cells in the tumor's microenvironment contain a higher level, which may mean that a patient could be a good candidate for immune checkpoint inhibitors (see *Treatment Options*, page 8). However, testing for this biomarker alone is not sufficient to determine a therapeutic response to immunotherapy in patients with melanoma or other skin cancers.
- Tumor mutational burden (TMB) is an assessment of the number of genetic mutations in a tumor. It can help doctors determine if a patient may respond to immunotherapy. It is believed that the higher the TMB level, the more likely the patient may be to respond.
- Tumor-infiltrating lymphocytes (TILs) are a type of immune cell that has moved from the blood into a tumor. They can recognize and kill cancer cells. The biopsy sample will be checked for the presence of TILs. Melanomas with higher numbers of TILs and those with TILs inside the tumor have been shown to have a better prognosis and may respond better to therapy. In addition, some treatments result in higher TILs, and they may be a biomarker for response with these therapies. ■

KEY TAKEAWAYS

- **A pathology report contains the description of cells and tissues written by a pathologist based on microscopic evidence and may include genomic and biomarker testing results.**
- **Your doctor will explain the details of your test results and pathology report.**
- **Your diagnosis may include words you haven't heard before. Ask your doctor to explain what they mean.**

GLOSSARY

➤ ***Words to know:*** *These definitions may help as you discuss your diagnosis and disease management plan with your health care team.*

Cutaneous: Related to the skin.

Dermatologist: A doctor trained in dermatology, a medical field dealing with skin function and diseases.

Dermis: The middle layer of the three main layers of the skin. The dermis has connective tissue, blood vessels, sebaceous (oil) and sweat glands, nerve endings, hair follicles and other structures.

Epidermis: The visible part of your skin; the thin, outermost layer that acts as a barrier to protect the body against infection, injury and the sun's ultraviolet (UV) rays.

Hypodermis: The innermost of the three main layers of the skin, sometimes called subcutaneous tissue. It consists of fat, lymphatic vessels and connective tissue.

In-transit metastasis: A type of metastasis in which skin cancer spreads from the primary tumor through a lymphatic vessel and begins to grow in the lymphatic vessel before it has reached the nearest lymph node.

Lymphocyte: A type of immune cell (white blood cell) in lymph tissue and blood that helps the immune system fight infections and cancer. The main types are B-lymphocytes (B-cells) and T-lymphocytes (T-cells).

Pigment: A substance that gives color. In the body, the pigment melanin gives color to the skin, eyes and hair.

Progression-free survival: The length of time during and after treatment that a patient lives with the disease but it does not get worse.

Satellite tumor: A group of tumor cells in an area near the primary (original) tumor. In melanoma, satellite tumors occur close to the primary tumor (within 2 centimeters), on or under the skin, and can be seen without a microscope.

Microsatellite tumor: A tumor that can be seen only with a microscope.

Sun protection factor (SPF): A rating scale for sunscreen products indicating how long a particular product provides protection against sunburn. The higher the SPF number, the longer the protection.

Topical: Refers to medication applied to a surface of the body, such as the skin or mucous membranes, usually as an ointment, cream, gel, etc.

Tumor microenvironment: The area that surrounds and sustains a tumor. It is made up of tumor cells, normal cells, immune cells and blood vessels.

Ultraviolet (UV) radiation: Invisible rays from the sun that can cause sunburn, premature aging of the skin, melanoma and other skin cancers, and eye problems. UV radiation also comes from tanning beds and sun lamps.

Some definitions courtesy of the website of the National Cancer Institute (www.cancer.gov)

Learn about the types of treatment that may be available

Therapies for treating melanoma continue to be introduced, offering many people hope. Research is also ongoing in clinical trials to find even more options to treat melanoma. To develop a disease management plan, your doctor will take into account the size and location of the tumor, its genetic mutations and the stage of the melanoma.

You'll work closely with your doctor to develop the plan, providing input about things that are important to you. Together, you will define the goals of treatment and discuss your expectations.

ABOUT CANCER TREATMENT

It is common to have more than one type of treatment for melanoma. Your treatments will be either local or systemic (involving drug therapy) or a combination (see Figures 1 and 3). Local treatments target specific areas of the body and include surgery and sometimes radiation therapy. Some treatments involve injecting the drug directly into the lesion or topical application to the skin close to a melanoma.

Systemic treatments, including drug therapies such as targeted therapy, immunotherapy and chemotherapy, affect different parts of the body. As a result, they can help destroy melanoma cells that may be hiding in other organs, such as the liver, lungs, bones or brain. These hidden cancer cells, called micrometastases, are usually too small to detect with laboratory testing or imaging studies.

Drug therapies can be given orally or intravenously (IV) through a vein in your arm or through an implanted infusion port. A port is surgically inserted under the skin in the upper chest area or arm to gain easier access to veins.

Treatments are described according to when they're given. Neoadjuvant treatment is given before surgery to shrink a tumor so it can be more easily or safely removed with surgery. Treatment given after primary treatment is adjuvant therapy. Treatment may be considered as first line or second line. Standard of care refers to a diagnostic and treatment process that a clinician is recommended to follow for a certain type of patient and illness. First-line therapy is the first treatment given. Second-line therapy is given when the first-line therapy doesn't work, is no longer effective or has side effects that are not tolerated. Following are descriptions of some common types of treatment.

