

[FINAL REPORT]

Best Practices in Psychosocial Oncology Exchange Between Hungary and the United States of America



A PRODUCT OF THE NATIONAL ASSOCIATION OF SOCIAL WORKERS, USA

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TABLE OF CONTENTS

SUMMIT CONVENERS	4
PREFACE	6
FINAL SUMMIT REPORT	8
Summit and Project Overview	8
Statement of Need for Improved Psychosocial Oncology Care in Hungary.....	8
NASW and CancerCare: A Longstanding Partnership	9
Building an International Relationship Bridge	10
Identification of Leaders in Psychosocial Oncology in Hungary	10
Summit Planning Committee	12
Summit Planning Meeting in Hungary, July 16-17, 2008.....	13
Identification of Summit Invitees.....	14
Planning for an International Summit	14
BEST PRACTICES SUMMIT IN PSYCHOSOCIAL ONCOLOGY, NOVEMBER 2008	16
Summit Overview	16
Opening Reception Held by the University of Debrecen and Local Health Leaders.....	16
A Profile of the Summit Participants	17
Keynote Speaker: “A Cancer Survivor’s Story and Experience”	17
Presentations in English and Hungarian with Simultaneous Translation	17
Presentation Agenda	18
Roundtable Topics and Discussions	20
Roundtable Discussions Summaries.....	21
Older Adults	21
Children and Families	22
Ethnic Minorities.....	22
Survivorship/Self-Help Advocacy	22

Social Work Networking/Professional Advocacy	23
Family Support and Volunteers	23
Roundtable Results Presented to Entire Summit Group	23
Opening of Sunday's Summit Half Day Session, November 9	24
Consensus on the Imperatives	24
The 10 Summit Imperatives	25
Methods to Achieve the Summit Imperatives	26
Achieving the Summit Imperatives	28
Summit Evaluations	31
Analysis of Participant Satisfaction Questionnaires	31
Web Sites for the Summit, The Summit Presentations and Translated Resources	35
Post-Summit Communication with Leaders and Participants	35
Development, Dissemination and Purpose of the Summit Final Report	36
Online Publication of Final Report: Web Sites in the USA and Hungary	36
References	36
ACKNOWLEDGEMENTS.....	37

SUMMIT CONVENERERS

NASW

The National Association of Social Workers (NASW) is the largest membership organization of professional social workers in the world, with 150,000 members. NASW works to enhance the professional growth and development of its members, to create and maintain professional standards, and to advance sound social policies.

The National Association of Social Workers, located in Washington, D.C., promotes, develops and protects the practice of social work and social workers. NASW continues the strong social justice and advocacy mission inherent to the profession.

Dr. Elizabeth Clark has served as the Executive Director of NASW since 2001. Her clinical specialty areas are oncology social work and loss and grief. She is past president of the National Coalition for Cancer Survivorship, and a past board member and current advisory board member of the Intercultural Cancer Council. She serves as a member of the Board of Directors of the National Hospice and Palliative Care Organization, the Leukemia and Lymphoma Society, and as a member of C-Change Collaborating to Conquer Cancer. Dr. Clark is a recipient of the Ray of Hope Award from the National Coalition for Cancer Survivorship, and of the Leadership Award in Oncology Social Work from the Association of Oncology Social Work.

CancerCare, Inc.

CancerCare is a national nonprofit organization that provides free, professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones, and the bereaved. CancerCare programs—including counseling and support groups, education, financial assistance and practical help—are provided by professional oncology social workers and are completely free of charge. Founded in 1944, CancerCare provided individual help to more than 100,000 people last year, in addition to the more than one million unique visitors to our web sites.

Diane S. Blum is Executive Director of CancerCare. She joined CancerCare in 1984 as Director of Social Service, and became Executive Director in 1990. Previously, Ms. Blum served as a social work supervisor at Memorial Sloan Kettering Cancer Center in New York City and the Dana Farber Cancer

Institute in Boston, MA. Ms. Blum's areas of expertise include the psychosocial needs of cancer patients and their families; costs of cancer treatments and care; women and breast cancer; cancer survivorship; and non-profit management. Co-founder of the National Alliance of Breast Cancer Organizations, Ms. Blum is also a founder of National Breast Cancer Awareness Month and serves as Editor-in-Chief of *cancer.net*, the American Society of Clinical Oncology Web site for patients and the public, and is also a member of the editorial boards of five other oncology-related publications.

UNIVERSITY OF DEBRECEN, FACULTY OF HEALTH

The University of Debrecen Faculty of Health, its centre functioning at Nyíregyháza, Hungary, is an educational unit of University of Debrecen and the Centre for Medical and Health Science. It is closely connected to the parent establishment, and at the same time the Faculty collaborates with the other colleges of Nyíregyháza, the College of Nyíregyháza and the Szent Atanaz Greek Catholic Theological Academy. The Faculty was established to help to tackle the task of economic renewal and reorganization of public health and social politics in the eastern region of Hungary to reduce the problems of expert provision, to give opportunity for graduate students for further education and to contribute to the reduction of employment by undertaking the trainings of experts needed in this region.

The Faculty made a pledge to run a branch for the training of social workers from the very first moment of its functioning and to make the arrangements for the health information management branch. The Faculty has started a health social work program. László Patyán, a social work instructor in the Faculty of Social Work, heads the bachelor of social work program and served as the coordinator of this Summit in Hungary. We extend our special appreciation to Dean Istvan Kalapos from the University of Debrecen, without his assistance this Summit would not have been possible.

PREFACE

According to the World Health Organization, in 2010 cancer will be the number one disease that kills people worldwide (WHO, 2009). Cancer remains a global health condition that affects people in every aspect of their lives, physically, psychologically, spiritually, socially, vocationally, sexually, financially, and in the important relationships in lives.

While, major strides have been made in medical and psychosocial care for persons affected by cancer, prevention, diagnosis, and treatment of cancer in Eastern Europe remains a challenge. Hungary is an Eastern European country that has one of the highest mortality rates for cancer, given its population of 10 million people.

NASW has long been a leader of social work and practice on a national and international level. CancerCare has provided psychosocial care and services to persons affected by cancer and to professionals both on a national and international scale. Together, these two organizations have partnered to educate social workers and other professionals about cancer, its treatment, and psychosocial issues and interventions that help people cope with the disease and its side effects.

When the Bristol Myers Squibb Foundation identified their initiative to target special funding for cancer in Eastern Europe, NASW and CancerCare welcomed the opportunity to build an international relationship with other groups and professionals in Eastern Europe, specifically Hungary. They developed a Summit to bring together multidisciplinary professionals to exchange their best practices in psychosocial oncology, in the hopes of improving knowledge, care, and services to people affected by cancer in Hungary and to Eastern European immigrants to the United States of America. The Summit also served as an opportunity for capacity building among social workers as part of NASW's international initiative, Social Workers Across Nations (SWAN).

