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A PROGRAM OF SUPPORT
FOR
PEOPLE WITH ORAL
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HEAD AND NECK CANCER

A REVIEW OF DEPRESSION IN HEAD AND NECK CANCER

WILLIAM M. LYDIATT, M.D.

The Vernal Equinox March 20th

*How important it must be
to someone
that I am alive, and walking,
and that I have written
these poems.*

*This morning the sun stood
right at the end of the road
and waited for me.*

Ted Kooser U. S. Poet Laureate
Winter Morning Walks,

Carnegie Mellon University Press, Pittsburgh, 2000
with permission from the author

The diagnosis of cancer marks one of the most significant events in a person's lifetime. The uncertainty of what lies ahead, the potential for pain and suffering, and the possibility of losing one's life all converge creating a feeling of shock. The treatment of cancer can also be arduous and debilitating. Psychiatric manifestations are therefore common with depression and anxiety occurring in many cancer patients.

Head and neck cancer patients are among those at highest risk for depression. One major reason is the physical location affected by this disease. The most basic aspects of our humanity including our ability to speak, eat, breathe and appear in public may all be affected

by the cancer or its treatment. This can lead to social isolation, a known risk factor for depression. Facial disfigurement cannot be concealed, creating significant impairment in social interactions and emotional expression, which can lead to further social withdrawal and avoidance of potentially helpful support systems. Studies have shown that up to half of people diagnosed with HNC will develop depression. The highest risk is in the first three months following diagnosis.

The importance of treatment for this depression cannot be overemphasized. Depression has been linked to a lower quality of life, lower immune function, prolonged hospital stay, and a reduction in self-care abilities. Fatigue is more disabling in the depressed patient. Completion of the prescribed treatment plan occurs less frequently in depressed patients than non depressed patients. The success of radiation therapy depends in part on completing the course of therapy as close as possible to the prescribed time. Depression may make that more difficult by increasing the need for treatment breaks. Therefore, given all of these adverse factors, survival is likely to be worse in patients suffering from depression when compared with those not suffering from depression. Other factors that reduce survival may also be in play.

Suicide is likely an underreported problem in head and neck cancer patients. Several studies done to assess the role of suicide among cancer patients demonstrate an increased risk in both men and women. The risk is highest in the first three months for men and the first year for women. When looking at specific cancer diagnoses and suicide risk, Hem et al, found men with respiratory cancers and women with buccal (cheek) and pharyngeal (throat) had the highest risk of suicide and again noted the highest risk in the first 3 months from diagnosis. A study evaluating suicides among cancer patients over an 8 year period, found that although tongue and larynx cancer represented only 2% of all cancer patients, accounted for almost 20% of the total suicides. Mann et al in a general review of suicide and its prevention noted that 90% of suicides involve a psychiatric disorder usually depression (60%).⁷ They found an astonishing 80% of people are untreated at the time of suicide. It is important to emphasize that this discussion is not dealing with the question of suicide at the end of life, rather the premature termination of life due to active depression, a potentially preventable tragedy.

Llewellyn et al, demonstrated five psycho-social factors that impacted on survival in patients with HNC. These factors included, social support, satisfaction with consultation and information, behavioral factors (alcohol and tobacco usage), personality and the presence of depressive symptoms. All five of these factors are relevant to this discussion so we will briefly discuss each in turn.

Dealing with social support tends to be one of the most difficult problems for physicians and patients. The critical first step for each cancer patient is to recognize its importance and attempt to mitigate the problem with assistance from social workers, clergy, friends and

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COMING IN OCTOBER 2006

“Tissue Banking for Head and Neck Cancer”

Elizabeth Hammond, MD

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loved ones. It is important for the patient to recognize their personal support network and use it to the fullest extent possible. More often than not, friends and loved ones want to help but do not know what is needed. Open communication and overcoming a reluctance to ask for help is vital.

Information to adequately inform and instruct the patient helps to reduce uncertainty. Information can come from written material about the upcoming treatment, the disease course, staging and important issues related to healing. The importance of this effort cannot be over emphasized. Reading material may offer some sense of order in an otherwise chaotic time.

