

CPEN QUARTERLY



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Partnering with the National Cancer Institute

Chair's Corner

By *Annette Mercurio, City of Hope*

Dear CPEN Colleagues,

As we reflect on the past year and anticipate the new one, CPEN's momentous past and promising future are on my mind. In 2009, we will celebrate the 20th Anniversary of CPEN! Three current CPEN members – Pat Agre, Louise Villejo and I – were present when Kathy Crosson, then Chief of Patient Education at NCI – convened the first CPEN meeting in 1989. Kathy envisioned CPEN as a network of patient education leaders that would elevate the quality of cancer patient education across the country. As we look back over the past two decades, Kathy Crosson's vision has clearly been realized.

I am thankful for past chairs who led CPEN through the challenging transition from NCI "offspring" to a non-profit, international organization. Louise Villejo, Susan DeCristofaro, Lydia Cheney, Jean Just, Diane Cole, Audrey Friedman, Tanya Smith, Kelli Fee-Schroeder – all remarkable, strong women who contributed the wisdom and leadership required for CPEN to survive and thrive.

CPEN has accomplished much over the past twenty years – from outstanding annual conferences, to published articles, a listserv, quarterly newsletter, resource guides, strong committees and more. When we ask CPEN members what they value most, it continues to be outstanding opportunities for networking among colleagues. The heart of CPEN has always been wonderful, supportive colleagues who are

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eager to share their experience and expertise and to learn from others. CPEN has undergone great transformation – yet, we have retained the essence of what makes our organization so valuable.

As I consider CPEN's promising future, I am particularly excited about opportunities arising from our merger with CPEN Canada. Those of us who attended the First Annual Canadian Cancer Patient Education Symposium in 2002 realized then how much could be gained from closer association between cancer patient educators in Canada and the United States. We have much to learn from each other. The Board of Directors has been enriched by the addition of Ann-Marie Stacey and the participation in monthly calls of Gale Turnbull, CPEN Canada Chair.

What thoughts do you have about the priorities and direction of CPEN in the coming year? I welcome your ideas and look forward to hearing from you by e-mail (amercurio@coh.org) or phone (626-301-8926).

With warmest wishes for a wonderful new year,
Annette Mercurio, MPH, CHES
2008-2009 CPEN Chair

CancerQuest

By *Gregg Orloff, PhD, Professor, Biology, Emory University*

I created the award winning website, CancerQuest (<http://cancerquest.org>), in response to my wife's experience with breast cancer. CancerQuest is designed to teach the biology of cancer and cancer treatments. The target audience includes patients, caregivers, medical professionals and students. The site was named by *Scientific American* as one of the top five sites in the category of medicine just 6 months after its launch. In 2007, CancerQuest was named the best cancer education site outside of Europe by the European School of Oncology.

CancerQuest is organized much like a textbook and has extensive coverage of many cancer treatments, survivorship issues and cancer prevention. Rich graphics, animations and videos present complex topics in an easily understood manner. The site contains numerous interviews with cancer patients, researchers and clinicians. A library of research seminars is available, including synchronized PowerPoint presentations. Much of the material on CancerQuest is available in multiple languages, with translations into Spanish, Simplified Mandarin, Traditional Mandarin, Russian and Italian.

Features of CancerQuest include complete references, self-testing modules, full printing capabilities and a custom dictionary. Interactive games and content make learning on CancerQuest enjoyable.

CancerQuest has produced free educational materials that are available for downloading or upon request.

PowerPoint files, lesson plans and other materials are available for skin cancer and cervical cancer. For more information or to obtain a free 3D skin cancer poster or breast cancer DVD contact CancerQuest at CancerQuest@emory.edu.

Cancer Patient Education Network
Canada 2009 Conference

***Connecting,
Collaborating and
Communicating:
Education at the Heart
of Cancer Care***

June 4-6, 2009

Fantasyland Hotel Edmonton,
Alberta, Canada

Deadline for abstract submission is
February 14, 2009

See cancerpatienteducation.org
for more information on the
conference and submitting an
abstract.

