NEWS FROM S•P•O•H•N•C

VOL. 24 NO. 7 SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER, INC. APRIL 2015

S•P•O•H•N•C
A PROGRAM OF SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER

HPV Vaccine and Oropharyngeal Cancer

Carole Fakhry, MD

Oropharyngeal squamous cell cancer is a unique subset of head and neck squamous cell cancers. Most head and neck cancers, with the exception of oropharyngeal squamous cell cancers (referred to as oropharyngeal cancer hereafter), are caused by tobacco and alcohol and other less common exposures. However, in the past decade a new entity of head and neck cancer, HPV-related oropharyngeal cancer has emerged. Human papillomavirus (HPV), the same virus that is responsible for the vast majority of cervical cancers is also responsible for the development of a growing subset of oropharyngeal malignancies in the United States and around the world. A recent study showed that oropharyngeal cancers are increasing in "developed countries", predominantly among men and younger individuals. HPV-related oropharyngeal malignancies differ from HPV-unrelated oropharyngeal malignancies in terms of risk factors, clinical presentation, prognosis and prevention.

Risk factors for oropharyngeal cancer

Risk factors for HPV-related oropharyngeal cancer and HPV-unrelated oropharyngeal cancer are distinct. Sex is the most important behavioral risk factor for HPV- oropharyngeal cancer. By contrast, tobacco is the most common risk factor for HPV-unrelated oropharyngeal cancer. There are several measures of exposure to HPV infection. These include number of lifetime oral sexual partners, lifetime number of any sexual partners and history of herpes simplex-2 virus, among other measures of sexual exposure. Additionally, marijuana appears to be associated with HPV- oropharyngeal cancer. The distinct risk factors reinforce that HPV- oropharyngeal cancer and HPV-unrelated oropharyngeal cancer are two distinct entities.

Risk factors for oral HPV infection

Oral HPV infection has been shown to be the dominant risk factor for HPV- oropharyngeal cancer. Oral sex is associated with the presence of oral HPV infection. Oral HPV infection is more commonly found in men and has two age peaks, an earlier peak in 30s and later one in 50s. Oral HPV infection is also more commonly found among whites as compared to non-whites. Of note, initial studies are showing that specific HPV infections in an individual can also be found in the anogenital tract of a sexual partner. However, early natural history studies (i.e. studies of oral HPV infections over time) have shown that the vast majority of oral HPV infections clear (i.e. are no longer detectable) within 18 months of their initial detection. Marijuana and current tobacco use are also risk factors for oral HPV infection. Whether these agents increase the likelihood of acquiring an infection when an individual is exposed to HPV or increase the chance of sexual behaviors which lead to exposure to HPV is unknown. However, marijuana or tobacco use without sexual exposure will not result in HPV infection. Not surprisingly, there is overlap in the risk factors for oral HPV infection and HPV-related oropharyngeal cancer.

Clinical presentation and prognosis

HPV-related oropharyngeal cancers tend to be diagnosed in individuals who are younger, men and white, when compared to HPV-unrelated oropharyngeal cancers. HPV-related tumors are more commonly small tumors of the tonsil or base of tongue and are accompanied by large lymph nodes in the neck. The neck node is most frequently the initial recognition of an abnormality. This combination of small tumor and large lymph nodes in the neck results in advanced overall stage. However, despite characteristically advanced overall stage of disease at the time of diagnosis, patients with HPV-related oropharyngeal cancers have very good prognoses.

Recently, we have learned that HPV tumor status is important even at the time of recurrence. At the time of recurrence HPV-positive oropharyngeal cancer patients often ask what happened to the good prognosis that they were supposedly afforded by their HPV tumor status at the time of diagnosis. Until now there was no answer to this question. Using data from RTOG studies with long term follow up, we found that HPV-positive patients have significantly longer survival even after recurrence. Of note, we found that both HPV-positive and HPV-negative patients with recurrent oropharyngeal cancer derive a survival benefit from salvage therapy, if they are candidates for either surgical or

HPV VACCINE continued on page 2

Find SPOHNC on Facebook

IN THIS ISSUE

HPV VACCINE continued from page 1

radiotherapy salvage. Even patients with distant metastatic disease from oropharyngeal cancer may have longer survival if salvage therapy can be performed.

Treatment considerations

Presently treatment considerations for HPV-related oropharyngeal cancer patients and HPV-unrelated oropharyngeal cancer patients are similar. Indeed, National Comprehensive Cancer Network (NCCN) guidelines caution against differential treatment of oropharyngeal cancer patients by HPV tumor status outside of clinical trials. Chemoradiation (platinum-based agent with concurrent radiation therapy) has been the standard of care, but the use of alternative therapeutic modalities is now being explored. The reason for these trials is the growing appreciation of the long-term toxicities of therapy in patients who are diagnosed at a young age, physically fit without co-morbidities and are expected to have long term survival after curative therapy.

There are several ongoing trials around the country designed to evaluate the role of upfront surgery, reduced radiation dose and/or need for chemotherapy with the goal of reducing long-term toxicities of therapy. Surgery for oropharyngeal cancer is now possible using minimally invasive methods (transoral robotic surgery and transoral laser microsurgery). Traditional surgical approaches for the oropharynx were accompanied by significant morbidities and were therefore relinquished for chemoradiotherapy in the early 2000s. Chemoradiotherapy has been the therapy of choice and has resulted in good survival and organ preservation, however has long term consequences that are increasingly relevant with longer survival. Therefore, the role of surgery in the paradigm of therapy is being explored both in the United States and abroad. Eastern cooperative oncology group (ECOG) 3311 is a multi-institutional trial with upfront transoral surgery for HPV-positive oropharyngeal cancers. Quarterback trial is a single center trial at Mount Sinai that is comparing a reduced dose of radiation therapy to standard chemoradiotherapy. ADEPT is a Washington University in St. Louis trial that randomizes patients currently considered to be "high-risk" after upfront surgery to radiation therapy versus chemoradiotherapy. RTOG 1016, the goal of which was to identify a treatment with less toxicity for HPV-positive oropharyngeal cancer patients, has closed to accrual after enrollment of ~1000 patients around the country and will inform us whether cetuximab can be used as an alternative chemotherapeutic agent to cisplatin. Results of these ongoing trials as well as others may change how HPV-positive oropharyngeal cancer is treated.

