

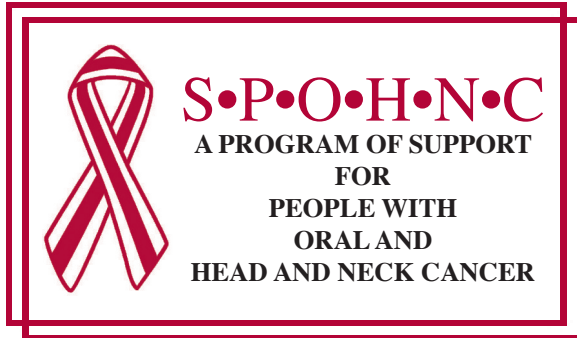
NEWS FROM S·P·O·H·N·C



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SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER, INC.

MARCH 2017



APRIL AWARENESS FOR ORAL, HEAD AND NECK CANCER The Importance of Support

April is Oral, Head and Neck Cancer Awareness Month. The month was designated by SPOHNC in recognition of our Founder, Nancy Leupold, and her diagnosis of oral cancer, in April of 1991. SPOHNC is dedicated to raising awareness and meeting the needs of oral and head and neck cancer patients through its resources and publications.

The Wall Street Journal recently did a piece entitled "When patients share stories, health insights emerge." SPOHNC's Chapter Support groups are a perfect example of the importance of support. The Wall Street Journal article states that people are willing to discuss things very frankly when they are in a roomful of people who share their experiences. Patients struggling with health challenges look to others who have gone through similar experiences.

Nancy Leupold, SPOHNC's Founder, knew when she was diagnosed that she, along with others, felt an overwhelming eagerness to seek out the support of patients and survivors of oral, head and neck cancer - hence the first support group was started 26 years ago.

In a SPOHNC Chapter Support group meeting, where newly diagnosed patients are thinking and talking about their fears, feelings and concerns, patients and their families are in an environment where they can feel safe and secure and know that there is hope.

Connecting with those who have "walked in your shoes" or healthcare professionals in the field of head and neck cancer can help you gather information and resources and find solutions to



cope with situations you face every day. No one should face the diagnosis and treatment of oral, head and neck cancer alone, and through SPOHNC's Chapter support groups, no one has to.

Chapters are facilitated by healthcare professionals and survivors, providing patients and survivors with an effective and rewarding alternative to coping with serious problems alone. Such social support can have a powerful and positive effect on one's health and recovery from oral, head and neck cancer.

Dan Stack, Facilitator of the Dallas, Texas SPOHNC Chapter, is one of several survivors who have chosen the path of supporting others as they begin the journey he travelled nearly 20 years ago. Dan shared these thoughts with SPOHNC about how support was crucial in his journey, and how the Chapter support group he attended was so instrumental in his decision to start a Chapter himself. Dan continues to facilitate his Dallas, TX Chapter, and is a dedicated and active volunteer with SPOHNC's National Survivor Volunteer Network match program as well.

"My very first SPOHNC meeting was in Atlanta, Georgia, in October of 1998. This was the second SPOHNC support group in the country and was a turning point in my recovery. After being told that I would be "back to normal" in four to six weeks after treatment, I was almost two months out from my last treatment and was still taking pain medication to eat solid foods (well, sort of solid...). I instantly realized that these 6 fellow survivors who were looking at me during the meeting knew more about the recovery process than anyone I had spoken to up until that point. They got it, they knew, and I very quickly became very close to my new SPOHNC "family" and looked forward to every month."

A job change moved Dan from Atlanta, to Dallas, Texas in 2000, and some life circumstances and a lack of a SPOHNC Chapter pointed Dan in the obvious direction - start a SPOHNC Chapter in Dallas, Texas and support newly diagnosed patients, just as he was supported by the experiences and knowledge of others when he was first diagnosed and going through treatment.