SURGERY

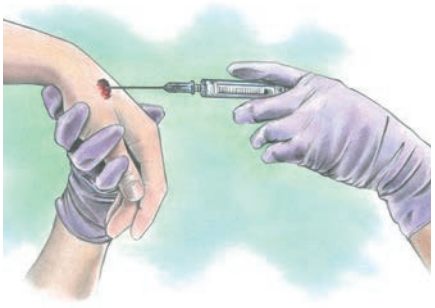
Surgery is usually the first treatment used for local and regional melanomas and is also used for some metastatic melanomas. Often, surgery is the only treatment needed. Surgical removal, or excision, of a melanoma is known as a wide excision. It is used to remove the melanoma and an additional portion of normal-looking tissue, which is called a surgical margin (see Figure 2). The thicker the melanoma is, the larger the surgical margin needed. The tissue removed from the margin will be carefully examined by a pathologist under a microscope to determine if any cancer cells remain. More surgery may be needed if the margins contain cancer cells.

A lymph node dissection is a type of surgery that is sometimes performed to remove lymph nodes in the region after a biopsy if pathology results show a melanoma spread (metastasis) in the sentinel lymph node (see *Understanding Your Diagnosis*, page 6). At the end of the procedure, the surgeon will likely place drains into the area to collect any blood or fluid from the region where the lymph nodes were removed. The incision will then be closed, and the wound will be covered by a dressing. Your health care team will give you information for incision and drain care, if applicable.

DRUG THERAPY

Various types of anticancer medications are used to help destroy cancer cells, prevent progression or slow their growth. The most widely used drug therapies for melanoma are targeted therapy, immunotherapy and chemotherapy.

FIGURE 1
LOCAL THERAPY



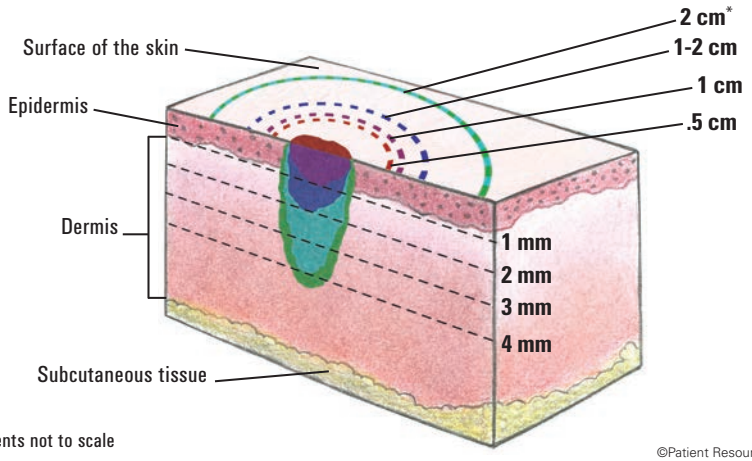
Targeted therapy is treatment with systemic drugs that can help slow the spread of melanoma by interfering with specific molecules involved in tumor growth and progression. For example, some melanomas may have mutations (abnormalities) in the *BRAF* gene, and a type of targeted therapy known as a *BRAF* inhibitor can be used as part of a regimen to treat melanomas with this mutation.

Another target is the *MEK* protein. Drugs that block *MEK* proteins are called *MEK* inhibitors and can also be used as part of a regimen to treat melanomas with *BRAF* mutations.

For patients with a *BRAF* mutation, doctors could prescribe a combination of a *BRAF* and *MEK* inhibitor.

Another mutation found in some melanomas is the *NTRK* gene. The treatment approved for this mutation is considered tumor-agnostic because it is approved to treat the *NTRK* fusion regardless of the type of cancer or where it is in the body.

FIGURE 2
RECOMMENDED SURGICAL MARGINS FOR EXCISION OF MELANOMA



*Measurements not to scale

Targeted therapies, which are taken orally, may be used to treat both Stage III and Stage IV melanomas. Some may be given in combination with other targeted therapies or types of immunotherapy.

Other common mutations that have been targeted are in the *NRAS* and *NF1* genes. However, research has identified some less common mutations, which could be the target of future therapies.

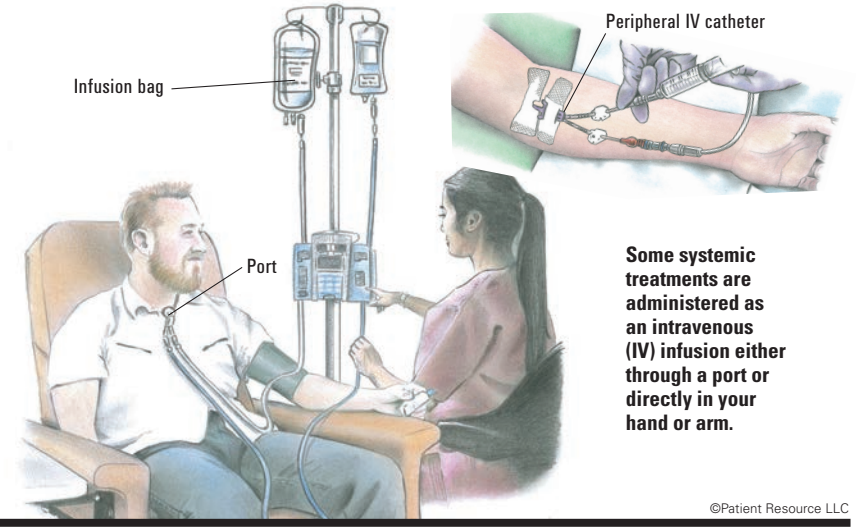
Immunotherapy uses the body's immune system to find and attack cancer (see Figure 4). Immunotherapy may be used as local or systemic therapy, as adjuvant therapy or as primary treatment for melanomas that can't be removed surgically. The immunotherapies approved by the U.S. Food and Drug Administration include monoclonal antibodies (mAbs), such as immune checkpoint inhibitors, cytokines, immunomodulators and oncolytic viruses.

