MRF MELANOMA RESEARCH FOUNDATION

MELANOMA PATIENT GUIDE

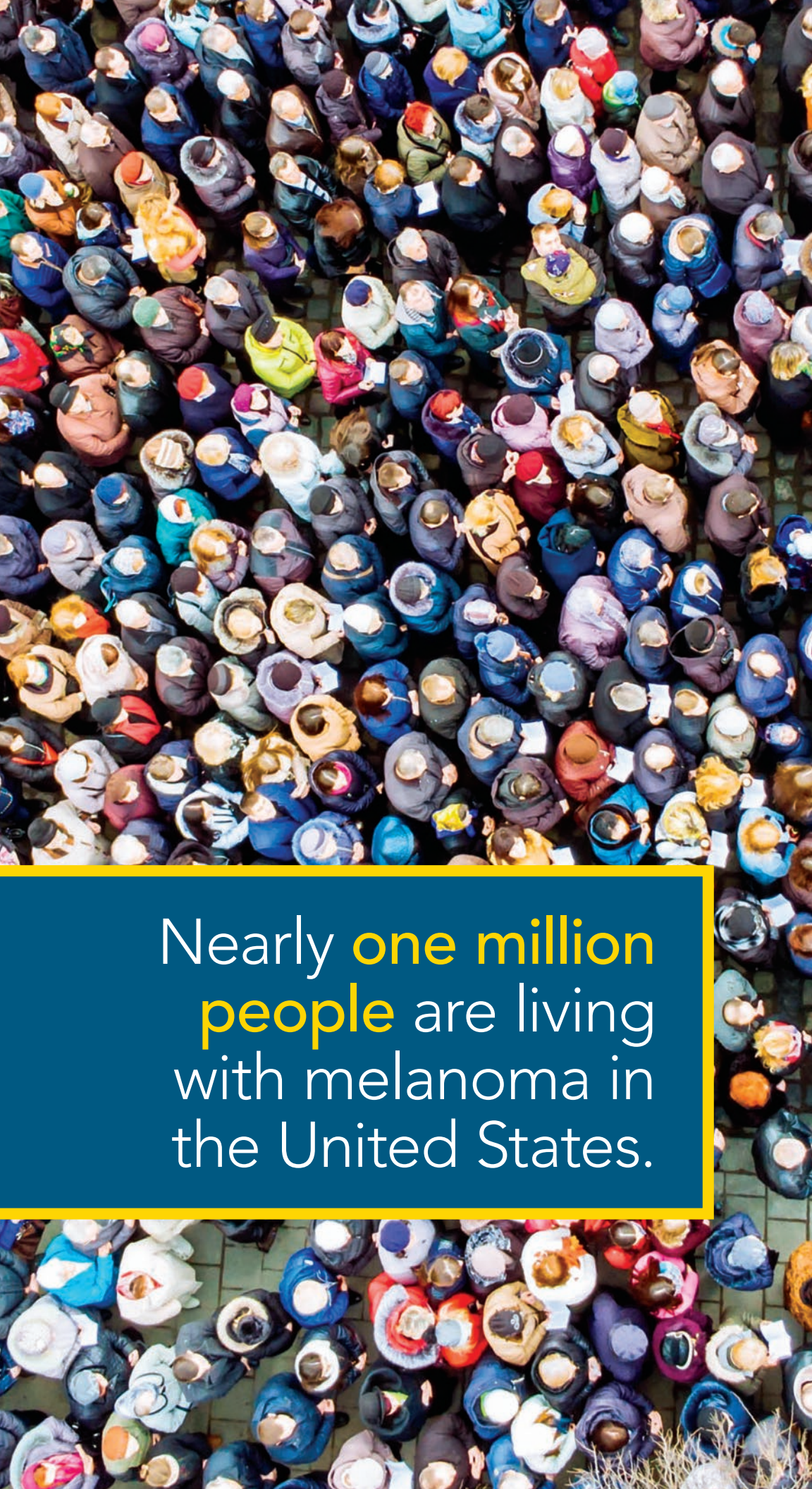
Guiding You at Every Stage

STAGE I

STAGE II

STAGE III

STAGE IV



Nearly **one million people** are living with melanoma in the United States.

