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Historical Threads in the Development of Oncology Social Work

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On the 25th anniversary of the Association of Oncology Social Work (AOSW), we take a moment to reflect on the threads of history that bring us together. In this paper, we tell the story of the birth and development of the Association of Oncology Social Work, first as a professional health organization from 1984–1993, and later becoming a charitable organization for educational purposes from 1994–2009.

We begin with a description of Oncology Social Work,(Association of Oncology Social Workers, 2001) and its role in helping cancer patients and their families. Next, important historical developments are reviewed: the birth of medical social work in hospitals in the early 20th Century;(I M Cannon, 1923) the medical improvements in the 1940's in treating cancer, and the shift to a consumer oriented American Cancer Society pushing a greater role for the federal government in funding cancer research. Oncology Social Work came to full blossom in the 1970's, a result of the physicians' need for a member of the health care team who understood cancer, treatment, and the patient's need to address their psychosocial needs. Oncology Social Work is today a fully developed profession with its national organization that provides education and support to the oncology social workers' use of multiple psychosocial interventions for cancer patients and their families.

Oncology Social Work Defined

Oncology Social Work is a humanizing influence felt throughout the hospital or cancer center. This is a profession “designed to promote the patient's best utilization of the health care system, the optimal development of coping strategies and the mobilization of community resources to support maximum functioning.” (Association of Oncology Social Workers, 2001) As a clinical practitioner, the oncology social worker draws upon knowledge from medical and psychosocial oncology, and when possible participates in research. Oncology social workers provide advocacy and clinical services to patients and their families; they work as team members with other health professionals, and provide education and mentoring for younger social work professionals. A central role of the oncology social worker is to assess patient, and family care needs, and provide interventions that help clients work towards solutions, solutions that address their physical, intra-psychic, interpersonal and environmental problems.(Hermann & Carter, 1994) Some oncology social workers become administrators and/or educators influencing the institutions in which they work and providing services to their community and profession.

Development of Oncology Social Work

The National Association of Oncology Social Workers (now AOSW) became an organization in New York City in 1983–1984, launched through the support of the American Cancer Society. As an organization, we are indebted to several historical developments: the development of hospitals in America at the turn of the 20th Century; early role models of medical social work in Boston; improvements in cancer treatment after World War II; the concern of public figures in New York City who helped shift the focus of the American Cancer Society towards funding cancer research; the expansion of the research program at the National Cancer Institute; the role of the American Hospital Association in developing federal standards, 1940–1970's, requiring hospitals to employ medical social workers; the increases in patient survival from cancer 1970–2000; and the development of a knowledge base on the nature of cancer, the side-

effects of treatment and the needs of cancer patient and their families, and ongoing challenge. This is our story.

Early Developments: Emergence of the American Hospital

Some of the earliest hospitals in the country are cancer centers today. Philadelphia, New York, and Boston, and Baltimore were the first to create hospitals in the 18th Century, and were leading cities in the development of cancer centers in the 20th Century. America's first hospital was built during the American Revolution in Philadelphia in 1751. Pennsylvania Hospital, founded by Benjamin Franklin and Dr. Thomas Bond, began in response to the need for medical care for soldiers in the Continental and British forces. New York Hospital, now New York-Presbyterian Weill Cornell Medical Center, the second oldest hospital has a charter going back to King George III signed in 1769. Massachusetts General Hospital, the third oldest hospital, was founded in 1811 to care for the poor. Johns Hopkins Hospital opened in Baltimore in 1889, and was first in admitting women for medical education.

As the 20th Century dawned, hospitals were built throughout the country to meet the growing need for organized health care to cope with the problems of infectious diseases. In the 1890's the major increase in European immigration led to increased problems with tuberculosis and other infectious diseases. In the 20 years from 1898 to 1918, the American Hospital Association grew from eight to over 1,000 members.

At the turn of the Century, social developments in caring for the sick in London, spread to the United States stimulating social services in settlement houses and hospitals.(Friedlander, 1968) In the 10 year period between 1905 and 1915 social workers were hired in more than 100 hospitals throughout America.(Barker, 1995) Massachusetts General Hospital in Boston (1905) and Johns Hopkins Hospital in Baltimore (1907), created Social Service departments to assist physicians in patient care. Memorial Sloan-Kettering Hospital in New York followed suit in 1920. Several of America's first hospitals, became America's cancer centers in the 1970's. In 1974, Massachusetts General, Memorial Sloan-Kettering, Johns Hopkins and Fox Chase Hospitals were named Cancer Centers by the National Cancer Institute.(Network, 2008) Each cancer center had a medical social work department from their outset that has continued their commitment to training oncology social workers along with providing clinical care for patients

Innovations in Medical Social Work

Oncology social work evolved as a specialty within medical social work. It grew up in the world of hospitals and clinics, maturing as an important field side by side with the medical development of effective cancer treatments. The pioneers in medical social work developed professional roles similar to those of today's oncology social workers, working along side physicians and nurses in hospitals and clinic settings.

In the early decades of the 20th Century, two medical social workers, Ida Cannon and Harriett Bartlett in Boston, were early role models for today's oncology social workers. Beginning in 1905, Dr. Richard Cabot, internist and medical reformer, introduced Cannon to the outpatient clinic staff in Massachusetts General Hospital (MGH) as a team member. Cabot's concept was that, "the social worker would help achieve a more accurate diagnosis and an effective treatment program."(Bruno, 1964; Shaffer, 1989) Ida Cannon had been a visiting nurse who shifted careers after hearing Jane Addams talk about the poor health conditions of children living in slums. She took a nine month course in social work at Simmons College at Boston University. When Cannon became the head social worker at MGH in 1914, she expanded the social work role to include both patient advocacy and clinical services. "*Social work should be assigned to represent the patient's point of view, someone who could work with the physician*

towards an adaptation of the medical treatment that would fit the patient's social condition." Cannon's definition of a medical social worker is relevant today, "One who sees the patient not as an isolated, unfortunate person occupying a hospital bed, but as a member belonging to a family or community group that is altered because of his ill health." Furthermore, Cannon wrote. "The social worker seeks to remove obstacles either in the patient's surroundings or in his mental attitude that interfere with successful treatment, thus freeing the patient to aid in his own recovery." (I M Cannon, 1923) She worked hard to ensure that immigrants with little English understood the nature of their illness and prescriptions. (Bartlett, 1970; I.M. Cannon, 1952)

During her long career (1905 to 1945), Cannon developed the *psycho-physiological approach* to disease, a medical, social, and psychological formulation of patient care. She initiated *group work services* to tubercular, cardiac and other patients, with her colleague, Dr. Pratt. Cannon participated in *clinical research, systematically studying patients* who presented with industrial diseases and, proposed the idea of a Social Diagnosis to link social work and medicine. Her idea was developed further by Mary Richmond who published, *Social Diagnosis* in 1917. In 1913, Cannon published, *Social Work in Hospitals*, dedicated to Dr. Cabot. (Bartlett, 1970; I M Cannon, 1923; I.M. Cannon, 1952) (Holland, 2002; Keigher, 2000) As a leader in *education*, Cannon initiated a program at the Boston School of Social Work that gave students a command of medical and social work expertise. She helped to develop a *standardized program for the training of medical social workers* and participated in the founding of the American Association of Hospital Social Workers in 1918. By 1919, medical social work had been established in 300 hospitals. The scope of Cannon's work, clinical services, education and research, her dedication to the importance of professionalism in hospitals and university training provides us with a role model relevant today.

Harriett Bartlett was hired by Cannon as MGH Social Service department's first educator. She was also a "moving force in the continued development of medical social worker and social work education. She did much to define social work practice as, "helping people in their environment." "Person-in-environment," was Bartlett's view of the social worker's comprehensive domain of practice.(Bartlett, 1970) Bartlett, like Cannon taught in the Simmons College School of Social Work in Boston. She wrote the first textbook, "Social Work Practice in the Health Field," and was well-known for her social research. In the 1960's she conducted a study on social work practice, which resulted in the book, *Common Base of Social Work Practice, published in 1970*. She viewed social work practice from a problem-solving approach.(Bartlett, 1970)

Today we see social work practice as both a problem-solving process and embodying a contemporary, holistic-growth-oriented approach to helping others.(Turner, 2003b) During the last 100 years, the achievements of medical social work have included *achieving recognition and legitimacy, effecting a change in the models of illness and health, knowledge development, direct interventions with patients, and development of culturally appropriate interventions*. (Auslander, 2001) Bartlett was correct when she emphasized the dynamic nature of our profession; it's definition always in process.(Bartlett, 1970) In addition to a problem solving approach, which Bartlett emphasized, Oncology Social Work also benefits from a growth-oriented perspective to working with patients.(Turner, 2003a) A growth-oriented perspective is implicit in psychosocial intervention research.(Spiegel, 2001)

The values and practices from medical social work inform Oncology Social Work today. Values like, the importance of being an *advocate* for the patient's point of view within the medical system and in the community, the importance of *understanding the cancer disease process*, and *participating as a team-member* with physicians and other health professionals, are values from medical social work described by Ida Cannon, one of the memorable

personalities that enriched our field.(IM Cannon, 1923) and are found today in the description of standards of practice in the Association of Oncology Social Work. (AOSW, 2001)