Tobacco and alcohol cessation is clearly important. This is not an easy task. Often it will take help from the physician in the form of nicotine replacement, or use of an anti-depressant called bupropion. Bupropion appears to work whether depression is present or not. Recent studies have shown a link between being susceptible to depression and nicotine addiction. In fact, it has been suggested that some tobacco users are actually attempting to treat their depression with nicotine and therefore quitting makes them feel worse by unmasking depression.

A personality with high levels of neuroticism may predict worse quality of life while extraversion seems associated with improved quality of life. Personality tends to be viewed as relatively fixed although Peter Kramer has suggested an interesting possibility of altering personality through the use of selective serotonin reuptake inhibitors in his book “Listening to Prozac”. This provocative notion is well beyond the scope of this article but does suggest another avenue that may be explored.

The role of depression and depressive symptoms requires careful examination and attention by the doctor and patient since making the diagnosis can be difficult. Depression is a complicated interplay between genetic predisposition and environmental influences. Concurrent life events such as the diagnosis of cancer and its treatment, a change in lifestyle, magnified by a lack of interpersonal support results in a significantly elevated risk of depression. Finally, the symbolic meaning of loss, such as the actual and symbolic loss of voice, can be profound. The first step in treating depression is to identify the problem.

Depression can present in different ways. Physical symptoms include sleep changes such as not being able to get to sleep, waking up early and not getting back to sleep or sleeping an excessive amount. Fatigue is common with depression as is weight change either loss or gain. These physical symptoms are similar to those almost everyone experiences with the treatment of head and neck cancer so they are often ignored. Feelings of guilt, helplessness, hopelessness, or suicidal thoughts are not part of the cancer treatment and should be brought to the attention of the physician. These are sometimes the only symptoms that can aid in the diagnosis of depression during and immediately after treatment.

It is important to find the cause of the depression. People with a family history or a personal history of depression are at higher risk. However, many depressed HNC patients have no personal or family history of depression. It is important to understand that anyone can develop a situational depression. It is not a sign of weakness but a medical illness that requires attention.

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There are also medical causes of depression. This is another reason why it is critical that the patient bring their feelings and symptoms to the attention of their doctor or nurse. A low or high thyroid level, electrolyte imbalances such as a low sodium, anemia or uncontrolled pain may all result in depression. These disorders need to be diagnosed and treated as part of the overall management. Sometimes drugs such as steroids or interferon can cause depression. They may be a necessary part of therapy and unavoidable. Sometimes however the dose may be reduced or the course of therapy limited. De Leeuw and others have reported risk factors for development of depression in HNC patients. They found that the most predictive risks were depressive symptoms as discussed above, a lack of emotional support, a lack of a social network, avoidance style of coping, advanced tumor stage, female sex, especially when facial surgery was involved, and a lack of openness to discuss cancer in the family.

If the depression requires treatment there are several broad options available. Treatment options for clinical depression include psychotherapy, pharmacological therapy and electroconvulsive therapy. Electroconvulsive therapy is generally reserved for difficult to treat depression that has failed other attempts.

Medication and/or psychotherapy are both effective in the majority of medically ill patients suffering from mild to moderate depression. Counseling and psychotherapy are important and helpful avenues for therapy. However, some patients with HNC may have significant impairment in communication, making psychotherapy more difficult and possibly limiting its effectiveness particularly in the first three months following diagnosis of cancer. Antidepressant medications may be particularly advantageous for these patients. None the less it is vital that patients talk with the physicians, nurses or others about their emotional state. Drugs do not magically solve ones problems but antidepressants can be an important aid in combating and treating depression.

Antidepressants are considered to be safe for the treatment of depression in cancer patients. The two main classes of medication utilized are selective serotonin reuptake inhibitors (SSRIs) and tricyclic antidepressants (TCAs). The SSRIs have several advantages over TCAs and may be the drugs of choice.

The side effects of SSRIs typically occur at the beginning of treatment and are usually mild and transient. They may include sexual dysfunction, insomnia, dry mouth, nausea, anxiety, or mild weight loss. There has been a question of an increased risk of suicide associated with SSRIs. It is not clear whether this is a risk in cancer patients but it is important to be aware and notify your doctor if you have suicidal thoughts whether you are on an antidepressant or not. Additionally, SSRIs are safer in overdose. Anti-depressants have not clearly shown a reduction in suicide rates however indirect evidence suggests they are beneficial.

