

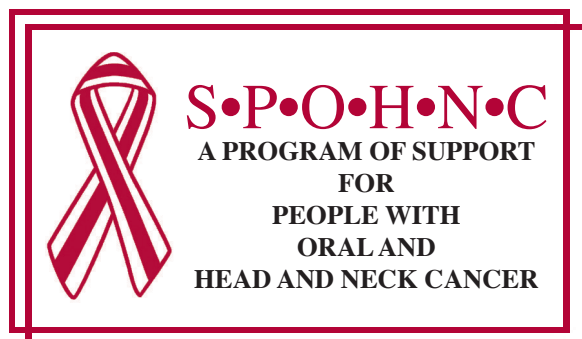
NEWS FROM S•P•O•H•N•C



VOL. 26 NO. 2

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

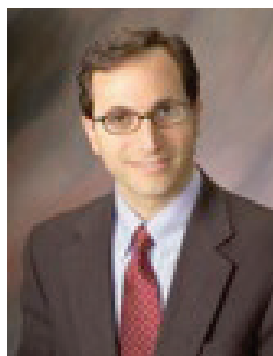
OCTOBER 2016



Why Are Clinical Trials Important?

Robert L. Ferris, MD, PhD

Clinical trials are a key research tool for advancing medical knowledge and patient care. Clinical research is done only if doctors do not know whether a new approach works well in people and is safe and which treatments or strategies work best for certain illnesses or groups of people. In cancer of the head and neck, many clinical trials are available, but new medicines or devices are only FDA approved every 5-10 years, reflecting the difficulty of bringing new treatments to patients and the need for cooperation with patient advocacy groups to move the field faster.



Clinical trials are important for discovering new treatments for cancer (and other diseases) as well as new ways to detect, diagnose, and reduce the chance of developing the disease. Clinical trials can demonstrate to researchers what does and doesn't work using humans that cannot be learned in the laboratory or using animals. Clinical trials also help doctors decide whether the side effects of a new treatment are acceptable when weighed against the potential benefits. Researchers don't know what the results of clinical trials will be. (If they did, they wouldn't have to do the trials!) This uncertainty can make it difficult for a patient to decide whether to participate in a clinical trial. While in rare cases, patient volunteers have been hurt by the treatment or procedure in a clinical trial, millions of people have been helped because other people before them chose to participate in a trial that resulted in a new, more effective treatment.

While clinical trials are important, the choice to participate in one is very personal and depends on your unique situation. When presented with a clinical trial, you and your doctor need to weigh the benefits against the risks and decide what's best for you. According to the American Cancer Society, about 1,000 potential medications are tested before one makes it to clinical trials. On average, new cancer treatments have been studied for at least 6 years (and sometimes many more) before a clinical trial is started. Usually by the time a treatment makes it to the stage of a clinical trial, it has been found to be safe and to have some chance of being effective. In some cases, a treatment is safe and already FDA-approved and standard practice in one disease (like lung cancer), and the clinical trial is simply testing it in another type of cancer (like cancer of the head and neck).

How Clinical Trials Work

If you take part in a clinical trial, you may get tests or treatments in a hospital, clinic, or doctor's office.

In some ways, taking part in a clinical trial is different from having regular care from your own doctor. For example, you may have more tests and medical examinations than you would otherwise.

The purpose of clinical trials is research, so the studies follow strict scientific standards. These standards protect patients and help to produce reliable study results.

Clinical Trial Protocol

Each clinical trial has a master plan called a protocol, which explains how the trial will work. The trial is led by a principal investigator (PI), who usually is a doctor. The PI prepares the protocol for the clinical trial.

The protocol outlines what will be done during the clinical trial and why. Each medical center that does the study uses the same protocol, which is reviewed and approved by various committees, whose job it is to ensure patient protections, and some potential of learning new information or benefitting patients who have the disease.

Key information in a protocol includes, how many patients will take part in the clinical trial, who is eligible to take part in the clinical trial; what tests patients will get and how often they will get them; what type of data will be collected during the clinical trial; and detailed information about the treatment plan.

The researchers doing clinical trials take steps to avoid bias. "Bias" means that human choices or other factors not related to the protocol affect the trial's results.

Comparison Groups

In most clinical trials, researchers use comparison groups. This means that the patients taking part in a trial are assigned to one

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Chris Leonardis

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of two or more similar groups. Each group will receive different medical strategies.

For example, one group may get the current standard treatment for a condition, while another group gets a new treatment. Researchers can then compare the results to see whether one group has better outcomes than the other.

Using comparison groups also ensures that no one in a study is left without treatment for the sake of research. Sometimes, when no accepted standard treatment exists for a condition, people in one group may receive a placebo (inactive pill that looks like the test product). You'll be told if a placebo will be used in a study before you agree to take part.

Randomization

Some clinical trials that have comparison groups use randomization. This involves assigning patients to different comparison groups by chance, rather than choice. This method helps to ensure that any differences observed during a trial are due to the different strategies being used, not to preexisting differences between the patients. Usually, a computer program makes the group assignments.

