

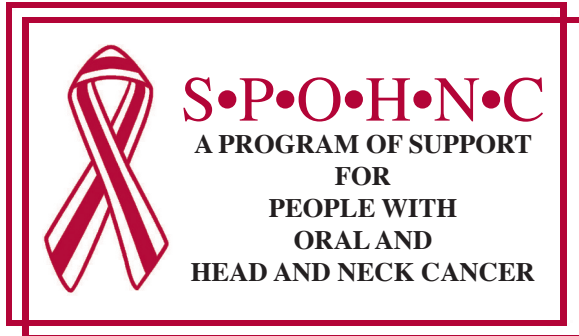
NEWS FROM S·P·O·H·N·C



VOL. 26 NO. 6

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

MARCH 2017



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

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

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

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

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

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



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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

We Want to Hear From You

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

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

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

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

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

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

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

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



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

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A Time For Sharing... Encounter

Something extraordinary happened to me in the summer of 2007 and again in winter 2008! I was given the news that I have cancer, not once but twice. Shaken to my core, wondering about my wife, two sons and prospects for life ahead; where would this lead? Words like extraordinary, encounter, blessings were not in consideration in those early days.

Extraordinary, however, can find a way to define anyone's cancer journey. I suppose for me this became a quest to not allow my cancers to be about cancer. What that meant nine years ago, I didn't initially understand, but I did know to at least give this journey a chance to play out in my life.

Life's happenings don't often explain themselves up front or even become clear until some period of time has passed and we can pause to look back, reflect and attempt to understand. In my case, what was so extraordinary - besides the obvious of a cancer diagnosis - was the relationship that I would develop with my healthcare facility and people who would treat my cancers. This is my story about meaningful *healthcare*.

"Encounter leads to mission, to sharing what we have received, and mission leads back to encounter in an expanding cycle of grace." Friends of mine, a group of young, devoted Sisters share this profound statement in their spiritual mentorship program that speaks to me, in my cancer journey about attempting to fully comprehend what it is that I have received through the rounds of radiation, chemotherapy and surgeries – on a much deeper level than medical treatment for a disease – and living it. My dear wife Gale felt early on after the initial diagnosis that this cancer was not about having cancer but more so a calling to mission; some meaningful purpose was hidden within. At that moment, I had no idea what that meant except some well-timed words of love, support and encouragement to think beyond this disease and consider right away how cancer might change my life. Very open ended I admit, having not even started treatment and the months of pain, illness,

weakness, fatigue and myriad side effects that are part of the process but it did give me something to consider that just might be larger than the cancer. Phew, that was a tall order as what could be larger than cancer when you've just been given a diagnosis? But I must admit those words set the tone for the journey.

Between 2007 and 2008

I was involved in radiation, chemotherapy and surgeries for head & neck cancer and shortly thereafter a second diagnosis of thyroid cancer. Living in northeast Ohio I am very fortunate to have the healthcare facilities we have in our region receiving my treatment at one of our world-renowned medical facilities in Cleveland.

Looking forward and counting the days until I would walk out of the hospital after my final treatment in the summer of 2008, I longed for the moment when I would wait and listen for the door of the hospital to close behind me and then I would march back in to my life. I found that goal to be misguided, however, when that day and moment presented itself and the door closed behind me. The life changing event that I was going through began to resonate ever more deeply within. The medical attention and level of compassion provided by my medical team was more than just treating these cancers. Doctors, nurses, technicians, lab workers, administrators, social workers and so many others revealed heart, soul and real emotions that fueled the healing energy within me. At that moment, I knew that I could not leave my healthcare facility behind; we had become friends and friends support and remain dedicated.