Just Diagnosed…
Now What?

Once you recover from the shock of being told you have melanoma, it's important to learn all you can about this disease. The truth is, informed and empowered patients live longer, better lives. By arming yourself with knowledge, you'll better understand what you're up against.

Soon, you will likely know more about melanoma than you ever thought possible. You will become familiar with terms and language you never knew before. You will understand the importance of regular skin exams, early detection, sun safety and possibly even advances in melanoma research. And, as a result of all of this knowledge, you may even help prevent someone you love from receiving a melanoma diagnosis.

This is not a community anyone wants to join. However, it is important to know that YOU ARE NOT ALONE. Nearly one million people are living with melanoma in the United States. At the end of this section, you will find ideas on how to meet others who have been diagnosed and, if you'd like, ways to get involved in the fight against this disease.

WHAT YOU NEED TO KNOW

- Melanoma is one of the fastest growing cancers in the United States and can strike men, women and children of all ages, races and skin types. Melanoma does not discriminate.
- Melanoma is the most common form of cancer in young adults aged 25–29 years old and the second most common cancer in adolescents and young adults aged 15–29 years old.
- About 90% of melanomas are thought to be caused by too much exposure to ultraviolet (UV) rays.

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Melanoma — The Basics

Melanoma is a type of cancer, most often of the skin. It begins in melanocytes, the cells that color the skin and make moles. It is the deadliest type of skin cancer because it can spread to lymph nodes and distant organs. Melanoma can also occur in the eye (ocular, or uveal melanoma), in mucous membranes (mucosal melanoma) or even beneath fingernails or toenails (acral, or subungual melanoma). Ocular, mucosal and acral melanoma are not thought to be related to UV exposure.

This year, more than 144,000 Americans are expected to be diagnosed with melanoma. Of these, approximately 76,000 will be diagnosed with invasive (Stage I, II, III or IV) melanoma and another 68,000 will be diagnosed with melanoma in situ (Stage 0).

WHAT YOU NEED TO KNOW

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

1 Take a breath and try to stay calm.

2 RESEARCH.
EDUCATE.
ADVOCATE.

Diagnosing Melanoma

Diagnosing melanoma can be a difficult task, even for a trained dermatologist or physician. Most often, once a suspicious lesion is identified — either by you or your doctor — a **biopsy** is done. When melanoma is expected, a "punch" biopsy is usually performed and the tissue is removed by a dermatologist and examined under a microscope. A trained **pathologist** or **dermatopathologist** should perform this examination.

After analyzing the tissue, the pathologist will issue a pathology report. This report will include detailed scientific information on the biopsy and will help your doctor determine which, if any, treatment options should be considered.

Additional surgery may be required to remove the entire tumor with normal tissue surrounding it in order to get clear **margins.** Depending on the thickness of the melanoma, your nearby lymph nodes may also be evaluated.

Staging Melanoma

Staging is the process used to describe the extent of the disease. It can be a complicated process and you may hear terms you don't know. Three factors are considered when staging melanoma:

T **Tumor thickness** refers to how thick the tumor is. **Ulceration** is also considered in this category. Ulceration can only be seen under the microscope. It cannot be seen by the naked eye.

N **Regional lymph nodes** refers to the extent of lymph node involvement (read more about this on the next page).

M **Distant metastasis** refers to if, and how far, the melanoma has spread.

WHAT YOU NEED TO KNOW

> You have been given a diagnosis — not a death sentence.

> Find a support system. Family, friends, strangers, in-person, online, phone support — choose one (or more) that is best for you.

> Every patient is different. There is no "blanket" treatment plan.

> It is important to be an active participant in your treatment. Be your own advocate.

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Lymph Node Status

Lymph nodes are small glands that work as filters throughout your body. They contain immune cells that help fight infection and destroy germs carried in lymph fluid. There are hundreds of lymph nodes throughout your body and they are located primarily in the neck, armpits and groin.