Oral HPV after treatment

A common concern among patients with HPV- oropharyngeal cancer and their partners is whether a patient's oral HPV infection is transmitted. In a multicenter study, oral HPV infection was sampled in patients and their partners at the time of diagnosis. While oral HPV infection was commonly detected in patients with HPV- oropharyngeal cancer it was not commonly detected among their partners. Oral HPV infection was as rare in partners as in a large representative United States population (~1%). Furthermore, partners of patients had no evidence of HPV-related cancer in their blood. A potential serum marker of risk for HPV-related cancers was

HPV VACCINE continued on page 3

HPV VACCINE continued from page 2

just as rare in spouses and partners of HPV-oropharyngeal cancer patients as healthy volunteers without cancer.

A recent study at Johns Hopkins recently showed that the presence of oral HPV infection or HPV DNA in the blood after treatment may herald a disease recurrence. These data are being used to plan large-scale studies to determine whether biomarkers of HPV in saliva or blood can be used in the clinical follow-up algorithm. Presently, surveillance after treatment is limited to clinical examination.

Prevention of HPV-related oropharyngeal cancer

The incidence of oropharyngeal cancers is increasing in the United States and abroad. These changes are most prominent in younger individuals and men. The number of new oropharyngeal cancer cases per year is expected to overtake the number of annual cases of cervical cancer in the United States in ten years. Given these trends, there is great interest in preventing oropharyngeal cancer.

The current vaccines have been shown to be highly effective for the prevention of anogenital HPV infection and anogenital precancers. However, no large scale vaccine studies have evaluated oral HPV infection as an outcome, and such studies are needed (albeit costly). The one study to date was performed in women in Guanacaste, Costa Rica. Women were randomized to receive either the bivalent vaccine, which was designed to protect against HPV 16 and 18, or placebo. Four years after vaccination, oral HPV infection was significantly less common in the vaccinated group as compared with the unvaccinated group. Only one infection was found in the vaccinated group, while 12 were detected in the unvaccinated women. While these data are compelling, they are limited to a one-time sampling in women. Further studies of the natural history of oral HPV infection and the effect of vaccine are needed. No data for vaccine efficacy against oral HPV infection are available in men, the gender that HPV- oropharyngeal cancer affects most commonly.

Vaccine efficacy for cervical cancer was shown not only in the context of a reduction of cervical HPV, but also for a reduction in cervical precancerous lesions. Unfortunately a precancerous lesion in HPV- oropharyngeal cancer has not been identified to date. It is agreed upon that one exists and that oral HPV infection leads to transformation of normal tissue to precancer and then cancer. However this progression in the tissue has not yet been visualized for HPV- oropharyngeal cancer to date. Therefore, in addition to not knowing whether vaccine reduces oral HPV infection, whether vaccine reduces malignancy is also unknown.

Despite the unknowns, we do expect that the vaccines will reduce oral HPV infection and associated cancers. The majority of HPV-oropharyngeal cancers are due to HPV16, one of the HPV infections covered in the available vaccines. However, there are a few cautionary statements that need to be made in this context. There are many differences between oral HPV infection and anogenital HPV infection that may alter the efficacy of the vaccine. For example, while anogenital HPV infection peaks soon after sexual debut, oral HPV infection has two different peaks which are somewhat later. Far fewer boys in the United States are receiving the vaccine than girls. Since HPV-related oropharyngeal cancer is a disease that predominantly affects men, the success of the vaccine is unlikely to be seen until compliance increases. The reduction of cervical HPV in women may indirectly reduce mens' exposure to HPV. Lastly, whether the vaccine remains effective for decades after immunization, since oropharyngeal cancer on average is diagnosed in late 50s and early 60s is unknown. Optimistically, the vaccine will have an impact, but won't be appreciated for another 40 years at least.

Although the ideal is to prevent a disease from occurring, the alternative option is to identify it earlier through screening, when a disease is more treatable and the morbidity of therapy is reduced. This option is difficult presently without the knowledge of precancer lesion. A pap test helped screen for cervical precancers in the US and therefore has been explored for HPV-related oropharyngeal cancer. The shortcoming of a pap test equivalent for the tonsils and base of tongue was the challenge of visualization. Therefore, there is an ongoing effort to better image the tonsils and base of tongue, with the hope of eventually combining such a technology with a pap test and identify disease at an earlier stage. A clinical trial at Johns Hopkins is evaluating the use of ultrasound to identify subclinical oropharyngeal cancers in the case of unknown primaries (which contemporarily are largely HPV-related). A large multicenter study organized by Ohio State University is exploring means of identifying healthy individuals at high-risk for HPV-oropharyngeal cancer and determining whether lesions are identifiable.

Conclusion

In summary, HPV-related oropharyngeal cancer is a distinct disease process that may be preventable with the vaccine, however well planned comprehensive long-term studies are needed to further evaluate the effect of the vaccine on oral HPV infection and development of cancer. Concurrently, novel tools must be developed to allow for the evaluation of screening strategies. A multi-prong approach might help reverse the trend of increasing the number of HPV-related oropharyngeal cancers diagnosed each year.

In the meantime, as the number of HPV-OPC survivors increases, our attention must turn to studying the issues that arise in the survivorship period. We must understand the consequences of therapy in long-term survivors and address these issues that undoubtedly affect quality of life.

Editors Note: Dr. Fakhry is a head and neck surgical oncologist at Johns Hopkins. After an undergraduate degree at Stanford University, she completed medical school, residency in otolaryngology head and neck surgery and fellowship in head and neck surgical oncology at Johns Hopkins. She has also received a masters in public health from the Johns Hopkins Bloomberg School of Public Health. She is presently Assistant Professor in the Johns Hopkins Department of Otolaryngology Head and Neck Surgery. Her research interest focuses on the role of human papillomavirus (HPV) in head and neck squamous cell cancer.

Exciting News!

SPOHNC Lights Up Niagara Falls Again For April Awareness!

See it live at www.niagarafallslive.com

Saturday, April 25th 10PM EST

"Like" SPOHNC on Facebook

Support for People with Oral and Head and Neck Cancer, Inc. is grateful for the generosity of its contributors in 2014. Thanks to their support, SPOHNC is able to maintain and extend its programs of education and support to cancer survivors, their families and friends. With sincere appreciation to all.