Cancer Treatment Comes of Age

By 1936, the world's top scientists understood that tobacco, diagnostic and solar radiation, arsenic, asbestos, benzene and hormones might be causes of cancer. The need to prepare and conduct World War II effectively postponed any action these early findings might have generated.(Davis, 2007) Growing concern over health issues in America became prominent in the 1940's anyway, when it was learned that(Holland, 2002; Profiles in Science, 2007) one-third of the men reporting for the draft were sent home following their medical examinations, due to "malnutrition and poor health." (Holland, 2002; Profiles in Science, 2007) (Profiles in Science, 2008)

Before World War II, medical research in the United States was modest in scale and conducted at universities, non-profit institutions or private companies with little in the of way of federal grants-in-aid.(Profiles in Science, 2007) Congress first established the NCI as an independent research institute with The National Cancer Institute Act, August 5, 1937. With greater awareness of need for research funds, Congress made the NCI an operating division of the National Institutes of Health by the Public Health Service Act, July 1, 1944.(Wikipedia, 2008)

The growing interest in improving the nation's health included the desire to make changes that would have an effect on cancer incidence and mortality. Innovations in treatment approaches had improved during World War II. During the war, surgeons on the battlefield improved their technical skills, partly assisted by better forms of anesthesia and the arrival of effective antibiotics. The chemotherapeutic agent, nitrogen mustard, used in war as mustard gas, was found to have a therapeutic purpose in cancer treatment, the first chemotherapy. Other improvements included better techniques in tumor visualization using ultrasound, and cancer treatment using high-energy sources of radiation. Such improvements raised the possibility of controlling and even curing cancer in future decades.(Holland, 2002, 2004)

In the 1950's further improvements in surgery, chemotherapy and radiation therapy created optimism about patient survival, creating enthusiasm for research on the effectiveness of various cancer treatments. In 1953, Radiation therapy was initially used to ease pain from cancer.(ACS, 2007; Milestones, 2008) In 1956, the first medical linear accelerator (now retired in the Smithsonian Institute) was installed at Stanford Hospital in San Francisco.(Linton, 2006) Radiation therapy was later shown to produce 40% of all cures. Methotrexate, developed by Sidney Farber, a pathologist at Harvard Medical School was recognized by the National Cancer Institute in 1953 as an important treatment inducing remission in children with acute lymphoblastic leukemia (ALL).(ACS, 2007)

Medical Social Work Become Necessary for Hospital Accreditation

During the 1940's, the American Hospital Association determined that having social work services on a hospital's staff was important for accreditation.(Keigher, 2000) Holland (2002) writes, "*During the 1940's an important role for social workers working with cancer patients was defined in the United States.*" "*Social workers were the first, alongside the physicians and nurses, to attend to the psychological and social problems of cancer patients and their families. They have continued as the 'front line' in clinical care and as important researchers in psycho-oncology,* (Holland, 2002, 2004) Keigher writes, "Social work was an expanding profession in the 1940's, employing college and graduate school trained medical social workers in hospitals as it became a part of the standards of practice encouraged by professional organizations."(Keigher, 2000) A professionally trained Social Work Department at Memorial

Sloan-Kettering was put into place in 1942, replacing former staff. Hospital social workers throughout the country were now encouraged to have graduate school education for employment in the leading hospitals.(E. M. Carter, 2005) Another role for professional social work came in 1944 when CancerCare was founded in New York City. CancerCare provided financial assistance for home care for patients with advanced cancer, with counseling by professional oncology social workers.(CancerCare, 2006)

Psychosocial Issues of Cancer Patients Gain Recognition

In the 1950's, health professionals including oncology social workers described the patient's experience in medical journals. The first research papers published on the patient's psychological reactions to cancer came from Memorial Sloan-Kettering, where Sutherland et al, 1952,(Sutherland, 1952) and Bard and Sutherland, 1955(Bard M., 1955) wrote about the psychological impact of cancer following surgery. In 1953, at Massachusetts General Hospital, Ruth Abrams,' an MSW working in the MGH Tumor Clinic, published, "Guilt Reactions in patients with cancer."(R. F. J. Abrams, 1953a) Her paper, "The Patient with Cancer: His Changing Pattern of Communication" led to Abrams receiving the Harriett M. Bartlett Award (Simmons College Library Archives) in 1966.(R. Abrams, 1966).

As treatments became more available, concerns about the patients right to informed consent, patient autonomy and debates on disclosing a cancer diagnosis became part of public discussion (Holland, 2002) Memories of the human experiments done in the name of science in Germany lead to the Nuremberg Code, an international code of ethics requiring that experiments be scientifically necessary, conducted by qualified personnel with written informed consent signed by the patient. (Sparks, 2002) At the same time mothers whose children had been born with limb deformities, following treatment with thalidomide, called for government protection of human subjects, to include the possible consequences of taking treatment. In 1962, the Kefauver-Harris amendment strengthened Federal oversight of drug testing and required informed consent on the possible consequences of taking prescription drugs. By 1966, U.S. regulations more clearly defined the specific requirements of informed consent. (Sparks, 2002)

Cancer centers in Boston, New York, Texas and California increased their social work staff during the 1960's in order to care for the additional needs of pediatric and adult cancer patients in clinical and research settings.(P Fobair, 2000) For example, Evelyn Cooper, Director of Social Work, Memorial Sloan-Kettering Cancer Center in New York increased her social work staff throughout the 1960's.(Carter, 2005) Anticipating the future of Psycho-Oncology as an evolving field, Dr. Jimmie Holland, at Memorial Sloan-Kettering initiated a training center in 1972, to focus on the emotional needs of cancer patients. It was called the Postgraduate Institute in Psychosocial Oncology. When the NCI's National Cancer Program Plan was published in 1974 indicating federal interest in the psychosocial problems of cancer patients, hospitals were encouraged to add additional positions for medical social workers to provide services to pediatric and adult cancer patients.(P Fobair, 2000)

American Society for Control of Cancer: Now, The American Cancer Society

In New York City, a personal tragedy stimulated positive changes in attention to cancer. A wealthy advertising executive learned late in the process that her housekeeper was dying of cancer, "a word that couldn't be said out-loud." After the housekeeper was sent to a home for the "incurable," Mary Lasker and her husband Albert joined forces to raise money for cancer research and influence changes in the purpose and name of the American Society for the Control of Cancer to the American Cancer Society.("The American Society for the Control of Cancer," 3/22/08) With their connections in New York's financial circles, in Congress and the White

House, the Lasker's used their influence to call for greater government involvement in cancer research at the National Cancer Institute. By 1945, the American Cancer Society was effective in calling for greater government involvement in cancer research at the National Cancer Institute. ("The American Society for the Control of Cancer," 3/22/08)

Mary Lasker (1900–1994) continued to fund raise for cancer research throughout life using her roles as director, chairman, or trustee in the American Cancer Society. She worked with several American Presidents, from Harry Truman, to Lyndon Johnson, and addressed Congress frequently lobbying to see to that there was growth in the budget for cancer research at the National Cancer Institute. She succeeded in seeing appropriations for the NCI grow from \$1.75 million in 1946 to more than \$14 million in 1947, and \$110 million in 1961. She played an important role, as a leader in the "medical research lobby," and conceived of the idea for the "War On Cancer." (McGeary, 2003) The Lasker group continued to push for Congressional legislation to create the National Cancer Act of 1971. When it passed, Congress made a record sum of \$1.59 billion available for cancer research over a three-year period. The act was widely supported by Congress, and marked a high point of Lasker's influence. (Profiles in Science, 2008)

In 1955, the American Cancer Society funded Emil Freireich and his colleagues to design the first scientific clinical trial for combination cancer chemotherapy; by 1962 they achieved a 15% cure rate in childhood leukemia. In 1955, Dr. Sidney Farber, Mary Lasker and others proposed to Congress the clinical trials program for studies of chemotherapy. Congress responded by giving \$5 million for chemotherapy research. Leukeran, a treatment for chronic lymphocytic leukemia (CLL) and Hodgkin's disease was recognized by the NCI in 1957, followed by Cytosan, in 1959 used to treat several forms of leukemia and lymphoma. By 1958's several effective treatments were available for treating cancer in children. There were 17 groups formed to test new anticancer agents from the NCI drug development program. (ACS, 2007)

The National Cancer Act and the "War on Cancer"

At the request of Senator Ralph Yarborough, April 27, 1970, the Senate approved the establishment of the National Panel of Consultants on the Conquest of Cancer. Within six months the national panel submitted their report to the Senate, "National Program for the Conquest of Cancer." On December 23, 1971, President Nixon signed PL 92-218, the National Cancer Act of 1971 into law, "to collect, analyze and disseminate all data useful in the prevention, diagnosis and treatment of cancer." (NIH 1999 Almanac, 1999) It was called, "The War on Cancer," (McGeary, 2003) a tribute to Mary Lasker and the American Cancer Society. "The act was widely supported by Congress, and marked the high point of Lasker's influence." (Profiles in Science, 2008)

