



STAGE III PATIENT FOCUS GROUP SUMMARY

On March 3, 2015, the Melanoma Research Foundation hosted a virtual focus group to get a better understanding of the unique concerns and needs of Stage III patients. Participants included a range of ages, diagnosis and experiences. While their stories were unique, several common themes emerged throughout the discussion.

INITIAL DIAGNOSIS

“Nothing to worry about”

Four of the five participants noticed something different on their skin. In each case, their doctors indicated there was nothing to worry about. In several cases, participants had to push their doctors to look deeper.

“Like being hit with a baseball bat”

The actual diagnosis left a lot to be desired. One participant reported receiving a call at work, without any warning that she was about to receive bad news. Since almost every participant had been told not to worry, a diagnosis of cancer was completely unexpected.

“Am I dead?”

Information and next steps were often unclear upon diagnosis. Two of the participants did not receive any information about the stage of disease at their initial diagnosis. In one case, the participant was diagnosed by a military doctor and had to wait three weeks for treatment information as her family was about to move.

“Dropped my dermatologist like a hot cake”

Upon diagnosis, most of the participants sought melanoma specialists. In several cases, they also reexamined relationships with the dermatologists who had told them they had nothing to worry about.

TREATMENT

“I hate melanoma and I don’t like to treat it”

Most of the participants sought out melanoma specialists to develop a treatment plan. They noted that it took a great deal of initiative to find information and figure out next steps given the lack of treatment options for a Stage III diagnosis. One of the participants noted that she was shocked to learn that there was no common treatment path. Three participants sought second opinions before deciding on a course of treatment.

“All doctors have their own dogmas”

One participant noted that no matter where you are treated, doctors tend to have their own dogmas about treatment and it can be tough to figure out the right treatment path if you are not a medical professional.

“I needed to do something”

All of the participants noted that even after initial treatment, they felt they had to do something. Two participants went on a clinical trial, one did interferon and one did radiation, even though she was considered free of disease after surgery.

“I never felt sick from melanoma”

Three of the participants noted that they never felt sick from melanoma; they went to the doctor because they noticed something on their skin. However, several reported serious side effects from the treatment paths they chose. One of the participants had just finished interferon the week before and was still feeling sick from the treatment. Another talked about her decision to go on a clinical trial, which she was eventually kicked out of due to side effects that has left her with some permanent health conditions.

DISEASE PROGRESSION

“Scanxiety”

Every participant talked about anxiety around the possibility of disease progression and recurrence. One participant coined the term “scanxiety” to describe the feeling that comes before follow-up appointments. He also noted that if you know anything about the nature of melanoma, the possibility of recurrence is not a surprise. Melanoma is not the best kind of cancer to have. All agreed that while the ultimate goal is a cure, if you have to have recurring disease, a treatment that would allow you to manage melanoma as a chronic condition would be desirable.

THE NEED FOR SELF EDUCATION AND SUPPORT

“Critically important to be one’s own advocate”

Each participant talked about the importance of educating themselves. Most reported going online to find information. Several mentioned finding the MRF’s online participant forums and noted that they were very helpful.

“A strange and wonderful outcome”

While initial diagnoses left a lot to be desired, participants talked about the process of finding a good doctor and the relationships they developed with their treatment teams. One participant noted that she did not expect the level of support and relationships that she developed with the nurses.

ABOUT THE MELANOMA RESEARCH FOUNDATION

The Melanoma Research Foundation is leading the fight to transform melanoma from one of the deadliest cancers to one of the most treatable through research, education and advocacy. Learn more and find resources at www.melanoma.org.

This focus group was made possible with a grant from Provectus Biopharmaceuticals.