Antibodies (a type of protein) are the body's natural way of tagging a specific antigen (foreign substance). They bind to the antigen, which allows the rest of the immune system to recognize the antigen as foreign and target it for destruction. A monoclonal antibody (mAb) is a type of protein made in the laboratory that can bind to substances in the body, including cancer cells. A mAb is made to bind to only one substance. They can be used alone or to carry drugs, toxins, or radioactive substances directly to cancer cells. The mABs are designed to target specific tumor targets, such as antigens or other proteins found on the cancer cell, and can work in different ways, including flagging targeted cancer cells for destruction, blocking growth signals and receptors, and delivering other therapeutic agents directly to targeted cancer cells.

Immune checkpoint inhibitors are a type of mAb that prevents the immune system from slowing down, which allows the immune cells to continue fighting the cancer. The immune checkpoint inhibitors are monoclonal antibodies that block the receptors of PD-1 (programmed cell death protein 1), PD-L1 (programmed cell death-ligand 1) and CTLA-4 (cytotoxic lymphocyte antigen 4), and thereby inhibit their activating signal to the cell. PD-1 is found on the surface of cells of the immune system. Normally, when these proteins interact, the immune system does not recognize the melanoma cells as a foreign invader and shuts down. When CTLA-4 or PD-L1 combine with various proteins, they signal to the immune system also to slow down. Anti-CTLA-4 or anti-PD-1 antibodies allow T-cells to continue fighting cancer cells instead of shutting down.

Cytokines are substances secreted by certain cells of the immune system that boost the whole immune system. They can be used alone or in combination with other treatments to produce increased and longer-lasting immune responses. Cytokines aid in immune cell communication and play a big role in the full activation of an immune response. This approach works by introducing large amounts of laboratory-made cytokines to the immune system to promote

FIGURE 3
SYSTEMIC THERAPY



Some systemic treatments are administered as an intravenous (IV) infusion either through a port or directly in your hand or arm.

Taking medication as prescribed is important

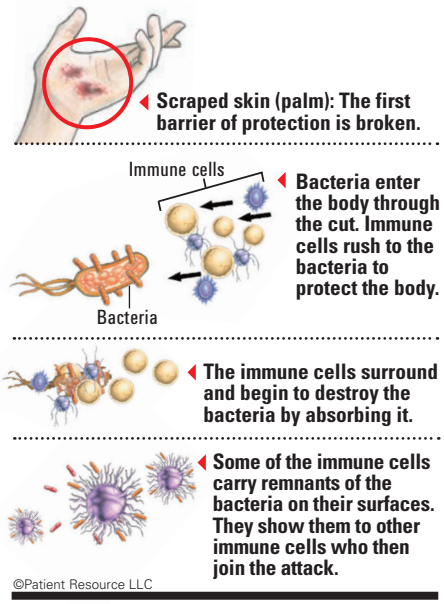
➥ Today, an increasing number of cancer treatments are oral therapies (pills). People undergoing cancer treatment may prefer the at-home option of oral therapy.

Most cancer therapies are designed to maintain a specific level of drugs in your system for a certain time based on your cancer type and stage, your overall health, previous therapies and other factors. Taking the prescribed dose of your medication at the right time on the right schedule is referred to as medication adherence, and it is very important when taking oral therapies.

If your medications aren't taken exactly as prescribed, the consequences can be serious.

Taking your cancer treatment correctly may sound simple, but it requires serious effort and coordination to make it happen. Explore the many tools available to help you stay on track. Set alarms or phone reminders, make a daily medication schedule, ask loved ones to remind you and track medications on a calendar. Ask your health care team for resources.

FIGURE 4
NORMAL IMMUNE RESPONSE



nonspecific immune responses as a systemic therapy.

1. Interferons boost the ability of certain immune cells to attack cancer cells. They may be given as adjuvant therapy (given after primary treatment).
2. Interleukins help control the activation of certain immune cells.

Immunomodulatory drugs may stimulate or slow down the immune system in indirect ways. They may boost the immune system and the effects of other therapies on the tumor and the tumor microenvironment, and slow or stop the growth of the tumor and its blood vessel formation. They are generally considered systemic treatments, but some may be given directly into the tumor.

WHO'S ON YOUR MEDICAL TEAM?

Once you are diagnosed with cancer, you will work closely with a multidisciplinary health care team. This team will be composed of a variety of specialists and other health care professionals, including the following.

- **Dermatologist, who specializes in skin diseases**
- **Medical oncologist, who treats cancer with medication**
- **Pathologist, who specializes in laboratory testing**
- **Radiation oncologist, who treats cancer with radiation**
- **Radiologist, who specializes in diagnosing disease from imaging tests**
- **Surgical oncologist, who treats cancer with surgery**

You may also work with oncology nurses, physician assistants, nurse practitioners, pharmacists, social workers, counselors, dietitians and others.

Oncolytic virus immunotherapy uses viruses that directly infect tumor cells to cause an immune response. It is typically given as a local treatment by injection directly into the tumor.

Chemotherapy treatment may consist of a single drug, a combination given at the same time or drugs given one after another. Chemotherapy may be used alone or with other forms of treatment. It can be used to treat advanced melanoma, but today it is not used often as a first-line therapy.

Isolated limb chemotherapy, either isolated limb perfusion or isolated limb infusion, is a procedure to place chemotherapy directly into a limb when a patient has numerous tumors on the leg or arm. During the procedure, a surgeon temporarily stops the flow of blood in the artery and vein to and from the limb using a tourniquet around the limb. Heated chemotherapy drugs travel through a tube directly into the bloodstream of the limb and are circulated for a certain period. The drugs go in one tube and come back out of the limb through the other. The tourniquet keeps the drugs from leaving the limb and going into the rest of the body. At the end of the procedure, any remnants of the drugs are flushed from the limb.