The Best Practices Exchange in Psychosocial Oncology Summit became a reality in November of 2008 at the University of Debrecen in Nyíregyháza, Hungary. This report details the process from the selection of Hungary for the Summit site to the Summit itself. The psychosocial professionals and individuals from Hungary who participated in the Summit are greatly appreciated for their

collaboration in this incredible project. It is our hope that the Summit will indeed help change the lives of people affected by cancer in Hungary and the United States of America, by exchanging best practices knowledge and interventions from multidisciplinary professionals, volunteers and individuals.

Dr. Elizabeth Clark, Executive Director, National Association of Social Workers–USA

Diane Blum, Executive Director, CancerCare

László Patyán, Vice Chair of the Social Work Department, University of Debrecen

FINAL SUMMIT REPORT

SUMMIT AND PROJECT OVERVIEW

The National Association of Social Workers and CancerCare formed a partnership, funded by the Bristol Myers Squibb Foundation, to focus on identifying best practices and improving psychosocial oncology care in Hungary. A multidisciplinary Summit was developed to bring together oncology psychosocial professionals in Hungary and the United States of America to exchange best practice information and identify strategies to improve the psychosocial oncology care throughout the cancer continuum in Hungary. The meeting provided an opportunity for networking, exchanging information about current best practices across the country, and identifying Imperatives for action. As a result of the Summit, ten Imperatives were identified by conference participants to improve psychosocial oncology practice in Hungary. This report provides a comprehensive look at how and why this Summit came together and the results that are contributing to improved psychosocial oncology care in Hungary and to Eastern European immigrants in the United States of America.

The project continues with translation and dissemination of the best practices presented at the Summit, as part of this report, and of the NASW web based course *Understanding Cancer: The Social Worker's Role*. Additionally, seed grants were awarded to six of the Hungarian leaders aimed at building the research and practice capacity in psychosocial oncology care. Although challenges exist, the participants were optimistic about working together with a newly formed network to increase knowledge and build resources to meet the psychosocial needs of people with cancer in Hungary.

STATEMENT OF NEED FOR IMPROVED PSYCHOSOCIAL ONCOLOGY CARE IN HUNGARY

Cancer is a disease that affects every society and health care system in the world. The disease has presented great issues in Eastern Europe, which is largely composed of former Soviet Bloc countries with still-developing economies. The governments and health systems of most of these countries are affected by the growing number of cancer mortalities in the region, caused largely by a growing older population, changes in lifestyle/health habits, as well as widening political, social, and economic gaps. These challenges are typified in Hungary, which has the highest cancer mortality rate (219.8 per 100,000; compared to 157.9 in the USA) and lowest 5-year survival rates, along with their Eastern

European neighbors (Berrino, F., De Angelis, R., Sant, M., Rosso, S., Lasota, M. B., Coebergh, J. W., Santaquilani, M. & the EURO CARE Working group, 2007). National government policy, driven by a still-developing economy, may cause problems in health care access, particularly to psychosocial services.

The standards for oncology care, hospice and palliative care, and pain relief are still insufficient when compared to Western European countries. What's more, there are few skilled professionals who are adequately trained to address the increasingly complex medical and psychosocial needs of people with cancer (Globisch, 2005).

NASW AND CANCERCARE: A LONGSTANDING PARTNERSHIP

The history of the connection between NASW and CancerCare began with a relationship between its two respective executive directors, Dr. Elizabeth Clark and Diane Blum, MSW. These two social work leaders have been important advocates for both social workers and the cancer community. The partnership became formalized in 2002, when Bristol Myers Squibb Foundation provided funding for a web-based education course for social workers on cancer, its treatment and psychosocial effects and interventions. The course, *Understanding Cancer: The Social Worker's Role*, launched on NASW's Web site, www.naswwebed.org, in 2003 and, to date, over 30,000 social workers and others from around the world have taken the course. A similar course can be accessed through NASW's consumer Web site, www.helpstartshere.org. The consumer version has social work content removed and is geared toward consumers.

NASW and CancerCare continued their partnership through collaboration on educating social workers and other professionals about cancer and the social work role through workshops across the USA, in conjunction with NASW state chapters. The curriculum was built on the Individual Cancer Assistance Network (ICAN) project, which CancerCare created with Bristol Myers Squibb Foundation funding (Blum, Clark, et al, 2006). From 2004-2007, NASW, CancerCare, and American Psychosocial Oncology Society (APOS) educated almost 800 social workers in face-to-face trainings that provided social workers with specific cancer and treatment knowledge, the psychosocial implications of cancer, and psychosocial interventions and resources. Twenty social workers also were trained as trainers in the cancer curriculum and have educated another 400 psychosocial and other professionals in the curriculum.

In 2007, NASW and CancerCare created a second web education course, *Understanding Cancer Caregiving: The Social Worker's Role*. The course launched in June of 2007, and to date, more than 14,000 social workers have taken the course. The course looks at the different cultures in the USA and how different cultures cope with cancer as individuals, families, and as cultural communities.

BUILDING AN INTERNATIONAL RELATIONSHIP BRIDGE

In identifying Hungary as the Eastern European country to host the Summit, a partnership was formed between NASW and the University of Debrecen, Faculty of Health, in Nyíregyháza, Hungary. This partnership was facilitated by Dr. Ellen L. Csikai, well-known to NASW and a former hospice social worker, who have received a Fulbright Scholar Lecturer Award and was teaching at the University of Debrecen during the semester leading up to the Summit Planning Committee meeting. Additionally, the College was to begin a master's degree program in Social Health Care in the fall of 2008, and it was believed that the collaboration with the University would be ideal to provide the best "in-country" support for the project. Dr. Csikai was hired as an NASW Consultant to help bring the Summit to fruition by serving as a bridge with the university and oncology psychosocial professionals she met while in Hungary.

The Faculty of Health offered to make translation/interpretation services available prior to the Planning Committee meeting. Ms. Agnes Tilki, head of the University language department, translated the invitation letters and emails that were sent to potential participants. The head of the Bachelor of Social Work program, László Patyán, was instrumental in ascertaining the interest and ability for participation of potential members, because he was able to follow-up with invited participants by phone and further explain the project to them. Mr. Patyan was the key liaison between the Faculty of Health, NASW, and CancerCare throughout the entire project.

IDENTIFICATION OF LEADERS IN PSYCHOSOCIAL ONCOLOGY IN HUNGARY

Another important task was to select the Hungarian leaders who could participate as members of the Summit Planning Committee. Ideal candidates were the experts among different psychosocial professionals providing psychosocial care to people with cancer in Hungary, and they needed to represent different geographic regions of the country.

Initially identified were two leaders who were responsible for much of the development of oncology services for people with cancer in Hungary. Dr. Katalin Hegedus (psychologist) was a leader in the development of educational training programs and the professional organization, the Hungarian Hospice Palliative Association (HHPA), organized in 1995. Dr. Katalin Muszbek (psychiatrist) is a well-known leader from the Hungarian Hospice Foundation (HHF), founded in 1991. She has been actively involved in the Hungarian and International Psycho-Oncology Associations. Both the HHPA and HHF had received grants from the Open Society Institute funded by philanthropist George Soros with the goal of developing hospice and palliative care resources in Hungary.