VISIONARY CIRCLE
Contributions of $15,000+

Bristol-Myers Squibb Oncology
Navidea Biopharmaceuticals

LEADERS CIRCLE
Contributions of $10,000+

Boehringer - Ingelheim
GlaxoSmithKline

FOUNDERS
Contributions of $5,000+

The Tomotherapy® System

BENEFACTORS
Contributions of $1,000+

Anonymous, Walter & Irene Boehmler, Genentech Inc., W.W. Grainger, Inc., Nancy Leupold, Thomas McCausland, Hoag Family, Cancer Institute, Joseph Piacentile, MD, James J. Sciubba, DMD, PhD, Siemens Caring Hands Foundation, Gale Simmons, Dan Stack, Borden & Cynthia Taylor

PATRONS
Contributions of $500+

Leonard & Rosemary Abrams, Anonymous, Peter F. Baker, Charles Banta, Chevron Humankind Employee Engagement Fund, Robert & Linda Culpepper, John & Roberta Davis, Janet C. Fried, Raymond D. Gambale & Sunny Ling, William & Barbara Gillaspie-Hargas, Diane Huston, Johnson & Johnson, Dennis H. Kraus, MD, Jason W. Much, David P. Ochicki, Mark S. Persky, MD, James Prange, Douglas E. Simms, Scott & Jana Stone, Daniel Sudler, Bill & Anne Wesp

SPOHNC'S VISIONARY CIRCLE

Bristol-Myers Squibb Oncology is a pharmaceutical and related health care products company whose mission is to discover, develop and deliver innovative medicines that help patients prevail over serious diseases. www.bms.com

Navidea Biopharmaceuticals is a global leader in precision diagnostics which pinpoint molecular sites and pathways to identify the presence and status of disease. www.navidea.com

SPOHNC'S LEADERS CIRCLE

Boehringer Ingelheim - Building on scientific expertise and excellence in the fields of pulmonary and cardiovascular medicine, metabolic disease, neurology, virology and immunology, Boehringer Ingelheim has embarked on a major research program to discover and develop innovative cancer treatments. www.us.boehringer-ingelheim.com

GlaxoSmithKline is a science-led global healthcare company whose mission is to help people to do more, feel better, live longer. www.gsk.com

SPOHNC'S FOUNDERS

Accuray is a radiation oncology company that develops, manufactures and sells precise, innovative treatment solutions that set the standard of care with the aim of helping patients live longer, better lives. www.tomotherapy.com

SPONSORS
Contributions of $100+

Allan L. Abramson, MD, FACS, Gabriel Garcia-Angeli, Angela Anderson, MD, Eugene H. Anderson, Dalton & Noreen Avery, Kris Barcelow, Chuck Bartlett, John & Mary Anne Bates, Lewis & Amy Beilman, Kenneth, Jr. & Dawn Berrier, Michael Birnbaum, Karen Seeger, Janis Borkowski, Richard Boucher, Cheryl Brandt, CNS, Jerry Brewer, Rita Burfitt, Richard & Cassandra Camacho, Richard Charny, R K. Chase, Richard Diciedue, Kurt & Agnes Dickinson, Terence Dowd, Rebecca Dresser, Patricia Drobnek, Marian Dwyer, Andrea Eckle, Alan & Debra Elkes, William & Linda Fleming, Brian Foley, MD, John Fredlund, Robert G. Fuller, Lewis R. Gainfort, Marie A. Gale, DDS, MS, Mark Gaulin, Harvey Gendreau, Barbara McCarty, Mark Gershenson, Mary Ellen Giacobbe, Frank & Jane Giancola, Dorothy Gold, LCSW-C, OCW-C, Julia Grabendike, John & Deb Groves, Carl Gustin, George Haas, Theresa B. Hambel, Blossom Handelsman, James Hayes, Amy Heffern, Steven Hendrickson, Heather Hohenthal, Harold & Jan Holady, IBM Employee Services Center, Jack & Temple Igleburger, Jerry & Kim Jackson, Michael Joyce, DC, Mark & Mildred Kilmartin, John M. Kim, DMD, PC, Dennis E. Korjenek, Jr., Jeffrey Kovner, Robert Kreps, Christy Lee, Kathryn Lehar, Suzanne K. Leupold, Michael & Monica Levine, Carlos & Frances Luna, Barry Maisel, MD, John & Regina Mapes, Thomas McCammon, Robert & Catherine McGeachie, Justin McNeill III, Diane Meehan, CDA, EFDA, Susan Minkowitz, MD, Catherine Mintautas, David & Connie Mohan, Larry Myers, Ben & Micki Naimoli, Claire C. Nelson, Robert & Sarah Nemeth, Eric Nielsen, Peter D. Nierman, Amy Goldberg, Paula OMansky, Marion Ott, David & Jeannie Paige, Bonnie Pate, Kevin & Alice Patent, Richard Pawl, John & Ann Pendergast, David B. Pendleton, Charles & Barbara Raabe, Eamon Raftery, Carl Reimerdes, Gary & Lisa Reiter, David & Janet Reser, Gerald & Gail Reynolds, Karrie Zampini Robinson, Fred Rosen, MD, Mona Joy Roth, Charles Sapp, Gerson D. Schumow, Lida Sethi, Chip Sharpe, Nancy N. Shaw, Irene B. Simonson, Rahel Smith, Joel Spieth, Dennis & Kathy Staropoli, Alice Steiner, John & Jane Stevenson, Mitchell Strear, Roger P. Tardie, William & Betty Temple, Glen Thomas, Rob Ann Tomlinson, Rocco Trotta, United Way of Central Maryland, United Way of New York City, Wayne Vosburg, Larry Waggoner, Robert & Patricia Warrington, Stephen & Becky Weber, Deborah C. Wendt, LCSW, Gerry & Florence Wixson, Charles Wolenben, MD, Laszlo Zeke