2009 Newsletter Schedule

<u>Submission Deadline</u>	<u>Newsletter Published</u>
February 6, 2009	February 17, 2009
May 1, 2009	May 18, 2009
August 3, 2009	August 17, 2009
November 2, 2009	November 16, 2009

Submit articles to:

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CPEN Annual Conference Awards

By Kelli Fee-Schroeder, Mayo Clinic

The Cancer Patient Education Network recognizes individuals and/or groups both within CPEN and affiliated groups who have made a significant contribution in the field of cancer patient education. This year, three recognition awards were given at the 2008 AACE/CPEN/EACE Annual conference in Clearwater Beach, Florida.

The Gold Star Award recognizes that cancer patient education is an aspect of quality care shared by the entire community. This award celebrates the achievements of individuals, groups or organizations whose efforts have resulted in extraordinary contributions to patient, families or health care practitioners.

This year's **2008 Gold Star** recipient is: **The National Bone Marrow Transplant LINK cGvHD Support Program** located in Southfield, Michigan Program participants include: Tina Rowe, MBA; Myra Jacobs, MA; Sandra Mitchell, PhD, CRNP, AOCN; Steven Pavletic, MD; and Kathleen Castro, RN, MSN, AOCN

The Excellence in Patient Education Award recognizes a CPEN member or group of CPEN members who have significantly contributed to patient education. This award recognizes creative approaches to developing and/or disseminating patient education based on resources available.

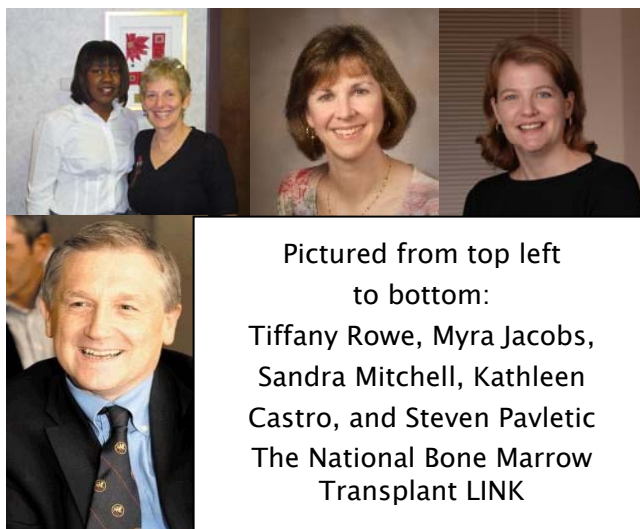
This year's **2008 Excellence in Patient Education** recipient is: **The Learning Center at M.D. Anderson Cancer Center** located in Houston, Texas Staff include: Elaina Cundiff, Louise Villejo, Amy Gonzalez, Rosemary Catallo, Jila Tanha, Linda Yarger, Liz Brackeen, Monica Taras, Rosa Fores, Nancy Robbins

The Distinguished Service Award is CPEN's highest form of recognition given to a CPEN member for

her/his outstanding contributions to the practice and profession of patient education. It is given for accomplishments and tangible contributions that have promoted excellence in patient education as an integral part of patient care.

This year's **2008 Distinguished Service Award** recipient is: **Jean Just, MSN, RN-BC** located at The Ohio State University Medical Center in Columbus, Ohio

Congratulations to all of the CPEN award recipients!!



Pictured from top left to bottom:
Tiffany Rowe, Myra Jacobs, Sandra Mitchell, Kathleen Castro, and Steven Pavletic
The National Bone Marrow Transplant LINK



Above: Jean Just
At Left: Staff of the Learning Center at M.D. Anderson

The Thy'vors Low Iodine Diet Project: The Role of Patient Groups in Enabling Patient Self-Management

By *Grace Wright and Rita Banach*

For decades, patient-led support groups have operated in response to the growing need of cancer patients to reach out and find each other, in the hopes of building positive relationships, sharing their experiences, seeking information, and dealing with uncertainty. These four needs have been concretely reflected in the National Cancer Institute's (NCI) "Six Functions of Patient/Clinician Communication in Cancer Settings": "fostering healing relationships, exchanging information, responding to emotions, managing uncertainty, making decisions and enabling patient self-management".¹ In light of the increased attention now focused on patient-centred communication in cancer care, the Canadian Thyroid Cancer Support Group (Thy'vors) Inc. was encouraged to learn that its efforts are supported by the NCI's publication and the follow-up attention given to it by the Cancer Patient Education Network (CPEN). In addition to working to meet the patient needs mentioned above, Thy'vors has also undertaken activities that carry out the sixth function of patient-centred communication, that of enabling patient self-management.