Possible Benefits and Risks of Clinical Trials

Taking part in a clinical trial can have many benefits. For example, you may gain access to new treatments before they're widely available. If a new treatment is proven to work and you're in the group getting it, you might be among the first to benefit. If you're in a clinical trial and don't get the new strategy being tested, you may receive the current standard care for your condition. This treatment might be as good as, or better than, the new approach. You also will have the support of a team of health care providers, who will likely monitor your health closely.

In late-phase clinical trials, possible benefits or risks of a treatment can be identified earlier than they would be in general medical practice. This is because late-phase trials have large groups of similar patients taking the same treatment the same way. These patients are closely watched by Data and Safety Monitoring Boards. Even if you don't directly benefit from the results of the clinical trial you take part in, the information gathered can help others and add to scientific knowledge. People who take part in clinical trials are vital to the process of improving medical care. Many people volunteer because they want to help others.

Clinical trials do have risks and some downsides, such as the following...

The new strategies and treatments being studied aren't always better than current standard care. Even if a new approach benefits some participants, it may not work for you. A new treatment may have side effects or risks that doctors don't know about or expect. This is especially true during phase I and phase II clinical trials. The risk of side effects might be even greater for trials with cutting-edge approaches, such as gene therapy or new biological treatments. Health insurance and health care providers don't always cover all patient care costs for clinical trials. If you're thinking about taking part in a clinical trial, find out ahead of time about costs and coverage. You should learn about the risks and benefits of any

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CLINICAL TRIALS continued from page 2

clinical trial before you agree to take part in the trial. Talk with your doctor about specific trials you're interested in.

Scientific Oversight

Institutional Review Board

Institutional review boards (IRBs) help to provide scientific oversight for clinical trials. An IRB is an independent committee created by the institution that sponsors a clinical trial. IRB members are doctors, statisticians, and community members.

The IRB's purpose is to ensure that clinical trials are ethical and that the participants' rights are protected. The IRB reviews the trial's protocol before the study begins.

An IRB will only approve research that deals with medically important questions in a scientific and responsible way. The IRB also checks on results during the trial. All U.S. clinical trials are required to have an IRB.

Office for Human Research Protections

The U.S. Department of Health and Human Services' (HHS') Office for Human Research Protections (OHRP) oversees all research done or supported by HHS. The OHRP helps protect the rights, welfare, and well-being of research participants. They provide guidance and oversight to the IRBs, develop educational programs and materials, and offer advice on research-related issues.

Data Safety Monitoring Board

Every National Institutes of Health (NIH) phase III clinical trial is required to have a Data and Safety Monitoring Board (DSMB). This board consists of a group of research and study topic experts. The NIH also requires DSMBs for large trials comparing alternative strategies for diagnosis or treatment. In addition, the NIH requires DSMBs for some earlier phase trials that involve high-risk procedures (such as gene therapy) or vulnerable patients (such as children).

A DSMB's role is to review data from a clinical trial for safety problems or differences in results among different groups. The DSMB also reviews research results from other relevant studies. These results may reveal unknown patient risks, or they may even answer the NIH study's

research question. Scientific oversight informs decisions about a trial while it's under way. For example, some trials are stopped early if benefits from a strategy or treatment are obvious. That way, wider access to the new strategy can occur sooner. Sponsors also may stop a trial, or part of a trial, early if the strategy or treatment is having harmful effects.

Food and Drug Administration

In the United States, the Food and Drug Administration (FDA) provides oversight for clinical trials that are testing new medicines or medical devices. The FDA reviews applications for new medicines and devices before any testing on humans is done. They check to make sure that the proposed studies have proper informed consent (see below) and protection for human subjects.

The FDA also provides oversight and guidance at various stages throughout the studies. For example, before large-scale phase III trials begin, the FDA provides input on how these studies should be done.

Patient Rights

Informed Consent

Informed consent is the process of giving those who participate in a clinical trial all of the facts about the trial. This happens before they agree to take part and during the course of the trial. Informed consent includes details about the treatments and tests that they must receive and the benefits and risks they may have.

Before you decide whether to enroll in a clinical trial, a doctor or nurse will give you an informed consent form that presents the key facts of the study. If you agree to take part in the trial, you'll be asked to sign the form.

You can and should ask questions about the trial to make sure you understand what's involved. Here are some questions to ask before enrolling in a clinical trial:

- *What is the purpose of the study?*
- *Who is sponsoring the study, and who has reviewed and approved it?*
- *What kinds of tests, medicines, surgery, or devices are involved? Are any procedures painful?*
- *What are the possible risks, side effects, and benefits of taking part in the study?*

- *How might this trial affect my daily life? Will I have to be in the hospital?*
- *How long will the trial last?*
- *Who will pay for the tests and treatments I receive?*
- *Will I be reimbursed for other expenses (for example, travel and child care)?*
- *Who will be in charge of my care?*
- *What will happen after the trial?*

The informed consent document is not a contract. You have the right to withdraw from a study at any time, for any reason. Also, during the trial, you have the right to learn about new risks or findings that emerge. If researchers learn that a treatment harms you, you'll be removed from the study. Taking part in a clinical trial is your decision. Talk with your doctor about all of your treatment options. Together, you can make the best choice for you.