Treatment courses tend to run about 4 to 6 months on average. The dose is typically slowly reduced to avoid an abrupt stoppage of the medication. Counseling is also beneficial particularly after cancer treatment has been completed. Many people find support groups to be of great benefit. There is little question that having a strong social network will help in recovery.

We are currently investigating the role of prevention of depression using an antidepressant taken prior to initiation of cancer therapy but at this time it is not clear whether this is an effective strategy. Preliminary results suggest there may be a role but clearly, additional work must be done before this can be recommended.

The most important point of this discussion is to stress the need for patients to discuss their emotional health with their doctors and care givers. Depression is a disease that can cause tremendous hardship not only in the individual with HNC but also their loved ones. Effective treatments exist but can only be started after the diagnosis is made.

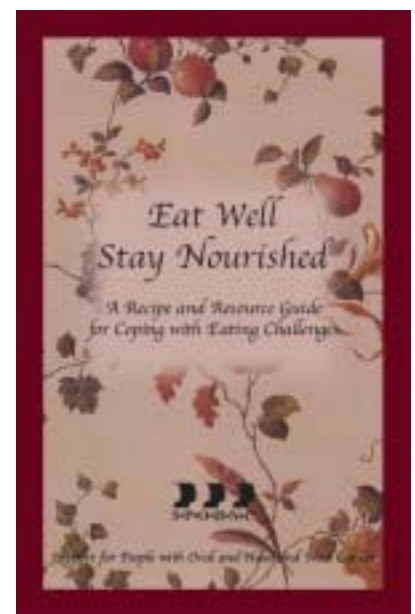
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A TIME FOR SHARING

The Beginning

In the summer of 2001 my wife and I left big-city life in New York City to pursue opportunities further west. Moving to Oberlin, OH felt like an adventure, and we were excited to see what life in a small town would be like. While my wife taught at the Oberlin Music Conservatory, I looked for gigs playing music (I'm a drummer) and worked from home doing telemarketing. After a couple of months, I began to feel bored and restless with my job, often fantasizing about quitting; but I really had no idea what I would do instead.

It is likely I would have remained in this quandary for a long time had I not begun feeling some discomfort in my throat and a dull pain in my left ear. At first, I attributed it to the plastic headset I had been wearing to keep my hands free while talking on the phone, but after a few weeks I noticed that it was getting somewhat worse. I wasn't overly concerned, assuming it was a tonsil infection or something equally benign, but I made an appointment to see a nearby ENT just to be sure.

On the day of the appointment I sat in the waiting room, impatiently browsing and discarding an array of old, dog-eared *Fisherman's Monthly* and *Woman's Day* magazines (why don't they have better magazines in doctors' offices?). Again, I didn't feel particularly worried, but I was anxious to find out what was going on. Finally, they called my name and I went in to see the doctor, an energetic man with a cheery demeanor. He asked me a few questions about my symptoms before asking me to "open wide and say ahhh." His first words were not exactly comforting: "Hmmm, I don't think we're looking at a tonsil infection here." I began to feel mildly nervous. "Uh, why not?" I asked, not certain I wanted to hear the answer.

"Because," he said kindly, but seriously, "if it were an infection both tonsils would be swollen. . . I only see a problem on the left one." He now had my complete attention.

"So what's the problem?" I asked. My heart beat faster as I considered for the first time that there might be something seriously wrong. Even so, I was completely unprepared for his next words: "I think it's a lymphoma

of some kind—either Hodgkin's or non-Hodgkin's." I was shocked and terrified by his words, but at the same time I felt disconnected from reality, like I was in the room watching a conversation between a doctor and his ashen-faced patient.

We spent the next twenty minutes talking about my situation and how to proceed. The doctor initially diagnosed the cancer T1N0M0: stage 1 with no lymph node involvement and no metastasis. His prognosis was upbeat, and he was very encouraging about my chances of survival. His treatment plan involved removing the tonsil and then radiating my face and neck to destroy any microscopic remnants of the disease he couldn't feel or see on a CT scan. In truth, I barely heard anything he said because all I could think was, "Oh my God, I'm going to die of cancer."