These two individuals suggested potential members for the Planning Committee who were subsequently contacted to ascertain their interest, and ability to attend a Planning Committee meeting to be held in July of 2008. This list included social workers, physicians, and psychologists. Another resource used to reach potential participants was the HHPA listing of hospice agencies. The primary health care settings in which psychosocial oncology care takes place in Hungary are hospitals, hospices, and home health agencies.

SUMMIT PLANNING COMMITTEE

The Planning Committee met July 16-17, 2008, in Budapest, Hungary, at the offices of the funder, the Bristol Myers Squibb Foundation.

COMMITTEE MEMBERS FROM THE UNITED STATES OF AMERICA WERE:

Dr. Elizabeth Clark, NASW Executive Director
Rebecca Myers, MSW, NASW Special Assistant to the Executive Director
Dr. Katherine Walsh, NASW Consultant, Springfield College
Dr. Ellen L. Csikai, NASW Consultant, The University of Alabama
Floyd Allen, MSW, LMSW, CancerCare, Director of Men's Cancer Services
Dr. Carolyn Messner, CancerCare, Director of Education and Training

COMMITTEE MEMBERS FROM HUNGARY WERE:

Dr. Jolan Demeter, Radiation Oncologist
Edit Szabo Laszlone Valki, Oncology Social Worker
Dr. Magda Rohánszky, Psycho-Oncologist
László Patyán, Social Work Instructor
Rita Dudas, Oncology Social Worker
Maria Marko, Oncology Social Worker
Anita Horvath, Oncology Social Worker
Dr. Katalin Muszbek, Psychiatrist and Director of Hospice in Budapest
Dr. Katalin Hegedus, Psycho-Oncologist
Dr. Eszter Biro, Psycho-Oncologist

SUMMIT PLANNING MEETING, JULY 16-17, 2008

NASW and CancerCare leaders and staff traveled to Nyíregyháza, Hungary, in July 2008, for a planning meeting of the Summit and to determine logistics. Psychosocial oncology professionals in Hungary had been previously identified and invited to the planning meeting. One of the tasks of the planning committee was to suggest participants to attend the Summit. Funds were provided to increase participation of professionals from across Hungary.

The charge of the Planning Committee was to determine the goals, content, and structure of the Summit as well as participants and the date for the *Best Practices in Psychosocial Oncology in Hungary* Summit. Dr. Elizabeth Clark began the meeting by familiarizing the Hungarian Planning Committee members with the mission of NASW: to protect and advance the practice of social work in the USA: to promote social justice: and to foster NASW's interest in international social work. Described was the new program called Social Workers Across Nations (SWAN) for building international capacity in social work. Previous countries that have been visited include China, Cambodia, and South Africa. The interest in and connection between NASW and addressing cancer issues was described. Dr. Clark provided an overview of the education and training that NASW and CancerCare have implemented both through web based education courses and face-to-face trainings for psychosocial professionals to learn more about cancer, its treatment and interventions. She explained that following the Summit exchange, the NASW *Understanding Cancer* web based course would be adapted for psychosocial oncology care in Hungary and translated into Hungarian and made available through the NASW Web site.

The members of the Planning Committee discussed the state of psychosocial oncology in Hungary and the USA. The Committee reviewed the needs of people with cancer, professionals who provide the psychosocial oncology services, and what the training methods and training needs are for psychosocial oncology professionals in both countries. Planning Committee members noted that the USA has some of the same problems related to access to care as Hungary. Similarities and differences in the utilization of volunteers who help patients and family members in Hungary and "patient navigators" who help in the USA, and the role of social workers in supervising and working with these helpers were discussed. Roles of interdisciplinary team members and the level and quality of collaboration among professionals in both countries were also a focus of the conversation.

The influence of culture, gender and age was discussed. Another major topic was that training for psychosocial oncology professionals was needed to address transference, counter transference, comprehensive assessment (including bereavement needs), the strengths perspective and methods of

screening, and interventions. It was determined that the Summit content should attempt to address the best practices in as many of these areas as possible. Planning Committee members offered to deliver presentations on the state of psycho-oncology in Hungary and current best practices and related topics at the Summit.

One expected outcome was the identification of areas of greatest need for action by professionals involved in psychosocial oncology care. Small group discussions of the needs among several stakeholder groups were recommended. The discussion group topics identified were: ethnic minorities, children, elders, survivorship, family/volunteers, and professional networks. It was hoped that top priority areas would emerge with the input of discussion group summaries, using a modified Delphi method.

IDENTIFICATION OF SUMMIT INVITEES

The Planning Committee members were asked to identify psychosocial oncology experts in Hungary to be invited to participate in the Summit (approximately 20, including the 9 Hungarian Planning Committee members). It was recommended that a cancer survivor and advocate present the keynote address at an opening reception. Members made several recommendations for potential invitees who then received official invitations via email from NASW project leaders (in the Hungarian language). A health social work professor was also identified in Romania, a neighboring Eastern European country, to invite to the Summit, so that education could also begin to be provided to professionals in that country.

PLANNING FOR AN INTERNATIONAL SUMMIT

The dates for the Summit were determined to be November 7-9, 2008, to be held in Nyíregyháza, Hungary; hosted by the University of Debrecen, Faculty of Health, Department of Social Work. Bi-monthly conference calls were held with University colleagues in Hungary. Karyn Walsh, Project Manager for the NASW and CancerCare joint collaborations, joined the Summit planning group after the Summit planning meeting. Ms. Tilki, the University language department head, continued in her role as translator during the calls. The relationships made during the planning meeting helped to strengthen the commitment to making this a successful Summit.

As the Summit dates approached, communication via email and phone became crucial to a successful meeting and outreach to invitees and speakers. A tentative agenda was crafted from the planning meeting, and as each speaker was confirmed, the final agenda became clearer. All presentations were received prior to the Summit and translated by Migal Translations in Hungary.

Invitations were sent to more than twenty psychosocial oncology professionals throughout Hungary and one in Romania. Travel grants were provided to help participants attend the Summit. László Patyán was able to personally contact many of the invitees to follow up with them. His efforts in this project helped to ensure a successful turnout at the Summit, and overall, an outstanding program.

BEST PRACTICES IN PSYCHOSOCIAL ONCOLOGY EXCHANGE SUMMIT

SUMMIT OVERVIEW

The Summit occurred over the course of a Friday evening to Sunday afternoon, November 7-9, 2008, in Nyíregyháza, Hungary. The University of Debrecen, Faculty of Health, Department of Social Work, served as the host site. A weekend was chosen to optimize the potential for busy professionals to attend. Both the University and NASW created web sites for the Summit and posted presentations and materials on both web sites in English and Hungarian. Arrangements were made by the University for the Summit to be webcast and archived on both the university and NASW Web sites.

