



SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER | EST. 1991



The SPOHNC Minneapolis, MN Chapter support group recently held their annual Potluck Supper at the beautiful home of group attendees Mike and Else Sevig. This annual event has been a tradition for the group for more than 10 years now, so by this time, we think quite a few favorite recipes have been shared!

SPOHNC is grateful to Chuck and Jody Bartlett for continuing to support their Minneapolis, MN SPOHNC family!

With Gratitude From Your SPOHNC Family

Turn to page 7.

She's Dancing Again!

Find out on who on page 10.

SPOHNC Honors a Caregiver

Read about a caregiver who shares some great advice!
Turn to page 13.

Caring for Yourself and Advocating for Change as a Caregiver

Margaret L. Longacre, PhD, MSHE

In This Issue

Caring for Yourself as a Caregiver	3
Thoughts from a Caregiver	6
From Your SPOHNC Family	7
Head and Neck Cancer News	8, 14
SPOHNC Celebrates You	9
Dancing Her Way Into Our HEART	10
In Memoriam	11,12
SPOHNC's Champion of Hope	13

SPOHNC is dedicated to raising awareness and meeting the needs of oral and head and neck cancer patients through its resources and publications.

“TOGETHER WE HEAL”

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In Memoriam

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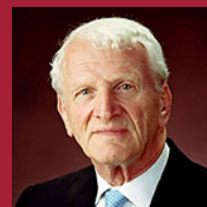
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Caring for Yourself and Advocating for Change as a Caregiver

Margaret L. Longacre, PhD, MSHE,

Caregiving can be both a rewarding and a challenging experience.

Cancer deeply impacts many individuals, families, and communities. Over the course of this year in the United States alone, over 1.9 million people will likely be told that they have cancer. For many, the burden of cancer will not be equal due to being from groups or populations at risk for heightened deficits. Specifically, persons of color experience poorer outcomes for most cancers, while certain forms of cancer can result in more severe and highly challenging functional declines.

For example, although head and neck cancer (HNC) accounts for a relatively small percentage of all U.S. cancer diagnoses (~6%), the deficits experienced in everyday activities, such as eating, speaking, and breathing, are often devastating. Not only is it common for patients to contend with symptoms and side effects of HNC and treatment, including dysphagia, pain, xerostomia, trismus, malnutrition, and neck stiffness, they also experience distress, anxiety, depression, and, post-traumatic stress disorder (PTSD).

HNC is not only distressing for those afflicted but also for those – relatives or friends – who support them. Someone supporting a patient is commonly termed or identified as the patient's 'family caregiver', but, in reality, they might identify best as simply being the patient's spouse, partner, sibling, parent, sister, brother or friend.

Thankfully, cancer is rarely experienced in isolation, and caregivers support patients in many ways. Common acts of support include

attending doctor visits, communicating with healthcare professionals, maintaining the household, managing insurance and billing, and performing nursing and medical-related tasks including navigating a patients' nutrition and speech needs.

Because of these and many other roles, it is common for caregivers to experience physical, emotional, and financial strain themselves. The financial toxicity of HNC cancer is a primary strain for many caregivers and includes their own medical out-of-pocket costs, such as cost sharing for treatments, as well as non-medical out-of-pocket costs of hotels, gas, parking, and public transportation. A caregiver might also experience immediate and long-term income loss as a result of reduced hours of work, quitting work or retiring early, forgone promotions or career development, reduced savings, or spending more on home help and child care.

Caregivers also know too well the experience of heightened emotional strain. In fact, there is evidence that caregivers can experience anxiety, distress, and higher levels of stress than patients. This can result in less engagement in their own health enhancing behaviors – e.g., little or no physical activity or poor nutrition. Compared to those not providing care, caregivers report poorer physical health and greater use of health services.