A particularly challenging demand of thyroid cancer treatment is the active role that the patient must take in adhering to regimens and protocols during and after treatment. One such regimen is adherence to the Low Iodine Diet (LID) which is widely prescribed for patients undergoing radioactive iodine ablation or testing. In a recent study, Hinds et al concluded that an LID is integral to the management of differentiated thyroid cancer.¹ A typical explanation by a clinician of the LID might go something like this: "You're going to get a dose of radioactive iodine to hopefully zap any thyroid cells that might have been left behind during your thyroidectomy. In order to maximize the effectiveness of the radioactive iodine, we need to starve your body of iodine so that your body absorbs as much of the radioactive iodine as possible. So, for a couple of weeks beforehand, don't eat any salt and avoid these foods." Then the patient is likely to be handed a faded photocopy of the do's and don't's of the LID, and often, that's where the instruction and explanation ends. In addition, there was great variation among the versions of the LID prescribed by clinicians across Canada. For example, up until a few years ago, patients at one hospital in Toronto would have seen that they are not allowed to eat bananas while on the LID, but directly across the street at another major hospital there is no mention of bananas in their LID handout. Most patients across the country will be told to avoid all dairy, but in the Maritime Provinces patients were likely to be cautioned to just cut back on milk products while on the LID. With the increased access to, and popularity of, internet communications, patients uncovered the variations in medical advice they were given. Confusing instructions and puzzling inconsistencies, such as the mysterious iodized bananas in one block of Toronto and low-iodine cows on the East Coast, magnified patient worry about the LID and whether they might jeopardize the effectiveness of the RAI treatment or testing. However, thanks to a landmark initiative carried out by the efforts of Thy'vors volunteers and members, much of the concern and confusion has now been alleviated.

Among its various support and resource programs for thyroid cancer patients, Thy'vors operates an on-line forum, and every year approximately 20% of the messages posted include questions or comments about the LID. In fact, since its inception in 2000, a large portion of the organization's volunteer efforts has been dedicated to addressing trepidation or confusion about the LID. After extensive research to prepare "Frequently Asked Questions about a Low Iodine Diet" to help explain what radioactive iodine is and where iodine can be commonly found in our food system, Thy'vors volunteers were still facing the problematic number of inconsistencies among the different versions of the LID being prescribed across the country.

In 2004, Thy'vors decided to embark on a mission to standardize the LID for all thyroid cancer patients in Canada who would be undergoing RAI ablation or testing. The process began with gathering over 30 versions of the LID from across North America, confirming that almost none of them were identical in their instructions and/or food listings. In consultation with medical, food manufacturing and food labelling industry and government experts, a team of six volunteers worked, in their spare time and through virtual meetings online, for over a year to develop the *Thy'vors Low Iodine Diet*. After 19 revisions, the final text version of the diet was reviewed by over 30 experts including the Thy'vors Medical Advisory Panel (MAP), patient educators, dietitians, government representatives, packaging experts and ten patients to comment on its usefulness and readability. One of Thy'vors objectives is to deliver its information resources in "plain English" and the *Thy'vors Low Iodine Diet* was no exception. The research and writing committee was greatly

motivated by comments such as “It’s high time there was one LID for everyone. It avoids confusion.”, “it clearly explains why we need to do the diet and how the treatment works.”, and “First-time LID’ers are worried and confused enough...with this, a quick glance and we are on our merry hypo[thyroid] way”. In consultation with a Clear Language Expert and with other valuable professional and patient feedback, the resource took shape in the format of a pamphlet, printed on cardstock; that opens up into a full-colour Food Guide for easy reference by patients. One of the most valuable bits of advice offered is the easy to understand, easy to follow **“if in doubt, leave it out”**.