The overall Summit is best summed up in the words of welcome that Dr. Clark delivered in the opening video segment at the beginning of the conference. She stated,

When someone is diagnosed with cancer, their world as they know it is changed. Their family and friends are affected by the illness and its treatment. As professionals who work with these individuals and their loved ones at such a vulnerable time and along the course of their illness, it is important to have excellent training to gain the knowledge and skills needed to practice in oncology. This Summit is an opportunity to present our mutual practice experiences and exchange ideas and resources on the interventions that best help those living with cancer. From the United States of America, we bring oncology social workers with experience working with individuals of all ages. From your country, we bring recognized psycho oncology experts that treat individuals with cancer.

OPENING RECEPTION HELD BY THE UNIVERSITY OF DEBRECEN AND LOCAL HEALTH LEADERS

The Summit began with an evening reception for all participants hosted by the Faculty of Health's deans and social work administrators. It was held at the Szabolcs-Szatmar County Hall in Nyíregyháza, Hungary, and City and University officials welcomed the group. The purpose and goals of the Summit and the project were enumerated by NASW project leaders: to bring together oncology psychosocial professionals in Hungary and the United States of America to exchange best practice information; and to identify strategies to improve the psychosocial oncology care throughout the cancer continuum in Hungary. The reception provided an opportunity to welcome participants to the conference and introduce Summit organizers to the Hungarian group, but more importantly it served as the first networking opportunity of the Summit.

A PROFILE OF THE SUMMIT PARTICIPANTS

A multidisciplinary group of 30 medical and psychosocial oncology professionals and consumers attended. They represented social workers, home care and hospice nurses, psychologists, psychiatrists, three cancer survivors, physicians (oncologists, radiation oncologist), and a hospice volunteer. In addition to the “officially” invited (funded) participants, local community health professionals were invited and several attended from surrounding health care agencies.

Five professionals (one social work professor and four nurses) traveled from Romania to participate. The four Romanian nurses came from an area of Romania where hospice services are not available, but they provide home care under the Caritas organization. They wanted to start providing hospice services and wanted to learn more about hospice and cancer care from the Summit.

KEYNOTE SPEAKER: A CANCER SURVIVOR’S STORY AND EXPERIENCE

Dobolyi Laszlo, a well-known cancer survivor in Hungary and head of the Hungarian Colon Cancer Association, opened the conference with a plenary session titled *Cancer: Still a Taboo!* He discussed how people do not talk about having cancer and how the disease remains a taboo subject in Hungary.

PRESENTATIONS IN ENGLISH AND HUNGARIAN WITH SIMULTANEOUS TRANSLATION

Subsequent sessions consisted of panels of Hungarian and American psychosocial oncology professionals presenting information and strategies on the best psychosocial practices for helping individuals affected by cancer and on creating a stronger psychosocial oncology workforce in Hungary. With the high cancer mortality rate, there is an emphasis on quality hospice and palliative care. Hence, it was important for the presentations to include not only cancer survivorship information, but also to address best practices in hospice and palliative care. Hungary has some exceptional leaders in hospice and palliative care and many of them participated in this Summit.

Additionally, information was presented to the group about the plan to develop an online course for psychosocial professionals to learn about cancer, its treatments, crisis points along the cancer continuum, psychosocial knowledge and skills, and for the Summit resources. NASW’s current online cancer course, *Understanding Cancer: The Social Worker’s Role*, was adapted as the basic template. The following is a description of the program.

PRESENTATION AGENDA

9:00—9:30 Opening Remarks and Welcome

Dr. István Kalapos, Dean of the University of Debrecen Faculty of Health

László Patyán, Vice Chair of the Social Work Department, University of Debrecen Faculty of Health

Welcome Remarks from the USA Colleagues and Introduction of the Goals and Purpose of Summit

Karyn Walsh, ACSW, LCSW, NASW

Floyd Allen, MSW, LMSW, CancerCare

Opening Plenary

Keynote Speaker: László Dobolyi, Chairman of Association of *You Can Survive:*

Cancer – Still a Taboo!

History of Psychosocial Oncology in the USA and Hungary

Kathy Walsh, PhD, LICSW, NASW

Tenets of Psychosocial Oncology in the USA

Dr. Magdolina Rohánszky

The History and State of Psychosocial Oncology in Hungary

Cancer Advocacy and Involvement in Hungary

Erika Betléri, Social Worker, Napraforgó Egyesület Nyíregyháza (Solstice Association)

The Activity of the National Alliance against Cancer

Dr. Jolán Demeter, Centre Leader, Head Physician, Szent János Hospital Budapest

Questions of Breast Cancer Patients' Collaboration throughout Treatment

László Patyán, Vice Chair of the Social Work Department, University of Debrecen Faculty of Health

Need for Principles and Social Advocacy of Cancer Patients from a Social Work Perspective

Best Practices in the USA

Karyn Walsh, ACSW, LCSW, NASW

NASW Strategies to Educate Social Workers about Cancer, its Psychosocial Effects, and the Social Work Role

Floyd Allen, MSW, LMSW, CancerCare

Oncology Patient Care

Ellen L. Csikai PhD, MSW, University of Alabama

Hospice and End of Life Care

Best Practices in Hungary

Dr. Katalin Muszbek, Medical Director of Hungarian Hospice Foundation

Distress Screening

Dr. Katalin Muszbek, Medical Director of Hungarian Hospice Foundation

Palliative Care Worldwide from Villages to Metropolis

Ildiko Kocsis, Social Worker, J6sa Andres' Training Hospital Nyiregyh6za,

Emotional Roller Coaster: Psychosocial Support, the Main Pillar of Oncology Social Work

Rita Dudas, Social Worker, University of Szeged, Clinic of Oncotherapy, Szeged

Social Workers' Role in Oncology Care

All of the presentations are available on the Web sites, in English and Hungarian. The Web sites are listed further in the report under Web sites for the Summit and Presentations.

ROUNDTABLE TOPICS AND DISCUSSIONS

To begin the process of brainstorming potential areas for action among the experts gathered at the meeting, all Summit participants were part of “roundtable” group discussions. The topics were identified during the Planning Committee meeting.

- Older Adults
- Children and Families
- Ethnic Minorities
- Survivorship and Self-Advocacy
- Volunteers
- Family Support and Advocacy

Participants registered during Saturday morning and early afternoon breaks for the roundtable discussions, according to their expertise and interests. Three roundtables were conducted on Saturday afternoon and three on Sunday morning. Each roundtable discussion was facilitated by a team of one USA Planning Committee member and one Hungarian Planning Committee member and one social work student (serving as recorder).

Each roundtable consisted of approximately ten expert participants who met for one hour to discuss three questions:

1. What are the priority needs related to the topic, in psychosocial oncology?
2. What resources are available to address these needs?
3. What are the gaps or challenges in addressing these needs?