RADIATION THERAPY

Radiation therapy uses high-energy radiation to destroy cancer cells and shrink tumors. It is often given as external-beam radiation therapy, which uses a machine outside the body to send radiation toward the cancer.

Though radiation therapy is not typically used to treat the original melanoma, it may be given to areas where lymph nodes were surgically removed or after surgery to remove the melanoma if the risk of recurrence is considered to be high.

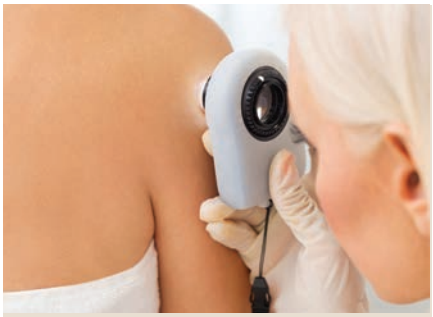
Radiation therapy may also be given to relieve symptoms related to the spread of melanoma, particularly to the bones or brain. When given to the brain, whole-brain radiation therapy or localized stereotactic radiation therapy may be used. Stereotactic radiation is given to a specific area of the body in a high dose.

CLINICAL TRIALS

These medical research studies may offer access to therapies not yet widely available. Multiple treatment options are being researched in clinical trials, including targeted therapies that target the *MAP* kinase pathway; immunotherapies with *TIM3* inhibitors, *LAG3* inhibitors, *OX40* agonists, *CD137* agonists, *GITR* agonists, *IDO* inhibitors and chimeric antigen receptor T-cell (CAR T-cell) therapy; and vaccines.

Ask your doctor if you should consider this option as a first-line treatment or at any other time during your treatment.

For a guide to learning how to search for a clinical trial, see *Clinical Trials*, page 11. ■



Watching for recurrence

➥ Even after successful treatment, melanoma may return — possibly years later. You may worry this could happen to you. However, learning how to watch for signs of recurrence may ease your mind.

Types of recurrence. Melanoma can return in one or more ways:

- Local recurrence is a regrowth of the cancer at a site of the original melanoma.
- Regional recurrence is reappearance of cancer in the lymph nodes near the melanoma.
- Distant recurrence is metastasis (spread) of the melanoma to distant organs. You may have symptoms or your doctor will see signs of a tumor on a CT or PET.

Keeping follow-up appointments is important because finding signs of a recurrence early is crucial to your treatment. Your doctor will ask questions about any ongoing symptoms you may have, especially those related to recurrence, and long-term side effects of treatment.

[KEY TAKEAWAYS]

- **It is important to work with your doctor to determine your goals for your disease management plan.**
- **Your treatment plan may consist of one or more types of treatment.**
- **Clinical trials are also an option worthy of discussion with your doctor after diagnosis.**

Educate yourself about clinical trials

As medical and scientific teams continue to learn more about melanoma and how it grows and spreads, they continue to test potential treatments by conducting clinical trials. You can ask your doctor about the availability of clinical trials that might apply to your situation.

Clinical trials are research studies that may be conducted to evaluate new methods for different areas of cancer care, including disease prevention, patient screening, diagnostic tools and procedures, genetic risk factors and lifestyle or behavioral changes. This includes testing drugs, biologics and other non-medication therapies such as radiation therapy and surgery, medical devices, screening approaches and other interventions.

From early-stage to metastatic melanoma, hundreds of melanoma trials may be underway at any given time. Areas of research include identifying drug therapies to treat genomic mutations; evaluating the risks and benefits of certain drug therapies used alone, in combination with other therapies or in a different order; treatment benefits and side effects of certain types of radiation therapy; treating metastatic melanoma; and vaccinations, among others.

Receiving your cancer treatment through a clinical trial may offer you the following:

- Access to cancer treatment that is not available outside a clinical trial.
- Additional monitoring by the clinical trial's medical team in addition to your regular oncologist.
- A role in advancing cancer research by helping to potentially expand treatment options for future patients.

Cancer treatments, including those being tested in clinical trials, present potential risks and side effects. They may require more medical appointments and/or tests than you would ordinarily have scheduled. Ask in advance to make sure you'll be able to rearrange your schedules for work, school, family commitments and other obligations to accommodate the appointments needed to meet the trial's requirements.

As you and your doctor discuss the potential treatment option of a clinical trial, keep in mind that many trials take place at the same time in a variety of locations. Finding one takes research, and that's where you come in. While your health care team is exploring potential trials, you can look for them online, too.

Navigating some sites can be confusing. To help prepare you for the different search sites available, we've created mock screens below to show you what you may see as you look for a trial and discuss with your doctor. ■

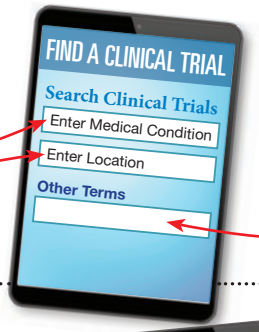
» HOW TO SEARCH FOR A CLINICAL TRIAL

▶ Before you begin, have your exact diagnosis, pathology report and details of your current or prior cancer treatments on hand to help determine if you meet the basic eligibility criteria. Then, start by using the list of clinical trial sites below. Your doctor may recommend additional sites.

[STEP 1] FILL IN YOUR INFORMATION

Enter Your Diagnosis
For example, enter "melanoma." To further customize the search, select applicable eligibility criteria, such as age and gender, on the results screen.