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As such, caregivers too often become the hidden patient – underscoring the impact cancer has on a caregiver’s own physical and emotional health. Not surprisingly, such decline can also negatively impact the patient. Though the strain in caregiving is often not fully avoidable, there are ways caregivers can reduce the likelihood of adverse impact on their long-term physical, emotional, and financial health and well-being. However, the onus cannot solely be on caregivers as systems and structures must be in place to support caregivers. Below are points for self-care and ways to advocate for enhanced caregiver support as a caregiver.

Know You Are Not Alone

It sounds overly simple but learning that you are not alone in experiencing strain as a caregiver can help you mobilize your self-care practice and advocate for the support you might need. Too often caregivers do not want to be a burden given the strain experienced by the patient and, thus, might view their needs as less significant and avoid or ignore them entirely. In reality, caregivers often have similar experiences and knowledge of this similarity might be a helpful form of coping. Being aware of common strains as shared in this article, stories of others, or even interacting together with other HNC caregivers, in person or virtually, might be a helpful source of support in difficult times. This awareness of common strains might also help in feeling more comfortable talking to others about your experiences and needs, including your own healthcare providers or your loved ones’ providers.

Consider Social Support

In HNC in particular, patients and caregivers can become isolated due to the cancer symptoms and treatment side effects, such as impaired eating or speech. Consider using your calendar to set times and modalities for interacting with others who give you energy and are supportive. This might be texting, emailing, being together on zoom or in-person with others you prefer to be

Engage regularly in
a healthy diet,
stress reduction,
and adequate physical activity
in ways that you enjoy.

with even if limited in time. You might also consider support groups or social resources provided at cancer centers or in the community.

Engage with Cancer Center, Hospital or Clinic Resources

Given the implications of the financial toxicity of cancer and emotional strain, more healthcare facilities and professionals are providing resources to patients and their caregivers. This holistic level of support is still not the norm so inquire if programs and support is available. If the patient’s place of care does not have such support, reach out to nonprofits that provide support for patients and caregivers in oncology, such as SPOHNC, the Cancer Support Community, and the American Cancer Society to name a few. Sometimes these organizations have specialty focus areas, including mental health or cancer survivorship. Many of these organization also offer free helplines and online resources.

Maintain Your Own Health Maintenance Routine

Though it is easy to put off your own healthcare needs, schedule and attend your regular well visits and prioritize screening behaviors rather than delaying. Engage regularly in a healthy diet, stress reduction, and adequate physical activity in ways that you enjoy.

Utilize Workplace Support

Most caregivers are juggling employment at a workplace with providing care. If this is the case for you, consider scheduling a meeting with your human resources representatives to explore how you can ensure your benefits enable you to provide care or access support for a leave from work. This Assisting Caregivers Today (ACT) Care and Career EMPLOYEE Checklist (<https://canceradvocacy.org/webinar-care-career-support-from-health-systems-to-employers/>) is designed to help you consider ways you can engage in benefits and conversations with your employer if willing. This checklist has tangible steps for you while caring, or if you are not currently providing care but likely will in the future so that you can plan ahead.

Find SPOHNC at www.spohnc.org

Advocate for System Change and Better Support

For many people, advocating for change is an important coping mechanism and this is no different for caregivers. Two areas for system change in better support for caregivers includes: 1) health systems and 2) employers.

Advocate for Health System Support of Caregivers

Providing support to family caregivers can benefit everyone – caregivers, patients, and, very likely, the healthcare system. Yet, currently, caregivers often do not receive the support they need to care for the patient or themselves. Healthcare providers may not know the best way to support caregivers, or might not have time given the focus on the patient. Hospital and physician practices typically do not have the resources to finance support to caregivers, and training is not commonly covered by insurance. These are all possible ways to advocate for change. You might also feel comfortable, especially with anonymous satisfaction surveys, providing feedback to systems that have been part of your relative or friend's treatment and care. Expressing your needs as a caregiver might be helpful for you and for the others to follow at that institution. You might even consider sharing your personal story of caregiving, or at least processing it in writing.