If the original, or primary, melanoma has certain high-risk characteristics, your doctor may want to examine your lymph nodes. This will help your doctor determine whether melanoma cells have traveled beyond the original site of the lesion. To check for this, your doctor will perform a *sentinel lymph node* ***biopsy.*** The sentinel node is the first lymph node to which cancer is most likely to spread. If melanoma is found, the surgeon may remove additional lymph nodes to check for melanoma.

The extent of lymph node involvement, as well as other factors, will help your doctor determine your stage of diagnosis. It is very important to find out your stage as this information will help drive your treatment plan. If no melanoma is found in the lymph nodes, then it is likely that no additional surgery will be performed.

Genetic Mutations in Melanoma

Knowing your mutation status is critical for laying out your treatment options. Several genetic mutations are found in melanoma that "drive" the disease.

BRAF	The BRAF mutation is the most common type of genetic mutation in cutaneous melanoma, appearing in approximately 50% of cases.
NRAS	The NRAS mutation is less common than the BRAF mutation but occurs in approximately 20% of cutaneous melanoma cases.
KIT	The KIT mutation is the most common mutation in mucosal melanoma. This mutation is also common in acral melanoma.
GNAQ and **GNA11**	The GNAQ and GNA11 mutations are the most common mutations in ocular melanoma (melanoma of the eye).

Experts recommend that patients with high-risk Stage II and all Stage III and Stage IV melanoma patients have their tumors tested for genetic mutations. This will provide you with necessary information to make the best treatment decision for your situation. Read about therapies that target these mutations in the Stage III and IV sections of this brochure.

Common Terms

ADJUVANT THERAPY
Used after the primary treatment, such as surgery, to decrease the chance of the ocular melanoma returning or spreading.

BIOPSY
The removal of cells or tissues for examination under a microscope.

BONE SCAN
Imaging test that uses radioactive material to check for bone involvement.

CT SCAN
Rather than just one picture like an x-ray, CT scanners can help detect melanoma in soft tissues, like internal organs and the liver, by taking many pictures that provide a detailed image of the body.

EXTENSION
The melanoma has spread outside the eye by extending through the wall of the eye.

MALIGNANT
A term often used in melanoma, meaning invasive, cancerous or capable of metastasis.

MEDICAL ONCOLOGIST
A doctor who specializes in diagnosing and treating cancer. A medical oncologist often is the main healthcare provider for someone who has cancer. He or she may also give supportive care and coordinate treatment given by other specialists.

METASTATIC
The spread of the melanoma from the original site to other places in the body.

MRI
Imaging test used primarily to determine if melanoma has spread to the brain, spinal cord or liver. Unlike x-rays and CT scans, MRIs use radio waves and magnets to create pictures of the body.

OCULAR ONCOLOGIST
An eye cancer physician who provides comprehensive care for patients with eye tumors. Ocular oncologists are trained in ophthalmology and have completed specialized training in eye cancers. Ocular oncologists diagnose, treat and research a variety of malignancies that include the eye, eyelid and surrounding tissue.

OPHTHALMOLOGIST
A medical or osteopathic doctor who specializes in eye and vision care. An ophthalmologist diagnoses and treats eye diseases and is licensed to practice medicine and surgery. Many ophthalmologists are also involved in scientific research in eye diseases and disorders.

OPTOMETRIST
A health professional who provides primary vision care, sight testing and management of vision changes. An optometrist can perform eye exams, vision tests and detect certain eye abnormalities. An optometrist does not perform surgery.

PATHOLOGIST
A specialist in pathology who interprets and diagnoses the changes caused by disease in tissues and body fluids.

PET SCAN
Imaging test that looks for metabolically active areas in the body. PET scans are not as detailed as CT or MRI scans but can provide helpful information about the whole body.

RECURRENCE
The return of the melanoma.

SURGICAL ONCOLOGIST
A doctor who performs biopsies and other surgical procedures in cancer patients.

SYSTEMIC TREATMENT
Treatments that travel through the bloodstream, affecting cells throughout the body. Examples include immunotherapy and chemotherapy.

ULTRASOUND
A procedure that uses high-energy sound waves to look at tissues and organs inside the body. May also be used to evaluate a tumor.

X-RAY
Imaging test most often used to determine if melanoma has spread to the lungs.