Desired Location
If you prefer a clinical trial close to home, enter your home address. Enter additional locations if you're willing and able to travel for treatment.



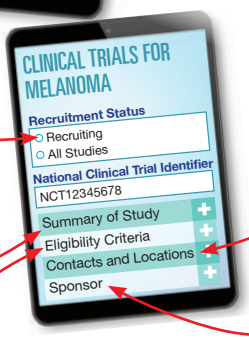
Other Terms
You can refine your search even more by adding a particular treatment type or genomic mutation. You can also add a National Clinical Trial identifier, which is a unique eight-digit code preceded by "NCT" that is assigned to each trial.

[STEP 2] READ YOUR SEARCH RESULTS

Recruitment Status
This indicates whether the trial is actively seeking patients, not yet recruiting or otherwise inactive. The status will change, so check often for updates.

Summary of Study
Here you'll find details about the purpose of the clinical trial and the treatment being studied. This section is usually written for health care providers, so it may be difficult to interpret. In that case, print out the information to discuss with your doctor.

Eligibility Criteria
This outlines the criteria you must meet to be eligible for the trial, such as the stage of disease, sites of metastasis, overall health requirements and previous treatments. Discuss any questions you may have about qualifying for clinical trials.



Contacts and Locations
This may contain contact information for the clinical trial investigators, staff or sponsors, who may be able to provide more details about the study.

Sponsor
This is the entity responsible for the clinical trial. It may be a pharmaceutical or biotechnology company, a university, the National Cancer Institute or others.

CLINICAL TRIAL RESOURCES **AIM at Melanoma Foundation:** www.aimatmelanoma.org/how-melanoma-is-treated/clinical-trials
ClinicalTrials.gov: www.clinicaltrials.gov / **National Cancer Institute:** www.cancer.gov/clinicaltrials
National Cancer Institute (NCI) Contact Center (cancer information service): 800-422-6237

Visit *PatientResource.com/Patient_Support_Groups.aspx* for additional resources.

Plan with your doctor for physical and emotional side effects

Do the physical side effects of cancer treatment unnerve you almost as much as having cancer? If so, you're not alone. It is a common concern shared by people who are diagnosed with cancer. Take comfort in the fact that a wide-ranging group of services known as supportive care is available to help you manage the physical and emotional side effects as well as the practical, spiritual, financial and family-related challenges you may experience.

A primary focus of these services is to help you deal with treatment-related side effects and to relieve cancer symptoms in an effort to keep you comfortable throughout treatment. Also called palliative care, these services may be declined because many people confuse them with hospice care. Palliative care can benefit anyone with a serious illness. It is available at any time, whereas hospice care is reserved for end of life.

This care is provided by a multidisciplinary team consisting of doctors, nurses, social workers and others who work together to limit your chance of expriencing these effects. As you and your doctor review your disease management plan, discuss the potential side effects of each type of therapy as well as the physical and emotional effects (see Table 1). Ask about any that need immediate attention and find out what to do if they occur. Prompt or even preventive treatment may help.

SIDE EFFECTS 101

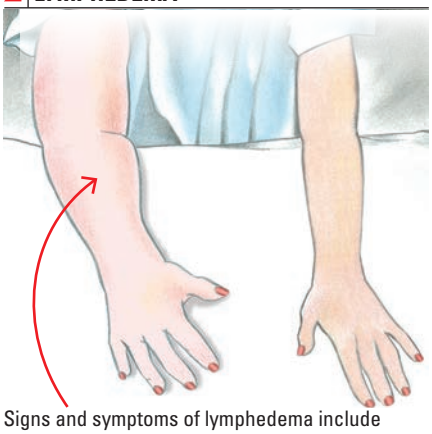
Though cancer treatments do have side effects, keep in mind that you likely won't experience all of them. Every person responds differently, even to the same type of treatment.

There are varying degrees of side effects. Examples include severe diarrhea that keeps you homebound or mouth sores that prevent you from eating and getting the nutrition your body needs, especially during cancer treatment. Still others have the potential to be serious or even life-threatening, making it crucial that you and your doctor discuss ahead of time what you should watch for and what to do if a potentially serious side effect occurs.

Find a support group for melanoma survivors online or in your area. People who have had a similar experience may offer invaluable help. You may also consider talking with a licensed counselor.

Contact your doctor about excessive crying or any feelings of hopelessness or despair. Get immediate medical attention for thoughts of suicide or death.

FIGURE 1
LYMPHEDEMA



Signs and symptoms of lymphedema include swelling in an area such as an arm or a leg (ranging from mild to severe), a heavy sensation in the limb, tightness and reddening of the skin and decreased flexibility. ©Patient Resource LLC

TABLE 1
SOME SIDE EFFECTS OF MELANOMA TREATMENT*

Common physical side effects
Abdominal pain: cramping, dull aches
Constipation: difficulty passing stools
Diarrhea: frequent loose or watery bowel movements
Dyspnea: difficulty breathing with or without coughing
Fatigue: more severe than general tiredness, lasts longer and may not be relieved by sleep
Fever: abnormally high body temperature
Hypertension: abnormally high blood pressure
Lymphedema: fluid buildup resulting from removed or damaged lymph nodes that causes swelling
Muscle and joint pain: may affect whole body or certain areas
Nausea and vomiting: upset stomach
Neutropenia: low white blood cell count that increases risk of infection
Skin reactions: changes in skin color, inflammation, blistering, hives, dryness, cracking around fingertips, flushing or redness, sensitivity to UV rays
Sleep problems: inability to fall asleep or stay asleep, excessive sleepiness

**These are not all the possible symptoms or side effects of treatment for melanoma. Talk to your doctor about any side effect you experience.*

FOR AN ADVANCED MELANOMA DIAGNOSIS

National cancer support groups and oncology organizations often recommend adding palliative care to the treatment plan of any individual who is diagnosed with advanced cancer.