A description of the National Cancer Program Plan was published in 1974. It included funds for cancer control, patient rehabilitation, and psychosocial research. By 1975, the NCI staff issued requests for proposals to tract the normal experiences of cancer patients over time. (Bloom JR, 1987; Spiegel, Bloom, & Yalom, 1981) There were over 3,000,000 cancer survivors in 1976. (Control, 2004)

In the newly developing psychosocial world, multidisciplinary team research projects employed medical social workers to interview cancer patients. (Castro, 1977) Project Omega in Boston "examined patients most at risk" following treatment, 1972–1980. (Weisman, 1976–1977.) In San Francisco, an exploratory study on cancer rehabilitation in 1977, described the normal patterns of cancer patients following treatment. (Castro, 1977; N. L. Mages et al., 1981; N. L. Mages & Mendelsohn, 1979) To further protect patients' rights the National Research Act in 1974, created the National Commission for the Protection of Human Subjects

in Medical Research. Federal guidelines now spelled out full protection of patients rights. (Holland, 2002)

By the 1980's the effectiveness of cancer treatments led to an increase in the number of cancer survivors.(NCI, 2004) Gradually the long term problems of cancer survivors became known, and health care professionals called attention to their patients' additional needs.(Smith & Lesko, 1988) (P. Fobair et al., 1986) (Loescher, Welch-McCaffrey, Leigh, Hoffman, & Meyskens, 1989) (Welch-McCaffrey, Hoffman, Leigh, Loescher, & Meyskens, 1989) Medical social workers, along with nurses and physicians responded to this challenge in their research, journal articles and conferences.(ACS, 1984b) Medical social workers became more sophisticated about the specific physical and emotional needs of cancer patients, and the difficulties of medical treatment. They participated in psychosocial research teams along with their clinical practice.(P. Fobair et al., 1986) By 1980, the term Oncology Social Work was a part of the vernacular. With the encouragement of the American Cancer Society, the formation of a new professional organization was planned.(M. Lauria, 1998)

Human Values Conferences Stimulate Psychosocial Oncology Groups

The American Cancer Society was responsible for offering oncology social work a spotlight on the national stage with their invitations to participate in the multidisciplinary talks given at the "Human Values Conferences" held throughout the country, 1972–1987. These conferences provided space for networking and discussion of research and practice. Those attending shared knowledge on the needs of cancer patients and survivors.(P. Fobair, 1981, 1987) Social workers participating in the Human Values Conferences included Joan Herman, 1972; Judith Ross, 1977; Pat Fobair, 1981; Grace Christ, 1984; Marie Lauria, 1987.(ACS, 1972, 1978, 1981, 1984, 1987 1981, 1984, 1987 #3929) The Human Values Conferences stimulated interest in the patients experience and recognized the collaborative research funded by the Robert Wood Johnson Foundation, the American Cancer Society and the NCI Division of Cancer Control. (P. Fobair et al., 1986; P. Fobair et al., 2001; P. Fobair, Stewart. S.L., Chang, S., D'Onofrio, C. D., Banks, PJ, Bloom JR, 2005)

As interest in psychosocial oncology grew, psychiatrists, social workers and nurses met to talk about there unique experiences and common interests. Grace Christ, MSW noted that social workers had been meeting for ten years (1974–1984) to support and educate themselves and others. In Boston, 1976–1981, a multidisciplinary group, the Psychosocial Oncology Group met, creating a forum for the discussion of cancer patients' needs and the ethical issues involved with treatment. In California, social work groups met in San Francisco and Los Angeles. (Fobair, 1973) There were 40 oncology social work groups throughout the United States that met monthly during the 1970's.(Christ, 1984) Oncology social workers gave lectures on their work with cancer patients, and their publications continued to appear. (P Fobair, 2000) (Patricia Fobair, 1981) In 1979, The American Cancer Society's national office hired their first social worker, Virginia Conkling, MSW. By 1980, Conkling formed a national Social Work committee and invited them to think about forming a professional organization.(P Fobair, 1979)

Oncology Social Work Comes of Age

Oncology Social Work was articulated as a specialty within medical social work by the 1980's. Their unique knowledge of patient needs and resource, their relationship with patients and their families contributed to a positive treatment outcome. Many oncology social work staff participated in the psychosocial and behavioral research funded during the 1980's. These studies tracked the "natural patterns of cancer patients following treatment" and examined the value of interventions like group therapy, self-hypnosis techniques and behavior modification (P. Fobair et al., 1986; Spiegel & Bloom, 1983; Spiegel, Bloom, Kraemer, & Gottheil, 1989)

As previously noted in 1979, The American Cancer Society's national office hired their first social worker, Virginia Conkling, MSW, and by 1980, Conkling had formed a national social work committee and invited them to think about forming a professional organization. (P Fobair, 1979) The National Oncology Social Work Advisory Committee met in the fall of 1982 in New York City. Twenty social workers met to advise the American Cancer Society of the professional education needs of oncology social workers. Together, they sponsored an invitational workshop on the state of the art in practice, education and research in oncology social work in St. Louis. Among the 30 social workers attending, there were informal discussions on forming a national organization. The two recommendations were to: 1) Establish a national ACS advisory committee on oncology social work; and 2) Convene a national educational workshop for oncology social workers that would have, as a secondary purpose, the creation of a national organization. (M. Lauria, 1998)

To honor the development of a new organization, Grace Christ, Chief of the Social Work Department at Memorial Sloan-Kettering saw the need for a professional journal. Christ organized the resources, and *The Journal of Psychosocial Oncology* received its copyright in 1983. (Zabora, 1983–2005)

In September 1983, the ACS National Advisory Committee on Oncology Social Work met with the participants agreeing to form a national group. At the March 1984 educational conference in New York City, participants formed several committees to handle the issues of becoming a new organization, called the National Association of Oncology Social Workers (NAOSW). In November and December 1984, the steering committee met with an attorney at the offices of Cancer Care, Inc. in New York to work on drafting the bylaws. In December, NAOSW was incorporated in Pennsylvania as a professional organization (501.(c) 6), whose key elements included opportunities for networking and communication, division into regions, and liaison with the Association of Pediatric Oncology Social Workers founded in 1977. (M. Lauria, 1998) Beginning in 1984, the National Association of Oncology Social Work held annual conferences that provided ongoing encouragement for the development of younger professionals. (ACS, 1984a)

Oncology Social Workers, like Executive Directors, Elizabeth Clark and Diane Blum have provided leadership in national organizations like, the National Association of Social Workers (NASW), Cancer Care, along with Virginia Conkling, Arlene Rabinowitz and Joan Herman and others at the American Cancer Society. In 1985, an Association of Oncology Social Work (AOSW) member, Diane Blum, MSW, Cancer Care's Executive Director, acted as co-founder of the National Breast Cancer Awareness Week, the forerunner of the National Breast Cancer Awareness Month each October. Betsy Clark, then President of the National Coalition of Cancer Survivorship worked with Ellen Stovall to organize the first March on Washington of Cancer Advocates in 1998. Oncology Social Workers were early participants in psychosocial research. (R. F. J. Abrams, 1953b) Beginning in the 1970's, this research expanded to include issues of quality of life, cancer prevention, and group interventions. (Altpeter, 1998; Blanchard, 1995; Bloom, 1991; Bloom et al., 1993; BrintzenhofeSzoc, 1999; P Fobair, 1998) *

In 1994, NAOSW, changed its name to Association of Oncology Social Work, and its 501 (c). 6 legal status as a professional organization, to a 501 (c).3, a charitable organization with educational purposes. The Association of Oncology Social Work (AOSW) is a non-profit, international organization dedicated to the enhancement of psychosocial services to people with cancer and their families. The growth of AOSW is a positive reflection of good leadership, and the needs created by the effectiveness of cancer treatment from the 1950's to the present time.