"We started with 6 survivors and a couple of caregivers attending the first meeting in October, and even though some have moved from the area, we still have four that either attend regularly or stay in touch and visit when they are in town. During the first several meetings, we had the Baylor Chaplain and several other local Oncology Professionals visit our meetings to make sure we were providing a benefit to the patients that they had referred. Referrals from the Oncology community are our lifeblood and will keep a group interacting with new survivors, who are crucial to the longevity of a group.

We quickly grew to a group of 15 to 20 regular attendees and the second Chapter started not long after that at the main Baylor

SUPPORT continued on page 2

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IN THIS ISSUE

Time For Sharing.....4
 The Recipe File.....6
 Chapter Facilitator News.....7
 Head and Neck Cancer News.....8
 Your Cancer Game Plan.....10

SUPPORT continued from page 1

University Hospital, where Jack Mitchell co-chaired that group along with the Chaplain’s group there. Today, we have four active groups in the Dallas Fort Worth, TX area. That was the beginning.

When new survivors visit their first SPOHNC meeting, it is a “life changer.” No matter where in the “battle” cycle they are - pre or post-treatment - it doesn’t matter. The fact that you finally connect with others who have “Walked In Your Shoes” and who are able to help you cope with quality-of-life issues, or just confirm that at some point during the long recovery, you will settle into your “New Normal” is the focus. Some visitors are very appreciative of the support and information they receive and use it to move on with their lives, and others become passionate about helping other survivors and become regular attendees, to be there to help other first time visitors.

The focus of every meeting is to promote awareness of head and neck cancer and provide support to anyone attending, who has gone through treatments or is a caregiver in need of support trying to assist a loved one dealing with the disease. We are there to answer questions and provide information and support to those that are in the “fog” of their cancer battle, and to help each other. After 14 years, I still come away from most meetings learning something new.

The true benefit comes from being able to provide feedback from different perspectives on similar challenges. We all have a lot going on in our lives, but without a doubt, members that are committed to attending as many meetings as their busy lives will allow are what makes a group thrive, because you never know when someone new will walk through the door. If you don’t have the human capital there to provide support, you may miss an opportunity to help those in need, very much like each one of us were helped when we attended our first meeting.”

Caregivers are a vital piece of the puzzle for those going through treatment and beyond. Not everyone has a caregiver, thereby making a SPOHNC Chapter even more important, but for those patients who have someone standing steadily by their side as they reach for tiny new goals each and every day, the caregiver is essential in the recovery process. SPOHNC is grateful to know many loving, selfless and dedicated caregivers, some of whom volunteer for our NSVN Caregiver match program, and some who Co-Facilitate SPOHNC Chapters as well. One such beloved volunteer is Amy Beilman, who facilitates the SPOHNC Palm Coast Northeast, Florida Chapter, alongside her husband, survivor Lewis Beilman. Amy shared her thoughts and her passion for caregiving, facilitating and for SPOHNC.

“My transition from an active retiree to “Nurse Ratchet” happened quickly. I had no time to prepare or study for this role, and this metamorphosis was not an easy one. I literally had flunked candy striper as a Brownie 60 years ago. Luckily, a good friend did some internet research for oral cancer support organizations, and thankfully, she suggested contacting SPOHNC. I did, and was immediately impressed. SPOHNC’s National Survivor Volunteer Network of others who had already been on the journey, was a huge help for both of us as we began the journey. There were no local chapters of SPOHNC within 100 miles of us at that time so we utilized the match program. When I reached out to survivors across the U.S., I found there were people all over who had similar experiences and were willing to share information. Those conversations with others helped us deal with all the unknowns.... like dry mouth, feeding tube questions, sores in the mouth, not being able to lay flat without

SUPPORT continued on page 3

SUPPORT continued from page 2

gagging, the mucous, and on and on. I was so grateful for the help.

I told Lewis that if we came out of this cancer free, we were going to give back by starting a local chapter of SPOHNC right here in Palm Coast. He said, "If and when I get back to normal (the new normal), I'm with you all the way."