Advocate for Employer Support of Caregivers

Employers represent a regular point of contact for caregivers. Employers supporting caregivers is not only the right thing to do as part of the collegial care for others (and it is), but better support in the workplace might also result in additional benefits. Such benefits might include stronger, longer-term commitment to an institution as well as improved health and reduced spending among caregivers and,

possibly, survivors. To best support caregivers, employers must create a care and career supportive culture. As with any major change in company culture, the employer must create and support a culture of empathy for caregiving, and this culture must be modeled by leadership from the top down. This Assisting Caregivers Today (ACT) Care and Career EMPLOYER Checklist (<https://canceradvocacy.org/webinar-care-career-support-from-health-systems-to-employers/>) is a way that employers can support their caregivers. Advocating is a personal choice and might be of interest to you, and this provides a tangible list of employer level support that might be feasible.

If advocacy is of interest to you as a way to cope and affect change, consider volunteering and joining forces with nonprofits in oncology that seek to have an impact on systems through policy at federal and state or local levels, such as the National Coalition for Cancer Survivorship.

Summary

Caregiving can be both a rewarding and a challenging experience. Taking small steps in supporting yourself while you provide care might help you through a very challenging time and support your long-term health and well-being. Importantly, the structures and systems to support caregivers must also be prioritized and advocated for as well. This change is something we can join in together to advocate for better support for all caregivers today.

Editors Note: Margaret L. Longacre, PhD, MSHE, Associate Professor, is Associate Dean of the College of Health Sciences and Chair of Public Health at Arcadia University. Dr. Longacre's research interest revolves around informal or family caregiving, including understanding policy and health system impacts and caregiver engagement.

How can SPOHNC help you?

Join a SPOHNC Chapter support group.

Be matched with a survivor or caregiver volunteer.

Contact SPOHNC today at 1-800-377-0928
or info@spohnc.org

Thoughts from a Caregiver

This is a part of a collection of poetry that was written by Barbara Provus, the caregiver and wife of survivor, Fred Wackerle, whose story you may have read in a previous issue of News from SPOHNC.

~ Babsbnz@aol.com

I See The Summer

Through windows, closed.
A hospital room during the day.
I sit. He sleeps. He opens his eyes and smiles
at me.
I am fearful. Summer will end.
And then what?

The Chair

I saw it. In an empty room.

May we please have that chair for my
husband? Voice pleasant, hopeful. NO
we cannot move chairs. There was a
memo. We cannot move chairs.

But my husband has a blood clot. He needs to
keep his legs elevated. It's a full recliner! My
voice, firmer now, logic versus emotion. May
we please have that chair? NO. It cannot be
done.

But it is done. My husband is now asleep in
that chair. But is that what I really want? A
chair for him?

I want his pain to go away. His sores to heal.
His bleeding to stop. His tumor to die and
never come back. That's what I really want.

I cannot do those things. So I will take the
chair.

“Caregiving” is a job we are given
because – more than anything
– we care.”

~ Linda C.

On The Bus

Where are you going?? All of you. Heads down
Buried in your SMART phones
Headed to work? To shop?
To enjoy the day?



I'm going to the hospital To be with my hus-
band And his pain
And his machines And his fear
And mine, too.
I open my eyes.
For a minute I think he's there. Then, too
quickly, I know he's not.
I don't want to get out of my bed, my haven,
my escape.
Covers over my head.
I have been hiding. But no longer.

SHARE your
JOURNEY

with our readers...

Contact SPOHNC today at 1-800-377-0928
or at info@spohnc.org to find out how.

You can find additional stories
by going to SPOHNC's website at
www.spohnc.org

From Your SPOHNC Family

As the year comes to a close, SPOHNC remains grateful for so much. We are grateful that we exist, thanks to the vision of our dear Founder, Nancy Leupold, more than 31 years ago. We are grateful for the continued ability to help newly diagnosed patients, survivors and caregivers who come to us each day, seeking hope. We are grateful, that thanks to your kindness and generosity, we are able to expand our programs and resources as new needs arise for those we serve.