Editors Note: Robert L. Ferris, MD, PhD is currently the UPMC Endowed Professor, Vice-Chair and Chief of Head and Neck Surgery, and Fellowship Director in Head and Neck Oncologic Surgery. At the University of Pittsburgh Cancer Institute, he is Co-Leader of the Cancer Immunology Program and Associate Director for Translational Research. Dr. Ferris serves on the Editorial Boards of JNCI, Clinical Cancer Research, Cancer Immunology Research and Section Editor for Cancer, and Head and Neck. He is Editor in Chief of Oral Oncology (the highest impact factor journal dedicated to Head and Neck Oncology). Dr. Ferris has published over 250 peer-reviewed manuscripts and was elected co-chair of the NCI Head and Neck Steering committee to facilitate prospective clinical trials.

Dr. Ferris' NIH-funded laboratory is focused on reversal of immune escape and immunotherapy using monoclonal antibodies and cellular vaccines. Dr. Ferris is leading several prospective randomized trials, including ECOG 3311, testing radiation dose-reduction after transoral robotic surgery (TORS) for HPV+ oropharynx cancer, and several randomized phase II-III trials of anti-PD-1 and anti-CTLA-4 immunotherapy. Dr. Ferris co-led the first positive phase III randomized trial of anti-PD-1 immunotherapy (nivolumab) in head and neck cancer, contributing to FDA approval of this class of therapies. He is Principal Investigator of the University of Pittsburgh Specialized Program of Research Excellence (SPORE) grant for translational head and neck research, and a T32 training grant, "Training of Head and Neck Oncologists," both funded by the National Cancer Institute until 2020. Dr. Ferris has authored numerous book chapters and helped co-edit two textbooks with Dr. Eugene N. Myers, MD, Salivary Gland Disorders and Master Techniques in Head and Neck Surgery.

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Nancy Leupold - 25 Years of SPOHNC

In her own words... "I am one of those survivors who was looking for support more than 25 years ago. When I began searching for information following my diagnosis, I found there was very little literature to be had. I was discouraged, frustrated and angry. Even though my family and friends were supportive, I felt very much alone with little information to encourage me. I needed to speak with someone who "had walked in my shoes."

Until 1991, there were few support groups specifically for oral and head and neck cancer patients in the U.S. Survivors found that coping with oral and head and neck cancer could be extremely difficult. Many patients had to endure alterations in facial appearance and dental problems. Speech, sight, smell, chewing, swallowing and taste could be affected. Survivors and their families needed a support group in which they could share their experiences and problems and help one another.

In 1991, with the encouragement of David P. Wolk, MD a head and neck surgeon and James J. Sciubba, DMD, PhD, Director of Dental Care at Long Island Jewish Medical Center on Long Island, NY, I founded Support for People with Oral and Head and Neck Cancer, Inc. (SPOHNC).

SPOHNC has come a long way from our first meeting, attended by 9 people at LIJ in September 1990 to more than 130 chapters throughout the United States. SPOHNC has now helped more than 16,000 people during the past 25 years. I have personally visited many of our chapters including those in Arizona, California, Florida, Maryland, Massachusetts, New Jersey, New York, New Jersey, Ohio, Pennsylvania, Texas, and Virginia.

From an upstairs room in my home in Locust Valley, where I developed a very simple newsletter on an old MAC, donated by my dentist, I later

moved into a two and a half room office converted from my garage, until more than ten years later when I found a three room office in a building in Locust Valley, which was ideal for SPOHNC. This has been the official SPOHNC office since then, and now has 3 employees and the necessary equipment to run an efficient office. Our newsletter became 12 pages of information about head and neck cancer, and I began to develop several books about head and neck cancer and cookbooks for patients with special nutritional needs.

Many years have passed since I was diagnosed with oral cancer and felt the need to organize a support group. Support groups have done wonders for so many people with many different diseases, and I am so happy that I was part of that movement for head and neck cancer patients."

After 25 years of service to SPOHNC, giving of herself, her time and her knowledge and resources, Nancy has decided that the time has come for her to enjoy her leisure, her family and her beloved cat, Cinnamon. SPOHNC's Board of Directors, staff and members are joining together to wish her well. She brought the organization to its 25th year, and will now enjoy the journey of retirement, and the next exciting chapter in her life.

Nancy has given selflessly since the end of her treatment for oral cancer, creating Support for People with Oral and Head and Neck Cancer, and its programs and services of support. In addition to our Chapter Support groups, SPOHNC's National Survivor Volunteer Network match program, many books and print resources and monthly newsletter, "News from SPOHNC," were all created under the loving care and supervision of Nancy.

SPOHNC Board Vice President James J. Sciubba, shared these sentiments with Nancy..."The plaudits from far and wide are all appropriate, sincere and

genuine. The numerous awards received over the years are also reflective of the achievements and effectiveness of your efforts over these many years that we have been together in and for a common cause. You have taught me a great deal in terms of perseverance, dogged determination, strong will and attitude and not settling when it comes to what you believe in. It has been my honor and pleasure to have served as your VP over the many years, with my pledge to maintain my efforts and help preserve what you have worked so hard for over the years."

