

CPEN QUARTERLY



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Partnering with the National Cancer Institute

Chair's Corner

By *Kelli Fee-Schroeder*

At some point, when the Chair position was transitioning from Tanya to me, I realized that one of my duties was to write a newsletter piece. I have to admit that it caused a little anxiety on my part. I sat down and drafted a number of paragraphs and I realized I was probably making this harder than it needed to be. I had to remind myself - keep this short and simple.

First of all, I am honored to be serving CPEN in this role. So many accomplishments and changes have occurred over the past few years and I think 2007-2008 will be no different. CPEN's strength and growth continues to be actualized through the dedication, passion, expertise and collaborative spirit of the membership.

A few of the issues/initiatives the Board will be addressing this year include:

-Planning the joint conference with the American Association for Cancer Education (AACE) on October 20-22, 2008

2008 Newsletter and Submission Schedule

By *Donna Branson*

In the box to the right you will find the article submission deadline and the schedule for the 2008 newsletters. Remember, this is your newsletter, so let us know what you are interested in. If you would like to be featured in our center/staff spotlight or have a resource you would like to share please let me know. I would like to thank Alissa Lewandowski and Desirae Nasrallah for their assistance with the newsletter.

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- Adopting CPEN-Canada as a Chapter organization
- Updating/refining the CPEN website
- Exploring establishment of a CPEN scholarship fund to attend the annual meeting
- Supporting CPEN committees as they continue to actualize goals outlined in the strategic plan

I will try to keep you all updated on these initiatives as changes occur, but please do not hesitate to contact me at feeschroeder.kelliann@mayo.edu if you have any questions or suggestions.

Thank you and I'll be in touch.

Kelli



Submission Deadline

February 4, 2008
May 5, 2008
August 4, 2008
November 3, 2008

Newsletter Published

February 18, 2008
May 19, 2008
August 18, 2008
November 17, 2008

Submit articles to:

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Big Thanks to Memorial Sloan–Kettering Cancer Center

By *Donna Branson*

The CPEN Board would like to express their gratitude to the local planning committee of Patricia Agre, Jessica Dirkes, and Irina Vinokur. The small committee of three from Memorial Sloan–Kettering Cancer Center did an outstanding job of hosting the 17th Annual CPEN Meeting. The meeting was held October 10–13, 2007.

In addition to providing an excellent program they arranged a memorable harbor cruise for all of us. Seeing the majestic Statue of Liberty at night is something I know I won't ever forget! Thanks again to Pat, Jessica, and Irina for all their hard work. The conference was a big success!



Irina Vinokur, Patricia Agre, and Jessica Dirkes

CPEN Annual Business Meeting Update

By *Janine Kokal and Donna Branson*

The CPEN Annual Business meeting is held each year at the annual conference. This year it was held on October 11, 2007 at the CPEN conference at Memorial Sloan–Kettering Cancer Center in New York City. There were 54 CPEN members who attended the meeting. The following is a brief overview of the information shared at the meeting.

Announcement of 2007–2008 Board of Directors

Susan Scritchfield thanked CPEN members for voting in the recent election and she announced the 2007–2008 Board of Directors.

- ❖ Kelli Fee–Schroeder, Chair
- ❖ Tanya Smith, Past Chair
- ❖ Donna Branson, Treasurer
- ❖ Janine Kokal, Secretary
- ❖ Lydia Cheney, Member at Large
- ❖ Kerry Harwood, Member at Large
- ❖ Lisa Horton, Member at Large
- ❖ Deborah Steele, Member at Large
- ❖ Rose Mary Padberg, NCI Liaison

Outgoing board members were also thanked for their service and included Audrey Friedman, Karen Stepan, Louise Villejo, and Susan Scritchfield.

2007 Past–Chair's Report

Tanya Smith reported on the progress made during her tenure as Chair. Accomplishments included:

- ❖ Receiving 501(c)3 status making CPEN an official non–profit organization.
- ❖ Building relationships with the American Association for Cancer Education, CPEN–Canada and CancerCare.
- ❖ Increasing communication with CPEN members through the CPEN Quarterly Newsletter and surveying the members.
- ❖ CPEN Committees were very active and worked on a number of projects to help CPEN accomplish the goals of the 5–Year Strategic Plan.