FREE PATIENT RESOURCES

Online Patient Forum (MPIP)	The MRF's online community for melanoma patients can be found at **www.mpip.org.**
Ask a Nurse	The MRF's nurse provides free, personalized answers to melanoma questions and can be emailed at **askanurse@melanoma.org.**
Melanoma Treatment Center Finder	An interactive map listing melanoma centers of excellence and treatment centers which have experience treating melanoma. Visit **www.melanoma.org** to learn more.
Educational Resources and Recordings	View webinars, slides and recordings from educational events at **www.melanoma.org/educational-recordings.**
Social Media	Follow the MRF on Facebook, Twitter and Instagram.

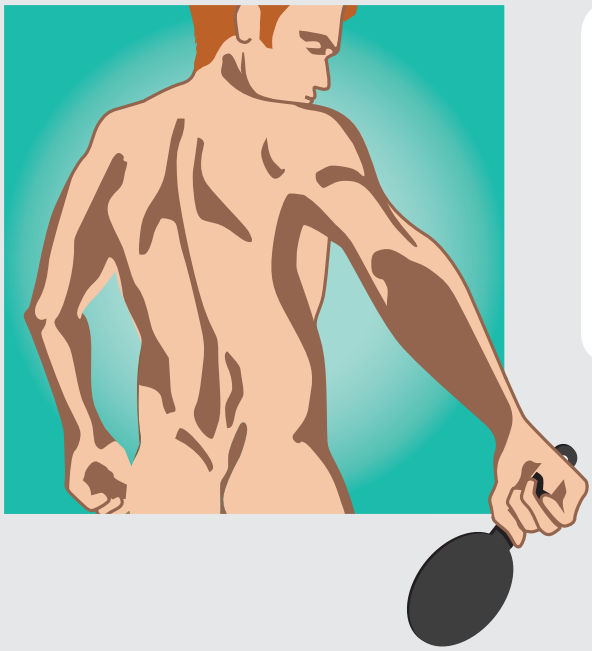
SELF SCREENING GUIDE

Check hands, nails, soles of the feet and between the fingers and toes.

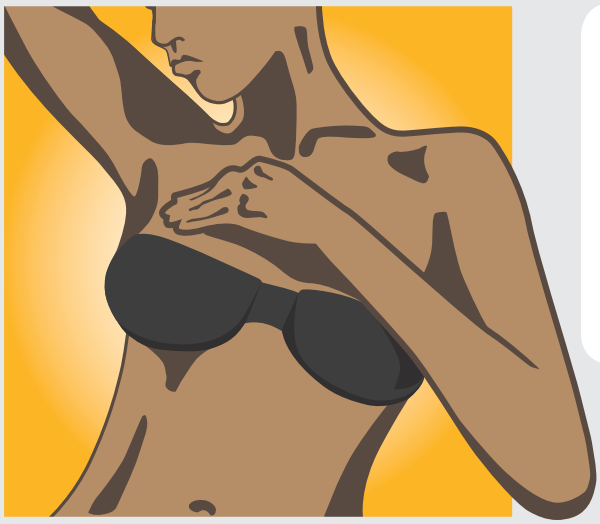
Check your head, face, ears and the back of your neck. A blow dryer may help you look at your scalp.

Be on the lookout for:

> Moles that begin to itch or bleed
> A spot that doesn't heal
> A dark spot under the toenail or fingernail
> A flat, red spot that is rough, dry or scaly
> A spot that becomes painful or tender



Check the front and back of your legs. Use a mirror to help you see your shoulders, back, buttocks and genitals.



Check your abdomen, arms, underarms and chest, including under your breasts.

STAGE I

What do I need to know?

Diagnosis

Stage I melanoma is broken down into Stage IA and Stage IB:

STAGE IA

What it means
The tumor is less than 1 millimeter thick, does not appear to be **ulcerated** and it has not spread to any lymph nodes or other organs.

STAGE IB

What it means
The tumor is either less than 1 millimeter thick and ulcerated or 1–2 millimeters thick and not **ulcerated.** It has not spread to any lymph nodes or other organs.