Heartfelt words from SPOHNC's Executive Director, Mary Ann Caputo..."It was November, 2004, 12 years ago, when I first met Nancy Leupold, Survivor, President & Founder of SPOHNC. When I accepted a position within the organization, it was truly an honor to work alongside a woman of such amazing inspiration and stature. Once I began my career at SPOHNC, Nancy immediately became my mentor.

I had never worked with such a driven, caring individual. It was a delight to come to work and be in the company of one woman who had accomplished so much after her diagnosis of oral, head and neck cancer. She exemplified a work ethic and dedication that I had never seen before. She, being a survivor of cancer, knew what she needed to achieve in order to help others who would be going through a similar journey with this type of cancer.

Every phone call, every program and every project would contain a high level of excitement that exuded from her and the team at SPOHNC. Each day each of us would leave the office with a feeling of accomplishment that even if we helped just one person it was making a difference in a person's life to be able to know SPOHNC was there for them, and we still are after 25 years. Nancy challenged the entire community to support and grow our commitment in order to ensure the future of SPOHNC. She is revered in this community for her dedication and many years of service and all that she was able to do throughout her 25 years. She will continue to

NANCY LEUPOLD continued on page 5



NANCY LEUPOLD continued from page 4



contribute her valuable ideas and concepts to the organization. However, we will miss her daily phone calls, which would always make her mark here ever present.

Nancy - your invaluable service and your community presence will continue to excel at SPOHNC for its eternity. Thank you for all your hard work, leadership and the support you have given to each one of us here at SPOHNC and to the entire community of patients, physicians and healthcare professionals who are involved in their care. Your mentorship and guidance will be with me throughout, and each day it is my honor to support a patient who is diagnosed with this disease.

All of us here at SPOHNC wish you all the very best in your retirement and thank you for giving each one of us the opportunity to be part of your team helping and supporting patients."

Anyone who knows Nancy, knows that she is dedicated, driven, and puts her heart and soul into all that she does. One look at all of SPOHNC's resources and publications, and the awards and accolades she has received during the past 25 years, will confirm the power of one very special woman.

Janet Fried, a dear friend of SPOHNC, has known Nancy for many years. Janet's history with the organization began in 1992, when she cared for Nancy's mother, Hannah. She became close with the SPOHNC family, as she watched Nancy begin her quest to offer hope to oral, head and neck cancer patients who, like herself, yearned for support along their cancer journey. In 2002, Janet began her work with SPOHNC as our official newsletter mailing maven. 8 times per year, since 2002, Janet has visited the SPOHNC office to take great care of mailing "News from SPOHNC" to our subscribers. A few staff members at SPOHNC have changed over the years, but



Janet's presence has remained, steadfast.

Janet had these endearing words to say about her good friend, Nancy... "Whatever Nancy did, she would research and investigate and find out as much information as she could, to make sure that whatever she did would be done right. She is one of the most dedicated people I have ever met, and she poured her heart and soul into SPOHNC. She is truly just very special."

SPOHNC's Chapter Facilitators are a huge component in the success of SPOHNC and its Chapter Support groups, which continue to grow each year. SPOHNC's Chapters are the cornerstone of the organization, crucial to the foundation of SPOHNC. Nancy led by example, as the very first SPOHNC Chapter Facilitator, understanding the need for support.

When the word of Nancy's retirement was announced, our Chapter Facilitators and support group attendees showered her with their gratitude and appreciation for all that she has done. Here, we share just some of the many kind words and sentiments received from these very special people. The gratitude expressed is truly overwhelming.

From SPOHNC Dallas at Baylor TX Chapter Facilitator, Chaplain Alan Wright... "SPOHNC Dallas at Baylor University Medical Center is so grateful for your commitment to oral, head and neck cancer survivors - even those way down here in Texas. As facilitator of this group for the past 8 years, I can honestly say you can be proud of the many people that have been helped physically, emotionally

and spiritually by this group that wouldn't have been possible without SPOHNC."

From SPOHNC Minneapolis, MN Chapter Facilitator, Chuck Bartlett... "Your efforts to help other Head and Neck Cancer patients and survivors through the very difficult process of living with this disease was an inspiration to me. That's why I became involved with the Minneapolis chapter and have been a Co-Facilitator for all of its ten years."

From SPOHNC Hershey, PA Chapter Facilitator, Patrice Saurman... "Thank you so much, Nancy, for all you have done, so that we are able to reach out to others who so desperately need support. You have made

a huge difference in the experience of our patients, families, and caregivers, those who are currently in treatment as well as long time survivors."

Survivors and their families, who sought out support through a SPOHNC Chapter, or through our National Survivor Volunteer Network matching program, have seen the value of connecting with others who have travelled a similar journey. To join in a conversation at a meeting, or to speak by phone with someone who has "walked in your shoes" creates a connection like no other. Deep and lasting friendships have developed, where they might not ever have before, and the bonds that are forged by sharing



challenges, questions and inspiration, bring hope to newly diagnosed patients and their families.