2008 Chair's Report

Kelli Fee–Schroeder was welcomed into her new role as CPEN Chair. She is from Rochester, Minnesota where she works as a Cancer Educator at Mayo Clinic Cancer Center. She has been a member of CPEN for 10 years.

Please see *Business Meeting* on page 5

Welcome New CPEN Members

By *Donna Branson*

We were pleased to have several new CPEN members attend the 2007 CPEN conference. Our new members represent various cancer centers and cancer concerned organizations in the U.S. and Canada. If you are new to CPEN and have any questions about being a CPEN member, please contact me at 801-585-6809 or donna.branson@hci.utah.edu.



New CPEN Members (l to r): Celia Muench, Chesley Cheatham, Keri Mercer, and Chris Perry



New CPEN Members (l to r, front): Patricia Boone, Janet Papadakos, Jill Bartholomew, Deborah Miller; (l to r, back): Bebe Guill, Sam Howland, Melissa Sileo, Lee Boerner, Haley Justice, and Nicole Engler

Editors Note: *Please accept my apology if your name is wrong.*

CPEN Award Recognition

By *Anne Sweet, RN, BSN, OCN, Chair, CPEN Awards Committee*

This year marked the eighth Cancer Patient Education Network (CPEN) Award program which provides a means to recognize individuals or groups for their dedication and contributions to cancer patient education. Three individuals were recognized at the annual conference during a luncheon on Friday, October 12.

Jean Hartford-Todd, CLLS, of the Preston Robert Tisch Brain Tumor Center at Duke University Medical Center in Durham, North Carolina, was awarded the *Excellence in Cancer Patient Education Award* for resource and program development for patients and families dealing with brain tumors. Jean's work includes development of the Learning Center at the Preston Robert Tisch Brain Tumor

Center which is the focal point of their educational program where patients and families gather in a non-threatening environment to partake in hands-on interactive learning.

In addition to a series of five animated learning modules, Jean has co-authored the following resources: *Things to Consider When Your Child Has a Terminal Illness*; *Legacy: Helping Your Children When You Have a Life-Threatening Illness*; and *Helping Children Cope With Behavior or Personality Changes in a Parent With a Brain Tumor*. Her contributions have significantly made a difference for numerous families over the years as evident by various letters of appreciation.

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CPEN Award Recognition from page 3

Recognizing the global need for plain and simple health information in multiple languages, **Diane Moyer, RN, MS**, of Ohio State University Medical Center, Consumer Health Education in Columbus, Ohio, spearheaded an initiative on behalf of her organization in conjunction with Ohio Health and Mt. Carmel Health System. Through this nonproprietary partnership the *Health Information Translations* website was born.

The website lists hundreds of titles in multiple languages without copyright restrictions. Each title provides the English page of the document followed by the foreign language page – a distinct feature compared to other translated resources. Diane also serves as a board member for the Health Care Education Association. As a tribute to Diane's commitment to the provision of easy to understand health information in multiple languages, Diane was honored with the *Excellence in Cancer Patient Education Award*.

Our final award recipient, **David Wiljer, PhD**, Director of Knowledge Management and Innovation for Oncology Education and the Radiation Medicine Program at Princess Margaret Hospital in Toronto was honored with the *Gold Star Award*. David's résumé is impressive with an emphasis on the use of technology in educating patients and their families.

His contributions include, but are not limited to: management of the development of the *Oncology Interactive Series* (a Jack Digital production); conduction of a pilot project which demonstrated the benefit of integrating patient teaching and patient access to their electronic medical record; co-chair of the CPEN website and 2003 CPEN conference; a leader in establishing CPEN Canada; and a frequent, well-respected national speaker. Although David was unable to accept his award in person, his prerecorded acceptance speech was very moving and entertainingly humorous.

As always it is a tremendous privilege and honor to be involved in the awards recognition process. CPEN is fortunate to be comprised of many talented and dedicated professionals with one common mission, "...to promote and provide models of excellence in patient, family, and community education across the continuum of care".