There are few harder tasks than healing and recovering from cancer. Helping one's body, emotional and spiritual health often takes longer than the treatment itself. And time and my efforts did march on. There came a time when I did consider myself healed from the treatments and surgeries - physically this took between four and five years - and yet recovery I have always thought would be a lifelong process as I

respond to the meaning of cancer in my life and allow that to continually shape who I am and who I shall become. Relationships with my medical team, deep with profound respect for their expertise have become friendships that offer me support, encouragement and lasting hope in the prospect that I have been healed. This continually reveals and confirms itself with every passing lab test and follow up visit that shows no sign of either cancer. My recovery is fueled by involvement in cancer support group activity, patient mentoring and other volunteer opportunities and these activities continue to shape the recovery of my mind, heart and spirit. In doing so, I can only hope that my participation brings some small ray of hope to other cancer patients in their journey. These relationships and positive life sharing volunteer activities remind me always to reflect and give thanks, continuing the *cycle of encounter*.

Throughout my post cancer years I have had the unique opportunity to be a member of a Patient Advisory Council at my healthcare facility, offering my perspective into many aspects of patient and family care within the institution. Invited to help shape the facility's vision for world class medical and compassionate care has been one of the more rewarding and enriching experiences in these years.

Over the past couple of years, our Patient Council has been involved with hospital administrators, architects and planners offering input on various aspects of the new cancer building which will be a state of the art facility to care for patients and families in their medical and personal needs. As a patient, my encounter with this healthcare institution resulted in my healing and this rare opportunity to have a voice in the new building design and its services has been a humbling and most extraordinary experience.

Our Patient Council has given opinion on various aspects of building design and planning; floor plan layouts, discussions on the design of patient changing and waiting areas, food service operations and healthy menu ideas and a voice in selecting the chair that would be used for chemotherapy infusion among other assignments. We've had tours of the cancer building as it has been under construction and were even

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invited to sign the final beam, which would be raised and set atop the new building in the “topping off” ceremony. All extraordinary experiences!

Nearly complete, the building opens in early March, an opportunity presented itself to participate in a few media events offering my perspective on our group involvement in the building design and planning. These events provided an opportunity to share with a larger audience about how our personal experiences and perspective will help future patients and families as they enter this new cancer building in their journey.

While I was at these media events, the new building has been fairly empty except for a few final construction and hospital workers putting on the finishing touches. Once again a rare and extraordinary experience presented itself and one that enhances my recovery. Afterwards, as I made my way around the building all by myself – somewhat of a self-guided tour – I visited

various locations: the building entrance and first floor area, upper floors medical areas, waiting rooms and a chemotherapy infusion room. At each point I had a moment of pause, deep reflection and thanksgiving to my Creator for my health and healing and offered a little prayer – *my blessing* – upon this new beautiful building. I hoped and prayed that all who work within these walls will provide patients and families the same measure of hope, comfort, health and healing that has been given to me.

I have developed over these years not only a deep and profound relationship with the institution and medical personnel but in an interesting way, a relationship with this new building. The new cancer building will stand as a beacon of health and healing for many who begin or continue their cancer journey at this hospital and as I go there for my regular follow up medical visits there will be moments of pause, reflection and thanksgiving for the extraordinary

experience that my cancer has given me. A small piece of me is in that building offering sentiments of hope that many others will experience *“encounter and this might lead them to mission and sharing what they have received from the Cleveland Clinic... the continuing on of an expanding cycle of grace.”*

Something extraordinary happened to me back then in 2007 and 2008 and it continues to play out in my life. In gratitude to my dear Gale and to my doctors, nurses, technicians, social workers, administrators and volunteer peers (you all know who you are) for my health, healing and helping to shape my lifelong recovery from cancer.

“For it is in giving that we receive.” ~ St. Francis of Assisi

In gratitude,
Jeff Husney, survivor!
jehusney@yahoo.com

SPOHNC Wants to Celebrate You!



Birthdays are very special. SPOHNC wants to celebrate and acknowledge your special day by wishing you a Happy Birthday in our newsletter. Each month, we will

dedicate a place in the publication to acknowledge your special day. Send us your name and your birthday, so we can celebrate YOU!

In recognition of our very first “SPOHNC Celebrates You!” we thought it only appropriate to celebrate the birthday of the woman who started it all – Survivor and SPOHNC Founder, Nancy Leupold. Nancy will celebrate her birthday on March 21st!