QUESTIONS TO ASK YOUR DOCTOR

- Do you have a lot of experience diagnosing melanoma?
- Was my **biopsy** examined by an experienced **pathologist** or **dermatopathologist?**
- Do I need a sentinel lymph node biopsy?
- What type of follow-up will I need?
- What are the chances that my melanoma will come back?
- How will we prevent a **recurrence?**

Treating Stage I Melanoma

The tumor and some surrounding, healthy tissue should be removed surgically, usually by a wide excision. The removal of the healthy tissue helps ensure clear **margins.**

Usually, no further treatment is necessary. However, a sentinel lymph node biopsy may be performed if the tumor is ulcerated or is equal to or deeper than 1 millimeter. Skin examination to evaluate for a new melanoma or other skin cancer should continue. Your dermatologist may recommend professional appointments every 3–6 months and self-skin exams at home should be performed every month.

STAGE II

What do I need to know?

Diagnosis

Stage II melanoma is broken down into Stage IIA, Stage IIB and Stage IIC:

STAGE IIA

What it means

The tumor is either 1–2 millimeters thick and **ulcerated,** or 2–4 millimeters thick and not **ulcerated.** It has not spread to any lymph nodes or other organs.

STAGE IIB

What it means

The tumor is either 2–4 millimeters thick and ulcerated, or more than 4 millimeters thick and not **ulcerated.** It has not spread to any lymph nodes or other organs.

STAGE IIC

What it means

The tumor is more than 4 millimeters thick and is **ulcerated.** It has not spread to any lymph nodes or other organs. These are aggressive tumors that are more likely to spread.

QUESTIONS TO ASK YOUR DOCTOR

- Do you have a lot of experience diagnosing melanoma?
- Was my **biopsy** examined by an experienced **pathologist** or **dermatopathologist?**
- Do I need a sentinel lymph node **biopsy?**
- What type of follow-up will I need?
- What are the chances that my melanoma will come back?
- How will we prevent a **recurrence?**

Treating Stage II Melanoma

The tumor and some surrounding, healthy tissue should be removed surgically, usually by a wide excision. The removal of the healthy tissue helps ensure clear **margins.**

A sentinel lymph node **biopsy** is recommended for Stage II melanomas. Additional, or **adjuvant,** treatment may be recommended after surgery for high-risk patients.

Skin examination to evaluate for a new melanoma or other skin cancer should continue. Your dermatologist may recommend professional appointments every 3–6 months and self-skin exams at home should be performed every month.

Second Opinions

Some people worry that doctors will be offended if they ask for a second opinion. However, most doctors welcome a second opinion and many health insurance companies will even pay for them. A second opinion may provide you with more information and, perhaps, a greater sense of control.

STAGE III

What do I need to know?

Diagnosis

Stage III melanoma is broken down into **Stage IIIA, Stage IIIB** and **Stage IIIC.** A variety of factors are involved in this breakdown, including tumor thickness, **ulceration,** regional lymph node involvement, in-transit metastases and satellite metastases.

In all cases of a Stage III diagnosis, the tumor may be of any thickness and it may or may not be ulcerated. The melanoma cells have spread either to a few nearby lymph nodes, or to some tissue just outside the tumor, but it has **not** spread to any distant organs.

Second Opinions

Some people worry that doctors will be offended if they ask for a second opinion. However, most doctors welcome a second opinion and many health insurance companies will even pay for them. A second opinion may provide you with more information and, perhaps, a greater sense of control.

QUESTIONS TO ASK YOUR DOCTOR

> Do you have a lot of experience treating melanoma?
> Do I need more tests to determine my stage?
> How will you determine if the melanoma has spread?
> Should I get a second opinion?
> There are a couple of FDA-approved treatments for Stage III melanoma — which do you recommend I start with?
> What is "Plan B" if I have a **recurrence?**
> Where will my treatment be done?
> Should I consider any clinical trials?

Treating Stage III Melanoma

As the following are only brief descriptions of each treatment option, please visit the MRF's website at **www.melanoma.org** for more detailed information.