DONORS

Contributions of $50+

Aaron P. Acker, Donald Ambrose, Edna Angeli, Gay Archer, Thomas M. Bardolf, Stephen Barry, Dorothy Bembry-Guet, Roosevelt Bembry, Gerald M. Berger, Karen & Stephen Berman, Sandra Black, J. Lawrie & Nan Bloom, Loreen Blumenthal, Richard & Ester Bowman, Mary Bryant, Debra L. Bucek, Jean & James Callahan, Barbara Carr, Anne Marie & Bill Carter, Jean O. Cashin, Connie Cocozzo, Martin Cole, John Comber, Kathryn Counts, Joseph & Michele Crandley, CranioMandibular Rehab, Inc., James Cullen, Colleen & John Davis, Kent & Susanne Davis, Patrick A. Day, Stephen Diana, Barbara Dominick, Rebecca S. Dresser, Morris Eaton, Melvin & Candace Edgerley, Thomas Eich, Maureen Erickson, Andrew Erman, Alan Evans, Craig & Linda Farr, Ted & Gail Fass, Penelope Fisher, Virginia Ford, Margaret Ann Frick, Cheryl Gaimon, Denise Gangler, Gloria Gelineau, Paul Gough, Jerry R. Grace, Lynn Graham, Valerie L. Hamel, Mary Haungs, Terry Healey, Sheila Hisle, Harry Holmes, Kathleen Hummel, Carol Humphries, Douglas & Stacy Hunter, Audrey Hyde, Susan Jankowski, Susan Rosenthal Jay, John L. Jenkins, Charlotte Karpinecz, Ellen & Rafe Katkin, Elly Kelnar, Lorelei Kilbane, Donald & Julia Klein, Sandra Knipe, Charles A. Knolls, Brent & Becky Koehler, Maria Latyshenko, Patricia & Rich Laumann, Carl Lawrence, David Lehman, Philip Litch, Laurie Lopez, Dennis Lyons, Howard J. Mann, Robert & Susan McAuliffe, Ronald & Cheryl McDaniel, John J. McGurk, Catherine J. McIlwee, Morgan McKee, Edwin & Bobbi Merrell, Robert D. Michael & Ireta M. Jimmie, Edward & Martha Miller, Leah M. Monger, Mary & Raymond Musser, Tetsuo & Elinor Najita, Sherry B. Niepp, David D. Noble, Ruth Opatz, William J. Pantesco, Patagonia, Peggy C. Payne, J. Wray Pearce, Daniel Perez, Susan Perez, G. Frederick Perkins, Edward Phillips, Michael & Sally Powers, Michael & Marge Putman, Marie Prete, Eleanor Rader, George Reeder, John Reeves II, Robert & Robin Reid, Peter Reimuller, Bruce Ribaudo, Jeanna Richelson, Marsha Rifkin, Regina Rivello, Lazaro & Dianne Rodriguez, Leo Roseman, Kurt Schwabe, Geraldine Strohsack, Sheila & Erika Studint, William Tobin, United Way of Mid-Maine, Wayne Vosburg, Thomas & Sandra Weishaar, Robert Wiederhorn, Diane E. Williams, Jean Wilson, Phillip Wilson, Nyla Wright, John Young

BOOSTERS

Contributions of $25+

Mary K. Adcock, Barbara Appel, Ruth Aptaker, Norman Arsenault, Sandra Bates, RN, Allen Baxter, Judy Bean, Michael & Barbara Beckerman, Paul Beranek, Susan Berghoff, Samuel & Mary Bishop, Adele R. Bitowft, Jessica Blum, Robert & Carole Boisits, Charles Bonini, Randall & Caroline Bosch, Stacey Brill LSP, Joan Brooks, Suzanne Brown, Mitchell & Margaret Budzenski, Denise A. Buss, Jodi Campbell, Edward & Donna Carfora, Barry & Mary Cartwright, Amy Chan, Elaine I. Charlesworth, Frank G. Clayton, Kristi Napoleon, Gary Cless, John & Marie Conneally, Mark Cortez, Robert Coyne, Constance Rode Craig, Patti Devillan, Hank & Lilian Deneski, Ellen Desper, Thomas Dobbin, Mary Donovan, Richard D'Ornellas, Morris L. Eaton, Robert Edmisson, Roslyn Factor, Kevin & Frances Fallon, Linda Faraldo, Michael D. Feit, Gary M. Fereno, Julie & Ken Flesher, Lynn A. Folkman, Sandra Fuggini, Marilyn Fuller, James B. Gaddy, MD, Patricia Gawron, George & Nancy Gebhart, Georgie A. Geyer, Francis & Shalil Giannone, Michael William Glynn, Darryl Godreau, Miriam S. Grodberg, Carolyn Guiser, Gregg & Cynthia Gutowski, Charlotte Gyory, James P. Hadden, Trudy Hanke, Cynthia Hanks, Sandy Hannigan, Lyla K. Hanson, Sara G. Henson, Mark & Gayle Hoffman, Patrick Holmes, Jarvis & Carol Hoppler, Capt. Edward W. Hosken, Jr., Nancy A. Houck, Patricia Lynn Houck, George A. Howell, Eleanor Patricia Hutwagner, Robert Hyams, Mick & Diane Hynek, Joanne Isopo, Anthony Izzo, Cheryl J. Johnson, Karl Kaplan, Evelyn Kelley, Patrick D. Kennedy, Jeffrey & Barbara Kennison, Bernice K. Klaben, PhD, Larry & Betty Knackstedt, Cynthia J. Knight, Kathryn Koch, Dawn & David Konarsky, Arthur Krasovich, Robert N. Kropff, Kathleen Kuniej-Cooper, Jane Zanca, Patricia Lee, Lorraine Lee-Masi, Mark Leonhart, Howard Lichtenstein, John & Barbara Lindell, Kathryn A. Long, Marian Lord, PT, John Loret, Diane Lowry, Dan Lucy, Dominick Macchia, Donna J. Martin, Linda G. Martin, Jane Maute, Jim Mayo, James & Jean McHenry, Merritt McKeon, Julie Mecum, Edward & Martha Miller, Joe & Grace Miller, Elizabeth G. Miller, Caroline & Dennis Mills, James Minter, Jeffrey Minton, David Mohr, Gene Monahan, Charles Moore, Charles & Beverly Mumford, Theodore Mynch, Dennis Newton, Georgeanne Nester, Guy & Marilyn Nottoli, Helen Ohsberg, Steven N. Olek, Mary Oliva, Gary Olsen, Dave Orr, David Paletz, Jim & Joan Palmer, Bernedia (Birdie) Perkins, Donald Peyton, Sherry Pinkof, Linda Powell, Steve & Judy Prettyman, Judith A. Racs, Janice Raftery, David Rea, Lois Reed, Steve Richardson, Jennifer Riker, John Robinson, DDS, Bridget Ross, John & Annette Sahatjian, Dianne Sawyer, Caroline M. Saylor, Ernst & Gail Schneck, Donald D. Schneider, Nancy Scholes, Carol Scicutella, Mabel C. Seewald, Linda F. Seiden, Delton Shilling, Charles Short, Hima Singh, Michael T. Skrak, Theodore J. Stalzer, Steven & Rachelle Stern, Elliot W. Strong, MD, Gerald Stutts, Robert & Barbara Sulkis, Claire J. Sullivan, Nancy C. Sully, Charles & Suzette Sweeny, Nancy Tamburro, SW, Jeff & Kenzie Thompson, Patrick & Georgann Tierney, Deborah Tingen, Nyra Traxler, Alan Trupkin, Marco & Judith Tufo, Patricia A. Van Auken, Mary VanDiepenbos, Thomas & Nancy Vincent, Margaret Von Der Linde, Debbie Wagner, Kay L. Walker, Lydia Ward, Anita Weinstein, Sheila West, Mary C. Wiak, Chester C. Wilcox, Susan & Tom Wilk, Merlin Wilson, Michael Wixom, Judith L. Wood, Debra Young, Jerome A. Young, Frank & Margaret Zadell, Tim Zemens