The side effects that you may have will commonly differ as your therapy is modified to accommodate changes such as disease progression. Talk with your doctor about all side effects you experience and be clear with your doctor about your expectations.

For a printable copy, go to: **PatientResource.com/HandWashing.aspx**

©Patient Resource LLC

BEING AWARE OF SCANXIETY

Though you might not be familiar with the name, "scanxiety" is the anxiety associated with follow-up scans. The feeling is understandable because the results will indicate whether your disease management plan is working the way it is intended. You may begin to feel anxious as the appointment nears and stay that way until you get your results.

That is a lot of stress to put on your mind and your body, so it is key to get a handle on your scanxiety. These suggestions may help:

- Recognize and accept that it is okay to be scared. Be open about your fears with your doctor, your friends, a support group or a therapist.
- Keep your mind occupied with things you enjoy, such as reading, playing games or gardening. Staying busy may give you less time to worry.
- Talk to your doctor about whether you can exercise daily, and how. It is a stress reliever, and you may feel better physically and emotionally.
- Help calm your nerves with meditation or deep breathing.
- Contact your doctor if you become overwhelmed. Medication or therapy may help. ■

Take care of your emotional well-being

➥ **Your diagnosis may stir up a variety** of unexpected feelings, such as stress, anxiety and sadness. Your life circumstances are changing, and this can be unsettling. It is important to recognize the effect that physical changes can have on your self-esteem and body image. For example, treatments may leave scars, discoloration of the skin, hair loss and lymphedema, which can all affect mood and self-image.

All these feelings are completely normal, and you must address them with your doctor for the sake of your emotional health. Although physical health is the priority, realistically, your emotional well-being may suffer when you are worried or concerned about your appearance.

Family and friends are wonderful sources of support, but they can only understand so much. Find a support group for melanoma survivors online or in your area. Opening up to people who have had a similar experience can offer comfort and support that is invaluable. Talking with a licensed counselor may also help you work through difficult emotions.

Contact your doctor about excessive crying or continued feelings of hopelessness or despair. Get immediate medical attention for thoughts of suicide or death.

And remember, receiving a cancer diagnosis and treatment is like being on a rollercoaster. You'll have ups and downs that may be unpredictable, but you don't have to go through them alone.

Stay alert for signs and symptoms of melanoma after treatment

Completing your primary melanoma treatment is a welcome milestone, but recurrence can sometimes happen. It is also important to know that being diagnosed with melanoma increases your risk of developing a new melanoma or skin cancer. That's why follow-up care and skin cancer prevention are vital. Knowing your risks and what to watch for are key to early detection.

Early-stage (thin) melanomas generally tend to recur less often but over a longer period of time. Later-stage melanomas, on the other hand, recur more often and over a shorter time period. For all stages, the risk of recurrence generally decreases over time, though it is never gone completely.

Following are ways to watch for recurrence or another melanoma.

Self-exams involve you and a loved one checking yourself for any moles or spots that change shape, size or color. The "ABCDE" rule will help you identify the common differences between a melanoma and a mole that is harmless (benign) (see Figure 1).

During self-exams, also look for any abnormal lumps. Know your skin so you can recognize any areas of change. In addition to self-exams, you should talk to your doctor about anything that concerns you.

Melanoma and other skin cancers may run in families, so encourage your family members to have regular skin screenings and learn how to protect their skin (see *Insights for Your Family and Friends*, page 15).

Doctor visits will be based on a follow-up schedule customized for you. Your doctor may consider your diagnosis, stage, type of treatment you received, national recommended guidelines and your risk factors, such as:

- A fair complexion
- Light-colored eyes
- Blonde or red hair
- A history of blistering sunburns
- A tendency to burn or freckle
- Large moles or many small moles
- A family history of melanoma

During these check-ups, your doctor will conduct a thorough physical exam, paying special attention to your skin. Melanoma can spread to lymph nodes, so your doctor will check those closely, too. Blood tests, regular X-rays and other imaging studies are not usually done for earlier-stage melanoma follow-up, but they may help if you have signs or symptoms of a possible recurrence.

If you are at a higher risk of having your melanoma return, your doctor may order one or more of these imaging studies to check for melanoma in your body:

- Chest X-ray
- Computed tomography (CT)
- Positron emission tomography (PET)
- Combined PET/CT
- Magnetic resonance imaging (MRI)

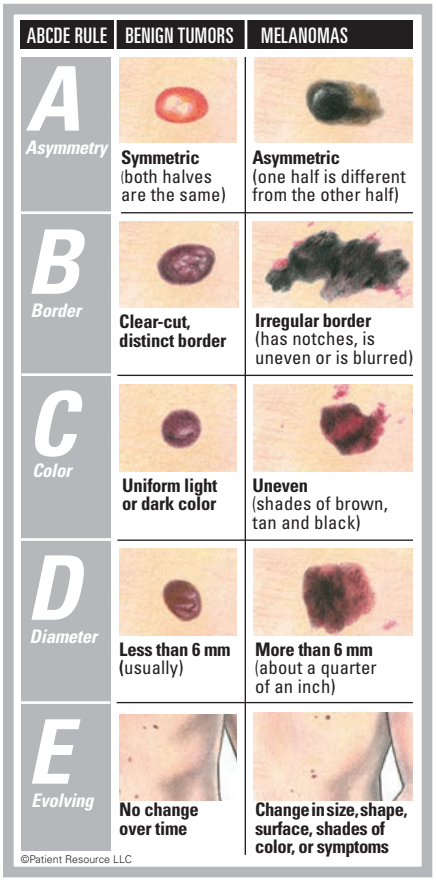
PREVENTION: A HABIT FOR EVERYONE

Even though your follow-up visits will get further apart in the future, skin cancer prevention should become something you do for the rest of your life, regardless of the color of your skin, though the risk is increased for people who are white or who have a fair complexion. The biggest risk factor: ultraviolet (UV) light, mostly from the sun. Indoor tanning is another dangerous source of UV rays, particularly for younger people.