26 years ago, an incredible woman saw a need for support that was so vital to those who would go through what she had just endured - the diagnosis and treatment of a very rare cancer. Starting in her home, and with one Chapter Support group, SPOHNC began to grow and change each year, raising awareness and meeting the needs of oral and head and neck cancer patients through its

resources and publications. Nancy nurtured SPOHNC, just as parents nurture a newborn baby.

Ever watchful and dedicated to the success of the organization, Nancy gave tirelessly, overseeing the evolution and success of SPOHNC. Her humility, drive and compassion were the spark that created more than 125 Chapter Support groups, the National Survivor Volunteer Network of more than 200 volunteer survivors and caregivers, “News from SPOHNC” and the many print resources that the organization has available to benefit patients and survivors today.

With gratitude, admiration and sincere respect for an inspiration to us all, we wish you a wonderful day, and a very exciting year.

Happy Birthday Nancy!

“SPOHNC will always be her lifelong legacy to those of us who have had to deal with head and neck cancer.”

~ Philip LoPresti, MD



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is almost here
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with SPOHNC's
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*“SPOHNC is such
a worthwhile organization
for information, perspective and
hope along the journey.”*

~ Jeff H.

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Eat Well Stay Nourished A Recipe and Resource Guide for Coping With Eating Challenges

compiled by Nancy E. Leupold, Survivor, Founder and President Emeritus

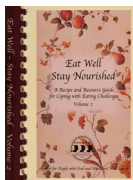


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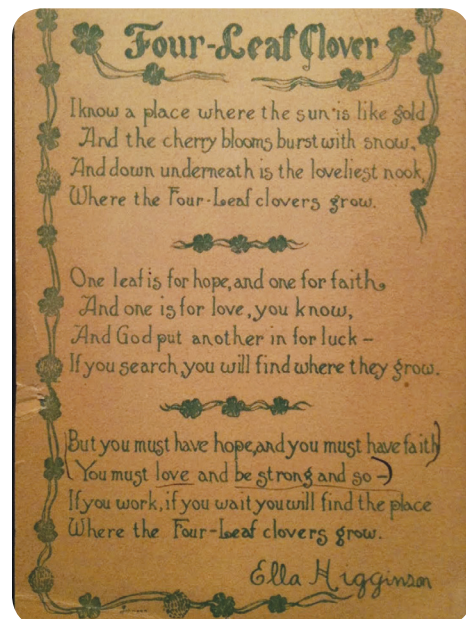
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St. Patricks Day Lunch from Eat Well Stay Nourished A Recipe and Resource Guide For Coping With Eating Challenges

Compiled and Edited by Nancy E. Leupold, Survivor, Founder & President Emeritus

Shepherds Pie 2

- ¾ lb. chopped meat
- ½ onion, diced
- 1 c. peas and carrots (frozen or canned, drained)
- 1 pkg. brown gravy mix (any brand)
- Ready made pie crusts (2 per package Pillsbury or store brand)
- or 3 c. mashed potatoes (ready made or made from dehydrated potato flakes)



Heat oven to 375 degrees. In a saucepan, brown chopped meat with onion. Add peas and carrots and gravy mix and enough water per package instructions. Cook until gravy thickens. Put one crust in pie plate and add the meat and vegetable mixture. Spread mashed potatoes on top. For a two crust pie, top with second crust and make two slits in the top crust to vent. Bake for 30 minutes. Serve with extra gravy and applesauce on the side. Serves 6. 251 calories per serving.

~ Jane Zanca, NY

Lime Bisque Pie

- 1 - 3 oz pkg. lime jello
- 1 c. sugar (scant)
- 1 ½ c. hot water
- juice and rind of 1 lemon
- 1 can evaporated milk
- 1 ½ tsp. salt
- Graham crackers or 2 ½ doz. vanilla wafers, crushed into fine crumbs



Place jello, rind, sugar and 1/8 teaspoon salt in bowl. Pour hot water into mixture, stirring until jello is dissolved. Add lemon juice. Place in refrigerator until jello is set. When set, beat jello with mixer until foamy. Set aside. Beat evaporated milk until thick. Fold this into the foamy jello mixture. Place crumbs into bottom of square glass baking dish. Pour jello whipped mixture in the dish. Save some of the cracker or wafer crumbs and sprinkle over the top. Place in refrigerator until firm. Yield 7 servings of ½ cup. 329 calories per serving.