A Tribute To A Very Dear Friend

SPOHNC's Board of Directors, staff, and attendees of the SPOHNC Dallas/Baylor Irving Chapter, facilitated by Jack Mitchell and Dan Stack, all mourn the loss of our very dear friend, Rick Agee, who lost his battle with oral, head and neck cancer on Thursday, February 19th. We are all deeply saddened, and will continue to support one another as Rick supported so many along their journey. Rick was a genuine, caring, true friend to SPOHNC.

John Richard (Rick) Agee…The Ultimate Friend, accumulated friends throughout his lifetime. His friends shared in his interests such as outdoor activities and athletics. Always there to lend a helping hand, Rick was loved by all; and every friend that he ever had has remained with him throughout his entire life.

Rick joined the SPOHNC Dallas/Baylor Irving Chapter support group in February of 2009. It was the beginning of a life changing relationship for Rick, and for those he spent time with and got to know and become good friends with through the years. SPOHNC Dallas Facilitator Dan Stack shared some deep and very personal thoughts with SPOHNC and those who attend the Chapter support group…. " What do you say about a very, very close friend, who, in light of the cancer battle that we have all endured, continued to be able to lumber into a room with a big smile on his face and within minutes infect everyone in that room with a good feeling?" This…was Rick.

Chapter Facilitator Jack Mitchell, who has also been profoundly affected by the loss of such a wonderful and gentle man, brought the sad news to SPOHNC. Bittersweet, he also shared with us that Rick was able to marry his soul mate, Lynn, just hours before he passed away, surrounded by his loving family and friends.

Alan Wright, Chaplain at Baylor Irving, who has maintained a very close relationship with the SPOHNC Chapter and its attendees, told us all "I married them at midnight last night. The doctor let his meds wear off just enough for him to be able to lift is leg in response to say "I do." Jack shared with us "I am sure that his marriage to Lynn gave him peace in his last few hours."

An avid in-line skater, in 2009 and 2010, Rick put together two Skate4SPOHNC events, to raise awareness, and funds for SPOHNC. These events were highly successful, and raised more than $25,000 for the organization.

In Loving Memory of Rick, the 5 SPOHNC Chapter Support Teams in the Dallas Forth Worth area, along with the Pegasus Skating Group, have planned a Memorial Event in Rick's honor. This will become a yearly event, to raise awareness of the needs of Oral & Head & Neck Cancer Patients/ Survivors and their Caregivers.

The planned event, now called SKATE/RUN-4-SPOHNC is an attempt to carry on Rick's efforts. It will include a 5k Fun Run and an In-Line Skating event to raise funds for SPOHNC and raise awareness of oral, head and neck cancer. The month of April is Oral & Head & Neck Cancer Awareness Month so the group felt that is was only natural to hold the event during April. This year, the event will be held on April 25, 2015 at Paloma Creek Amenity Center, 1501 Bluebird Drive, Little Elm, Texas 75068.

More details concerning the event will be forthcoming. Nancy Leupold, President & Founder of SPOHNC and Mary Ann Caputo, Executive Director of SPOHNC, will be attending the SKATE/RUN-4-SPOHNC event this year.

In 2012, SPOHNC held its 20th Anniversary Conference and Celebration in New York. Hundreds of survivors, newly diagnosed patients, caregivers, and healthcare professionals attended the event. The weather across the country that Friday played a significant role in delaying several individuals from getting to the conference on time. Rick was to attend, and as SPOHNC staff and other friends from the Dallas area waited in the hotel lobby for the last delayed arrivals, we had almost given up hope that our friend Rick would be able to fly in. Suddenly, we looked toward the door, and who was walking into the lobby, but Rick. The crowd that had gathered, erupted into applause for our good friend and he came cheerfully through the door to join us. He made it! After many delays and re-routed travel plans, Rick, probably exhausted, still found it within himself to smile, crack a joke our two, and greet everyone who was there. This…was Rick.

SPOHNC Executive Director, Mary Ann Caputo, shares her memories of Rick… "Nancy and I first met Rick when he traveled by car from Dallas to New York after his first SKATE4SPOHNC fundraiser. He didn't tell us he was coming and surprised us. As he opened up the door to our office we heard that familiar Dallas twang and we knew it was Rick. He had kidded with us that he was making the trip but we never imagined he was serious about traveling so far by car by himself. This was a special man. Rick felt indebted to SPOHNC for all the support everyone gave him after his diagnosis of oral cancer. He then went on to do another SKATE4SPOHNC the following year where I had the opportunity to attend. Rick and the "Dallas SPOHNC Family" welcomed me with open arms. It was a trip I would never forget. He, with his many helpers including his parents and family were there from sunrise to sunset making the event a very special day for all oral, head and neck cancer survivors, caregivers and their family members, with all proceeds going to the organization. Rick always referred to us as his "SPOHNC Chicks", and referred to himself as "Your New Friend For Life." SPOHNC is indebted to Rick Agee for his amazing spirit, making a difference, and for the kind and caring smile he wore, no matter what the day presented. He was a true friend to so many and will remain a part of the SPOHNC family, forever in our hearts. We love and will miss you, Rick…"

Visit the SPOHNC website at www.spohnc.org

HEAD AND NECK CANCER NEWS

Innovative Global Clinical Trial for Head & Neck Cancer Now Enrolling

Trial Description:
The HAWK study is an open-label, single-arm, Phase II study of MEDI4736 in patients with recurrent or metastatic squamous cell carcinoma of the head and neck (SCCHN). All patients who meet the eligibility criteria will be assigned to study treatment.

