

Cancer Patient Education Network (CPEN) Celebrates 25 Years

Sheryl M. Ness • J. Kokal

Published online: 20 November 2014
© Springer Science+Business Media New York 2014

The Cancer Patient Education Network (CPEN) is celebrating 25 years of advancing excellence in cancer patient education this year. Scientific discoveries, innovative approaches to health care delivery, and improved health care outcomes are often the result of a very simple idea. CPEN, launched by the National Cancer Institute (NCI), is such an example. The simple idea was this—bring together educators from the NCI-designated comprehensive cancer centers to share the tools and approaches they used to educate cancer patients and their families. The expected result—best practices in education that enabled cancer patients, their families, and those that supported them to more easily navigate the health care delivery system, better understand their diagnosis, tests, and treatments being prescribed, and deal with the uncertainty of living with cancer. The vision was for formal education interventions to be recognized as integral components of cancer patient care.

Twenty-five years ago, in 1989, the National Cancer Institute (NCI) hosted the first gathering of 22 representatives from NCI-designated cancer centers. Modest in scope, the simple idea took root and steadily grew, nurtured by the commitment, and engagement of these health professionals and government leaders. Formal communication channels, such as monthly conference calls, newsletters, and annual meetings held at cancer centers across the USA strengthened the emerging network. With feedback from CPEN members and needs assessment data from cancer center patients, the NCI developed educational tools and resources needed by the cancer centers including: chemotherapy drug information sheets in English and Spanish, pamphlets and videotapes focused on childhood cancers, information on cancer survivorship and

clinical trials, and resources focused on what to expect prior to cancer treatment. These resources were made available by the NCI and widely promoted and disseminated throughout the USA and often translated by international groups for use in Europe, Asia, and South America.

As the network grew, CPEN recognized that the members would be well served by guidelines, outlining the necessary components of a formal Cancer Patient Education Program including: staffing, budget, administrative processes, and resources. Training and collaboration occurred during the annual meetings of the CPEN members and special conference calls focused on the specifics of introducing new programs within existing hospitals, clinics, and larger health care systems. The importance of documentation and evaluation was stressed to insure that the educators could demonstrate the value of formal educational interventions, including measureable outcomes for patients.

Integrating patient education into routine patient care involved the training of health care professionals—nurses, health educators, physicians, social workers, dietitians, physical and occupational therapists, child life specialists, and volunteers. CPEN members worked across disciplines in their cancer centers and were increasingly requested to assist with introducing new initiatives for patients and families, as well as coordinating and facilitating training programs for their colleagues.

CPEN members saw the value of the cancer centers partnering with national and local organizations to promote the importance of educating patients and those that supported them throughout their cancer experiences. Collaborative organizations included the American Cancer Society, the National Coalition for Cancer Survivorship, and professional associations like the Oncology Nursing Society, the Association of Oncology Social Worker, and the American Society of Clinical Oncology. While reaching out, CPEN continued to work in close collaboration with other NCI programs, the

S. M. Ness (✉) • J. Kokal
Mayo Clinic College of Medicine, 200 First Street, SW, Rochester,
MN 55905, USA
e-mail: Ness.sheryl@mayo.edu

Cancer Information Service, the Public Affairs Network, and the NCI Cancer Center Program.

The CPEN mission and vision continued to focus on quality patient education with the goal of sharing best practices, research, and programs. Each year, an annual meeting was hosted by NCI-designated cancer centers. In 2005, CPEN became incorporated as an independent non-profit organization and opened up membership to include all professionals interested in cancer education. It was during this period that NCI suggested that CPEN collaborate with the American Association of Cancer Educators (AACE) as they had been partners with both organizations and suggested that we would benefit from a collaborative relationship, especially focusing on the annual conference and supporting the *Journal of Cancer Education* (JCE).

In 2008, CPEN, AACE, and the European Association of Cancer Educators (EACE) collaborated on the first joint International Cancer Education Conference (ICEC). In the spirit of collaboration and sharing of best practices, the three organizations continue to work together each year to plan and support the ICEC as well as support the efforts of the JCE.

Canada became the first international chapter for CPEN in 2007. As the organization grows, CPEN is collaborating across the globe and welcomes the idea of establishing additional international chapters.

CPEN has more than fulfilled the dreams of its original founders. As CPEN marks a quarter century of advancing excellence in cancer patient education, our gratitude goes out to the founders who met in 1989 under the direction of Kathy Crosson, then Chief of the Patient Education Section within the Information Projects Branch of the NCI Office of Cancer Communications. CPEN would not exist without Kathy Crosson. We all owe a great deal to the extraordinary group of educators who had such wisdom and vision to make this happen. The founding members included Pat Agre, Kathy Conrad, Kathy Crosson, Annette Mercurio, Barb Schroeder, Louise Villejo, and other patient education leaders from NCI-designated comprehensive cancer centers.

Gratitude and thanks are also extended to all of our members who generously gave their time, skills, and expertise to

make CPEN such a robust organization. People say that exceptional individuals choose to work in the field of oncology and looking at the remarkable individuals who have given so much to our organization that has certainly proven true. We look forward to the next 25 years of CPEN's leadership in cancer patient and family education.

Accomplishments over the past 25 years include the following:

- Guidelines for establishing comprehensive cancer patient education services
- Guidelines for establishing and maintaining learning resource centers
- Health Literacy Toolkit, Social Media Toolkit, and Cancer-Related Fatigue Tool
- CPEN Bulk printing program of NCI materials
- Professional Development webinars for CEU credit and recordings
- Recommended resources for Learning Resource Center collections
- Virtual Tour of CPEN's Learning Resource Centers
- FAQs and resources on complementary and alternative medicine in cancer
- Evidence-Based Practice (EBP) Resources
- Survey data and self-assessment tools on a variety of topics
- Patient educator resources
- Annual International Cancer Education Conference

CPEN welcomes new members who are working in the field of cancer education or have an interest in cancer education. For more information about CPEN and how to become a member, we invite you to visit our website at: <http://www.cancerpatienteducation.org/> and download the membership application from <http://www.cancerpatienteducation.org/apply.shtml>.

CPEN is also on Facebook at <https://www.facebook.com/JoinCPEN> and on Twitter @CPEN2014 <https://twitter.com/CPEN2014>.