- **Surgery**
  Standard surgical treatment is removal of the primary melanoma and a small amount of normal skin around the lesion. Recommended **margins** range from 1-2 cm and are determined by the size of the primary melanoma. If your doctor cannot completely remove all of the primary melanoma, it is referred to as ***unresectable.*** In some cases, unresectable Stage III melanoma may be treated much like Stage IV melanoma.

- **Close observation**
  Close observation after surgery may be recommended by your treatment team, especially if your recurrence risk is low. This type of approach may be the best option for you, or it may make you uncomfortable. Either way, it is important to discuss this option with your treatment team.

- **Immunotherapy**
  Immunotherapy is a type of **systemic treatment** and attempts to activate a person's immune system so that it will destroy melanoma cells. It is prescribed and administered by a **medical oncologist.** A couple of FDA-approved immunotherapies now exist for high-risk Stage III patients to consider as **adjuvant therapies.**

- **Targeted therapy**
  Targeted therapy is a form of treatment designed to interfere with the specific proteins that are driving the growth and spread of the tumor. Because they are "targeted" to the tumor, these therapies may be more effective and associated with fewer side effects compared to some other therapies. A targeted therapy approach allows patients to receive a somewhat personalized treatment since the drugs are based on the unique genetic profile, or subtype, of their tumor. Learn more about testing for these treatments in the main section of this booklet.

- **Clinical trials**
  Clinical trials offer access to drugs or combinations of drugs that are not yet approved by the FDA. Many experts believe these drugs offer great promise in lowering the risk of recurrence. As with any treatment decision, enrolling in a trial is a personal decision and many factors should be considered.

Clinical Trial Facts

Below is some important information you should know about clinical trials in melanoma:

- Most melanoma clinical trials provide either the best treatment option OR a new, and possibly better, treatment option. Many trials even combine the standard therapy with a new treatment.
- Trials help physicians determine which patients should receive which drugs in which order (sequence).
- Trials give you access to therapies that are not yet approved by the FDA but that are, oftentimes, more effective in the treatment of melanoma.
- Trials often give you greater control over your care.
- It is free to participate in clinical trials and you often have more diagnostic tests while participating than you otherwise would have during regular treatment.
- You can choose to stop participating in a trial at any time.

Follow Up

As with other stages of diagnosis, skin exams to evaluate for a new melanoma or other skin cancer should continue. Your dermatologist or oncologist may recommend professional appointments every 3–6 months and self-skin exams at home should be performed every month. A variety of diagnostic tests will also be performed regularly.

STAGE IV

What do I need to know?

Diagnosis

Stage IV melanoma, or **metastatic** melanoma, means that melanoma cells have spread to other organs in the body, or areas far from the original site of the tumor. The lungs, liver and brain are areas in the body where melanoma tends to spread most often.

Second Opinions

Some people worry that doctors will be offended if they ask for a second opinion. However, most doctors welcome a second opinion and many health insurance companies will even pay for them. A second opinion may provide you with more information and, perhaps, a greater sense of control.

QUESTIONS TO ASK YOUR DOCTOR

- > Do you have a lot of experience treating melanoma?
- > How will you determine where the melanoma has spread?
- > Should I get a second opinion?
- > Several FDA-approved treatments for Stage IV melanoma now exist — which do you recommend I start with?
- > Where will my treatment be done?
- > What are the common side effects of my treatment?
- > What is "Plan B" if "Plan A" doesn't work?
- > Should I consider any clinical trials?
- > What type of follow-up will I need?

Treating Stage IV Melanoma

Prior to 2011, no drug had ever been shown to extend life for patients with metastatic melanoma. Thirteen years passed with no new approved treatments. Since then, the melanoma community has seen an astonishing number of treatment advances. As the following are only brief descriptions of each treatment option, please visit the MRF's website at **www.melanoma.org** for more detailed information.