What is immune therapy?
The immune system is capable of recognizing, controlling, and even eliminating cancers; however cancers constantly find ways to hide from the immune system. Immune therapies work by either turning up the immune system to fight cancer, or blocking the ways cancer hides.

What is MEDI 4736?
MEDI4736 is a human monoclonal antibody being developed by AstraZeneca/MedImmune for potential use in the treatment of cancer. The antibody inhibits binding of PD-L1, which is one of the ways cancer hides from the immune system. By blocking PD-L1, MEDI4736 allows the immune system to detect and fight the cancer.

You may be eligible for the trial if you meet these criteria:

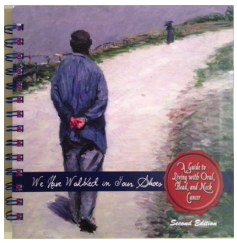
- You are 18 years of age or older.
- You have squamous cell cancer that started in the head and neck region.
- Your cancer has returned after prior treatment, or has spread to other parts of the body.
- You have previously been treated with chemotherapy containing a platinum drug (such as cisplatin or carboplatin) after the disease recurred or spread.
- You do not have any autoimmune diseases, such as inflammatory bowel disease (Crohn's disease or ulcerative colitis) or rheumatoid arthritis.
- You must be willing to allow the doctor to take a biopsy tumor sample for testing.

How do I find out more information about the study?
To learn more about this study and to find out if there is a center near you, call AstraZeneca Clinical Study Information Center toll free at 1-877-240-9479 or information.center@astrazeneca.com. Additional information is also available at Clinicaltrials.gov NCT Number: NCT02207530.

###

Great News!!

We Have Walked In Your Shoes - Second Edition *Is Here!*



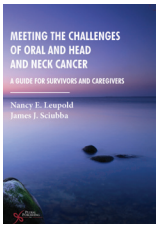
The long-anticipated and **updated** version of ***We Have Walked in Your Shoes: A Guide to Living with Oral, Head and Neck Cancer Second Edition*** is now available!

Go to www.spohnc.org to purchase your copy. For bulk orders please call 1-800-377-0928 or email us at info@spohnc.org. **Bulk order pricing - 25+ books $13.50/book and 50+ books $12.50/book includes shipping & handling.**

We Have Walked In Your Shoes… contains a wealth of information for newly diagnosed patients, caregivers, and those patients going through treatment. Healthcare professionals, clinics, diagnostic centers and cancer institutions throughout the U.S. will also find this book to be of great value for their patients.

Order your book today for only $14.95 - includes shipping & handling.

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



featuring
5 New Chapters, Updated Information, Product Resources

$27.00 includes shipping and handling
Place your order today at www.spohnc.org or call 1-800-377-0928

Connect with SPOHNC's "group" on Facebook

TIME FOR SHARING... Just Another Canker Sore?

It was just another canker sore; this time inside my left cheek, the kind that come and go frequently with me. Yet this one didn't go away; instead, it kept getting bigger, thicker and more painful as winter became spring in 2013. I went to my long-time devoted dentist; she took one look inside my mouth and remarked, "That's no canker sore, it's a mouth ulcer. Get it checked out right away with an oral surgeon." She took x-rays, emailed them to him and made me an immediate appointment with a very bright fresh-faced surgeon who had the second look at my lesion and blurted, "I've never seen an ulcer that big!" I quickly replied, "You're young, give it time!" That day in April 2013 was the on-ramp of my journey to cancer freedom (although I didn't know it was cancer then, but since hindsight is 20-20, I know it now!) Early detection is key—do not hesitate to seek professional counsel if you have even the slightest suspicion!

In the Hollywood version of this tale, there would be some back-story about why I'm so used to pesky canker sores—relevant since it has a lot to do with how I approach my health and life in general. I was diagnosed with rheumatoid arthritis almost 50 years ago when I was five years old (a rather aggressive auto-immune disease when your body thinks your joints are foreign objects and wants to attack and destroy them). On that health journey, I've had 13 orthopedic surgeries to repair damaged arthritic joints including both knees replaced, my right ankle and wrist reconstructed and both elbows roto-rootered (synovectomy). Plus, I've done physical and occupational therapies, diet modification, alternative treatments; not to mention hundreds of prescription medications to deal with that diagnosis—which ironically is in partial remission for the past year or so. Therefore, I've got decades of experience in dealing with doctors, nurses, hospitals, chronic disease management and life attitude adjustment—namely I didn't choose the arthritis diagnosis but I choose how I deal with it. Since several of those arthritis medications have canker sores as a side-effect, I'd grown used to mouth lesions arriving and departing frequently. Yet I'd never had anything like this sore the size of half-dollar that decided to take up residence inside my left cheek.

Spring became summer in 2013 and the oral surgeon did a "brush biopsy" that returned the verdict of atypical cells; so we decided to initially treat it topically with ointments and oral rinses. No improvement, more burning pain, and definitely no chewing on the left side. In October 2013, my oral surgeon did a blade biopsy of the site (scraping a significant amount of inner cheek tissue) and the results came 10 days later with his phone call. The words no one ever wants to hear: "You've got cancer. It's squamous cell carcinoma." He immediately referred me to a top head/neck cancer surgeon at UCLA Medical Center for consult and treatment.

I was able to get an appointment in early November 2013 to see the man, the myth, the legend—one of the highest rated "flap" surgeons in the country at UCLA. He did a thorough consult and offered two options—do radiation and see if the cancer would retreat OR since it was "only" Stage 1, excise the oral lesion and fill the hole with a skin flap taken from my thigh. I chose to have him remove it; then radiate post-op if necessary. Since we live 150 miles north of Los Angeles (a 3-hour drive depending on traffic), the logistics of this decision kicked in right away—especially since I own a marketing/public relations consulting business. Time to rally my family, friends, clients and get organized (one of my specialties, thank goodness.)