~ Bette Denlinger, AZ

Cooking Tips - From Eat Well Stay Nourished - Volume 2

"What can I add to give this more calories?"

- | | |
|---------------------------------------|---------------------------------|
| Butter/Margarine - 1 Tbsp. - 100 cal. | Maple Syrup - 2 Tbsp. - 100 |
| Mayonnaise - 1 Tbsp. - 100 | Honey - 1 Tbsp. - 64 |
| Oil - 1 Tbsp. - 120 | Sugar - 1 Tbsp. - 45 |
| Cream Cheese - 2 Tbsp. - 100 | Jelly - 1 Tbsp. - 50 |
| Peanut Butter - 1 Tbsp. - 100 | Chocolate Syrup - 2 Tbsp. - 100 |
| Salad Dressing - 2 Tbsp. - 170 | Chocolate Fudge - 1 Tbsp. - 75 |
| Cheese - 1 oz. - 100 | Caramel Sauce - 1 Tbsp. - 60 |
| Ricotta Cheese - ½ c. - 216 | Frosting - 2 Tbsp. - 134 |
| Heavy Cream - 1 Tbsp. - 52 | Whipped Topping - 2 Tbsp. - 30 |



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Chapter Facilitator News

SPOHNC San Diego, CA Chapter Facilitator Valerie Targia Attends PCORI 2016 ANNUAL MEETING

PCORI—Patient Centered Outcomes Research Institute, as the name suggests, is an organization dedicated to making health research more patient-centered, and stakeholder-driven. Their focus is not solely on oncology, but on clinical research, and studies designed to illustrate the best outcomes for patients. Their goal is to assist patients, and caregivers make better-informed decisions about their health care. They bring together community healthcare stakeholders trying to change the path and culture of research to encourage more relevant and useful studies for patients and caregivers. In other words, research done differently.



Last November 17-19, the PCORI 2016 annual meeting, to which I was invited, was held in the huge and impressive Gaylord Convention Center in National Harbor, Washington DC. The theme for the 2016 meeting was “Changing the Conversation about Health Research.” There were approximately 1,200 participating attendees.

For the last three years, I’ve been working with doctors at the University of Rochester on a study to develop a standardized, pretreatment assessment that will benefit geriatric cancer patients. One

of the doctors spoke at the conference. This work is funded by PCORI, so, I knew generally what their mission was, but I was really impressed at the conference by the absolute commitment and dedication illustrated in their ethics, and workshop sessions, by every one of their employees, speakers, participating patients, and invited guests.

The entire preconference day, with various speakers, was dedicated to teaching new participants an overview of the PCORI organization and the work that it does. A couple of the speakers’ quotes that spoke volumes about their theme were, “The secret of caring for the patient is actually caring for the patient”. And, “You can’t do anything differently until you see things differently.”

The next two days were jam-packed

with workshops, plenary sessions with speakers, discussion panels, and the huge, and varied, stakeholder audience Q & A participation. Brain-diving, immersion education at its finest!

There were far too many sessions to list, but the following is just a small sample:

- How is PCORI Advancing Patient-centered Care?
- Patient and Stakeholder Engagement in Research Identifying Challenges and Developing Solutions.
- Golden Years and Easing Fears.
- Achievements in Data, Research, and Engagement.
- A New Vision for Health Research.