- **Immunotherapy**
  Immunotherapy is a type of **systemic treatment** and attempts to activate a person's immune system so that it will destroy melanoma cells. It is prescribed and administered by a **medical oncologist.** A few FDA-approved immunotherapy options now exist for Stage IV melanoma patients.
- **Targeted therapy**
  Targeted therapy is a form of treatment designed to interfere with the specific proteins that are driving the growth and spread of the tumor. Because they are "targeted" to the tumor, these therapies may be more effective and associated with fewer side effects compared to some other therapies. A targeted therapy approach allows patients to receive a somewhat personalized treatment since the drugs are based on the unique genetic profile, or subtype, of their tumor. Learn more about testing for these treatments in the main section of this booklet.
- **Radiation**
  Radiation is most often used as a symptom-relieving therapy in patients whose melanoma has spread to the brain or bones. In these situations, it would be used to make the patient more comfortable.
- **Chemotherapy**
  Chemotherapy is not often used in the treatment of melanoma. Although it is an FDA-approved treatment, research has shown limited overall survival benefits with this type of treatment.
- **Clinical Trials**
  Clinical trials offer access to drugs or combinations of drugs that are not yet approved by the FDA. Many experts believe these drugs offer great promise in lowering the risk of **recurrence.** As with any treatment decision, enrolling in a trial is a personal decision and many factors should be considered.

Clinical Trial Facts

Below is some important information you should know about clinical trials in melanoma:

- Most melanoma clinical trials provide either the best treatment option OR a new, and possibly better, treatment option. Many trials even combine the standard therapy with a new treatment.
- Trials help physicians determine which patients should receive which drugs in which order (sequence).
- Trials give you access to therapies that are not yet approved by the FDA but that are, oftentimes, more effective in the treatment of melanoma.
- Trials often give you greater control over your care.
- It is free to participate in clinical trials and you often have more diagnostic tests while participating than you otherwise would have during regular treatment.
- You can choose to stop participating in a trial at any time.

Follow Up

As with other stages of diagnosis, skin exams to evaluate for a new melanoma or other skin cancer should continue. Your dermatologist or oncologist may recommend professional appointments every 3–6 months and self-skin exams at home should be performed every month. A variety of diagnostic tests will also be performed regularly.

Managing Side Effects

Unfortunately, side effects are a reality of every treatment option. Side effects vary by treatment and by individual. Some patients experience every possible side effect while others experience very few, and sometimes no side effects from their treatment.

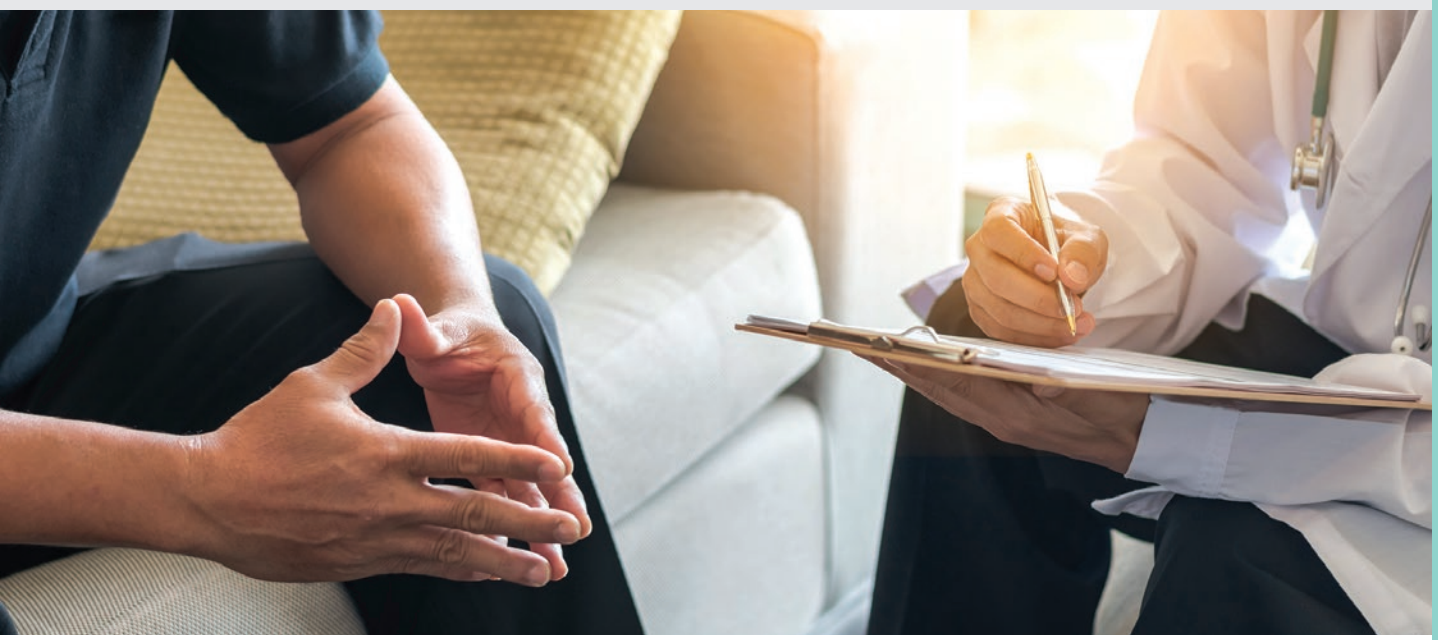
Common side effects of certain immunotherapy and targeted therapy melanoma treatments include, but are not limited to:

- Diarrhea
- Vitiligo (loss of pigment)
- Skin rash
- Lymphedema
- Thyroid issues
- Colitis
- Itching
- Fever
- Fatigue
- Nausea
- Constipation
- Joint pain

Be sure to **talk to your doctor about all side effects that you experience** as soon as you begin experiencing them. This will allow your treatment team to manage the side effects more effectively.

TIPS TO REMEMBER

1. Never hesitate to mention your side effects to your treatment team. Keeping your treatment team informed of all side effects as soon as they occur is of the utmost importance.
2. Experiencing few or no side effects does not mean the treatment isn't working.
3. It's impossible to know how you will react to any given treatment.
4. There is no blanket treatment for melanoma — everyone's case is different.



Living with Melanoma

A melanoma diagnosis affects everyone differently. Patients, caregivers and loved ones will all face physical and emotional challenges and encounter a wide range of feelings including fear, shock and isolation. Know that there is no right or wrong way to act or feel — everyone is different.

MANAGING STRESS

Stress can be felt physically, mentally and emotionally. At times, this stress may feel unmanageable. Be aware of the following signs and be sure to discuss all signs of stress, depression and anxiety with your doctor.

- Sad or "empty" feeling
- Loss of interest or pleasure
- Trouble sleeping or concentrating
- Increase or decrease in appetite
- Chronic fatigue or restlessness
- Thoughts of suicide or death
- Nausea or increased heart rate
- Chest or abdominal pain

STRESS MANAGEMENT TECHNIQUES

Stress management techniques are a very important component in living with melanoma and can help you feel empowered and improve your quality of life. Not every technique works the same for everyone, but here are few ideas to get you started:

- Join a support group
- Talk with a therapist or counselor
- Exercise
- Listen to music
- Practice yoga
- Keep a journal
- Call a friend
- Read a book
- Watch a comedy
- Get a massage

NUTRITION AND PHYSICAL ACTIVITY

Eating well plays an important role in developing a lifelong melanoma survivorship plan. It is important to eat a variety of foods every day. Be aware of portion sizes and understand the amount of carbohydrates, proteins and fats your body needs.

Eating small meals or snacks throughout the day, varying your diet and making meals into social events may help improve your appetite and make eating more enjoyable.

Improving your physical fitness after treatments can provide many benefits to your overall health and well-being.

Exercise can help with:

- Increased energy and self-esteem
- Improved sleep, blood flow and sexual functioning
- Stress relief
- Decreased risk of osteoporosis
- Reduced risk of blood clots and heart disease

Don't overdo it and, as always, you should consult your doctor before beginning any exercise regimen.

JOIN THE FIGHT AGAINST MELANOMA

Melanoma does not discriminate by race, age or gender. It knows no boundaries and is being diagnosed at alarming rates in children, teens, women and men.

You can join the fight by visiting **www.melanoma.org/get-involved.**

MRF MELANOMA RESEARCH FOUNDATION

1420 K Street, NW, 7th Floor
Washington, DC 20005
202.347.9675

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