We are especially grateful, for the many volunteers who have come to SPOHNC first as a newly diagnosed patient, or a caregiver in need, and have stayed in our SPOHNC family, with the intention to pay it forward by being there to help others who are travelling their cancer journey, though our National Survivor Volunteer Network

matching program. You held onto hope throughout your treatment, and now you are providing hope to those who really need it – so they know they are not alone.

We are truly forever grateful to our SPOHNC Chapter Facilitators and Co-Facilitators, who continue to go the extra mile, whether you are a survivor or a healthcare professional, overseeing your monthly group. Through the pandemic and beyond, you have supported patients and survivors and their families with a listening ear, a shoulder, and with the information that you share at your monthly SPOHNC Chapter support groups. What you provide is crucial to your meeting attendees...HOPE.

We are grateful to our Board of Directors, and our Medical Advisory Board, who provide professional knowledge and expertise, and serve as our guiding hand each day.

We are also grateful for everyone who has shared our name with someone who needs us...because that's how we grow. A flower needs soil, water and sunlight. SPOHNC needs you, our volunteers, so that we can continue to serve patients and their loved ones, who rely upon us to be there for them, from diagnosis through treatment and beyond. Today, we share our appreciation for your help, your service and for giving of your heart, which means so much to us all. The world is a much better place, because you chose to be there for that person who came to SPOHNC, looking for answers, a friend, and especially hope.

We wish you all peace and blessings this holiday season, and we extend our most heartfelt thanks to you all as you remember that Together, WE Heal.

With gratitude,

Margaret

Chair

Cynthia

Christie



Head and Neck Cancer News

SCIENTIFIC PEER REVIEW OF CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAMS' PEER REVIEWED CANCER RESEARCH PROGRAM FOR THE DEPARTMENT OF DEFENSE

The Congressionally Directed Medical Research Programs' (CDMRP), Peer Reviewed Cancer Research Program (PRCRP) consumer advocate recently participated in the evaluation of research applications submitted to the PRCRP. Lawrence "Laurie" Traynor was nominated for participation in the program by SPOHNC—Support for People with Oral and Head and Neck Cancer located in Locust Valley, New York. As a consumer reviewer, Laurie was a full voting member, (along with prominent scientists) at meetings to help determine how the \$130 million appropriated by Congress for Fiscal Year 2022 will be spent on peer reviewed cancer research.



Consumer reviewers are asked to represent the collective view of patients by preparing comments on the impact of the research on issues such as diagnosis, treatment, and quality of life. When commenting on serving as a consumer reviewer, Laurie said that "it is an honor to represent SPOHNC and all Head and Neck cancer survivors throughout the U.S."

Consumer advocates and scientists have worked together in this unique partnership to evaluate the merit of research applications since FY09. COL Sarah B. Goldman, Director of the CDMRP, expressed her appreciation for the consumer advocates' hard work. "Integrating consumer perspectives into our decision-making process brings energy and focus to our research programs. Patients, caregivers, family members, and advocates help us keep our efforts centered around what

is truly important to those impacted. We very much value this critical input from our consumers who help ensure that CDMRP's work remains critical and relevant," she said.

Researchers applying to the PRCRP propose to advance mission readiness of U.S. military members affected by cancer and to improve quality of life by decreasing the burden of cancer on Service members, their families, Veterans, and the American public.

More information about the CDMRP PRCRP is available at the website: <https://cdmrp.health.mil/PRCRP/default>.

SPOHNC's RESOURCES

We Have Walked In Your Shoes: A Guide to Living With Oral, Head and Neck Cancer
- by Nancy E. Leupold & James J. Sciubba, DMD, PhD

DIGITAL EDITION available now on our website for \$7.99

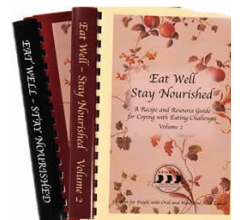
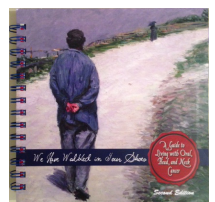
PRINT EDITION \$14.95 includes shipping and handling

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or email us at info@spohnc.org

Eat Well Stay Nourished
A Recipe and Resource Guide
for Coping With Eating Challenges
compiled by Nancy E. Leupold, Founder


VOLUME ONE \$20.00 includes shipping and handling

VOLUME TWO \$23.00 includes shipping and handling



Two Volume Set - LIMITED TIME SPECIAL OFFER
\$25 PER SET - A SAVINGS OF \$15!!