Here are five ways that may help protect your skin:

1. Wear protective clothing. If you sunburn easily, consider clothes with a rated ultraviolet protection factor (UPF).
2. Limit sun exposure from 10 a.m. to 4 p.m.
3. Wear a broad-brimmed hat and sunglasses that protect against UV rays.
4. Choose a sunscreen and a lip balm with an SPF of at least 15 to 30 that protects against both UVA and UVB rays. Labels on sunscreen may say "broad spectrum" or "multi-spectrum" and may include ingredients such as titanium dioxide or zinc oxide.
5. Apply sunscreen liberally on all exposed skin, and reapply at least every two hours (sooner if swimming or sweating). Don't forget ears, the back of your neck and exposed parts of your scalp. ■

FIGURE 1
ABCDE RULE: HOW TO DETECT A MELANOMA



KEY TAKEAWAYS

- **A melanoma diagnosis increases your risk of developing a new melanoma or skin cancer, making follow-up care essential.**
- **Self-exams are an important part of watching for recurrence or another melanoma.**
- **Every person, no matter their skin tone, is vulnerable to the harmful effect of ultraviolet (UV) rays.**

Get facts about protecting your skin

Knowledge really is power, especially when it comes to your health. As a melanoma survivor, you have learned firsthand about the disease. Sharing what you know, along with the information below, with your family members and friends will increase their awareness about how to reduce their risks of melanoma.

The most important preventive measure is to avoid excessive exposure to ultraviolet (UV) rays. The sun is the primary source of UV rays. Contrary to popular belief, every person who is exposed to the sun needs protection. Though it is especially important for people with a fair complexion, light-colored eyes, blonde or red hair and a tendency to burn or freckle with exposure to the sun, people with any skin tone — light to dark — are at risk. Research shows that when people with dark skin are diagnosed with melanoma, it is often later stage. The reason is that many people simply aren't aware that they are at risk so they aren't practicing the preventive measures that may reduce those risks.

PROPER SUNSCREEN USE

Using sunscreen is an easy way to help protect yourself, but it is important to use it correctly.

- Choose a sunscreen with an SPF of at least 15 to 30. A higher SPF may be necessary to avoid burning.
- Look for "blocks UVA and UVB" or "broad spectrum" on the label.
- Use sunscreen anytime you plan to be in the sun for more than 15 minutes, even when it's cloudy.
- Apply liberally (minimum of 1 ounce, about the same amount as in a shot glass) at least 30 minutes before sun exposure. If you use spray sunscreen, be sure to cover all exposed skin.
- Also apply to your ears, scalp, lips, neck, tops of feet and backs of hands.
- Reapply at least every 2 hours and each time you get out of the water or sweat heavily.
- Apply underneath your makeup and lip balm, even if they already contain SPF.
- Apply sunscreen first and bug spray second. Sunscreen may need to be reapplied more often.
- Sunscreen expires! Throw it away after 1 to 2 years to ensure what you're using is effective.
- Use sunscreen in all seasons, even when it is cloudy. Snow reflects up to 80 percent of the sun's rays.
- Avoid indoor tanning, and do not use sun exposure to increase your levels of vitamin D. To be sure you get enough vitamin D, your doctor may check your blood levels and may suggest an oral supplement.

SELF-EXAMS CAN LEAD TO EARLY DETECTION

Early detection can make a difference in the treatment and outcome for people with melanoma, and performing self-exams is key. See the ABCDE rule on page 14 to help know what you're looking for. It's hard to spot something when you can't see it, so ask a loved one or a dermatologist to check the areas of your body that are hard to see for yourself (see *Self-Exams*, page 16).

Be aware that a tattoo may make it difficult to spot something out of the ordinary. Tattoos have been popular for centuries.

Generally, tattoo artists steer clear of covering any existing moles or problem areas of your skin with ink, which is recommended. However, that isn't always possible with more extensive tattoos, such as sleeves (designs that cover the arm from the wrist to the shoulder). These elaborate designs span more skin on your body and often include many colors of ink, which can make it difficult to spot a problem area.

If you have one or more tattoos, be diligent about performing regular self-exams and seeing a dermatologist for preventive checks. ■

[KEY TAKEAWAYS]

- **No matter your skin tone, the most important preventive measure is to avoid excessive exposure to ultraviolet (UV) rays.**
- **Self-exams can help detect melanoma early.**

Take the Quiz

Test Your Skin Health Knowledge

***TRUE or FALSE** (circle one)...*

1. **Only light-skinned people need to wear sunscreen.** *TRUE or FALSE?*
2. **Some types of medicine may increase your risk of sunburn.** *TRUE or FALSE?*
3. **Dark-skinned people don't need sunscreen because the increased amount of melanin in their skin provides natural protection.** *TRUE or FALSE?*
4. **You can get melanoma in places that are never exposed to sunlight.** *TRUE or FALSE?*
5. **Dark lines in your toenails mean you have toe fungus.** *TRUE or FALSE?*

How did you do?