From SPOHNC Stony Brook, NY Chapter Attendee and NSVN Volunteer Jim V. ... "Thank you

so very much for all you have done. I too, am a survivor and the support of SPOHNC and people like you helped that to happen."

SPOHNC Syosset, NY Chapter attendees Bill & Ann W. ... "Over the past 13 years, SPOHNC has been an anchor in lives. We are deeply grateful for the organization that you started. Thank you SO much."

The words, stories shared and sentiments expressed are a testament to the incredible devotion shown by a woman who was determined to make a difference in the world. SPOHNC is the only organization of its kind, and it is so, because Nancy saw a need, and worked tirelessly for 25 years, to meet that need, and to be there for those who are seeking hope, when faced with a diagnosis of oral, head and neck cancer. Nancy gave of herself, to bring SPOHNC to life. Her vision to create the organization, 25 years ago, and her drive to make it a success, has brought SPOHNC to where it is today.

Editors Note: It has been, and continues to be, my honor and pleasure to be an integral part of such an amazing organization. When I began at SPOHNC, nearly 6 years ago, little did I know the difference I would be making in the lives of those who reach out to us every day. I also was unaware of how much there was to learn, about oral, head and neck cancer,

NANCY LEUPOLD continued on page 6

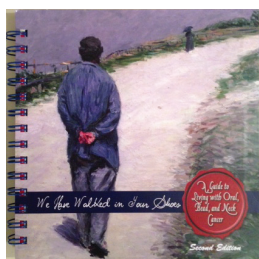
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NANCY LEUPOLD continued from page 5

SPOHNC's resources and about putting together a 12 page newsletter 8 times a year. Nancy patiently wore her teaching hat for several months as she took me under her wing, and taught me to become the Editor of this newsletter. Learning a new publishing program has been challenging, sometimes frustrating, and exciting, all at the same time. Nancy's skill and expert eye have always been crucial to the success of the newsletter. I will always remember the day she told me "You are the Editor now. My name should not be there." Thank you Nancy, for your patience, and for sharing your knowledge with me. I hope you continue to enjoy reading the newsletter each month, secure in the knowledge that you taught me very well.



We Have Walked in Your Shoes Takes a Journey



As many of you know, *through the generosity of Lilly Oncology, SPOHNC's newly updated book – We Have Walked In Your Shoes – A Guide To Living With Oral and Head and Neck Cancer – Second Edition, has made its way across the United States and into the hands of the Facilitators of nearly 130 SPOHNC Chapters.*

These books will be shared with newly diagnosed patients across the country as they begin their cancer journey and seek information, comfort and hope.

SPOHNC is very pleased with this recent collaboration, and it seems that our Chapter Facilitators are thrilled as well. Here are a few notes, e-mails and comments we received. Thanks for sharing your joy!

"How very nice! Look forward to getting these valuable books to share with our patients. Thanks!" – Sharon Tavener – Dallas, TX – UT Southwestern

"I am so excited to receive these books!" – Kathleen Crowley, LCSW, OSW-C – Morristown, NJ

Send Us Your Selfies!

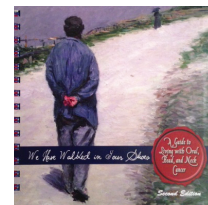
In December 2014, "News from SPOHNC" had a very special feature, celebrating survivorship. SPOHNC's "Family of Faces" was such a success, that we've decided to do an encore!

We will do a new "Family of Faces" feature in the December issue of "News from SPOHNC."

If you participated in our last "Family of Faces" feature, please send us a new photo. If you've never been a part of our Family of Faces, send us your photos today! In order to be included in the feature, photos must be received by no later than November 11th.

Send your selfies to c.leonardis@sphnc.org. We look forward to celebrating survivorship this holiday season through our December "Family of Faces."

We Have Walked In Your Shoes: A Guide to Living With Oral, Head and Neck Cancer Second Edition



- Contains the basics about the symptoms and diagnosis of head and neck cancer, types of treatment and common side effects.
- Offers a section to list your healthcare team, a personal calendar and journal, diet and nutrition information, and a list of resources.
- Beautifully illustrated with impressionistic paintings of the 1800's.

\$14.95 includes shipping and handling.

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50+ books \$12.50/book
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For bulk orders please call
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or email us at info@sphnc.org

"Wow, wow, wow! Looking forward to being able to hand them out to new patients." - Valerie Targia – San Diego, CA

"We will send a note to Lilly Oncology for donating the books! We are very thankful for the SPOHNC organization and for the books." – Chuck Bartlett – Minneapolis, MN

"We are delighted to receive the shipment of SPOHNC's We Have Walked In Your Shoes and look forward to sharing them with those we serve who are facing a diagnosis of oral, head, and neck cancer." – Betsy Booth – Baylor – Plano, TX

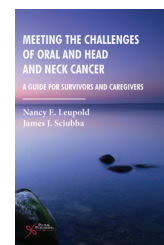
"Thank you soooooo much. I cannot wait to receive these books – They are amazing! Thank You!" – Becky Kopke, RN, BSN, OCN - Long Branch, NJ

"This is great news. We have a supply that we purchased but will make an effort to get them out to ALL patients now." – Gwen Paull – Cleveland, OH