One facilitator led the discussion while the second facilitator contributed and took notes on a flip chart. An interpreter was assigned to each group, and a student who was fluent in both English and Hungarian copied the notes into the other language (either English or Hungarian), depending on the primary language of the note-taker. This process was developed to ensure uniformity of outcome products and ensure mutuality among the USA and Hungarian facilitators.

The discussions often revealed major differences in the perspectives and experiences of the diverse members of the groups. For example, in the children and families group, the director of a Budapest hospice discussed the effectiveness of communication and collaboration among hospice team members and families in addressing needs of children. However, a social worker representing an oncology unit in a hospital in a distant city and a medical director of a hospice covering a large rural geographic area said there was little time and sometimes no staff available to communicate with family members regarding children and no resources to guide parents or professional in communicating with or assisting children affected by cancer.

Despite differences within the groups, each group agreed on several needs in their topic areas. Also, part of the discussion that took place in each group was the exchange of best practices and resources that had been developed to address that area by both USA and Hungarian participants. All of the group discussions were lively and, many times, passionate. Although the discussions were limited to one hour on the Summit agenda, discussion among participants continued after the “official” time frame had ended. All round-table discussions were summarized and presented to the larger group, by someone from each discussion group.

ROUNDTABLE DISCUSSION SUMMARIES

Although several topics were addressed in the six groups, some topics were collapsed into one group that had a strong correlation, such as survivorship and self-advocacy. The roundtable topics and summaries are listed below.

OLDER ADULTS

A primary need expressed was for improved communication between patients/families and health care professionals and between medical and social professionals. General information (public awareness) is needed about available services and treatments. Ensuring support (security) for family caregivers was also seen as important. The concern was that patients may postpone treatment, because of family responsibilities. Support services, especially in rural areas, were needed in addition to assistance with paying for medicine and medical equipment. Specialized training was recommended for those working with older adult patients and their families. Challenges faced in meeting these needs were identified as separate training for medical and social professionals; lack of networking with institutions in the field; lack of knowledge of the social worker role among the public and professionals; lack of professional support/development of a professional network and collaboration between professionals;

limited financial resources; isolation in rural areas; changing the regulations about the treatment, and access to medical equipment.

CHILDREN AND FAMILIES

Greatest needs centered around training for all health professionals about working with children. Another area was the need to identify /collect/disseminate information (phone numbers, agencies contact information, web sites) on services currently available and continue to develop and widely disseminate information to parents, families and organizations that serve them (i.e. family advisory centers). Networking was also needed between psychosocial-medical and families and other helping professionals. Challenges were seen in limited financing for services of trained professionals, training, and research; lack of collaboration and communication among institutions and prevention field specialists; and health policies and social policies that are separate and prevent cooperation.

ETHNIC MINORITIES

The minority most identified as needing attention was the Roma population. The group described behaviors that were seen as “problematic” by professionals that the behaviors were part of the cultural norm. These primarily include large numbers of family members that want to be with the patient in the hospital room and loud expressions of grief. They also tend to be isolated in institutions because they do not communicate with non-Roma patients and vice versa. However, if there is a choice, the Roma people prefer to die at home because of a mistrust of the health care professionals. The group participants believed that improved communication was essential within institutions, along with allowing adequate space for families to visit. Another need identified was for employment of Roma nurses in the hospitals and hospices to address the mistrust: however, participants acknowledged that Roma nurses may not be welcomed by the majority population. Overall, more education is needed for professionals and the public to learn about cultural beliefs/behaviors of the Roma population. One of the biggest challenges identified was in changing the attitudes of the institutions (expressed through policies) and the best responses to cultural needs/differences.

SURVIVORSHIP/SELF-HELP ADVOCACY

This group discussed an increased need for the formation of self-help groups to address many survivorship needs. However, the financing through the Hungarian Ministry of Health is decreasing and the poor economy effects make the formation of such groups difficult. Another issue described was long waiting periods before care (testing and treatment) could be received. A major challenge

identified for survivors was the decreasing quality of care. Public education and information about the economic impact on quality of care is needed. This session discussion was passionate, and there were differing opinions expressed by oncology psychosocial professionals and cancer survivors alike.

SOCIAL WORK NETWORKING/PROFESSIONAL ADVOCACY

A need was identified for the formation of a professional network in psychosocial oncology, in order to reach all the social workers who are currently working in the field. A call was made for employing more social workers in health care settings, as not all hospitals have social workers, and that each oncology unit should have a social worker assigned. Standardized competencies for social workers should be developed and disseminated. National policies and regulations need to require the availability of social workers in oncology settings. A lack of current understanding/awareness of social work role by other professionals and the general public was identified as a challenge.

FAMILY SUPPORT AND VOLUNTEERS

Access to psychosocial support in order to normalize the experience of cancer caregiving and development of family support networks was believed to be important. Public education and dissemination of accurate information about resources needs to be improved. A need for family support was also discussed in the context of improving communication between and among patients, caregivers, and medical/health professionals. Information about diagnosis, prognosis, and treatment options needs to be given clearly with more time provide for the discussion and in more than a single conversation. Overall, more volunteers were believed to be needed; specifically to have someone outside the system who could facilitate communication. A need also exists for increased training, support and supervision for volunteers. Identified challenges working with volunteers include: coordination and advocacy, selection (survivors, students), training (especially in relation to religion), the need to see their volunteer value in the systems, and identifying clear tasks for volunteers.

ROUNDTABLE RESULTS PRESENTED TO ENTIRE SUMMIT GROUP

Each of the lead group facilitators presented their group's flip chart notes in Hungarian, with interpreters, so the results were reported in both languages from all of the groups to all of the Summit participants. There was some overlap among the groups in all three areas: needs, available resources, and challenges; as well as some uniqueness. For example, training for physicians, nurses and social workers was identified as a need in all of the topical areas, but with different foci. Training in cultural competence was a focus in the ethnic minorities group, while psychosocial training to address

children's needs related to cancer was a focus in the children's group. Another need identified by all of the groups was improved communication and collaboration among the different disciplines and organizations addressing the psychosocial needs of cancer patients and families. Public and professional education about the role of health social workers and how they assist patients, families, and team members was identified in several groups.

OPENING OF SUNDAY'S SUMMIT HALF DAY SESSION, NOVEMBER 9

On the last day of the Summit, participants were guided through a process to select the top ten needs to improve psychosocial oncology from the identified needs in all of the round table discussions. After the presentations of the group discussions, the flip chart lists of the greatest needs for each topical area were taped to the walls in the meeting room. Each Summit attendee was then given three "stickers" and were instructed to place one sticker next to each of three statements from among the six discussion group lists that they perceived to be the greatest overall needs (for action) in psychosocial oncology. The number of stickers placed next to the items was tallied and a priority list of ten items was constructed. This list was then presented to the larger group of participants to ensure a consensus among the group.