For me, this participation in the PCORI Annual Meeting was such a beneficial, mind-expanding experience that I am grateful for, and will never forget. I came away from the PCORI annual meeting full of information and admiration for the foresight and the work that they are doing. You can access the entire 2016 PCORI Annual Meeting agenda on their website at pcori.org

~ Valerie Targia
Facilitator SPOHNC San Diego, CA

HEAD AND NECK CANCER NEWS

ASCO Endorses Head and Neck Cancer Guideline

March 7, 2017 - The American Society of Clinical Oncology (ASCO) has endorsed the American Cancer Society’s head and neck cancer survivorship care guideline, adding qualifying statements aimed at promoting team-based, multispecialty, multidisciplinary, collaborative head and neck survivorship care. Among the recommendations:

- * Caring for head and neck cancer survivors requires a team-based approach that includes primary care clinicians, oncology specialists, otolaryngologists, dentists, and other allied professionals.
- * The head and neck cancer treatment team should educate primary care clinicians and patients about the type of treatment received, the likelihood of potential recurrence, and the potential late and long-term complications.
- * Primary care clinicians should recognize symptoms of recurrence and coordinate a prompt evaluation.
- * They should also be prepared to manage late effects either directly or by referral to appropriate specialists.
- * Health promotion is critical, particularly regarding tobacco cessation and dental care.

Editors Note: SPOHNC is excited to announce that we will be attending the 2017 ASCO Conference in Chicago, from June 2 - 5th. The conference offers SPOHNC many opportunities to connect with world renowned head and neck cancer physicians and to educate conference attendees about the programs and services of support that SPOHNC continues to offer to oral, head and neck cancer patients, survivors and the healthcare professionals involved in their care.



***“As the flower blooms in
spring, compassion grows
in mindfulness.”***

~ Amit Ray

Visit the SPOHNC website at www.spohnc.org

Head and Neck Cancer News

A revolutionary blood test that can detect cancer

Liquid biopsies: A \$20 billion market ready to explode

Dr. Victor Velculescu envisions a day — not so far off — when screening for cancer will become as simple as a blood test during your annual physical.

Unique cancer mutations show up in microscopic fragments of DNA in a patient's blood, which can give physicians a telltale sign of the presence of the disease in almost all types of cancer mutations — within cells or floating freely in the bloodstream.

The “liquid biopsies,” as the tests are known, have become something of a Holy Grail in cancer treatment among physicians, researchers and companies betting big on the technology. Liquid biopsies — unlike traditional biopsies involving invasive surgery — rely on an ordinary blood draw. Advances in sequencing the human genome, enabling researchers to detect genetic mutations of cancers, have made the tests possible.

“It is revolutionary,” said Velculescu, the co-director of cancer biology and professor of oncology and pathology at the Johns Hopkins University Kimmel Cancer Center. “I think in the next, let's say, five years, it'll become part of an annual physical.”

That could lead to early detection of cancers, said Velculescu, who, along with colleagues at Hopkins, has studied liquid biopsies in hundreds of patients with lung, breast, colon, pancreatic and ovarian cancers.

“Early detection has exciting possibilities because it allows us to imagine getting cancers at the time at which they could still be taken out surgically,” Velculescu noted. “It allows us to think about using therapies that'll be more effective, because they'll be applied earlier on in the disease — with all sorts of improvements in the overall outcome, survival and morbidity or how patients do — just based on detecting the cancer earlier.”

The liquid biopsies are already being used commercially on a limited basis, though mainly in patients with Stage 3 or Stage 4 cancers, to help determine how well treatment is working.

As recently as a few years ago, the liquid biopsies were rarely used except

in research. Today, thousands of the tests are being used in clinical practices in the United States and abroad, including at the M.D. Anderson Cancer Center in Houston; the University of California, San Diego; the University of California, San Francisco; the Duke Cancer Institute and numerous other cancer centers.

And Silicon Valley venture firms like Sequoia Capital, New Enterprise Associates and Khosla Ventures have invested tens of millions of dollars in the technology. That's because the market potential is huge.

Velculescu and fellow Hopkins researcher Luis Diaz have co-founded Baltimore-based Personal Genome Diagnostics to develop the tests. PGD raised \$21 million in October from New Enterprise Associates, a venture capitalist firm in Menlo Park, California.

On Sunday, Illumina announced the formation of a new company, called GRAIL, which will focus on blood-based cancer screening. The company is majority owned by Illumina and funded by more than \$100 million in Series A financing from Illumina and ARCH Venture Partners, with participating investments from Bezos Expeditions and Sutter Hill Ventures.