"THANK YOU!!! – We have two new Comprehensive Cancer Centers, and several new Treatment Centers, all with reading rooms or information/library areas where these will be placed. As well, they will be available at meetings for newly diagnosed patients." - Hank Deneski – Dayton, OH

Meeting the Challenges of Oral and Head and Neck Cancer A Guide for Survivors and Caregivers - Second Edition

\$27.00 includes shipping and handling



Place your order today at
www.sphnc.org or
call 1-800-377-0928

Visit the SPOHNC website at www.sphnc.org

Defeating Cancer: It's A Team Effort

I'm Jim Kelly, Football Hall of Famer, and back in 2013, I was diagnosed with head and neck squamous cell cancer. It was really scary. I'm not afraid to share that I walked out of that doctor's office and cried, not for me, but for my family that had already lost my son to a rare disease.

Playing professional football was challenging, but fighting head and neck cancer was harder. My physical and emotional strength was tested every day. I was really blessed, though; I had my wife, my two daughters, and my five brothers who provided support and encouragement to get me through the radiation and chemotherapy treatments. But, I know that some people aren't so fortunate.

For 25 years, SPOHNC (Support for People with Oral and Head and Neck Cancer) has helped people by raising awareness and meeting the needs of oral and head and neck cancer patients through its resources and publications. I'm proud to partner with SPOHNC, Merck, the Head

and Neck Cancer Alliance, and Savor Health to launch *Your Cancer Game Plan*. This program will provide people living with head and neck cancer and their caregivers with tools and resources designed to help each patient stay positive and hopeful.

To kick off the program, we're encouraging people living with cancer, caregivers, and the head and neck cancer community to join me and my partners on *Your Cancer Game Plan* for a webinar or 'live' online chat to share my story, and talk about nutrition, emotion and communication when dealing with a cancer diagnosis. The webinar will be on Wednesday, October 19, 2016 between 11am-12 noon EST.



For additional details and to register for the webinar, please visit www.spohnc.org. *Your Cancer Game Plan* is sponsored by Merck Sharp & Dohme Corp., a subsidiary of Merck & Co., Inc., Kenilworth, NJ, USA.

*Please join us for
Your Cancer Game Plan
Webinar
Featuring Pro Football
Hall of Famer
Jim Kelly*

*Wednesday, Oct. 19, 2016
11am - 12pm EST*

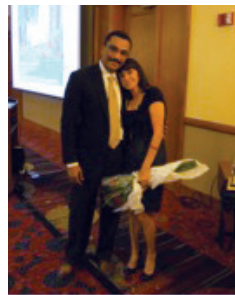
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Time For Sharing...“Stay Positive! Be Strong!”

At the age of 48, divorced and a single parent of two children, with a son and a daughter, it all began. One day late in June of 2008, I broke a tooth and went to my dentist. After my exam, he told me I needed “dental work” such as implants, root canals and crowns, which would have cost around \$13,000. Being a single parent, without any financial support, this was not something I could afford, so I let it go. After 3 months, while at work one day, another tooth broke. This time, my mouth began to bleed. My boss came into my office and saw that I was in discomfort. Knowing my situation about the dental costs, she called her dentist and I went to his office that very same day. He looked in my mouth and immediately said “I can't help you because you have something going on inside which I don't have a clue as to what it is.” He sent me to an oral maxillofacial dentist that same day. The doctor took one look and said, “You have a growth that appears to be a tumor.” He took a biopsy and did a 3D CAT scan. He requested a rush for the biopsy results. Within 5 days I was given the news that nobody ever want to hear...I had stage IV cancer, more specifically, squamous cell carcinoma! He called his friend, a world-

renowned oral maxillofacial surgeon at UF Shands in Jacksonville, FL.

I met with the doctor that week and he ordered several other scans. After all of the tests were completed, he told me I had two options: One – leave it alone and have about 3-4 months left to live or two – have a radical free flap surgery, which consisted of cutting my neck/throat from my right ear straight up the middle of my lip, nose and face, removing all of my right cheekbone, jaw bone, teeth, sinus and 23 lymph nodes, taking the fibula bone, muscle tissue and vein from my right leg, several skin grafts from my thigh, 5 days in a medically induced coma, tracheotomy and a feeding tube. Then after surgery I had a minimal chance of waking up. Once the recovery process began, I would start chemotherapy and radiation therapy. I was labeled as an “unsalvageable” case. The odds were stacked against me but giving up was NOT an option. I had to fight for my two children. They needed me and I was not going down without a fight.



I don't know how I drove the 3-hour drive home that day! I didn't feel bad for myself. I felt sad and angry because I knew I had to tell my son and my daughter! I didn't know how to tell them and I knew this was going to devastate them.

Seven years and over 20 surgeries later, I am here and cancer free and still undergoing reconstructive surgeries. It's been a hard, long, painful battle. I fight every day with a POSITIVE attitude because I refuse to let this awful disease win. My children are my rock and inspiration! If not for them and my wonderful friends, I honestly don't know how I would have managed.