My long-time medical self-advocacy kicked into high gear on what I have named my healing journey to cancer freedom. The irony of a publicist having mouth cancer is not lost on me. Being able to communicate openly and honestly about my cancer journey is actually a blessing in my opinion. I hope that my experiences can bring others hope and strength. One of the things I did was start a personal blog to keep family & friends who live near and far apprised of my progress. I highly recommend the easy-to-use website www.caringbridge.org. Frankly, who wants to take phone calls, texts, emails and repeat the same status reports and surgery outcomes when talking is physically difficult and you're beyond tired? Don't mistake me, I deeply appreciate and need the care, support and healing energy I receive and continue to receive; yet communicating clearly is easier for me in writing during this healing time (plus, my blog serves as a great archive!)

Six days before Christmas 2013, I had an 18 mm (7/10 inch) diameter and 9 mm (1/3 inch) deep piece of my left buccal mucosa removed from my cheek and replaced with a thin section of my left thigh (that area looks like a cheese slice I named Skinee; the graft tissue in my cheek I named juicy-fruit since it feels like a wad of gum). I resided at UCLA Medical Center for three days/two nights and came home to heal. My surgeon strongly recommended follow-up radiation treatments. It turns out one of his former residents is a compassionate radiation oncologist at Marian Cancer Center in Santa Maria only 20 minutes from our home. In January 2014, while having a CT scan prepping for radiation there, my oncologist discovered some suspicious lesions in my left lower jaw/neck and did a PET/CT scan. They were biopsied back at UCLA and during that procedure; the doctor saw a possible facial artery aneurysm (that potentially could blow out at anytime so he advised me to stop talking! Me? Stop talking? Yes, that got my attention.) So I was admitted to the hospital for an emergency angiogram and my left facial artery was embolized with cute little platinum coils for safety. The biopsy did show that the original oral cancer had metastasized to my neck—welcome to Stage 2.

Three weeks later in February 2014, I had my second cancer removal surgery at UCLA—a neck dissection featuring a 8-inch incision in a convenient neck fold (according to my amazing surgeon) with 29 lymph nodes excised from the affected area (fortunately, only one turned out to be malignant). I was in the hospital for four

continued on page 10

continued from page 9

days/three nights with two pulsing neck drains to remove confused lymph fluids. Once they were tugged out, I returned home once again to heal and prepare for the next phase of this roller-coaster ride. For example, I got connected with a fantastic physical therapist at Marian Medical Center to help me raise/use my left arm again and reduce the lymphedema (lymph swelling in my neck area). Who knew that a neck dissection would involve the surgeon "exploring" all the way back to your scapula and trapezius muscle and nearby nerves—and have so many after effects (that still linger today)?

Since my professional career (and a great deal of my life) is wrapped up in talking, smiling, eating, speaking in public and coordinating events such as press conferences, I was determined to regain my speech and appearance! Through my oncology care team, I quickly got connected to the Santa Maria, California chapter of SPOHNC—facilitated by the compassionate speech therapist Aundie Werner. With this group of fellow cancer patients and caregivers, I experienced the power of one-on-one sharing from those who are living with this cancer diagnosis. I cannot advocate enough the importance of working with professionals combined with other cancer thrivers.

Unless you've had radiation treatments for oral/head/neck cancer, I don't think you can appreciate the weird/scary/bizarre sensation of having a plastic mesh mask fitted tightly to your face and then having it/you bolted to a steel table while being zapped. It's just a natural instinct to want to rise up and vocalize "OH NO" but I didn't—due in part to the caring nurses/docs/staff and my long-time meditation practice and belief in a Higher Power greater than radiation! I constantly silently chanted heal/heal during the process of having 30 sessions of IMRT (Intensity Modulated Radiation Therapy) five days a week for six weeks straight. I was able to have my treatments in the late afternoon, so I could get in 5-6 hours of business work in my home/office beforehand. It was an intense schedule, yet having the option to work from home was a blessing - combined with very supportive, understanding clients who didn't see much of me for awhile but communicated via email/text/phone. I believe that being able to focus on my professional work instead of my personal post-surgical and radiation pains facilitated my healing. Paradoxically, getting out of my own head and helping others really helped me!

The potential side-effects of my surgeries and radiation treatments are as long as my freckled arm. There was no way to predict where/when/how long they would appear and most of them did: dry-mouth, swelling, loss of taste, facial/neck and lip numbness, thrush, trismus (inability to open my mouth), blisters, stabbing neck pains, peeling facial skin, fatigue and the kicker—extremely painful swallowing. During/post radiation treatments, I subsisted on a complete smoothie diet for three months (bless my loving partner Jeff who is retired, loves to cook and made me fresh, healthy-from-scratch protein-powder shakes of fruit, veggies and nuts three times a day—if you'd like his recipes, please email me and we'll be happy to share them with you). I forced myself to swallow them despite the pain and I only lost about 10 pounds during radiation. This seemed to amaze my oncologist who indicated that some folks have to get a feeding tube and take pain meds to get through radiation and/or chemotherapy treatments. Fortunately, I only had radiation and no chemo. Since I tend to be a chronic pain pro with all my arthritis management experience, I vowed I would not get a tube or do narcotics and am eternally grateful I did not have to—yet sure understand why you might want to!

I worked closely with my oncology team, physical therapist and speech therapist—frequently and vociferously communicating about my side-effects, pains and figuring out ways to mitigate them: from Magic Mouthwash, lidocaine ointment, oral sprays, baking soda rinses, aloe vera gel, creams, lotions, elastic neck supporter I dubbed "the wimple," scar gel strips, and mouth stretching devices from tongue depressors and beyond! Who knew that simple exercises to improve lip balance, strength, mouth muscle tone even existed? Ask me about the joy of doing "the duck" or "the snarl" exercises and lip-ups!

In late June 2014, I had my second PET/CT scan that indicated "No evidence of metastases." Hooray! To celebrate, I had a combined birthday /cancer freedom party surrounded by caring family & friends in July 2014 (complete with my dream gift of a back-yard pool—just like the one I had when I was a little girl! See photo).

I had another PET/CT scan in early March 2015 and it reconfirmed "no significant' change." I'm still experiencing many radiation & surgical side-effects yet grateful to be on the healing path. I currently do physical therapy, lymphedema therapy, acupuncture and speech/mouth movement therapy every week as well as customized daily home PT exercise routines along with my traditional prayer & meditation. One of the most significant issues that I still face (every pun intended) is trismus—the ability to open my mouth beyond 20-22 mm despite the scar tissue fibrosis caused by the surgeries & radiation. ("Normal" mouth opening is 40-45 mm). I am determined to stay on the winding road to cancer freedom. I fully understand that I am not "cancer free" and that "remission" is more accurate; yet I am a firm believer in the power of up-lifting affirmations and body-mind-spirit balance.