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Besides Illumina, other public companies in this field include Genomic Health and Myriad Genetics. Private companies developing liquid biopsies include Guardant Health and Pathway Genomics.

Guardant is among the leaders in developing the liquid biopsy, and CEO and co-founder Helmy Eltoukhy said its test has been used in more than 20,000 patients in the U.S. and abroad. As Eltoukhy pointed out: “It's a much more game-changing paradigm than I think a lot of people realize.”

Guardant, founded in 2012, has been supported by nearly \$200 million from

venture capitalists, including Sequoia Capital and Khosla Ventures.

But the liquid biopsy remains pricey — Guardant's costs \$5,400 per test, with some health insurance plans picking up a portion of that — and the cost may still be prohibitive for many patients.

Including blood tests for the estimated 14.5 million cancer survivors in the United States, Eltoukhy projects the U.S. market potential for the liquid biopsy at more than \$20 billion a year.

How long it takes to get results for the test depends on how comprehensive it is, Eltoukhy explained. Guardant's takes an average of 12 days, compared with nearly a month for traditional biopsies.

According to Samir Kaul, a founding general partner at Khosla Ventures, “It's not a cure, it's not a therapy, but it will improve and extend duration and quality of life of all the people who get diagnosed with a horrible disease.”

Dr. David Hyman, an oncologist at Memorial Sloan Kettering Cancer Center in New York City, likens the genetic markers that cancers shed into the bloodstream to UPC bar-coding on products.

“The concept is, essentially, each genetic mutation is unique, and it kind of labels the DNA as having come from the cancer,” Hyman said. “In that sense, you can kind of think of it as a bar code.”

“There's no question that this technology has tremendous promise in identifying mutations of clinical relevance to patients with cancer and helping guide therapy,” Hyman explained. “I think it will start to enter into the realm of routine clinical practice, in limited areas at first, where it's well studied and well proven.”

Nanotechnology advances have helped move commercial development forward. At Cornell, researchers have created a new tool that sorts and collects DNA, one molecule at a time and pinpoints the molecules that have characteristics that cause cancer because of external or environmental factors that switch genes on and off.

Victor Velculescu, a researcher at Johns Hopkins University School of Medicine, is [shown in a lab at the Johns Hopkins Kimmel](#)

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Cancer Center where DNA samples from blood are sequenced to detect cancer-related mutations.

For cancer patients undergoing treatment, liquid biopsies could spare them some of the painful, expensive and risky tissue tumor biopsies and reduce reliance on CT scans, which must be limited because of the danger posed by overexposure to radiation.

With patients for whom physicians cannot get a tissue biopsy — e.g. some lung cancer patients with tumors too dangerously close to arteries or the heart — the liquid biopsy could prove a safe and effective alternative that could help determine whether treatment is helping eradicate the cancer.

“We can actually do it without even looking at the tumor,” Velculescu said. “We can just look at the blood.”

However, experts caution that more studies are necessary to determine the accuracy of the test, precisely which cancers it can detect at what stages and whether it improves care or survival rates.

Early research on the liquid biopsy has focused heavily on patients with later-stage cancers who have undergone treatments, including chemotherapy, radiation, surgery, immunotherapy or drugs that target molecules involved in the growth, progression and spread of cancer. The tests can quickly assess the effectiveness of surgery or other treatment, while traditional biopsies and CT scans can still remain inconclusive as a result of scar tissue near the tumor site.

“You could actually follow how your tumor is growing or shrinking while you’re on a certain therapy,” Velculescu said. “And you could use that to determine whether the therapy’s working or whether you should switch to another therapy.”

DNA fragments are found in relatively high concentrations in the blood of most patients with metastatic cancer and at much lower, but detectable, concentrations in a substantial fraction of patients with localized cancers.

Researchers at Hopkins and 23 other cancer centers did a survey in 2014 of liquid biopsies in 846 patients with 15 different types of cancer, and the tests revealed cancers in the blood of 80 percent of those with advanced cancers, but only 47 percent of those with localized disease.

