



World's Largest Oral Cancer Support Group is Helping Thousands Worldwide

*The Oral Cancer Foundation is connecting cancer patients and survivors through the web
Oral Cancer Support Group
Connects Thousands of Patients and Survivors on the Internet*

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It's no secret that people don't want to hear their name and cancer in the same sentence. When Oral Cancer Founder Brian Hill was diagnosed with oral cancer in 1999, he had a lot of questions. Brian recalls, "When I was going through treatment I remember thinking, 'When am I going to get rid of all these sores in my mouth? What about tasting things again? I was desperate to find someone to talk to who had gone through the same thing I was experiencing but there was nowhere to go.'"

Brian decided to take matters into his own hands and become a student of the disease. With a small budget, he founded the non-profit Oral Cancer Foundation, and launched a Patient/Survivor Support Forum shortly after completing treatment for the disease. Today, eleven years after Brian faced dim prospects as a stage 4 cancer patient, the Foundation's Survivor/Patient forum is the world's largest support group for oral, head and neck cancer. The message boards have thousands of individuals--survivors, patients and caregivers, as well as doctors and nurses--posting on a real-time asking for and providing information and support to those just starting on this path. The OCF forum is a free, anonymous, safe environment for patients to get the answers and support they need 24/7/ 365 days a year. Patients and caregivers worldwide are interacting with each other.

Currently more than 7,450 members on the forum interact with one another on a daily basis; tens of thousands of non-participants read the board routinely. David Hastings, a 1,000+ poster said, "Daily, I feel I have learned something new that may be of some benefit to a future oral cancer patient." This comes as no surprise to Jamie O'Day, the Treatment Facilities Coordinator for the Foundation. "The OCF members come from all walks of life; they bring different ethnicities, financial situations, life experiences, and treatment experiences to the table."

Jamie adds, "The people on the forum are the heart and soul of OCF. It's a beautiful thing to see these people, who don't know each other and have never met, yet share a common battle and genuinely want to help each other out-- even when they may be going through the hardest time of their lives. Many long-term friendships have started here."

Although the Oral Cancer Foundation is located in the US, the web forum has the

capacity to connect people that are affected by this disease. Gabriele, who lives in Australia, was diagnosed with oral cancer in 2006 and has been active on the forum since then. Gabriele admits, "I did a lot of searching on the Internet before finding OCF because there was little available locally. I always try to keep an eye out for my fellow Australian OCF members and look for new ones joining. I remember being instantly befriended by two other OCF Aussies. Now nearly four years later, I try to help and encourage others on the forum that are going through the same treatment I had."

Brian Hill comments, "Sometimes only the voice and perspective of someone who has been there before can give you the answer that you need. No one gets through this battle alone. Most people initially come to the forum for information and to ask questions, but they stay on the forum because they develop relationships with one another. We have people that have been regular posters since the beginning, a decade ago. Many express their gratitude of survivorship by helping others behind them on this path."

Christine is one of those "regular posters" with over 2,700 posts. She said, "When I first came to OCF in June of 2007, I was scared and alone. The forum members reached out immediately and embraced me, assuring me that I would get through it and be okay. They quickly became my adopted cyber family, always encouraging me and keeping track of my progress. In fact, the post about my operation and 2-month hospital stay is the most-read post on the forum with over 78,800 views". That number of views speaks to the huge audience of "lurkers", those who read but do not join in the discussions. Christine continues, "The forum is a wonderful place to get quick answers and opinions about questions concerning treatment, after-effects, medications, etc. The bonds of friendship that have been formed over the years will be with me forever. As a survivor, it is my duty to give back, to aid the weak when they are down. It's kind of like holding someone's hand when they are scared. I try to make a difference in someone's life with every post I make."

The forum allows people to stay in the comfort of their own home and access it 24 hours a day, to find both information and emotional support. By design, the forum allows caregivers and family members to participate as well in their own forums. Spouses often seek the advice of other spouses, asking questions they would hesitate to ask their partner fearing those uncertainties would further add to the patient's burden."

The forum does not operate in the format of a chat room, as those conversations are lost forever when they are finished. In OCF's forum format, the knowledge is archived, and remains permanently for future access. More than 100,000 posts (even with month pruning of older, less informative posts) can be searched with key words, yielding a rich resource of the most common questions and thoughtful answers to them.

Rosie, a participant who lost her daughter to the disease, had this to say about the forum: "The OCF forum was an invaluable resource when my daughter Heather was battling squamous cell cancer on the base of her tongue. I often learned more from people on the forum than I did from the doctors. Someone was always there offering help within hours, or even minutes, of my posting a question. And when Heather died, the OCF members came through once again. Danny Boy, who was relatively new to the forum and only came on board during the last weeks of Heather's ordeal, started a memorial fund in Heather's name. He made a generous donation himself, then rallied the troops and garnered a sizeable donation for OCF in memory of Heather. The bottom line is that the people on the OCF forum were my lifeline during the most horrendous 13

months of my life. Heather didn't survive this horrible disease, but I still will be forever grateful to Brian Hill for creating the OCF website, and to all the OCF members on the forum that helped us through those dark months. I only wish we had found the site sooner. It may not have changed the outcome, but I feel that Heather would have had a better chance had I learned more before she started treatment.”

To ensure that accurate information is given out, and the appropriateness of postings is maintained, there are board monitors, drawn from the ranks of medical and dental professionals who volunteer on a daily basis to read the postings. Some like Dr. Jerry Wilke are even oral cancer survivors themselves. The foundation is very aware that the web, and its many sources of information and interaction can be a source of incorrect information that may cause harm. All postings are closely monitored for their content and appropriateness.

When Brian Hill planted the seed that would become the Oral Cancer Foundation nearly 12 years ago, he would never have dared to dream that it would become the world's leading source of information and advocacy for the deadly disease. Brian concludes, “Because oral cancer often results in disfigurement or the inability speak clearly, many patients find their social lives taken away from them. Besides good information and support I think a much overlooked aspects of the forum is that it helps give these people a social life, a community of caring people that become friends across great distances.” He added, “I urge anyone with oral cancer, or who is a friend or family member of one, to participate and tell others about our community. The battle against oral cancer is not only fought with drugs, radiation and surgery; it is fought on the emotional field as well. I am always touched by the altruistic nature of those who populate our forums, and I can only aspire to the inner strengths that I see displayed by patients there every day. I am truly privileged to have this opportunity to interact with these amazing individuals. “

Many people battling cancer, or any illness for that matter, feel alone and tend to isolate themselves from those that are closest to them as because they do not want to be a burden. That is why the OCF message boards have touched so many lives. Often members will refer to each other as their OCF family, even brothers and sisters. It's a wonderful, safe place to come and share inspiration, hope, acceptance and even daily frustrations with one another. The forum and its members are the very definition of a symbiotic relationship: the forum owes its existence to its members, and its members in many cases owe their existence—and certainly their enhanced quality of life—to the forum.

The Oral Cancer Foundation is a non-profit 501(c) (3) public service charity that provides information, patient support, sponsorship of research, and advocacy related to this disease. It maintains a Web site at <http://www.oralcancer.org>, which receives millions of hits per month. The Oral Cancer Foundation runs the Patient/Survivor forum. If you or someone you know could benefit from the message boards, please log onto www.oralcancersupport.org.

Source: The Oral Cancer Foundation
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