Over the years, AOSW members have collaborated with each other on conferences, with many organizations on mutual goals. Our members practice in hospital, outpatient clinics, home care and hospice agencies, community wellness program, patient advocacy organizations and other settings. We connect persons diagnosed with cancer, and their families, with essential community, state, national, and international resources. We do this as part of the oncology team. We are as diverse as the clients and communities we serve.(AOSW, 2001) Some of our accomplishments include:

- Annual conferences have increased in size of participation, improved content.
- Journal of Psychosocial Oncology: published for 25 years, 1984–2009.
- AOSW Standards of Practice are a model for other professional groups.
- Cancer Survivor Toolbox (with NCCS, and ONS) continually improved.
- Online Classes are available to assist members with requirements.
- Educational Programs bring members up-to-date information.
- AOSW conference in Hong Kong, 2006
- AOSW partnered film, “A Lion in the House.”
- International AOSW supports psychosocial services to patients and families.
- Collaboration with American Cancer Society, National Association of Social Workers, National Cancer Institute, National Coalition of Cancer Survivorship, and the Lance Armstrong Foundation.
- AOSW Members Honored (partial list): Presentations for the US Presidents Cancer Panel: Fobair, 1993,(PA Fobair, 1993), Zebrack, 2005, Walsh, 2006; Distinguished Practitioner Awards, Yvette Colon, National Academies of Practice in Social Work, 2008; R.R.Dickens, Distinguished Practitioner Award, National Academies of Practice, 2008; Karlynn BrintzenhofeSzoc, the American Cancer Society’s St. George National Award, 2008.(AOSW, 2008)

Cancer Survivors Create the Survivorship Movement

As the number of cancer survivors increased from 3 million in the 1970’s to 7 million at the end of the 1980’s, cancer survivors began to write and talk about their experience, seeking connection with other survivors and professionals. The development of the Survivorship movement completed the circle of an interdependent world between medicine, oncology social work and survivorship. Dr. Fitzhugh Mullan, a physician patient toured the country in 1984 and 1985 discussing, “*Vital Signs*,” his experience being treated for testicular cancer. Mullan’s goal was to improve communication between the healers and patients, and work towards better funding for research on quality of life after cancer. He led the development of the National Coalition for Cancer Survivorship (NCCS) signaling the beginning of a national Survivorship movement. The Cancer Survival Toolbox was a joint effort of NCCS, with AOSW, NASW and the Oncology Nursing Society. In 1996, the Office of Survivorship was established by the National Cancer Institute in recognition of the large number of individuals now surviving cancer for long period of time and their unique and poorly understood needs. By 2004, the number of survivors increased to 11 million.

During the last 20 years, the number of survivor advocacy groups increased. Breast Cancer and Prostate Cancer groups and other emerged and became advocates for federal funding and better patient care. Documenting the long term problems of surviving cancer and treatment has increased steadily since the 1950’s,(Shands, 1951) flowering into an international garden in the 1990’s and early 21st Century. (R. Abrams, 1966; R. F. J. Abrams, 1953b;N. L. Mages &

Mendelsohn, 1979; Polivy, 1977; Sanger & Reznikoff, 1981; Schain, Edwards, Gorrell, & al., 1983; Sutherland, 1952) (P. Fobair et al., 1986; Ganz, Desmond, Belin, Meyerowitz, & Rowland, 1999; Zebrack, 2007; Zebrack BJ, 2007)

Recent events point to the interconnected relations of AOSW with collegial organizations. In 2005 a book, “*From Cancer Patient to Cancer Survivor*” was published by the National Cancer Institute and the American Cancer Society. Ellen Stovall, of the National Coalition Cancer Survivorship, co-edited the book with Maria Hewitt, the Study Director and Sheldon Greenfield, Director for Health Policy Research, University of California-Irvine. (Hewitt, 2005) Diane Blum, MSW, from CancerCare, Inc, reviewer. In the description of Oncology Social Work with cancer patients, there is a description of the AOSW Scope of Practice, the Journal of Psychosocial Oncology, and the book, *Social Work in Oncology: Supporting Survivors, Families, and Caregivers*, co-edited by Marie M. Lauria, Elizabeth J. Clark, Joan F. Hermann, and Naomi M Stearns, and published by the American Cancer Society. (M. M. Lauria, Clark, Elizabeth J., Herman, Joan F., Stearns, Naomi M., 2001) One could say that the history and partnerships of AOSW reflect the interconnectedness with other organizations with overlapping purpose. Many organizations, including the American Cancer Society, National Cancer Institute, National Coalition for Cancer Survivors, National Association of Social Workers, Cancer Care, Inc., are represented through the membership and committee work of the Association of Oncology Social Work.

In summary, the lives of cancer patients improved as continuous improvement in medical treatment for cancer improved from the 1940’s to the present time. Today’s medical successes were made possible, in part, by actions of the American Cancer Society. It was the American Cancer Society who raised funds for a cancer research program and then lobbied Congress for greater research to be done at the National Cancer Institute. The National Cancer Act, a “War on Cancer,” became law in 1971, and created an action plan in 1974. Psychosocial research projects began in 1975 (Bloom JR, Flamer DP, Fotopolis S, Holland J, Gates C, Murowski B, Penman D & Ross R., 1987; Spiegel et al., 1981) thereby increasing the attention to the emotional and psychosocial needs of the patient. Oncology social workers with support from the ACS began organizing in 1981, and by 1984 formed an organization, AOSW, which over time has created standards of care, assessment tools and interventions for the quality of survival of cancer patients. Cancer survivors began to find their voice in 1986. With the leadership of Fitzhugh Mullan and Ellen Stovall they formed the National Coalition of Cancer Survivors, an organization that called for the development of the Office of Cancer Survivorship. In 1996, the Office of Cancer Survivorship was created within Cancer Control at the National Cancer Institute.

The values and practices from medical social work inform Oncology Social Work today. Values like, the importance of being an *advocate* for the patient’s point of view within the medical system and in the community, the importance of *understanding the cancer disease process*, and *participating as a team-member* with physicians and other health professionals, are values from medical social work described by Ida Cannon, one of the memorable personalities that enriched our field. (IM Cannon, 1923) and are found today in the description of standards of practice in the Association of Oncology Social Work. (AOSW, 2001)

In the following sections of this paper, many of AOSW’s Presidents share brief reflections concerning the challenges associated with each of their tenures.

Naomi “Noni” Stearns (1984–1988)

The actual beginning of NAOSW (now AOSW) occurred as the country was recovering from the economic recession of ’81 and ’82. Ronald Reagan was elected President; AIDS was emerging as a major public health issue; the term cyberspace was coined and Apple Computer

introduced the first MacIntosh PC. It was also a time when significant alterations occurred in health care reimbursement including the implementation of Diagnosis Related Groups (DRG's) and other regulations, raising serious concerns regarding access to and quality of care for patients. Prior to 1984, oncology social workers had far greater latitude in determining and implementing programs for the patients and families they served, with little worry about cost either to the patient or the hospital.

In 1984, the American Cancer Society (ACS) sponsored an educational conference in New York for oncology social workers during which a half day was set aside for an open session to encourage the support for a national oncology social work group. The discussion was lively, and at times, quite heated. Most attendees supported the idea of a national organization, but there were also skeptics who raised concerns about the need for yet another social work specialty organization. These critics cited the existence of other organizations such as the National Association of Social Workers (NASW), and the Society of Hospital Social Work Directors (SHSWD). Others expressed dismay that this idea seemed to be driven by an East Coast cohort and worried that other geographic areas would lack adequate representation. Enthusiasm on the part of the initiators, most of who were from the East Coast, might have given the impression that control would remain with them. It was certainly not their intention. Reassurances were given that once there was a mandate to proceed; all constituencies would be represented in the process. By the end of the day, the Steering, By-Laws, and Program/Conference Committees were formed. It was fairly clear that once this group was up and running, active participation would not be a problem. Those wishing to be counted as Charter Members were asked to make a \$20 initial contribution. In November of 1984, the Steering Committee met with an attorney at Cancer Care in NYC. Initial By-Laws were created and in December NAOSW was incorporated as a professional organization (501 (c) 6). NAOSW was changed to AOSW in 1993, but will be referred to as NAOSW here as that was its legal name during this tenure.

The initial tasks identified for the Steering Committee were:

- Networking
- Communication
- Division into Geographic Regions
- Initiating a liaison with APOSW (Association of Pediatric Oncology Social Workers)
- Developing By-Laws
- Financing the organization
- Producing a newsletter

By a vote of confidence Naomi Stearns was elected the first President of NAOSW and served from 1984–1988. The goals for this term evolved as the organization took shape. The primary task was to increase the membership of NAOSW by reaching out to the various constituencies. Most oncology social workers at the time were hospital based and these people were helpful in identifying other practitioners in their communities and educating them about the fledgling organization. Dues were initially established at \$20. Building financial stability was, and remains, a major priority. At the end of the day, 45 charter members had signed on. By the end of the first year, NAOSW boasted a membership of 454.

In addition to establishing four regions with directors for each, committee chairs were appointed in the following areas: By-Laws, Conference Planning, Communication (Newsletter), Finance, Membership, and Nominating.

Based on the discussion at the NY conference's open meeting, it was clear that frequent communication with the constituency would be essential to the success of NAOSW. This was reflected early on in the newly appointed Regional Directors' reports. Relationships within the fledgling organization had to be quickly built. At the same time, NAOSW began explore collaborative possibilities with other cancer related organizations. This particular goal was most notably achieved as the organization matured.

Planning the first "solo" conference began almost immediately in order to build on the momentum and increase visibility. In 1985, this was held in Houston, TX with keynote speakers Rita Beck Black, Grace Christ, Susan Bailis and John Wax. Catherine Cordoba and Carolyn Russell served as co-chairs. MD Anderson Cancer Center provided strong support for this gathering. Representatives from ASCO, ONS and APOSW were on hand to welcome NAOSW as a colleague. The theme of this conference was "Social Work: A Core Profession in Cancer Care." 225 oncology social workers attended.

At about this time, NASW and SHSWD expressed in a newsletter concerns regarding their difficulty in achieving a closer relationship as well as the "proliferation" of social work health care related groups. NAOSW, being one of those groups, responded by allowing that it represented an increasing number of social workers whose interests could not be fully represented by either NASW or SHSWD. Reassurances were given that collaboration among the groups would be pursued by NAOSW.