“The results showed that in early-stage cancer, we still have some work to do,” Velculescu said. “In those cases, repeating liquid biopsies may be needed.”

The liquid biopsies also appear to work better in some cancers than others. The tests, for instance, appear to be less effective in detecting brain cancers, partly due to the blood-brain barrier, a natural defense system that regulates the passages of substances between blood and the brain.

Dr. Mark Roschewski, a staff clinician at the National Cancer Institute (NCI) in Bethesda, Maryland, predicts it’ll take three to five years for the test to go mainstream in the detection and treatment of cancer.

“It’s not quite ready for prime time, but it’s moving in that direction,” Roschewski said. But he noted the liquid biopsy shows real promise: An NCI study published in April in “The Lancet Oncology” involving 126 patients with the most common form of lymphoma showed the test predicted recurrences more than three months before they turned up in CT scans.

The study also revealed which of the patients would likely respond well to therapy and which would respond poorly. That knowledge can help doctors in deciding whether to pursue a different treatment course.

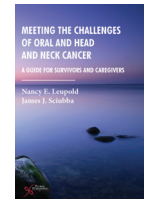
Guardant’s Eltoukhy is optimistic and said the liquid biopsy has come a long way even in the past year and a half. “When we launched the tests commercially in June of 2014, very few people, including oncologists, knew what a liquid biopsy was.”

Fast-forwarding to today, doctors and medical researchers are excited by the prospect that liquid biopsies would be a way to help people already fighting the disease. Doctors can pick a drug according to the specific DNA mutation driving cancer forward. Tests to identify the mutation are sometimes done on tissue taken from a tumor, but a noninvasive blood test would be appropriate in many cases.

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SPOHNC has now published several unique print resources to help newly diagnosed patients and their families.

“News from SPOHNC” has been published for 26 years, offering the latest head and neck cancer news, information and inspiration.

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SPOHNC & Pro Football Hall of Famer Jim Kelly Stay in the Game with “Your Cancer Game Plan”

The excitement of Super Bowl Sunday has long passed, but SPOHNC continues to stay in the game, with Jim Kelly and the “Your Cancer Game Plan” campaign. We have been sharing lots of great information as part of the campaign on SPOHNC’s Facebook group and page, and on SPOHNC’s website as well. The videos are a powerful tool, conveying the campaign messages about the importance of support, nutrition and communication.



SPOHNC’s friends, Dennis Staropoli (survivor), and Maria (survivor) and Tom (caregiver) Folchetti deserve great recognition and many accolades for their bravery and their willingness to open up their hearts and share their stories with our audience in the video presentations on the campaign website.

SPOHNC thanks you all, from the bottom of our hearts, for taking the time from your busy lives, to help impart the message of the “Your Cancer Game Plan” campaign. Comments from patient callers and survivors are coming in every day, from those who have seen the webinar, the videos and read the postings on Facebook. Important information for those along their own cancer journey has been shared through the campaign in a very unique way.

It has been and continues to be an honor and a pleasure to work with Jim Kelly. SPOHNC is grateful for the opportunity to partner with Merck, the Head and Neck Cancer Alliance and Savor Health on this very important initiative, raising awareness of oral, head and neck cancer.

News from Niagara Falls

SPOHNC is very excited to share the news that once again this year, Niagara Falls will be illuminated in SPOHNC’s colors in April. The request was submitted many months ago in the hopes of raising awareness of oral, head and neck cancer and SPOHNC.

On April 3rd in the evening, from 10 til 10:15pm, the magnificent falls will light the night sky with beautiful burgundy and ivory, recognizing all of those who have been affected by the diagnosis of oral, head and neck cancer.



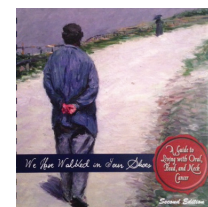
If you happen to be in the area, you can see it, from both the New York and Canadian side.

If you can’t schedule a trip in April, but still want to see the beautiful Falls as they are lit up in SPOHNC’s colors at night, look online at the Niagara Falls webcam for a live video feed at www.niagarafallslive.com/Niagara_Falls_Webcam.htm.

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