SAVE THE DATE

AACE & CPEN 2008 Annual Meeting

October 20-22, 2008
Sheraton Sand Key Resort
Clearwater, Florida

Program Chairs

Patricia Mullan, PhD, Chair
Associate Professor, Department of Medical Education,
University of Michigan Ann Arbor, Michigan

Frank D. Ferris, MD, Co-Chair
Director, International Programs,
San Diego Hospice & Palliative Care,
San Diego, California

Miriam Bell, Local Arrangements
Director, Patient Advocacy & Rehabilitation
H. Lee Moffitt Cancer Center & Research Institute

Jointly sponsored by:




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Diane Moyer (left) accepting award from Susan Scritchfield at ceremony at Ohio State Univ. Medical Ctr.

Business Meeting from page 2

Kelli shared highlights of CPEN's past history, present status, and future vision. Her vision for the future of CPEN includes:

- ❖ Supporting goals and initiatives of the 5-year strategic plan
- ❖ Fostering communication between the board of directors and membership
- ❖ Continuing to expand the partnership process with CPEN Canada, AACE, CancerCare, and others
- ❖ Exploring CPEN scholarship awards.
- ❖ Promoting further marketing strategies

Treasurer's Report

Donna Branson shared the budget report for 2007. CPEN assets at present are \$44,086.80 (last year's assets were \$29,551.77). She also mentioned that contributions made to CPEN are tax deductible.

Headquarters' Report

Tanya Smith gave an overview of the report for Allison Travis. Current membership is at 153 members with the countries of Australia, Canada, Japan, and the United States represented.

Headquarters is responsible for:

- ❖ Membership application and dues processing
- ❖ Journal subscription processing
- ❖ CPEN website maintenance
- ❖ Supporting Board of Directors
- ❖ Communication with membership

Minutes from the CPEN Business Meeting can be found on the CPEN web site and provide a comprehensive review.

CPEN membership has grown to 153 members.

Resource Corner

By *Desirae Nasrallah, MPH*

Taking Care of Patients and their Families.

Knowledge is definitely power! At Moffitt Cancer Center's Patient Education Resource Center (PERC), we strive to keep current and accurate information available to our patients. While serving our patients is of the utmost importance, serving their families and friends is also a priority. A patient's support system, as we all know, is a vital factor in their health care.

Coping with a loved one's disease is a multi-faceted issue and it is mostly likely to involve several people. In the PERC, we keep a variety of books to help patients and their families understand what lies ahead. In particular we have a selection of material to help children deal with a parent's diagnosis; books like *Little Kids, Big Questions* (Judi Craig, Ph.D.) and *Why Do People*

Die? (Cynthia MacGregor). *When a Parent Has Cancer* (Wendy Schlessel, M.D.) is written for parents to help them deal with the anxiety of caring for children when they need care themselves.

The power of friendship is a topic explored by Amy Harvell in *When Your Friend Gets Cancer*. A friend's role, being distinct from the family's role, serves a special purpose. Amy Harvell writes, "Because [friends] are not as dependant on the patient, friends can be less frightened about the consequences of treatment and can usually live better in the ambiguity of the situation. Friends can objectively help the cancer patient get through the cancer crisis."

The Human Side of Cancer: Living with Hope, Coping with Uncertainty (Jimmie C. Holland, M.D. and Sheldon Lewis) describes how coping with Please see **Resource Corner** on page 6

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cancer is not a one-size-fits-all experience. The book has been described by Kathleen Chalfant (actress) as “a compassionate guide that tells you all the things you wanted to know but were too afraid to ask.” The book is written for patients, caregivers and friends of someone diagnosed with cancer.

It is common to find that people simply don't know what to say to someone who has just been diagnosed. *Help Me Live: 20 Things People with Cancer Want You to Know* (Lori Hope) provides a personal, thoughtful and practical account of actions that are most helpful to people and families dealing with a cancer diagnosis.

Keeping resources that speak to a variety of coping topics has helped us in the PERC to work with our patients and their families. Enabling healthy coping mechanisms for the patient and for their friends and family will help guide everyone involved in this journey.

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