It was important to maximize the awareness of the oncology social work role among our employers, interdisciplinary teams, community agencies and the public. Our continued collaboration with ACS was quite helpful in this area. As the liaison from NAOSW, the President chaired the ACS National Advisory Committee on Oncology Social Work. A proposal was submitted to the ACS Board to provide training stipends for future oncology social workers. This was approved in 1988.

Three additional conferences were held during this tenure, in 1986 in Los Angeles, CA and titled "Empowerment Through Expertise: Oncology Social Work Practice in the 80's". The attendance proved that the original vision was, in fact, viable. The President made the following remarks at the start of this meeting: "The status of NAOSW is that it is healthy and growing. This is the time when we need to define our hopes for this group. What we have accomplished so far is a reflection of the vision held by many people whose volunteer efforts made this conference possible. Those of you who have spent hours preparing workshops and who have come at your own expense to present them are further evidence of support for this organization. The status of NAOSW will indeed reflect the support of its members. Your involvement is encouraged and welcomed and will affect the actual and potential benefits you will derive from it." APOSW participated in that conference after voting in a one year trial run to produce a joint conference.

In 1987 we met in Boston, in collaboration with APOSW. Although this would be the last joint conference, there was, for a number of years, an informal affiliation between the two organizations with some cross attendance at conferences. The first Oncology Social Worker of the Year award was also at this conference. The final conference during this tenure was held in Cincinnati, Ohio.

During this time as more people were living with cancer and survivorship rates were increasing, Fitzhugh Mullan, MD and cancer survivor launched a movement that resulted in the formation of National Coalition of Cancer Survivors (NCCS). NAOSW was an early supporter of this movement. Looking back at the challenges of this first presidency, the most difficult was trying to prioritize the needs of this newly created entity. Financial viability was certainly prominent, but even more immediate was the necessity to quickly dispel the anxiety of many regarding

potential control. Divisiveness could have ruined any chance of NAOSW surviving. A significant amount of the Board's time and energy was directed toward engendering feelings of inclusiveness. Listening skills were tested on a daily basis as attempts were made to bring various constituencies together. In the end, the effort paid off and the Board reflected the geographic diversity of the constituency. As always, communication was the critical issue.

In retrospect, the core values of NAOSW remain consistent with the original vision for the organization. Of course, the goals have appropriately expanded in 25 years. It seems like the challenges are much greater today with the loss of most of the institutional and governmental support that was available in the early 1980's. NAOSW found its voice at a time when oncology social work was still in its infancy, or possibly its adolescence. In the ensuing years, the organization has experienced an incremental increase in collaborative relationships and status in the larger medical community.

The experience of serving as President during this start-up phase was invaluable. The skills learned as Director of Social Work as well as prior experience facilitating groups proved useful in dealing with the complexities of leading this evolving organization. Since its inception, the organization has been committed to leadership training. This President was a beneficiary of that commitment. It was most satisfying to have played a role in the development of what is now AOSW, and to have watched it mature into such a vital presence in the greater oncology community. The network of oncology social workers sustained many of its practitioners throughout their years in the field and, for those who have since retired, but remain connected to the organization; it continues to be a valuable resource.

Charter Members of AOSW

Diane Blum

Grace Christ

Elizabeth Clark

Kathleen Ell

Pat Fobair

Deborah Dozier-Hall

Joan Hermann

Hester Hill (Schnipper)

Marie Lauria

Matthew Loscalzo

Joanne Mantell

Carol Meyer

Rosemary Moynihan

Nancy Wells Newman (Elkins)

Julianne Oktay

Antoinette Pieroni
Arlene Erlich (Robinovitch)
Arlene Rosenberg
Diane Rosenstein
Judith Ross
Carolyn Russell
Phyllis Silverman
Naomi Stearns
Virginia Vaitones
Lois Weinstein
James Zabora

Grace Christ (1988–1990)

It will always be important to remember that Dr. Diane Fink and Dr. Arthur Holleb of the American Cancer Society were both instrumental in supporting the development of Oncology Social Work. Dr. Fink was very interested in women's professional development and she worked with Virginia Conkling and Grace Christ to develop ways to support the movement. This support included:

- Funding the 1982 meeting in St. Louis;
- Funding the needs assessment survey of Oncology Social Workers led by Grace Christ;
- Funding for Oncology Social Work master's and post-master's fellowships (that later became the doctoral dissertation awards);
- Funding for the 1984 conference in NY where the steering, bylaws, and program conference committees of NAOSW were established.

These ACS funding opportunities put Oncology Social Work on the map with the schools of social work and the cancer centers. Many schools wanted to have an ACS supported student intern. Over time, other opportunities for funding were developed by AOSW members' relationships with the cancer centers and local organizations and foundations.

The "stepping stones" in developing the NAOSW as a national organization were the regional and cancer center training programs. In 1973, the Social Work Department of Memorial Sloan-Kettering Cancer Center in New York, assisted by a grant from the American Cancer Society, developed a postgraduate training program for social workers that provided a week-long course, 10 times a year for over 15 years. This training program was first led by Kay Davidson (who later became the Dean of University of Connecticut School of Social Work), and then by Lois Weinstein (who later became the Director of the Department of Social Work). More than 100 social workers and other mental health professionals from cancer centers and other health-care institutions throughout the country participated in this training each year. In 1975, the Social Work Oncology Group (SWOG) was developed out of the Sidney Farber Cancer Institute in response to the expressed needs and interests of social workers in Boston. This

program expanded with support from the National Cancer Institute in 1978, to provide continuing education programs, peer support, and communication networks to social workers throughout New England.

Similar programs were developed in other geographic areas. A mid-Atlantic SWOG functioned out of the Fox Chase Cancer Center in Philadelphia. The California division of the American Cancer Society conducted ongoing professional education programs for social workers and other mental-health professionals. In the late 80's the MD Anderson Department of Social Work began to develop training programs in Texas. In addition, many social work oncology support groups were developed in rural and urban areas throughout the United States. Cancer Care Inc., a social work service agency in NYC, began to emerge as a national organization to provide service, education and advocacy.

In 1984, oncology social workers from postgraduate training programs, social work organizations, cancer centers, and treatment institutions and agencies throughout the country joined together to form the National Association of Oncology Social Workers (NAOSW). The stated purpose of the NAOSW was to 1) promote the members' clinical, educational, and research development; 2) to devise and maintain professional standards for oncology social workers; and 3) to serve as an advocate for the rights of patients and their families to obtain necessary services. These purposes were carried out through an annual conference, quarterly newsletter, and established network communication. Below, a number of challenges and accomplishments are briefed noted.

During my presidency the central office for the organization was established at Memorial Sloan Kettering Cancer Center. The concept was to utilize the resources of the larger cancer centers to support our fledgling group. The possibility of the organizational home moving from one center to another depending on the president was considered. Johns Hopkins, Sidney Farber, MSKCC, H. Lee Moffitt, MD Anderson all contributed presidents and provided support for a number of years. This helped develop the organization, but met with resistance from the cancer centers as well as NAOSW organization members.

By-Laws Changes

Because of the time demands of presiding over such a new organization it seemed unlikely anyone would be able to fulfill their presidency as well as their "day job" for more than three years. Consequently, the membership adopted the one year as president elect, one year as president, and one year as immediate past president model during this period.

Membership Directory and Special Interest Groups (SIGs)

The first membership directory was developed and importantly special interest groups began to be developed. This was a response to the growing knowledge and sophistication of members who desired for a specific focus on issues such as bone marrow transplantation or radiation therapy.

Challenging Issues

NAOSW began to confront a number of inter- and intra-organizational issues during this period, issues that continue to be debated in AOSW as they are in other professional organizations.

1. Central was the question about the goals and mission of the organization. The overall question was whether NAOSW would become a national professional organization or would continue as a network of affiliated social workers. Specifically, would the organization take on larger challenges of broad based professional training,

credentialing, research development, policy, advocacy, and international initiatives? This requires collaboration, coalition building as well as fund raising and leadership. Initially, we had not understood the task so clearly, but it emerged as a central issue over time. While there were different views about these goals, the organization continued to move forward and to thrive with an understanding that the consensus was to aim to fulfill the broader mission to the greatest extent possible. Advancing professional development and leadership goals is particularly challenging in social work for three reasons:

- Social work by virtue of the income of many of its members does not have the same financial base as nurses and physicians.
 - The social work profession nationally is divided into practice, education and research that are all somewhat competitive with each other. Specialty organizations do not readily receive support from any one of these larger entities.
 - Social work does not have a national research institute with all of the financial support for development of scholars that it offers. Therefore developing research and training within social work is not easy.
2. The second, related challenge concerned collaboration: how to prioritize and strengthen relationships with other organizations that could provide support. What would be the relationships with the schools of social work as well as other social work national organizations? What about relationships with the medical and nursing organizations, the NIH, the Cancer Coalition, and a broad range of cancer related organizations and foundations? One approach we took to fulfill some of these collaborative roles was to use the past president in that capacity.
 3. The third challenge was how to strengthen ties between practice, research, education, and policy. This was largely addressed through special interest groups, later through the development of the research network within AOSW. The relationship with the Journal of Psychosocial Oncology was not always smooth, but it did provide a “voice” of social work in Oncology and gave opportunities for recognition of social work research, teaching and practice.
 4. 4During my presidency the central office for the organization was established at Memorial Sloan Kettering Cancer Center. The concept was to utilize the resources of the larger cancer centers to support our fledgling group. The possibility of the organizational home moving from one center to another depending on the president was considered. Johns Hopkins, Sidney Farber, MSKCC, H. Lee Moffitt, MD Anderson all contributed presidents and provided support for a number of years. This helped develop the organization, but met with resistance from the cancer centers as well as NAOSW organization members.