One year later, in June of 2012, Lewis was on his way to getting back to "normal". It was a tough year. Lewis had been through quarterly check ups after radiation and chemo, and all showed that he was cancer free. Even though a number of after effects still persisted, we held our first SPOHNC Chapter Support group meeting, in the Clubhouse of the gated community where we live. SPOHNC headquarters on Long Island, in New York had been giving us counsel about how to set it up and what to expect etc. We received SPOHNC materials and guidelines which helped us tremendously.

We thought a lot about how we wanted our Chapter to be, and how it would be most helpful to those who came to us, seeking support. We decided that we wanted it to be a place where it was safe, a place to share information, a place to support one another and a place that gives hope to others.

At every meeting, we ask participants to share where they are on their own journey. They are encouraged to ask questions, and offer their advice to others who have similar issues. Every new participant is called on to share their own story if they are comfortable doing so. What's special about this group is their overwhelming desire to give back to others. They all look forward to our monthly meetings. Our group also welcomes spouses, family members and caregivers in addition to the cancer patient.

We are grateful to SPOHNC for their support and for their dedication to get as much information as possible to anyone who needs information about oral, head and neck cancer. Each and every time a new person contacts us and joins the club that no one really wants to join, we all try to make sure that a new member walks away feeling better. Lewis and I feel so proud to have made a difference in the community and to have the support of SPOHNC who is there for all of us."

SPOHNC's Chapter support groups, and National Survivor Volunteer Network, along with the many print resources offered,

all speak to the importance of support for a community of patients, survivors and caregivers who inspire, share information and provide hope to one another each and every day. Oral, head and neck cancer continues to be among a group of rare cancers, so sharing experiences and first hand knowledge of the disease with other helps to promote awareness among families, friends and even the community as a whole.

April Oral, Head and Neck Cancer Awareness Month is recognized across the United States in many different ways. Its purpose is to raise awareness of oral, head and neck cancer, and promote the message that early diagnosis is critical to more successful treatment of these types of cancers. Awareness Month provides opportunities for individuals, SPOHNC Chapter Support group attendees and their families, as well as healthcare professionals, to participate in events and activities that help to raise awareness of oral, head and neck cancer and its often life altering daily challenges. Participation in local taste events, oral cancer screenings, walks and runs, health fairs and many other unique types of events, have assisted in informing the public about this disease that so many are still unaware of. Education is a powerful tool, and SPOHNC provides education for hope and support.

As SPOHNC Chapters across the United States raise awareness through a variety of events and programs, the importance of supporting this community is paramount to each and every patient diagnosed.

SPOHNC values all of the support received through our volunteers who facilitate and co facilitate and are mentors in our matching program. Your continued dedication has given each patient and their loved ones the promise of a better, brighter future.

Share your inspiring stories to give hope to newly diagnosed patients and those going through treatment, so they can be empowered with the tools they need.

Let's all work together to raise awareness, so no one travels this journey alone.

Editors Note: This article was written by SPOHNC, with contributing authors Dan Stack, and Amy Beilman.

We Want to Hear From You

Have a topic you'd like us to feature? Let us know.

Have you shared your story with SPOHNC? Time For Sharing is always in need of survivor stories to share with our readers.

Chapter News or Survivor News? Special occasion or celebration? We're always looking for good news to share!

Read a great book or found a website that inspired you and helped you on your journey? We'd love to let our readers know.

Out of treatment for a year or more? Become a volunteer for our National Survivor Volunteer Network. Caregiver volunteers are needed too!

No SPOHNC Chapter nearby? Find out how we can help you start one.

Need SPOHNC brochures to share? We'll be glad to send you some.

And finally...just keep in touch. SPOHNC is here to help, listen and learn from you. Call us at 1-800-377-0928, or e-mail us at info@spohnc.org.



*Mallards in Belmont Lake State Park
West Babylon, NY
photo courtesy of Brian McMahon*

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