When I got in my car to drive home I was numb with fear and my head was spinning with confusing thoughts: How could this be happening? What am I going to do? Am I going to die? It's a miracle that I made it home without crashing the car. Along the way, I was also struck with a profound sadness about having to tell my wife and family about my illness. Up until then I had been preoccupied with thoughts of my imagined imminent demise; however, as I got closer to home I began envisioning my wife's reaction to hearing I had cancer. I knew she would be devastated, and I was heartsick at the thought of telling her the news. As I entered the house she could see on my face that something was terribly wrong. I looked in her eyes and simply told her, "I have cancer." While holding each other tightly a floodgate of tears opened. In fact, I cried a lot in the following days: there is just no easy way to tell loved ones you have cancer without feeling incredibly sad.

The Treatment

Following my diagnosis, I got a CT scan, a Pan-Endoscopy, and then had tonsil surgery and a biopsy. The scans were clear, while the biopsy revealed good news and bad: the bad news was that the tumor was not Hodgkin's, but rather Squamous Cell Carcinoma—a more dangerous type of cancer. The good news was that the original diagnosis of T1N0M0 was

still valid and his treatment plan remained the same.

I was fortunate to get sick in close proximity to the Cleveland Clinic, one of the best cancer treatment centers in the country. My radiation oncologist, was a serious man with a no-nonsense attitude. Frankly, speaking to him always made me a bit nervous; however, I felt confident in his "err on the side of caution" approach. He believed the pathologist's report showed my cancer to be on the cusp between stage one and stage two, but he concurred with my ENT's prognosis and recommendation for radiation therapy. My treatment would begin in three weeks, after my throat healed from tonsil surgery.

I still remember how claustrophobic I felt getting fit with the mask and marked with tattoos that would guide the technicians during thirty-one sessions of radiation. The surreal feelings I had experienced early on continued throughout my treatment; I just couldn't shake the sense that this was all happening to someone else.

My daily routine became consisted of driving an hour to the clinic, spending twenty minutes "getting zapped," and then driving home. I had given up my day job after a couple of weeks—the soreness and dryness made it too hard to talk on the phone—so I spent my days resting and trying to keep strong, both physically and mentally. I experienced a number of unpleasant side effects during treatment. My mouth became very dry and sore, and everything tasted awful (like a mouthful of pennies). Dr. Saxton had emphasized the importance of maintaining my weight during treatment (and mentioned using a PEG tube, if necessary), so I was determined to keep eating in spite of the discomfort. Eventually solid food became impossible, but a thrice daily, blended concoction of whole milk, peanut butter, yogurt, fresh fruit, and Muscle Milk (a high-calorie protein powder) did the trick. Although these shakes tasted bad (everything did), I managed to maintain my caloric and nutritional intake with them.

Of course, over time most of the side effects resolved: the soreness in my throat and mouth faded, the sunburn-like cracks on my skin healed, and the lymphedema under my chin dissipated. Only the dry mouth remained

as a permanent reminder of treatment (note: I find that Biotène toothpaste, mouthwash, and Oral Balance Gel are wonderful for mitigating the dryness).

For me, food issues became the biggest obstacle to recovering fully from treatment. Throughout the two months of radiation therapy, the once pleasurable social pastime of eating had become a difficult and tedious chore. And although I felt hungry for “real” food, I couldn’t get past the dryness, bad taste, and stiffness in my jaw. My doctor encouraged me to be patient, reminding me that things would improve over time, but there were many disheartening moments when I thought I’d be living on milk shakes for the rest of my life. Eventually, as my taste buds returned to normal and I learned how to eat with a dry mouth (LOTS of water), I weaned myself off the shakes completely. I’m happy to say that today I can eat everything I could before getting sick.

Afterwards

Surviving cancer provided me with an opportunity to carefully consider my life. For years I took many things for granted. Now I was determined not to squander any more time. I had spent my life as a successful working musician, but also supplemented my income by working in sales—a profession that paid decently, but offered little in the way of satisfying my soul. Prior to getting sick I was doing much more selling than music making, and I knew this was not good. Unfortunately, there were fewer opportunities to play music in Oberlin than there had been in New York City, so I had to find another option.

After giving it much thought and discussing things with my wife, I decided to go back to school to resume the education I had abandoned some 25 years earlier to pursue my musical aspirations; I had always regretted quitting college after only one year and was eager to try it again. The local Community College was close to home and affordable, so that’s where I started.