Finally, there was tremendous momentum when the organization was originally developed and excitement about social work finally taking a more visible place at the table. The response to the assessment survey we initially completed in order to demonstrate the need to our supporters was very compelling. The ground work of passion and commitment had been laid by the informal communities and inspired the American Cancer Society, the NCI and others stakeholders to recognize our contribution and the needs of patients, families, and communities we represented. It has succeeded beyond what any of us imagined, and so much of through the extraordinary work of such dedicated volunteer efforts. It is the most successful specialty organization within the profession of social work. We can celebrate these remarkable achievements as AOSW continues to fulfill the broader and challenging mission of professional development.

Deborah Dozier-Hall (1990–1991)

Although the nineties were challenging times for health care systems, it was a period for growth and development for NAOSW. As a charter member of the organization, it was my goal to illustrate that direct service practitioners could contribute significantly to the mission and vision of the organization as committee members or in leadership roles. After participating on a number of committee and board positions, in 1990, I became the first and only African American President of the Association of Oncology Social Work. In addition, I was the first President who functioned as a direct service clinician in a teaching hospital in her “day job”. During my tenure, I felt it was imperative for the organization to develop specific strategies to address the diverse needs of the membership. Most NAOSW members were direct service practitioners in teaching and private health care settings. Often these clinicians were the sole oncology social workers in their settings. There were few opportunities for additional specialized training, networking or peer support for most workers in their communities. However, there was a wealth of knowledge, clinical and administrative skills and resources that would benefit the membership. The 1990 Board of Directors did the following:

1. Accepted the challenge to further implement strategies to promote greater inclusion of all members;
2. Created additional strategies for improved financial stability.
3. Focused on outreach strategies for the general membership and ways to decrease administrative costs.
4. Expanded the Regional representative role to assume more outreach and liaison roles between the Board of Directors and the membership. Securing a steady membership was important to the organization’s fiscal stability since membership dues and conference proceeds in 1990–1991 were the sole funding sources.
5. Restructured the annual conference abstract review process was to further focus on diverse representation from all membership groups.
6. Developed coalitions with other health care organizations to strengthen AOSW political initiatives.
7. Organized a successful AOSW conference in Monterey, CA. More than 300 oncology social workers gathered in May 1991, to share knowledge, network, provide peer support and further the social work research agenda at the annual conference in Monterey, CA. It was very satisfying when conference attendees acknowledged that there had been a cultural change and that a culture of inclusion had been advanced. I felt very pleased that the efforts of the AOSW board, 1990–1991 had been successful.

Nancy Wells Newman (1991–1992)

Nancy Wells Newman (formerly Elkins) became NAOSW President in July, 1991 after serving on the board in numerous capacities since 1987. The late 80’s and early 90’s were transformational times. In those years, a central office was created, membership services were developed and the organization began to become financially viable. NAOSW moved from its early grassroots stage to becoming more structured and formalized. As chair of the bylaws committee in 1987, this president and her committee drafted the first policies and procedures of the organization, which defined processes and provided greater continuity from year to year. In 1990–1992, the Long-Range Planning Committee, chaired by Lois Weinstein, had a significant accomplishment in the development and publication of the **Standards of Practice for Oncology Social Work**. Each member received a copy of these standards, and cancer centers began using these standards as a guideline for providing the highest quality of care.

This achievement was a culmination of a goal that was initiated in the original Long-Range Planning Committee Report of 1984–1986.

During the 1991–1992 term, *The Journal of Psychosocial Oncology* became the official journal of the National Association of Oncology Social Workers, with Grace Christ as the Editor, and James Zabora as the Co-Editor. This opportunity was made possible by the founding editor of this journal, and an early president of NAOSW, Grace Christ.

As NAOSW gained more recognition outside of the profession of social work, other groups began seeking greater involvement and collaboration from our members. Leaders, such as Matthew Loscalzo and James Zabora, represented NAOSW, at the International Psycho-Oncology Conference in France. In response to such requests, a formal speakers' bureau was developed within NAOSW.

The annual conference was held April 29- May 2, 1992 in Detroit, Michigan. During this conference the Los Angeles riots broke out after the Rodney King verdict. It was a turbulent time in our nation, and the effects were keenly felt by those in attendance. However, the wonderful hospitality, dancing to the Contours at the Motown Dinner Show, and rich content of the presentations, allowed the attendees to move beyond the grief felt for our fellow human beings, and be inspired by not only our fellow colleagues' knowledge but the organization's growth, direction and value to the field.

James Zabora (1992–1993)

From the founding of NAOSW in 1984, numerous financial challenges seem to always confront NAOSW as an organization. Despite the success of the conferences, the fiscal viability was seriously questioned given the organization's dependency on a consistent increase in membership dues and conference revenues as the only means to support annual operating expenses. The actual tax status of NAOSW was that of a trade organization (i.e. 506) which was similar to that of the National Football League. As a result, if NAOSW was to achieve long-term financial stability that would promote its survival, dramatic steps needed to be taken. With ongoing legal and tax consultation, the following steps were implemented:

1. A new 501 (c) 3 tax-exempt entity was established to run parallel to NAOSW which was entitled the Oncology Social Work Educational Foundation with its own Board of Directors. Linda Scott served as the first and only president of the Foundation.
2. The Board of Directors and the membership of NAOSW voted to dissolve the organization and transfer its membership to the Foundation.
3. The Board of Directors of the Foundation voted to accept all NAOSW members into the Foundation with new articles of incorporation and by-laws.
4. Finally, the Foundation board along with its new members from NAOSW voted to change the name of the organization to the Association of Oncology Social Work.

While this course of action seems straightforward, the change of the name of the organization and the tax status generated a significant upheaval of concerns. A secondary rationale for the name change was the growing number of international members. There was consideration to replace "national" with "international" in order to embrace members from Australia, Europe, Hong Kong, Japan, and other countries. However, members from the U.S. believed that the designation of "international" might inhibit funding from cancer centers and hospitals for attendance at the annual conference. In some ways, the name AOSW was a compromise that welcomed members from around the globe and set the organization on a secure path with a new tax status.

These changes reached a peak at the NYC Conference when all of these proposed changes were presented to the membership of NAOSW. Emotional reactions were quite high and an example was that Region 1 threatened to secede from the national organization in order to maintain the “status quo” as a regional organization. At this same meeting, financial projections predicted a bleak future given that membership dues and conference surpluses would not be able to sustain the organization over the long-term. While some conferences produced a significant profit, others did not. Without new sources of revenue such as grants and financial gifts, NAOSW’s lifespan was limited. As a 506 trade organization, NAOSW simply could not receive grants or gifts. As president during the first phase of this important transition, I received a significant amount of criticism. Many members perceived the primary motivation for my desire to change the tax status was to bring attention to myself. Some believed that my motivation was “to beat taxes”. Still, others thought that I was more concerned about our international members than our members from the U.S. In fact, from the outset, my primary goal was always to enhance the functioning of NAOSW on any level possible. For example, following the departure of Grace Christ from MSKCCC, NAOSW was later asked to move its central office out of the cancer center. Under the presidency of Vicki Kennedy, a request for proposals was developed that encouraged other cancer centers or organizations to submit specific documents to have the central office relocated to another center, hospital, or organization. About 30 minutes prior to the deadline, I contacted Vicki Kennedy to learn if any proposals had been submitted. When I learned that there were no submissions, I quickly submitted a proposal on behalf of Johns Hopkins. Hence, the central office resided at Hopkins until 2000.

Also, during this time in an effort to respond to the crisis of managed care and Matthew Loscalzo’s passion for data, Chris Blanchard and I formed the AOSW’s Social Work Oncology Research Group (SWORG) to educate the membership about research methodologies to produce data that could demonstrate the benefit of oncology social work services. A secondary goal was to create a structure for AOSW members to actually participate in the development of protocols and the implementation of research studies. SWORG published its first paper, entitled “The Prevalence of Psychological Distress Across the Disease Continuum” in the *Journal of Psychosocial Oncology* in 1997. Finally, while I have attempted to serve AOSW in many capacities, my goal was always to examine the needs of AOSW and how I could potentially contribute to the development of solutions. AOSW has been a dynamic organization over the past 25 years, and clearly, it has significantly contributed to my professional growth and development. Although I now work in an academic environment, I owe a significant level of gratitude for the opportunities to be challenged by the best oncology social workers from around the globe.