CONSENSUS ON THE IMPERATIVES

Participants were next guided through a process to select the top ten challenges to improve psychosocial oncology from the issues identified in all of the roundtable discussions. The group dialogued about the potential strategies and challenges in meeting these needs. This discussion was the most spirited and challenging portion of the Summit. The Summit participants were energized and dedicated practitioners and consumers in the cancer community of Hungary. There were different opinions expressed and dialogue became passionate about the top needs and the challenges faced on many levels. However, in the end the Summit group did arrive at consensus on ten Imperatives to improve care and services, based upon the needs for psychosocial oncology care in Hungary.

Summit Imperatives

The Summit goals were to bring together psychosocial oncology professionals in Hungary and the United States of America to exchange best practice information and identify strategies to improve the psychosocial oncology care throughout the cancer continuum in Hungary and to improve care for Hungarian immigrants in America. With this goal, the Summit participants identified the following Imperatives to meet the greatest needs for action to improve psychosocial oncology in Hungary:

- 1. Improve communication between patients and families, and between patients, families, and health care professionals.*
 - 2. Collect and disseminate information to consumers and professionals about services for children and families by using the internet, phone, and other communication strategies.*
 - 3. Continue to build a network between multidisciplinary professionals and organizations in psychosocial oncology.*
 - 4. Increase public education efforts about available cancer treatments and other medical and psychosocial services.*
 - 5. Increase financing for family support/services and self-help groups.*
 - 6. Increase training opportunities for volunteers who work with individuals and their loved ones affected by cancer.*
 - 7. Define and disseminate social work competencies in health and psychosocial oncology.*
 - 8. Increase collaboration between medical and psychosocial professionals, to include developing policies and regulations that mandate comprehensive cancer teams.*
 - 9. Develop a standard of practice so that every oncology unit has a social worker and psychologist available to patients and families.*
 - 10. Advocate for improved quality and timeliness of care, such as access to adequate medical, psychosocial, and hospice services, especially in underserved rural areas.*
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METHODS TO ACHIEVE IMPERATIVES

The participants also discussed existing and potential methods for achieving the Imperatives.

1. The Summit itself will help achieve Imperatives.

The exchange between the USA and Hungarian colleagues was productive and it was striking that many participants indicated that they had not previously had such an opportunity to network with other psychosocial disciplines in the country that are doing the same work. Participants expressed an eagerness to work across disciplines and a need to continue to build this professional network and other such opportunities, communication and trainings, which will be important in addressing the identified Imperatives and improving psychosocial care. The Summit itself became an important achievement to the Imperatives as relationships were established, networking and training in best practices occurred, and a network of professionals came together to improve psychosocial oncology care in Hungary.

2. Funding will be an important method to achieve Summit Imperatives, such as increasing public education efforts about cancer, training and education opportunities for professionals, persons affected by cancer and volunteers, support and self-help groups, improving medical and psychosocial oncology care, and developing professional standards for disciplines such as social work.

Public and private entities can increase financing for the Imperatives. The initial six seed grant projects designed to contribute to and/or improve psychosocial care and services in oncology in Hungary is one way to achieve many Imperatives. The seed grant proposals are discussed further in the report under the section, Achieving Summit Imperatives.

The role of the Hungarian government in financing any of the aforementioned imperative topics was broadly discussed in the large group. Again, the passion and frustration expressed by both professionals and cancer survivors were striking. Many participants are avid advocates with the government for quality medical and psychosocial services, but many also expressed their frustration in not being heard or the change was not coming fast enough to make a difference in the lives of persons with cancer. This relates to the next method to achieve Summit Imperatives.

3. Advocacy is an important method to achieve many of the Summit Imperatives, including improved access to, and timely, psychosocial oncology care, including hospice and palliative care.

Summit participants identified writing letters or campaigns with their government for increased financing of quality medical and psychosocial care and services in oncology. Whether it be professionals or persons affected by cancer, each can advocate individually and collectively with the government to improve care and services. The importance of self-help groups to advocate for persons affected by different cancers such as colon or breast cancer was discussed. The young adult cancer survivor who participated with a social worker quietly told some of the USA leaders her hopes for being at the Summit. She hoped to reach more young adult cancer survivors in Hungary with support and advocacy. The young adult cancer survivor is volunteering with the social worker, who is one of the seed grant awardees. Self-help groups are gaining increasing importance in Hungary and lessening the stigma and helping equate cancer more with life rather than death.

4. Education and training of professionals and volunteers in cancer care are important methods to achieve Summit Imperatives.

Increasing the essential educational content about cancer (treatment, prevention and early diagnosis/treatment, quality hospice and palliative care) in curricula in schools or health programs of all ages of volunteers, persons affected by cancer, and professionals, particularly social work, is another method of achieving many of the Summit Imperatives. For example, the University of Debrecen has started a health social work program and is continuing to bring professionals into the classroom to teach social work students. The Romanian social work professor participant is networking with both his Hungarian and USA psychosocial oncology Summit colleagues by teaching in Hungary, bringing Summit information to Romania, reaching out to the nurses from Romania who desperately wanted hospice services in their underserved area and traveled all the way to Hungary for the Summit to learn more. The nurses have been made aware of different funding opportunities they can apply for to try and develop hospice services in their region of Romania.

Many of the social workers, psychologists, and physicians are instructors in their own fields with students and professionals from their respective disciplines. One of the key psycho-oncology leaders in Hungary has received funding from another source to educate young children in the classroom about cancer to increase awareness about cancer and the importance of prevention efforts and medical and psychosocial care as they grow into adulthood and face their own experience with loved ones being diagnosed with cancer.

5. The upcoming course, *Understanding Cancer: The Psychosocial Professional's Role*, translated into Hungarian will be another method of meeting Summit Imperatives by educating and training professionals in Hungary and in the USA, who work with Eastern European immigrants, about cancer and its care in Hungary.

NASW and CancerCare, in conjunction with University of Debrecen faculty and Summit leaders, are developing a web based education course to educate professionals in Hungary about cancer, its treatment, and the best practices and resources in psychosocial oncology. The course will incorporate information from Summit presentations and other resources, and will be based on the current *Understanding Cancer: The Social Worker's Role* web course. The course will be available in Hungarian, and also in English as there are Hungarian immigrants in the United States of America, and health professionals will be able to use the information to better provide competency-based services.

ACHIEVING THE SUMMIT IMPERATIVES

To date, each of the ten Summit Imperatives are achieving some degree of success. The Summit helped with establishing relationships and an email network of psychosocial and medical oncology professionals in Hungary and Romania to improve communication between professionals. The USA project manager has maintained contact with many of the Summit participants and has further developed relationships. Several of the psychosocial professionals met at the 8th Annual Psycho Oncology Conference in Hungary. Multiple disciplines were represented, but social work is still finding its professional voice in Hungary.

The Summit helped to create a much larger network of oncology psychosocial and medical professionals in Hungary and Romania. For instance, although nurses were not part of the Planning Committee, at least eight nurses traveled to the Summit and contributed greatly to the entire process and to crafting the Imperatives. Nurses provide most of the direct care to the cancer community, and they also have a strong role in psychosocial support and working with psychosocial professionals to deliver services and care as well.