As a kid, I had been an okay student at best—doing well in courses I liked, not so well in others. This time around, however, I found school to be a challenging and rewarding endeavor where hard work led to success. Honestly, the hardest part was being “the old guy” in all my classes—I had severely underestimated how strange it would feel taking classes with kids young enough to be

my children (heck, some of the *teachers* were young enough to be my children). I eventually got used to it and set about the business of completing my education.

While working on my degree, I also became a mentor/counselor with the Cleveland Clinic’s 4th Angel Program, which matches newly diagnosed cancer patients with mentor/counselors who are survivors of similar diagnoses. Although I received some training prior to my first call, I was still a bit nervous—I didn’t know if I’d be able to address all the questions that might come up. I said little during that call, but listened a lot as “Dave” expressed concerns and fears about his cancer and pending treatment. After nearly two hours, he thanked me for being such a big help and we said goodbye.

I learned some important things that day: First, that knowing all the answers is not necessary—listening and sharing are often enough. Also, that the rewards of mentoring come not just from the help I offer, but also from what I get in return. Over the years I have met some amazing people while mentoring, and am always humbled and inspired by the courage, compassion, and strength of spirit people show while enduring the debilitating surgeries, radiation, and chemotherapy needed to treat their cancers. Most importantly, my experiences as a 4th Angel (and later for SPOHNC) made me realize that I wanted to make a career helping people cope with the trials and tribulations of serious illness.

In December of 2005, I completed my Bachelor’s Degree in Psychology at Cleveland State University, graduating summa cum laude. I was also fortunate enough to receive an Ohio Board of Regents Graduate/Professional Fellowship that I will use to help finance my Master’s Degree in Social Work from CSU (the program begins this fall). I look forward to finishing school so that I can work providing counseling and resources to others who are going through what I have.

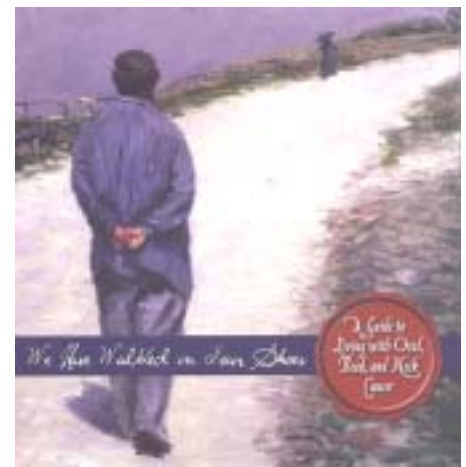
It has been nearly four and a half years since I finished my treatment. I confess that I still have moments of anxiety about my health, sometimes referring to myself as “The Boy Who Cried Cancer” (unexplained aches or pains can send me running to my family physician), but I suppose this is normal in light of my past. More often than not, however, I view my cancer as a mere bump in the long road of life. I also know that with the love and

support of my wife and family I can contend with whatever life throws my way.

Finally, my thanks to Janine Cortese and Nancy Leupold for allowing me the opportunity to share my story with others. The resources and information offered by SPOHNC are invaluable, and I am grateful for their efforts on behalf of survivors of oral head and neck cancers.

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SECOND PRINTING



“We Have Walked In Your Shoes, A Resource Guide to Living with Oral, Head and Neck Cancer”

This book contains basic information about oral and head and neck cancer and provides resources for patients and families facing a diagnosis of this type of cancer, its treatment, rehabilitation, and recovery. It is not intended to replace any information and/or recommendations made by health care professionals. It is designed to help you get the answers you need. It summarizes the most common advice on living with oral and head and neck cancer, provides you with resources if you want more information, and offers practical tips as well as weekly and monthly calendars to help you track your treatment. This book is free.

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Scientists Identify an Inherited Gene That Strongly Affects Risk for the Most Common Form of Melanoma

Researchers at the National Cancer Institute (NCI), part of the National Institutes of Health, have identified a link between inherited and acquired genetic factors that dramatically increase the chance of developing a very common type of melanoma. This finding appears in an online version of *Science* on June 29, 2006, and was a collaborative effort led by scientists at NCI and the University of California San Francisco. Also involved in the study were researchers at the University of Pennsylvania, Philadelphia, and Bufalini Hospital in Cesena, Italy.