1. False. *Plain and simple, anyone who is exposed to the sun needs sunscreen, no matter how light or dark their skin is. Keep in mind that different tints are available for different skin tones, which helps avoid a white residue after application. Ask your dermatologist for recommendations if you have allergies or skin conditions.*

2. True. *Some medicines make your skin more sensitive to the sun, which may increase your risk of melanoma. Ask your doctor or pharmacist about this side effect so you can be extra diligent about protecting your skin. Other lesser known risks include certain medical conditions, scars, skin conditions, skin ulcers and a high level of exposure to arsenic.*

3. False. *Though darker skin has more melanin (the pigment that gives skin its color), which does offer some protection from harmful UV rays, it is still vulnerable.*

4. True. *Along with forming on your skin, melanoma can develop in the mucosal lining of the body, a membrane that covers many body cavities and passageways. The body's moist mucosal linings are in the respiratory tract; in areas such as the sinuses, nasal passages and mouth; in the gastrointestinal tract, including the anus and rectum; and in the female genital tract, including the vagina and vulva.*

5. COULD BE EITHER! *You might have toe fungus, but a discolored spot or dark streaks in a toenail or fingernail may be a warning sign of a rare type of cutaneous malignant melanoma called subungual melanoma. Again, early detection is important. To be sure, ask your doctor.*

Creating your survivorship roadmap

As a cancer survivor, you still need information and support to help you on the road to emotional as well as physical recovery. What follows may assist you in making a plan that helps you focus on enjoying your life.

WHAT IS CANCER SURVIVORSHIP?

People define cancer survivorship in one of two ways:

- Completing treatment and having no sign of disease
- Living with and beyond cancer

With the second definition, survivorship begins at diagnosis and continues through and past treatment. It includes people who are living disease-free and those who are managing cancer as a chronic condition. However you define it, knowing what to expect and where to find help can guide you as you continue to move forward.

CREATING A SURVIVORSHIP PLAN

A survivorship plan is essential once you finish treatment. You may think of it as a life wellness plan or a roadmap that helps you figure out where you're going and how to get there. You may be able to compile most of the information on your own, but be sure to discuss each part of your plan with your doctor. Following are certain key elements to include. Download a sample survivorship plan and schedule at *PatientResource.com/SurvivorshipPlan.pdf*

- Medical history and summary of your cancer treatments. This information can help doctors continue to provide you the best possible care.
- Your family's medical history, including any history of cancer
- Your cancer diagnosis, including the date of diagnosis and the type, stage and location of your cancer
- Your diagnostic test results
- Your symptoms
- Your procedures
- Your medical treatments, including drug names, dosages, dates and any side effects; include ongoing maintenance therapy
- Any supportive care you have received, such as emotional counseling

Health care team. Keep a contact log for your entire health care team. Include names, titles, phone numbers, addresses and each person's role in your care.

Late effects and risks. Late effects are side effects that may last or show up weeks, months or even years after your treatment ends. Be sure to ask your doctor about the signs and symptoms to watch for so you can detect and manage them early. Also ask about your risk for cancer coming back where it first started (local recurrence) or spreading to other parts of your body (metastasis).

Follow-up schedule. This may include information about future appointments, diagnostic tests and exams to monitor for signs of a recurrence or another cancer.

If your doctor does not provide you with this schedule, ask. It is important to know how often you will need checkups in the coming years. Include any other procedures, such as reconstruction, that are part of your overall treatment plan. If you had a larger tumor removed, for example, a plastic surgeon may repair it with reconstructive techniques.

As always, it is important to conduct self-exams in between follow-up appointments.

Your survivorship plan is only useful if you understand and use it. Don't hesitate to ask your doctor any questions. ■

SELF-EXAMS

To conduct a thorough self-exam, use a mirror to examine these key checkpoints: neck, chest, torso, arms, legs, groin and face, including the skin around your eyes, ears and inside your nose and mouth. Don't forget these often overlooked areas:

Scalp | Soles of feet | Between the toes | Back / between buttocks | Underarms

Getting back into the swing of things

You may be looking forward to resuming your pre-cancer schedule, or you may decide to change your approach. Either way, here are a few things to keep in mind.

Lifestyle choices. Staying healthy and active is an important part of survivorship. Eating right and exercising continue to offer multiple health benefits and help you build a solid foundation for going forward. It may be helpful to consider nutrition and exercise as treatments your body needs to continue to be well.

Talk to your doctor about appropriate nutrition and exercise, and also consider these general suggestions:

- Work with a dietitian to create healthier eating habits
- Maintain or start an exercise plan as discussed with your doctor
- Quit smoking
- Wear sunscreen every time you go outside (see *Follow-up Care*, page 14).

Returning to work. Did you quit working or cut back hours while in treatment? If so, you may be thinking about returning. Work with your supervisor as you plan for this. Refer to the Americans with Disabilities Act to know your rights in the workplace. You may have long-term effects that could require some short-term changes such as these:

- A flexible schedule or reduced hours
- A redesigned workstation
- The ability to work from home
- Different responsibilities

Heading back to class. Maintain open communication with the faculty, and consider requesting resources from the school, such as emotional and social support, to help transition between treatment and school. Consider visiting the school or campus before returning. You might ask for simple accommodations, such as having extra time between classes to move from one building or classroom to another, having two sets of textbooks so you can keep one set at home, and being excused from a physical education class.

Worries about getting an infection, not having enough energy to keep up or that your friends and classmates have moved on without you may add to your concerns. Give yourself time to transition back. Being prepared may help ease anxiety and keep you from getting overwhelmed.

Notes

Funding and Support by:

Pfizer

PP-BMK-USA-0301 February 2021