It was crucial to the success of the project that the *Thry’vors Low Iodine Diet (T-LID)* be credible and that its development be transparent. To this end, the 11-page document “Low Iodine Project 2006: Purpose, References, Writers and Reviewers” was compiled and available at www.thryvors.org. In November 2006 the *T-LID* was launched with a mass mailing of a sample copy to 700 doctors and healthcare providers across the Canada. Within six months, 18 bulk orders requests for the *T-LID* were filled and to date over 80 different clinicians and/or cancer centres (from every province and parts of the US) have placed repeat bulk orders. Awareness was further raised through an article featured in the inaugural of CancerSmart – the patient information newsletter published by Wellspring Cancer Support Foundation – and through a presentation made at the 2007 CPEN-Canada conference in Montreal, Quebec. The efforts of Thry’vors outreach volunteers has ensured that as of August 2008, over 8,160 copies of the LID have been distributed, and links to the online PDF have been found on patient education sites in the U.S., Europe, Asia, and Australia.

While the resource is being well-received by clinicians and patients, we at Thry’vors know that our work in supporting this aspect of self-management is not done. As we continue to listen to our members, we know that it is not enough to explain what a patient can or can’t eat. We hear the anxiety about reading food labels properly or preparing meals that comply with the LID but don’t require a second meal to be made for the rest of the family (women are much more likely than men to be diagnosed with thyroid cancer and frequently our female members continue to play a key role in food preparation for their families). For many individuals the thought of avoiding prepared food and cooking from scratch is overwhelming. Add to that being in the midst of cancer treatment and the increased need for support to adhere to a protocol is undeniable. A patient reviewer who had just completed RAI treatment commented “when hypo[thyroid] it would be very handy to have that info posted”. Thry’vors is answering this call for more help by developing a Shopping Guide and Menu Planner. Currently in the final revision stage, these two new resources are due to be launched in November 2008 along with some updates to the LID. The launch will coincide with features about Thry’vors and our services in the newsletters of the Canadian Nuclear Medicine Association and the Canadian Society of Endocrinologists, and an article about the *T-LID* will be printed in an upcoming issue of the Dietitians of Canada Oncology Network Infoletter.

The effectiveness of any tool is improved when the user is taught how to use it properly. Thry’vors supports clinicians by providing in-service information sessions to explain the *T-LID* and how patients can be helped to more easily adhere to the LID protocol. Just as the NCI stated, “...healthcare systems have an important role in supporting patients’ self-management by providing easy access to personnel, experts, programs, and media that can guide and inform self-management.”¹ Among the suggested ways by which this can be achieved is the sponsoring of community-based programs. Communities of cancer patients are growing and developing increasingly relevant, credible and valuable education and support programs, such as the *Thry’vors Low Iodine Diet*. At Thry’vors we hope that our successes may serve as an example of how patient groups and clinicians can collaborate in the delivery of supportive cancer care through patient-centred communication initiatives.

(The Canadian Thyroid Cancer Support Group (Thry’vors) is an incorporated non-profit group, operated by volunteers who are themselves affected by thyroid cancer. Thry’vors is dedicated to providing emotional support and information to those affected by the disease For more information please visit www.thryvors.org)

¹National Cancer Institute, Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. National Cancer Institute, 2007. <http://outcomes.cancer.gov/areas/pcc/communicationp.67>

²This recent case-study states the “proper guidance and emphasis on the implementation of the diet needs to be provided to patients. Non-compliance may lead to false negative imaging results, misleading the medical professionals and patient. Potentially inadequate management of the patients’ thyroid cancer may follow. “Low Iodine Diet Revisited: Importance in Nuclear Medicine Imaging and Management”, Clinical Nuclear Medicine, 33 (4): 247-250, April 2008.

³National Cancer Institute, pg. 30

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