My passion is to help spread the word, making awareness of this type of cancer and help others who can't help themselves. I can relate to their struggles, from losing what is a normal life, to losing my health insurance, to sacrificing every part of me and my body, in hopes to see my children another day! I am thankful for every day that I wake up and I'm here!

*~ Denise Matteo
dfm1620@yahoo.com*

Become a Member! Renew Your Membership! Gain These Benefits!

Right now, you're probably thinking... "but I am a member! I get this newsletter a couple of times a year." Or maybe you're saying to yourself... "Oh, I'm already a member because I go to a SPOHNC Chapter support group."

Did you know that you're receiving this October issue of "News from SPOHNC" because you're part of a family of people that has been helped by SPOHNC?

If you have ever called us, e-mailed us or have ever been touched by SPOHNC in any way, we like to thank you, by sending you the October issue of "News from SPOHNC." In fact, you receive another one with our compliments, in April.

SPOHNC members, who pay \$30 per year, are already receiving the benefits listed here. If you haven't paid your membership fee, please consider doing so, and gain the "**MEMBERS ONLY**" benefits offered just for you. If you're not already a member, you're missing out on some great resources that have been designed

with care, to help you. SPOHNC wants to provide you with all that you need. We are here to support you!

- **NEW!!** Are you still dealing with side effects from your treatment? SPOHNC's 32 page **PRODUCT**



MEMBER BENEFITS!


DIRECTORY is here! Full of product suggestions and how they can help you, the book also tells you where to find them. This book is a must for anyone who is seeking relief.

- "**News from SPOHNC**" Feature articles written by distinguished healthcare professionals, sharing stories written by survivors, current head and neck cancer

news, survivor and chapter human interest stories and more. Receive 8 issues per year.

- **Access to** SPOHNC's nearly 130 Chapter **Support** groups.
- **Access to** SPOHNC's National Survivor Volunteer Network of more than 225 survivor and caregiver volunteers, ready and willing to serve as a **mentor** to a newly diagnosed patient or caregiver.
- Opportunity to **connect with patients and survivors**. Contact SPOHNC to find out how.
- **Insider information** about special programs and resources. You will be the first to know.
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What Matters Is How We Live and Love - A Memorial Tribute to Micki Naimoli

In September, SPOHNC's Philadelphia, PA Chapter Support group had planned to celebrate 15 years of support and encouragement. There were big plans for special surprises at the September meeting.

With deep sadness, the September SPOHNC Philly Chapter support group meeting became something very different, and very unexpected...it became a memorial celebration of the life of longtime Chapter Facilitator, Micki Naimoli.

The shocking news of the sudden passing of such a ray of sunshine and hope in the community had everyone in the SPOHNC family in utter disbelief. The woman who always displayed such spunk and a zest for life, had been taken from the world, and from her husband, Ben, who is the other half of her heart...way too soon. When SPOHNC received the call from Ben, there were no words...

Micki Naimoli, described as "small, but mighty," "joyful, kind and amazing," was such an inspiration to everyone who knew her. Her loving husband and partner for life, Ben, shocked and dismayed at the loss of his beautiful Micki, spoke to Mary Ann Caputo, Executive Director of SPOHNC, and had these words to say... "Micki was the 90 pound woman who was the light at the end of the tunnel for so many. Her attitude was so strong, even with all of the maladies that were a part of her life. Out of 150 SPOHNC Chapter support group meetings, maybe Micki missed 5?" At their home, following the funeral service for Micki, Ben shared with us the story of how Micki had planned a special surprise for the 15th Anniversary meeting. She had placed an order for several pounds of M & M's and had the SPOHNC logo imprinted on them. She was going to put them in little bags and hand them out to everyone in attendance at the meeting. Ben told us she was "so excited for such a small gesture. It was a big thing to her." In fact, Ben said, "It was the little things

that would keep us together, like coffee in the morning, or even spending time with our beloved cat, Teddy." Ben said that "the little things became the big things."

SPOHNC's Executive Director, Mary Ann Caputo, and SPOHNC's Outreach Administrator/Newsletter Editor, Chris Leonardis, attended the services for Micki, held in Moorestown, NJ. The day was a flurry of emotions for everyone, as loved ones, friends and doctors spoke about Micki and her bright spirit. Ben spoke so eloquently of Micki, and of the beautiful life that they shared together.

At the luncheon following services, we were honored to be seated at a table with Micki's hairdresser, her wonderful neighbors and several of her very close friends. Stories of Micki, and Micki and Ben were lovingly told, and even some laughter was shared, as thoughts of Micki brought smiles to our faces. We were sad to no longer have her with us, yet each of us was blessed to have known such an amazing woman.

Upon visiting their home, Micki's love of animals (especially teddy bears), and art, were very apparent. The love that she and Ben shared was also very visible, through the many framed photographs carefully placed throughout their beautiful home.

Micki had a great energy, and a smile and a brightness about her that was so special – so unique. She was indeed a very special lady, to so many. SPOHNC Chapter Co-Facilitator, Tracy Lautenbach, shared words with SPOHNC, about the September 14th group meeting.

"The September 14th group was very special. It was a beautiful tribute to Micki. Ben brought in framed pictures of he and Micki and placed them all around the room. I had flowers and a framed copy of the Poem "The Dash" (read at Micki's funeral) which he read aloud.