Hester Hill (1993–1994)

The twelve months of my Presidency were personally and professionally significant. I was diagnosed with my first breast cancer in 1993, and spent most of this year receiving chemotherapy, and, for a period, concurrent radiation therapy. Consequently, I was not at my physical or cognitive best and relied heavily on others for consultation and assistance. Professionally, this was the year that NAOSW became AOSW, and the high point of my tenure was presiding over that transition.

During the previous year, the membership voted overwhelmingly for the new name, and the Board began to move forward with the development of the Oncology Social Work Foundation. The difficult organizational decisions had past, and our focus was on the practical issues of change. The Foundation began with helping plan the annual conference and hoped to move in new directions of other educational opportunities both for ourselves and for our patients and their families. The most difficult Board decision in the fall of 1993 was raising annual dues by

\$25.00 in each category (e.g. Full Member dues increased from \$55.00 to \$80.00). One piece of good news with this increase was that members would begin to receive a subscription to the *Journal of Psychosocial Oncology* as a membership benefit.

AOSW had grown to a membership of more than 900 by the spring of 2004. All of us were concerned about change at our institutions and in our systems of national health care delivery. The hope of national health care was evolving and was a major political issue for both parties. We had learned that we needed to be proactive in our advocacy for our clients and for our profession. Oncology social work increasingly was seen as the profession that defined psychosocial care, and our voice was included and heard in more debates, offices, and board rooms. Our first regional conference was held in the Twin Cities in the fall of 1993 and other regions began to plan similar meetings. Julie Cain represented us at the Department of Health and Human Services press conference to announce the release of Cancer Pain Guidelines on March 2, 1994. Chris Blanchard and the Long Range Planning Committee surveyed the membership and began working with the Board towards the development of a thoughtful and exciting plan focusing on our goals for the next decade.

Our Annual Conference took place at the Stouffer Orlando Resort in Orlando, Florida from May 25-May 28, 2004. Titled “The Past as Prologue: Positioning Oncology Social Work for Challenges of Change”, it marked a decade of growth for our organization. Keynote speakers were Leonard Fleck, Ph.D. from Michigan State University who spoke on “Just Caring: Health Reform and Health Care Rationing—Challenges and Choices for Patients and Providers” and June Simmons, LCSW from the Visiting Nurse Association in Los Angeles who spoke on: “Shaping our Future—Challenges and Opportunities.”

On Saturday morning, May 28, 1994, at the Annual Meeting, I led the vote that ended the National Association of Oncology Social Workers (NAOSW) followed by the vote that established the Association of Oncology Social Work (AOSW). After several years of planning, we had truly become an international organization.

Vicki Kennedy (1994–1995)

Finalization of the shift started with James Zabora’s presidency with the legal dissolution of the *National Association of Oncology Social Workers* (NAOSW), a 501(c) (6) professional association to the *Association of Oncology Social Work* (AOSW), a 501(c) (3) non-profit public charity was an almost all-consuming process for the entire volunteer board during the 1994–1995 presidency of Vicki Kennedy, LCSW. Beyond navigating the transition of both the legal and logistical management of AOSW, the most challenging crisis for this era in ASOW history would indeed become a financial one. AOSW was in dire financial straits—starting the fiscal year with less than \$62,000 in cash reserves. At that time, AOSW had a membership of approximately 934 members representing over 508 institutions worldwide. Topics of health care reform were rampant in the news and hospitals and cancer centers nationwide were facing their own financial hardships with layoffs of key personnel including oncology social workers.

The 1994–1995 Board of Directors included: Vicki Kennedy (President), Matthew Loscalzo (President Elect), Hester Lampert Hill (Past President), Linda Supple-Diaz (Secretary), Susan Stensland (Treasurer), Joan Hermann (Communications), Carolyn Russell (Membership), Katherine Cilli (Region I), Doretta Stark (Region II), Carole Seddon (Region III), and Katherine Walsh-Burke (Region IV). AOSW had six Special Interest Groups at that time: HIV/AIDS, Bone Marrow Transplant (started by Vicki Kennedy and Susan Stensland), Children and Cancer, Pain, Ambulatory Care/Fee for Service, and Computing/SWON.

On August 25–26, 1994, the Board of Directors held a retreat in Baltimore, Maryland to further examine the purpose, goals, and objectives of AOSW as well as to delineate the first three-

year strategic plan for the organization. Issues related to name recognition and profile, bylaws, revised board member job descriptions, policies and procedures, and fund development were central to the development of the new strategic plan. For the first time, the board began to evolve from leading a professional association to thinking of AOSW as a “public charity” driven to improve the quality of life for people affected by cancer. This significant paradigm shift would significantly impact AOSW towards what it is today. Of course, no AOSW gathering in Baltimore would have been complete without a trip to Obrycki’s Crab House where many a great organizational idea and strategy would develop.

After nearly a decade, administrative and financial stressors at Memorial Sloan Kettering Cancer Center necessitated the challenge of finding a new home for the AOSW Central Office. Effective October, 1994, AOSW moved from the Social Work Department at Memorial Sloan-Kettering Cancer Center (MSKCC) to the John Hopkins Oncology Center thanks to the generosity and vision of James Zabora who was the head of the oncology center. AOSW had to say good-bye to its dear friend and colleague, Linda Sibia, executive secretary of the Social Work Department at MSKCC who had served AOSW for so many years. Ms. Sibia had somehow managed to keep a group of spirited, committed individuals focused and directed as the organization grew. AOSW is forever indebted to her dedication, passion, and support in its formative years.

In addition to moving the physical location of the Central Office and engaging new administrative staff, the Board also moved the AOSW database management services from a contracted individual to the Central Office. Prior to the move, AOSW was experiencing significant difficulties in managing the database effectively including being able to generate reports and dues renewal invoices in an accurate and timely manner. The new Administrative Coordinator, Kimberly Bell, took on a paid, shared position between AOSW and the Johns Hopkins Oncology Center. MS. Bell would now assume all responsibilities for managing the membership database and all pertinent AOSW materials and documentation as well as providing staff support for the annual conference which up until this time was almost exclusively managed by the volunteer Conference Committee chairperson(s).

In response to financial shortfalls and an opportunity to strengthen AOSW member benefits, a new dues structure was put into place in January 1995: Full members would be charged \$85 compared to the previous \$55. AOSW designated Associate Members (\$75), students (\$65), retired members (\$65), and a special joint membership fee for members of the Association of Pediatric Oncology Social Workers (APOSW) (\$70). Most remarkable was the addition of the Journal of Psychosocial Oncology (JPO) as a benefit of membership. A significant number of members had voted in May of 1994 to adopt JPO as the official journal of AOSW and the dues increase made it possible for members to receive a hard copy of the journal at that time.

The addition of the Journal of Psychosocial Oncology as a part of AOSW was not without its controversy. There were expenses and logistical management issues associated with the journal that created some stress within the organization. While it generated modest royalties for AOSW, it was not a profitable venture in its early years. What JPO did obtain for AOSW was a level of professionalism and visibility that was critical for the field of oncology social work and the Board viewed it as an investment in positioning oncology social work as a key leader in the field of psychosocial oncology.

During this important transition year, other seeds were planted that later evolved into significant AOSW projects. The board began to explore the idea of oncology social work certification and empowering social workers in an era of managed care as well as creation of an online network for oncology social workers (SWON). The steps towards formally certifying oncology social workers would take a few more years to come to fruition but the critical dialogue and gathering

of best practices from other professional organizations had begun. Thanks to the vision and technological talents of Greg Jamnetski and John Sharp, the Computing Special Interest Group (aka Social Workers Oncology Network-SWON) became a valuable tool in increasing member competencies in computers and in the establishment of an online network that remains vital to the membership today.

Frequently a measure of the success of an organization is formed by its inclusion in critical discourse among thought leaders about key issues. Ms. Kennedy represented AOSW at two milestone events in 1995. The Association of Community Cancer Centers (ACCC) hosted a President's Retreat for 80 cancer organizations. AOSW was able to represent the oncology social work perspective in a forum focused on patient advocacy, patient care management standards, and changes in the multidisciplinary care paradigm. Additionally, AOSW was invited to participate in a forum sponsored by the Center for Advancement of Health in Washington, DC. This purpose of this forum was to define the essential domains of psychosocial support that should be made available to all cancer patients. Ironically, it would be another twelve years before the landmark Institute of Medicine Report, *Cancer Care for the Whole Patient*: would legitimize these issues and create a standard of care for psychosocial support.

The Legislative Task Force, led by Cynthia Medeiros and Susan Hedlund, worked hard to keep membership apprised of what would soon become a failing health care reform movement of the mid-1990's. Topics such as universal health coverage, single payer systems, and shared individual-employer responsibilities were discussed as AOSW worked closely with the National Association of Social Workers (NASW) to keep members active and involved in the movement.