I didn't choose my diagnosis of cancer yet I can choose my attitude about it. I make a conscious choice every day to have a positive outlook on my prognosis. I will never know for certain what caused my oral and neck cancer. There is a possibility that the biologic prescription medications I did for 14 years for the rheumatoid arthritis diagnosis could be a contributory factor since cancers are a rare but unwanted effect. Since I don't smoke, drink alcohol or eat processed sugars, red meat or dairy, my cancer risk factors are pretty low. I don't take the time to worry about the cause since I prefer to embrace a one-day-at-a-time, live for the surprises philosophy. Orison Swett Marden (1850-1924) said it succinctly: "There is no medicine like hope, no incentive so great and no tonic so powerful as the expectation of something better tomorrow."

Laura Kath is president of Mariah Marketing, her own consulting firm founded in 1989 in Santa Barbara County, California; and the author of 19 non-fiction books. She volunteers with several non-profit organizations and is a proud attendee of the Santa Maria, California chapter of SPOHNC. To contact her, feel free to email laura@mariahmarketing.com

CHAPTERS OF SPOHNC
(120+ and growing!)

Contact SPOHNC at 1-800-377-0928 for Chapter information & Facilitator contact information

ALABAMA
BIRMINGHAM

ARIZONA
MESA/GILBERT, PHOENIX, SCOTTSDALE

ARKANSAS
HOT SPRINGS, NORTHWEST

CALIFORNIA
CARLSBAD, LOS ANGELES-UCLA, NEWPORT BEACH, ORANGE-UCI, SAN DIEGO, SOUTH SAN FRANCISCO, SANTA MARIA, STANFORD, VENTURA

COLORADO
COLORADO SPRINGS, DENVER, PUEBLO

CONNECTICUT
NEW LONDON, NORWICH

DC
GEORGETOWN

FLORIDA
BOCA RATON, FT MYERS, FT WALTONBEACH/NW FL, GAINESVILLE, JACKSONVILLE/ACC, JACKSONVILLE/UFS, JUPITER, LECANTO, MIAMI/UMS, NAPLES, OCALA, PALM COAST/NORTHEAST, SARASOTA, TAMPA, THE VILLAGES, WINTER PARK

GEORGIA
ATLANTA-EMORY, AUGUSTA, COLUMBUS, SAVANNAH

ILLINOIS
EVANSTON/HIGHLAND PARK, MAYWOOD, MORRIS, SPRINGFIELD

INDIANA
FORT WAYNE, INDY-WEST, SOUTH BEND, TERRE HAUTE

IOWA
DES MOINES

KANSAS
KANSAS CITY, TOPEKA

LOUISIANA
BATON ROUGE

MARYLAND
BALTIMORE-GBMC, BALTIMORE-JHMI, LIBERTYTOWN

MASSACHUSETTS
BOSTON, CAPE COD, MID-CAPE ON CAPE COD, DANVERS

MICHIGAN
ANN ARBOR, DETROIT, ST. JOSEPH

MINNESOTA
MINNEAPOLIS, ST. PAUL

MISSOURI
ST. LOUIS/SLUCC, ST. LOUIS/DPCC, ST. PAUL

MONTANA
BOZEMAN, KALISPELL

NEBRASKA
OMAHA/MCC, OMAHA/NMC

NEW JERSEY
ENGLEWOOD, LONG BRANCH, MORRISTOWN, PRINCETON/UMC, SOMERVILLE, TOMS RIVER

NEW MEXICO
ALBUQUERQUE

NEW YORK
ALBANY, BUFFALO, MANHATTAN/BI, MANHATTAN/MS, MANHATTAN/NYU, MIDDLETOWN, NEW HYDE PARK, ROCHESTER, STONY BROOK, SYOSSET

NORTH CAROLINA
ASHVILLE, DURHAM/CHAPEL HILL, HUNTERSVILLE

OHIO
CINCINNATI, CLEVELAND, DAYTON, LIMA

OKLAHOMA
TULSA

OREGON
MEDFORD

PENNSYLVANIA
DUNMORE, HARRISBURG, HERSHEY, LANCASTER, PHILADELPHIA/PMP, PHILADELPHIA/HUH, YORK

RHODE ISLAND
WAKEFIELD

SOUTH CAROLINA
OF THE UPSTATE

TENNESSEE
CHATTANOOGA, NASHVILLE

TEXAS
DALLAS/BICMC, DALLAS/NCC, DALLAS/UTS, FORT WORTH, HOUSTON, McALLEN, PLANO, SAN ANTONIO

VIRGINIA
CHARLOTTESVILLE, FAIRFAX, NORFOLK

WASHINGTON
SEATTLE

WISCONSIN
EAU CLAIRE, MADISON, MILWAUKEE

SUPPORT FOR PEOPLE WITH
ORAL AND HEAD AND NECK CANCER
P. O. BOX 53
LOCUST VALLEY, NY 11560-0053

The promise of Spring brings hope to all.

Help SPOHNC bring hope to a newly diagnosed patient.

Look inside for your Spring Appeal envelope.

Give a Gift Today...

SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER (SPOHNC)

MEMBERSHIP APPLICATION
SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER, INC.
P.O. Box 53, Locust Valley, NY 11560
Membership includes subscription to eight issues of *News From SPOHNC*

Name_____Phone (_____)_____

Address_____Email Address_____

Address_____

City_____State_____Zip_____

Please Check: Survivor ____Friend ____Health Professional (Specialty) ___

First time member_____ Returning member_____

ANNUAL MEMBERSHIP
❑ $25.00 individual ❑ $30.00 family
❑ $35.00 Foreign (US Currency)

CONTRIBUTIONS
❑ Booster, $25+ ❑ Donor, $50+ ❑ Sponsor, $100+
❑ Patron, $500+ ❑ Benefactor, $1,000+ ❑ Founder, $5,000+
❑ Leaders Circle, $10,000+ ❑ Visionary Circle $15,000+

Call 1-800-377-0928
to become a member and make a contribution by credit card or order online at www.spohnc.org