“Knowing who is at greater risk for melanoma due to heredity, and understanding the pathways leading to cancer, are important steps in addressing a disease which is expected to be diagnosed in over 62,000 Americans in 2006,” said National Institutes of Health Director Elias A. Zerhouni, M.D.

People with fair skin are generally at increased risk of developing melanoma. Differences in skin color, or pigmentation, are due largely to the melanocortin-1 receptor (MC1R) gene. Everyone has two copies of MC1R; one inherited from the mother and one from the father, and either can be the standard form or a variant. Some variant forms of MC1R are responsible for traits such as fair skin, freckling, and red hair. But MC1R may do much more than influence pigmentation.

“We previously observed that subjects who inherit one or two variant forms of the MC1R gene had a modest increase in risk of developing melanoma, even if they have darker pigmentation,” said Maria Teresa Landi, M.D., Ph.D., lead study investigator at NCI. “We have now discovered that MC1R dramatically predisposes individuals with no excessive sun exposure and variable pigmentation to developing a particular type of melanoma.”

Melanomas, which are tumors that arise from cells which produce skin pigment, can occur on all parts of the body where these

cells are present. Caucasians have a much higher chance than other populations of developing these tumors on skin areas that are exposed to the sun. Sun exposure has many effects on skin, including causing chronic sun damage, with wrinkling on areas subject to high exposure over a lifetime. Sun exposure may also lead to mutations in cancer-causing genes, such as BRAF, which are frequent in melanoma.

According to Boris Bastian, M.D., University of California, San Francisco, “The relationship between BRAF mutations in melanoma and sun exposure is complex and intriguing. On the one hand, sun exposure appears necessary for development of BRAF mutations; melanomas on areas such as the soles of feet and palms of hands, which have low exposure, have low mutation frequencies compared to the approximately 60 percent mutation frequency in sun-induced melanomas on skin without chronic sun damage. On the other hand, melanomas developing in older subjects with sufficient accumulated sun exposure to produce chronic damage also exhibit lower BRAF mutation frequencies.”

Because melanomas on skin areas with few signs of chronic sun-induced damage occur in younger people and exhibit frequent mutations in BRAF, the researchers hypothesized that there were inherited genetic factor(s) that predispose to the development of these melanomas with BRAF mutations. An interesting candidate for this genetic risk factor was the MC1R gene.

To determine if there was an association between inherited variant forms of MC1R and the development of BRAF-mutant melanoma, the researchers studied the skin surrounding the melanomas in 85 patients from the Bufalini Hospital of Cesena, Italy, and 112 patients from the Department of Dermatology at the University of California, San Francisco, and identified subjects with no or little signs of chronic sun damage. They then sequenced MC1R genes in

normal cells and BRAF in tumor cells and found that BRAF mutations were more frequent in non-chronic sun-induced melanoma cases with hereditary genetic variant forms of MC1R.

By categorizing patients into two groups, those with no variant forms of MC1R versus those who had at least one variant, the scientists found that BRAF mutations were six to 13 times more frequent in those with at least one MC1R variant form. Looking more closely, the investigators found that the risk for melanoma with BRAF mutations rose with increasing number of MC1R variant forms. Comparing data from melanoma patients and healthy controls, the risk for melanomas with BRAF mutations increased from seven times for individuals with one MC1R variant form, to 17 times for those with two variant forms, when compared with individuals with the standard MC1R.

The study results show that normal variations in the MC1R gene in Caucasians have a very specific effect on melanoma susceptibility. Additional inherited factors that affect susceptibility may also be present, but they have yet to be discovered. “The mechanism by which variant forms of the MC1R gene facilitate development of melanomas with BRAF mutations is currently unknown,” said Landi. “One possibility is that people with MC1R variant forms and variable pigmentation generate more reactive chemicals in their cells as a result of the ultraviolet exposure in sunlight. These reactive chemicals can induce mutations, like those in the BRAF gene, which may lead to cancer.”

Clinical trials for melanoma using pharmaceutical drugs directed against the BRAF gene are ongoing. Knowledge of predisposing factors in the development of BRAF mutations, such as MC1R, might aid prevention and therapeutic strategies in the future.

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