The grant funding also provided assistance to six seed grant applicants. The successful applicants were awarded grants in late 2008, and are currently implementing their proposals through 2009. All of the awardees were part of the Summit Planning Committee and the Summit. Their funded proposals are directly tied to achieving the Summit Imperatives. The seed grant proposals are the following:

1) Dr. Magdolina Rohanszky, Clinical Psychologist

President, Hungarian Psychological Oncology Association
Szent Lazlo Hospital

Proposal: Study the Romany minority patient group to better understand their cultural characteristics, behaviors, and medication habits by conducting interviews and surveys with the patient population. Oncology professionals in Hungary often experience challenges in caring for this patient population, and it is hoped that understanding their culture will help professionals improve their services

Meets the Summit Imperative #1:

Improving communication between patients and families, and patients/families and health care professionals.

2) Anita Horvath, Chief Hospice Social Worker

Elizabeth Hospice Foundation

Proposal: Develop an information booklet on children's grief for educators, using a pilot group to test the effectiveness of the booklet. The booklet will be distributed to schools and an educators' training course will be implemented using the booklet.

Meets the Summit Imperatives #2 and #6:

Collect and disseminate information to consumers and professionals about services for children and families by using the internet, phone, and other communication strategies.

Increase training opportunities for professionals and volunteers to learn more about children's grief.

3) Rita Dudas, Social Worker

University of Szeged, Faculty of Medicine, Department of Oncotherapy

Proposal: Improve psychosocial cancer care by researching mood disorders and other psychosocial variables in their patient population. Research results will be compiled and used to contribute to better psychosocial services for patients and families. Another plan is to begin a civil organization led by a social worker to collaborate with the oncotherapy ward.

Meets the Summit Imperative #10:

Advocate for improved quality and timeliness of care, such as access to adequate medical, psychosocial, and hospice services.

4) Szabo Laszlong Valki Edit, Social Worker

Oncoradiology Center, Kecskemet

Proposal: With the help of volunteers, develop a cancer information center for patients. The project stems from the patient's need to have information and knowledge more rapidly, as they currently have to wait for the information.

Meets the Summit Imperatives #2 and #6:

Collect and disseminate information to consumers and professionals about cancer and its services for children and families by using the internet, phone, and other communication strategies. This proposal would collect and disseminate information to all persons with cancer more quickly. Increase training opportunities for volunteers who work with individuals and their loved ones affected by cancer.

5) Dr. Demeter Jolan, Radiation Oncologist

Szent Janos Hospital

Proposal: Administer questionnaires to individuals treated for breast cancer to ascertain their physical, spiritual, and social conditions. The goal is to find solutions to their needs and to see if there has been any change from ten years ago, when the questionnaire was first administered to 166 women affected by breast cancer. From findings in the first study, the hospital and cancer team made changes to improve psychosocial care to persons affected by breast cancer.

Meets the Summit Imperatives #5 and #10:

This proposal has the potential to meet a number of Imperatives. The study results could justify increased financing for family support services and self-help groups, and demonstrate the importance of high quality psychosocial oncology care.

6) Dr. Katalin Muszbek and Maria Marko, Psychiatrist and Social Worker

Hungarian Hospice Foundation, Budapest

Proposal: Implement a new element into the education in primary schools by creating a community program about human dignity. The intent is to shape public opinion about end-of-life-care, beginning at a primary school level.

Meets the Summit Imperative #4:

Increase public education efforts about cancer and its treatments, so that attitudes about end of life care and human dignity are shaped young and in a positive manner.

SUMMIT EVALUATIONS

Summit facilitators created a questionnaire for participants to complete and worked with the college’s social work department for translation from English to Hungarian. The questionnaires measuring participant satisfaction were distributed before the closing section and were completed by 30 participants.

ANALYSIS OF PARTICIPANT SATISFACTION QUESTIONNAIRES

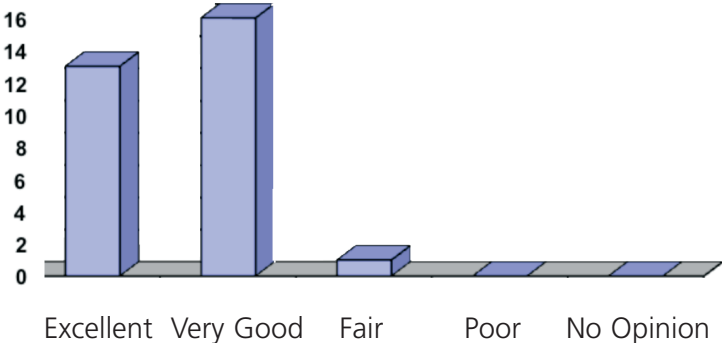
The following analysis was prepared by László Patyán, University of Debrecen Faculty of Health, School of Social Work.

Participants registered for the Summit included experts of oncology, several health professionals working in this field, and colleagues and students from our faculty. We were also pleased to welcome five colleagues from Romania, including a social work professor from Babes Bolyai University.

This analysis contains diagrams for each question.

In answering the first 4 questions, a five-level Likert item was used, with 1 for excellent, 2 for very good, 3 for moderate, 4 for poor and 5 for no opinion. *The diagrams show the number of respondents and their evaluations.*

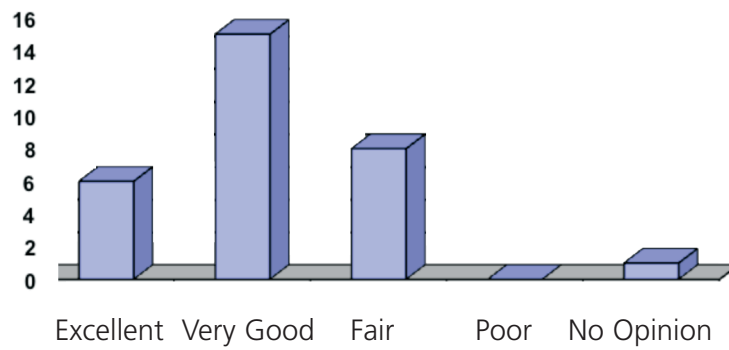
1. WHAT IS YOUR OVERALL EVALUATION OF THE SUMMIT?



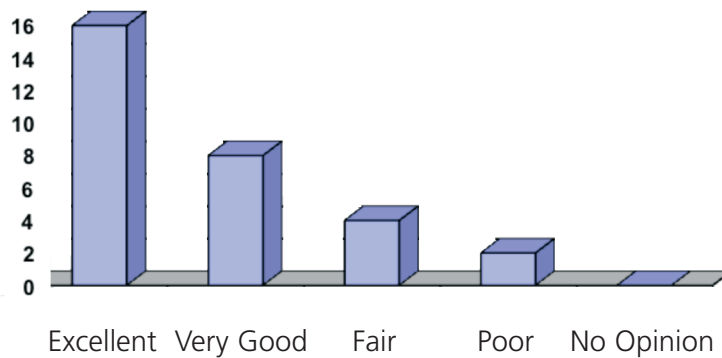
2. HOW WOULD YOU EVALUATE THE LECTURES?