Get Cozy with Comfort Food



Chicken Braised in Cider — RECIPE —

INGREDIENTS

- 3 boneless chicken breasts, sliced thinly
- 3 Tbsp. olive oil
- 2 onions, chopped
- 2½ c. apple cider or juice
- 2 c. button mushrooms, sliced (fresh or canned)
- ½ c. plain yogurt or sour cream
- Salt to taste
- Milk as needed

- Fry chopped onion in the olive oil until soft. Salt the chicken pieces and add to onion. Cook chicken gently 5 minutes on each side. Add mushrooms and apple cider; simmer for 20 minutes or until the chicken is cooked through.
- Put mixture into blender and add yogurt and milk as needed. Yields 4 (11 ounce) servings.

Nutritional Information Per Serving:

Calories 297(kcal), Total Fat 13(g), Saturated Fat 2(g), Cholesterol 53(mg), Sodium 210(mg), Carbohydrate 24(g), Dietary Fiber 2(g), Protein 22(g)

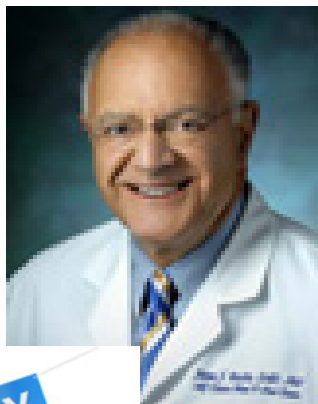


SPOHNC Celebrates You!

Happy Birthday Dr. Sciubba! Monday December 12th was an ordinary Monday for some of us, but for SPOHNC's President of the Board, it was a very special day. It was his birthday. What a way to start the week!

Dr. Sciubba has been an integral part of our SPOHNC family since the beginning, more than 31 years ago, when Nancy founded the organization.

He has watched us grow and change...all while staying the same age – miraculous!



He has been the guiding hand and the voice of reason, sharing his professional knowledge and expertise through participation on meetings, webinars and phone conversations with SPOHNC staff as well. He is a wealth of information and when we need help, he is always at the ready. He is a dedicated volunteer, and was happy to take on the role of President when Nancy retired.

Dr. Sciubba enjoys travel, nature and especially photography. We hope whatever you did on your birthday, Dr Sciubba, it involved all the things, and the people, that you love. We wish you well this special year, and we thank you for your service to SPOHNC. We are honored to celebrate you!!



Dancing Her Way Into Our HEART

Most recently, it was grooves, tunes and sharing the love, for this very talented dancer. Katie Drablos and her best friend Willis Johnson held a dance workshop called “HEART” during the last weekend of October in her hometown of Dallas, TX. KJ Dance and Cindy’s School of Dance were the 2 dance studios that hosted the workshop.

HEART was co-founded by Katie and Willis in 2015. A portion of the proceeds from each HEART event go to a charity of the studio’s choosing. KJ Dance and Cindy’s School of Dance chose SPOHNC as the beneficiary of this year’s HEART event!

Full of rhythm
and love.

You may remember Katie from her awe inspiring dance performance held in NYC in April. “35: a celebration of being alive” was Katie’s beautiful and truly heartfelt gift to the community on her birthday, raising awareness of Oral, Head and Neck Cancer, during April Awareness month. Katie donated the proceeds of that event to SPOHNC as well, in the spirit of survivorship and gratitude.

Katie, our hearts are overflowing with joy and appreciation for the gifts you have given to the dance community, your SPOHNC family, and the world. We cannot thank you and your fellow dancers enough for selecting SPOHNC. This is quite an honor, and we are forever thankful!