Ben invited neighbors and good friends of he and Micki. There were also support group members there - regular members and those we have not seen in a while - all who wanted to remember Micki and how she

touched their lives. The two dietitians that work with the Head and Neck Cancer group were also in attendance. Ben read several letters that people had sent him regarding Micki. Dr. Joe Carver stood beside him as he read these aloud to the group. Following that people remarked one at a time about how Micki impacted them.

Dr. Ara Chalian was there and addressed the crowd. To close our meeting/service, Kava (the Hospital Oncology Chaplain), who has often been a presenter at our group and knows the members, did a blessing, bringing in thoughts from a neighborhood newsletter article written about Micki. It was all very touching."

Micki's Chapter Support group attendees and friends shared these thoughts with SPOHNC, about their dear friend Micki...

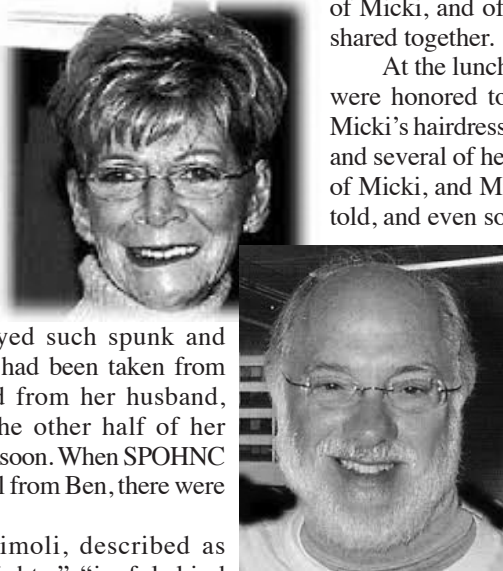
"Micki was an inspiration to me. At the time I first met her, I was still in shock with the realization that I could no longer eat. Micki's acceptance and peace with her condition helped me begin to find acceptance and peace with my future. She gave me something to aspire to, she was very brave. God bless you Micki, and thank you."

~ Gary D.

"Marvelous Micki. Never at a loss for words and always able to verbalize her opinions in no uncertain terms, she was the spark plug of our Chapter. Without being dramatic she caused us all to remember the importance of providing service to others.

Micki's diligent work in establishing, single handedly, the support group for head and neck cancer patients at the University of Pennsylvania, was a spectacular challenge. When I think of the hundreds of patients that were helped because of this little fragile lady who had the determination to establish a badly needed support group at this fine institution. Her comments during the meetings often improved the lives of those going through the terrible side effects of surgery and radiation therapy. Despite her discomforts and limitations in eating and drinking she never, never, never complained about her personal difficulties. In my mind that is the quality of a true hero.

Her determination in the last few years to overcome numerous medical crises, which often were truly life threatening, was beyond belief. Few people could tolerate MICKI NAIMOLI continued on page 10



MICKI NAIMOLI continued from page 9

such medical challenges and not have a psychological breakdown. Not our Micki! She seemed to get stronger with each malady that arose. Her determination to recover and return to her daily routine was inspiring. What a special human being.

There are a few people that anyone will meet in their lifetime who will convey all the human qualities that Micki radiated with her warm personality and genuine smile. Micki brightened the day of everyone who came to know her and was in her presence. I speak for our entire group that we have had a tremendous loss to our organization. We shall all miss her beaming smile and warm hug. We have lost a national treasure.”

~ Phil LoPresti, MD

“I am so very grateful for Micki and Ben having started the Head and Neck Group fifteen years ago. It has been crucial to my treatment. Knowing Micki has been a blessing in my life. We will miss her smile and her humor.”

~ Vince G.

“She was a very inspiring person to me personally and many others I am sure. What a wonderful asset to our small but strong community of patients and caregivers.”

~ Meredith Pauly, MA CCC-SLP

“I met Micki Naimoli and her husband, Ben, about a year after surgery had saved my life, but at the same time, changed it forever. A therapist mentioned that a support group had just formed and it might help me transition. The transition would be from person I was before surgery, to the survivor I had become, learning to speak and eat again.

The group is where I met Micki and Ben. Micki became my role model. She loved life, and never let a challenge get in the way of something she wanted to do. Ben was a caregiver to the whole “Group.” Together they helped me look ahead to what

I could still do and enjoy, and not feel sorry for myself for the fact that I would have to do it differently. They helped me realize I was still me.” ~ David C.

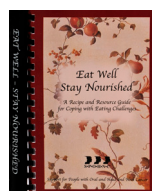
SPOHNC was deeply saddened to share the news of the passing of Micki Naimoli. Our hearts are broken as we share the memories of such a beautiful soul. She was one of the most amazing women we have ever known, and she will remain in our hearts and in our prayers forever. She was a woman who surely did great things with “the dash between her years.”



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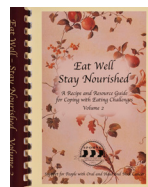
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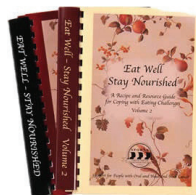
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