3. HOW WOULD YOU EVALUATE THE ROUNDTABLE DISCUSSIONS ON PSYCHOSOCIAL ONCOLOGY ISSUES?



4. HOW WOULD YOU EVALUATE THE OPPORTUNITY TO MEET AND TALK WITH OTHERS?



SUMMARY OF QUESTIONS 1-4

The diagrams show that between 85-90% of the respondents' answers to the first four questions were "excellent" or "very good." From the first question, almost 100% of the respondents evaluated the overall Summit as either excellent or very good. All of the respondents answered that the lectures were excellent or very good. The roundtable discussions to address psychosocial oncology needs and issues in Hungary were evaluated by participants as moderate to excellent with half of respondents answering a "very good" satisfaction with the discussions. In question #four, 24 of 30 respondents agreed that networking with each other was "excellent" or "very good."

A frequent remark from participants was that more time could have been spent both on the roundtable discussions and informal talking during the breaks.

QUESTIONS 5-8

The remaining questions gave participants an opportunity to express their opinion about the conference.

5. Will you be able to use the best practices presented at the Summit?

A total of 22 respondents (N=30) gave positive answers to this question. Best practices in the order of frequency:

- Disseminating information by phone or on-line, and trainings
- Self-support and patient support organizations
- National social work models, information on social work
- Volunteers in action
- Family support
- The significance of interdisciplinary jobs
- Communication methods and techniques in practice

6. What were the strengths of the Summit?

The list of strong points in the order of frequency:

- Interdisciplinary aspect of Summit (they worked together with experts from other fields)
- Well arranged
- Free services during the Summit
- Openness
- Friendly atmosphere and style
- Essential, pointed lectures
- Informal talks
- Well-prepared lecturers, presenters were experts of best practices
- New information in general and on international trends

7. What could have been improved at the Summit?

In the order of frequency:

- More time for roundtable discussions and responses
- More time for closing the conference
- More decision makers could have been invited

8. Would you like to be correspondent member of the Summit-net?

A total of 22 respondents would like to be members of the correspondent net and continue participation.

WEB SITES FOR THE SUMMIT, THE SUMMIT PRESENTATIONS AND TRANSLATED RESOURCES

The Summit was videotaped and webcast on the University's Web site at <http://odin.de-efk.hu/content/view/1242/48/>. The Summit webcast is archived and all of the materials and presentations are available at this site. NASW set up a web link, www.socialworkers.org/practice/intl/hungary2008/default.asp, for Summit documents and link to the University's Web site. University leaders arranged to have the conference and presentations simultaneously translated by two professors from their English department. Presentations and resource information are available on both Web sites in English and Hungarian.

POST-SUMMIT COMMUNICATION WITH LEADERS AND PARTICIPANTS

After the Summit was completed, László Patyán and Karyn Walsh each developed thank you letters to all Summit leaders and participants. The letters were sent out within one month of the Summit, completion. One of the university language teachers translated the letter that NASW and CancerCare sent jointly to Summit participants. The letters included a reminder of the next steps from the Summit which include the final Summit report and the online course *Understanding Cancer: The Psychosocial Professional's Role*. The letter welcomed feedback and communication from participants. The letter also encouraged continued networking among the professionals who participated in the conference.

László Patyán continues to serve as the contact in Hungary for matters related to the Summit, seed grants, and assistance in translation with any of the participants. Laszlo Csaba Degi, Social Work Professor of Romania, has been helpful in contacting the group of nurses in Romania about post Summit questions and needs.

Karyn Walsh, NASW, continues to serve as the main USA contact and communicates with Summit participants with the help of the translators. All Summit participants have been made aware of new grant opportunities for Eastern Europe from the Bristol Myers Squibb Foundation for 2009 and beyond.

DEVELOPMENT, DISSEMINATION AND PURPOSE OF THE SUMMIT FINAL REPORT

This final Summit report has been developed from the collective work and contributions of Summit leaders and participants. Summit report authors include Karyn Walsh, Ellen Csikai, László Patyán, Floyd Allen, and Katherine Walsh.

ONLINE PUBLICATION OF FINAL REPORT: WEB SITES IN THE UNITED STATES OF AMERICA AND HUNGARY

The final Summit report will be posted on the Web sites of NASW, CancerCare and the University of Debrecen by July 2009. Each Summit participant will be given a copy of the report via email and limited hard copies will be made available.

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NASW and CancerCare thank all of our colleagues from Hungary who were involved from the Summit planning through the actual Summit and subsequent communications as we put together this report. This opportunity was special in so many ways, but most of all, the relationships that developed between participants and the opportunity to exchange best psychosocial practices with other psychosocial oncology professionals was exceptional.

The importance of the partnership with the University of Debrecen, Faculty of Health, cannot be overstated. The social work department was supportive in many ways that were instrumental in ensuring the success of the Summit meeting. László Patyán, administrator of the bachelor of social work program, served as the primary coordinator in Hungary. He was active in helping secure participants (as described earlier) as well as resources that would be needed on-site during the Summit meeting. In addition, several social work students played a critical role during the meeting. They served as hosts/greeters and helped to register participants and assisted with the small group discussions. In addition, they served as “tour guides” throughout the weekend. Still other interested students attended the presentations. Technical support was provided by the school which included equipment assistance for PowerPoint presentations, microphones, photography, and arranging for a live webcast of the event. Printing of all conference material was done by the school before the arrival of the USA project leaders and consultants. We wish to express our great appreciation to everyone involved at the University of Debrecen, Faculty of Health, Nyíregyháza, Department of Health and Social Work, for their incredible commitment to the success of this Summit.

SUMMIT TRANSLATORS

It is with special thanks from all of the Summit leaders and participants that we acknowledge the dedicated and tireless translation work of Ilona Bay and Agnes Tilki, University Language Department, at the University of Debrecen, Faculty of Health, in Nyíregyháza, Hungary. Both were an invaluable resource who provided professional language interpretation for the conference; from English to Hungarian to the larger group of participants (consecutive) and also from Hungarian to English for the English speakers (simultaneous). These individuals were available for the “official” meeting events as well as the informal gatherings. The importance of these native language interpreters was also seen in helping the project leaders understand the cultural aspects of the primary problem of lack of adequate psychosocial services for the Hungarian people and how that could be addressed.

SUMMIT PLANNING COMMITTEE MEMBERS

The Summit came together through the efforts of the following individuals who served in the capacity of pre-planning and/or Summit planning and implementation. We hope that the Summit truly reflects the contributions everyone made to help meet the goal of the Summit, to improve psychosocial services and care in Hungary with the help of this best practices exchange. Thank you.

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