State Bill Seeks to Improve Dental Coverage



Massachusetts Oncology Patient Survivors and Supporters (MOPSS) is working with elected representatives on Massachusetts House Bill 1154. This bill, if passed, would require insurers doing business in the state to cover medically-related dental treatment.

For more information about the bill or to join MOPSS, email THealy4109@gmail.com or call 781-686-3774.

In Memoriam Barbara L. Myers

SPOHNC is deeply saddened to share the news of the passing of Mrs. Barbara Myers, wife of highly esteemed SPOHNC Board of Directors member, Eugene N. Myers MD, FACS, FRCS Edin (Hon), on November 16th, 2022.

Barbara Labov was born and raised in Atlantic City, New Jersey. After her high school graduation, she moved to Philadelphia and enrolled in the Albert Einstein School of Nursing.

During nursing school, a mutual friend introduced her to Gene Myers, a recent graduate of the Wharton School at the University of Pennsylvania. They fell in love and married in 1956. Their children were born in 1957 and 1961 and after Dr. Myers completed his internship and residency, the family moved to Frankfurt, Germany, where Gene was a Captain in the US Army Medical Corps, and then New York City where Gene completed a Fellowship with John Conley, the most outstanding Head and Neck Surgeon in the



world. From NYC, the family headed to Philadelphia where Gene joined the ENT practice of his father, Dr. David Myers.

In Philadelphia, Barbara attended Interior Design classes at the Philadelphia College of Art as well as a two-year educational course at the Barnes Foundation where she studied their renowned collection of Impressionist Paintings and embraced their philosophy of aesthetics. This was a transformative experience for her career in Interior Design and her life.

After Dr. Myers was appointed to the position of Chairman of the Department of Otolaryngology at the University of Pittsburgh, Barbara began her career by working in several well established design studios, and then went on to open her own studio with a long-time friend and colleague, where she enjoyed creating unique designs for both the home and commercial settings. As part of Dr. Myers career, both lecturing and performing surgeries,

they traveled to more than 100 countries.

SPOHNC extends our deepest sympathies to Dr. Myers and his family at this time of sorrow. We will continue to keep you all in our thoughts and prayers.

Bountiful Harvest in Minneapolis

Here we are again! Seventeen years as a support group and thirteen years celebrating survivorship with our annual pot luck at Mike and Else Sevig's home. They have been wonderful hosts as well as staunch supporters for many years. Even though some members cannot eat they still attend for the camaraderie. We celebrate with a variety of foods; salads, casseroles, chicken, bread, desserts, and even sliders from White Castle (this has become a tradition). And we can't forget the soups: beet, squash, bean, tomato, chili. No one goes home hungry!

Even though we really enjoy the food, that is not the most important part; it is the sense of family that brings us together. We enjoy fellowship, pray, laugh and cry together, and we listen to the cares and concerns that others wouldn't understand. We talk of many things

besides cancer: siblings, children, vacations, occupations, and the ups and downs of our daily lives. Like any family we celebrate the good times and mourn the losses; and there have been many of each.

We are thankful and blessed to be part of such a wonderful family and hold the hope that we can continue for many years to come.

Thanksgiving
Blessings,

Jody & Chuck



In Memoriam

Mel Jordan – NSVN Volunteer

Our SPOHNC family was deeply saddened to learn of the sudden passing of Mel Jordan, husband of PJ Jordan, and SPOHNC National Survivor Volunteer Network volunteer.

Mel and PJ joined our National Survivor Volunteer Network in 2017. They have both served as invaluable volunteers for those who came to SPOHNC seeking help, and hope.

Their story is inspiring, and their willingness to share it with others has been uplifting to so many. Even with all that Mel had been through, he always concentrated on moving forward in a positive way and helping others when he could.

PJ wrote the story of their cancer journey and we shared it in the May 2012 issue of **News from SPOHNC**. In the story, she said



“Mel’s journey has been a long one and despite the physical changes to his face he is probably one of the most carefree people I know...” Mel definitely enjoyed life and made the most of every day. Handy with a hammer, he took great joy in fixing things around the house, both inside and out. He was a lover of animals, including Mary Sue, Riley and a fairly recent addition to the household named George, who has remained an outside cat, but Mel always made sure that George was well fed and cared for even when the worst of the elements came their way. He had a kind heart and a giving spirit, that always shown through with everything and everyone that he cared for.

Mel was a fixture in their hometown of Chester, and he and PJ were often seen out and about, enjoying local music, nature and local fare as well. PJ often referred to their adventures as Mel “Driving Miss Daisy” about town, so she could photograph beautiful scenery, architectural wonders and anything that struck her fancy. They were inseparable.

SPOHNC extends our most heartfelt condolences to PJ. We pray for peace in your heart, and we hope that your memories will bring you comfort and serenity at this time, and always. We send our love to you...

Sweet Potato Pie

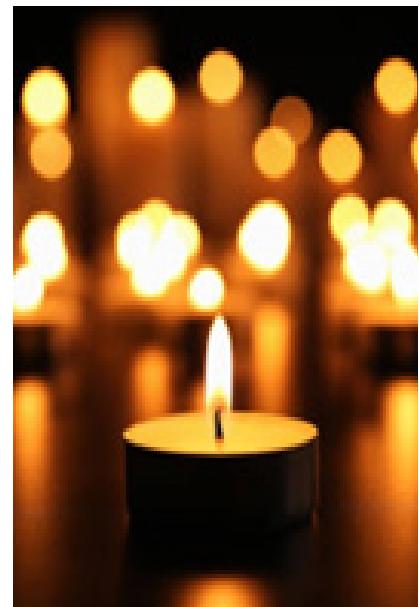
1½ c. cooked mashed sweet potato or 1 can pumpkin
1 can evaporated skim milk
½ tsp. nutmeg 1 tsp. cinnamon
½ c. sugar (1 c. if you prefer it sweeter)

Preheat oven to 350. Mix sweet potatoes, evaporated milk & spices, then add sugar. Grease a 9 inch pie pan with oil. Sprinkle pan with cornmeal to cover (shake off excess). Pour mixture into pie pan. Bake for 45 min. Test with toothpick; if it comes out dry, its done. Yields 8 wedges.

Nutritional Information Per Serving:

Calories 141(kcal), Total Fat 3(g), Saturated Fat 2(g), Cholesterol 9(mg), Sodium 69(mg), Carbohydrate 27(g), Dietary Fiber 1(g), Protein 3(g).

Member of PTRP, New York



November/December Champion of Hope

Caregiver, Connie Lunt, became a National Survivor Volunteer Network caregiver volunteer in 2015 – 4 years after her husband Chris’ diagnosis and treatment for throat, tonsil, and neck cancer. It was a rough and very unexpected road for them both as the diagnosis caught them completely by surprise. Chris is a volunteer as well, and SPOHNC is grateful!

Through her story, which Connie shared in the December 2018 issue of **News from SPOHNC**, Connie gave a

clear picture of not only Chris’ diagnosis and treatment, but also of what it meant to her to be a caregiver. She also wrote some great tips for caregivers to help them along their own journey. Connie shared with us that that she learned quickly that she needed to “jump in and just do what you need to and learn a lot about yourself and the real inner strength you can pull out when needed.” Connie was a nurse, a cheerleader, chef and at some points, the angry drill sergeant, who had some strong words for Chris when he decided he wasn’t going back for any more treatments. Let’s just say she changed his mind!

Connie mentions in her story that the time came when Chris asked her to reach out to SPOHNC for help. That was a win, and a “game changer” according to her. Apparently, it was a game changer for SPOHNC too because were it not for that, we would not have Connie and Chris as volunteers for our National Survivor Volunteer Network!



Here are some words of wisdom from Connie...

“There is a lot to be said about the power of positive thinking and the strong support group in place to keep you focused.”

Here’s something I put together given my experience in the caregiver role. I share these with people if asked how to approach being a caregiver.

H - Have Patience - This is a learning process for you and the patient.

E - Everyone wants to know. Designate a spokesperson to share info and respond to calls, etc.

R - Read the two books that are recommended (*Meeting the Challenges of Oral, Head & Neck Cancer* and *We Have Walked in Your Shoes*). Both are available through SPOHNC.

E - Every patient has difficult moments. You might have to get tough and push them.

F - Friends and Family - It will take a Village - get yours in place and ask for support.

O - Open your mouth! Do not be afraid to ask! Any question is OK! Ask them to spell the big words!

R - Roles change - you will wear many “Hats”- some of them will be new to you!

Y - You need to take time for yourself - Breathe - do something that makes you feel good.

O - One important phone call - SPOHNC! You and your patient can receive support!

U - Use your smile! Nurses and doctors will be your best friends. Treat them with respect and say thank you!

It is SPOHNC’s pleasure to honor Connie Lunt as our November/December Champion of Hope. Always ready to jump in and assist, just as she did with Chris, Connie has been matched with more than a dozen caregivers over time and has provided them with the foundation they needed in order to be there for their loved one. For your love, patience, and your ability to ease the worries of those caregivers, we THANK YOU!

Head and Neck Cancer News

NOVEMBER 14, 2022 - To guide patients through the options for treatment of cancer, patient navigation programs are now in place at several institutions, but a new study has shown that these types of programs can be used on a far larger scale.

The study evaluated a patient cancer navigation program deployed statewide in partnership with a Medicaid Advantage program. A retrospective study of the impact of the program, which was coordinated with a staff of nurses and other health workers interacting with patients by video or telephone, showed numerous benefits, including cost savings, according to Ravi B. Parikh, MD, an assistant professor of health policy at the University of Pennsylvania, in Philadelphia.

“Care coordination can often be fragmented, education about the best care options can be lacking and access to care is not always easy,” reported Dr. Parikh, explaining the basis for cancer patient navigation programs overall and the effort to extend the concept to larger patient populations.

In the new study, presented at the 2022 American Society of Clinical Oncology (ASCO) Quality of Care Symposium, in Chicago (abstract 4), 4,172 cancer patients who received care over 42-month period were eligible for analysis.

Of these, 662 patients treated across 25 community practices and 45 hospital-based practices participating in the navigation program were evaluated. Several types of outcomes among these patients were compared with the remaining patients whose care was not guided by a navigation program.

To evaluate impact on costs, propensity matching was conducted with 188 patients drawn from the navigation program and from the non-navigation pool of patients. The

Medicaid-Embedded Patient Navigation Programs Reduce the Costs of Cancer Care

primary outcome was total cost of care based on propensity matching derived from clinical and demographic covariates. Sensitivity analyses were conducted with Monte Carlo simulations.

On average, patients had 2.6 interactions per month with the navigation team. The mean reduction in total cost of care per month per patient was \$459. In a sensitivity analysis, the range was \$209 to \$708.

Cancer navigation programs have been employed, particularly for lower income people, for more than 30 years, and there are numerous studies to suggest that they are cost-effective, but “this is the first study to demonstrate a cost savings for a program deployed in collaboration with a health plan across a wide geography and range of practice types,” according to Dr. Parikh.

There are several notable features of this study, according to Julie R. Gralow, MD, the chief medical officer of ASCO. Not least, this study shows a cost savings through virtual care, which facilitates implementation of a large-scale approach.

“Patient navigators play a vital role in helping patients with cancer move through various organizational and other challenges related to their care,” Dr. Gralow said. She agreed that the potential complexity of care make these programs appealing, and not just from a cost perspective.

In addition to saving money, she pointed “to the tremendous social services navigators offer.”

—Ted Bosworth



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PLEASE NOTE: Some Chapters are not yet holding meetings in person due to COVID-19.

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Send us your SPOHNC support group photo (with permissions) to be featured here in a future issue!

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