As always, the highlight of the year was the Eleventh Annual Conference in San Antonio, Texas, May 24–27, 1995. Conference Co-Chairs, Carol Marcusen and Michael Fife did an outstanding job in creating a productive and stimulating meeting. The conference, *Exploring Our Frontiers: Revolutionizing the Practice Paradigms of Oncology Social Work*, had a total of 62 abstracts and 32 poster presentations and over 300 attendees. The Hyatt Riverwalk provided a wonderful backdrop for learning and networking. Social events at Fiesta Texas theme park followed by a barbeque and rodeo at RioCibolo Ranch capped off the fabulous weekend. One of the more significant outcomes of the 1995 conference was the establishment of the Oncology Social Workers Survivor Network for those members who were also cancer survivors. In order to obtain an optimum price advantage for future conferences, Ms. Kennedy and the Board were able to negotiate a multi-year contract with Hyatt hotels to secure conference locations and room rates at desirable locations for the subsequent five years.

Thanks to a successful conference, aggressive fundraising efforts and fiscal management by Ms. Kennedy and the Board, AOSW cash reserves grew from \$62,000 at that start of the term to over \$103,000 in May 1995. However, financial shortfalls would continue to plague the organization during an economic downturn and as it struggled to define its new role in public service. Nevertheless, AOSW continued to provide a vital lifeline of continuing education and support to oncology social workers across institutions and the globe.

This essential year of transition provided the foundation by which AOSW would begin to emerge as a leader in the field of psychosocial oncology by not only ensuring the highest standards in oncology social work practice but in harnessing the collective talents and expertise of its membership in creating landmark programs for cancer patients and their families.

Matthew Loscalzo (1995–1996)

It is simply impossible to tell the story of any presidency without consideration of the team of leaders who preceded each of us as well as who kept the vision of the organization in motion. The presidents came from diverse backgrounds and perspectives, but each focused on unity within the organization in order to enable AOSW to thrive. Each president also attempted to develop a vision, enhance the infrastructure, and consistently focus on the financial solvency of the organization. Within the lifespan of NAOSW and AOSW, some members enjoyed maintaining the ‘feel of a small family’ while others perceived the opportunity for AOSW to link oncology social workers on an international level.

The experience of serving as Chair of the New York City Conference in 1992 was excellent preparation for my role as president in the following year. Based on all of our efforts including those of Carolyn Messner, Priscilla Hartung, Les Gallo Silver, and Linda Sibilgia resulted in a great conference based on the evaluations. The NYC Conference also occurred at a time when NAOSW was attempting to move beyond regional perspectives in order to develop a national focus. Through the efforts of Grace Christ, a 1-year presidency was established that provided the opportunity for presidents to emerge from all types of hospitals and agencies. The previous 2-year term was often too demanding for members from smaller hospitals or social work departments. This fundamental change produced an avenue for the development of new leaders within the organization which coincided with the mission of NAOSW.

Another critical development during the planning for the NYC conference was my move from Memorial Sloan-Kettering Cancer Center in New York to Johns Hopkins in Baltimore. In the year prior to this event, Grace Christ left MSKCC for the School of Social Work at Columbia University and support for NAOSW dramatically declined. Upon arrival at Johns Hopkins, significant support was present from Jim Zabora for finalizing all conference preparations as well as for the assumption of the role of the presidency of NAOSW. Jim recognized that this was a difficult time for the organization as it was becoming apparent that the financial structure of NAOSW was highly problematic and that new avenues needed to be explored and adopted.

These years also coincided with great changes in how health care was financed in the new era of managed care. The beginning of this reengineering of health care financing generated a number of concerns for medical social workers including job insecurity and elimination of entire departments of medical social work. This was a scary time. In response to the many problems created by managed care, I along with Kathy Walsh-Burke and Dana Naughton developed the Managed Care Survival Guide for Oncology Social Workers. The Guide served as a primary reference to enable oncology social workers to use data to support the role psychosocial care in various health care settings. After years have passed, I still receive comments related to the relevance of this approach in today’s health care system.

This is how it was as NAOSW transitioned into becoming AOSW. Many of our members were solo clinicians as well as practitioners in cancer centers of varying sizes. During this stressful time, AOSW became a sanctuary as well as an empowerment zone. Even in large cancer centers with a high number of social workers, significant competition for resources within these centers came from other departments that also threatened social work programs. But, it became clear during the early 90’s that oncology social work needed to develop its research skills. Fortunately, individuals such as Christina Blanchard, Grace Christ, and Jim Zabora provided leadership in encouraging members to embrace the need for research as an essential component of the organization.

Finally, NAOSW served as the foundation for my early professional life and was the genesis for path of my leadership odyssey. While NAOSW was the source of many friendships, the people to whom we provide care, the opportunities for growth and development, and the

commitment of colleagues all contributed to what became my value system and what I hold to be most worthy in my life.

Susan Stensland (1996–1997)

Financial issues were tight in fiscal year 1996–1997. Thus, the Board of Directors needed to limit financial support of Regional Directors and Special Interest Group activities. The Board held only one face to face meeting outside of the annual conference, and often had conference calls paid by various health care institutions. However, frugal practices and a successful annual conference contributed to a positive balance. A Fund-raising Task Force was developed to build AOSW's financial viability by formulating a development plan, prospectus, and options for donations. Membership totaled 833 in April, 1997. The AOSW web page was launched in September, 1996 with assistance of Neil O'Connor and John Sharp as well as support and assistance from the Wisconsin Medical School, Department of Biostatistics staff engineers.

In the Fall of 1996, the *Journal of Psychosocial Oncology* (JPO) had about 1200 subscriptions. The JPO Steering Committee was initiated in September, 1996, which addressed funding an anthology, a book series, and timeliness of receiving the Journal. In the Spring of 1997, the membership was offered contribution to a three-book series related to oncology social work. Elizabeth Smith was the Managing Editor and Chair of the Book Series Steering Committee.

The thirteenth Annual Conference title "A Journey of Empowerment: New Skills for A New Era" was held in Pittsburgh, Pennsylvania. Joan Hermann was the Conference Chair with Joyce Herschl as Local Arrangements Chair. The Oncology Social Worker of the Year was Agnes Barba of St Raphael's Hospital, New Haven, CT. Matthew Loscalzo was awarded the Leadership in Oncology Social Work award. Regional Conferences were held in October, 1996 in Kansas City and October 1997 in Pensacola, Florida (in cooperation with Florida Society of Oncology Social Workers). The Board updated the policy on Regional Conferences to facilitate consistency for those activities.

The Social Work Oncology Research Group (SWORG) was approved as a Special Committee of the Board in May 1996. The SWORG goals included development and implementation of research protocols to be used at multiple sites, stimulate interest in research within AOSW, and generate proposals with AOSW as recipient of those funds. Three Special Interest Groups (SIG) were added in the Fall 1996: Brain Tumor, Complementary/Alternative Medicine, and Spirituality. Those SIGs were added to the other eight (AIDS, Ambulatory Care/Fee for Service, BMT, Cancer Risk Screening, Children and Cancer, Computing, Hospice, and Pain) for a total of eleven.

The AOSW Board discussed options of more linkages with local oncology social work groups, including local chapters. However, the decision was made AOSW did not have adequate staff to develop and to monitor local chapters. An alternative was to provide guidelines for developing and supporting local groups, beginning with assessment of status of local Social Work Oncology Groups (SWOGs) by Regional Directors. The Board approved guidelines for Position Statements in May 1996. The first request was to address Physician Assisted Suicide. The Board appointed a committee chaired by Susan Hedlund, along with Terry Atilio and Kathy Smolinski. The Board accepted their recommendation to develop guidelines for oncology social workers in responding to physician assisted suicide.

AOSW had liaisons with several organizations in 1996 – 1997. The President attended the Association of Community Cancer Cancers (ACCC) Patient Advocacy Meeting as well of the Annual President's Retreat. AOSW presented a workshop on psychosocial issues and managed at an ACCC Texas State Meeting in June, 1996. Plans were to cooperate with ACCC for some of their state meetings in the future. AOSW was asked to participate in the American Federation

of Clinical Oncologic Societies (AFCOS), which is a coalition of clinical-oriented professional organizations committee to the provisions of quality cancer care. AFCOS developed a consensus statement of “Access to Quality Cancer Care”. The participation was an excellent opportunity for AOSW to contribute in this manner. AOSW joined in an agreement with National Cancer Institute (NCI) and Cancer Care to share resources and information. AOSW was the first group in which NCI provided training for oncology professionals regarding promotion of clinical trials, which was at the AOSW annual conference in 1997.

Susan Hedlund (1997–1998)

After overcoming my initial “shock” that I had been elected president of the organization that has been my rock and foundation for many years, I settled into the excitement of what might lie ahead. The years prior had been exciting. Under Susan Stensland’s leadership, the first Genentech grant was offered to AOSW, NCCS, and ONS to create the first **Cancer Survival Toolbox**. It was an exciting time for AOSW with regards to our collaborative relationships with other oncology professional organizations. One of these was “AFCOS” the American Federation of Clinical Oncologic Societies”. This organization, sponsored by ASCO and involving the primary oncology professional organizations, collaboratively drafted the *Consensus Statement on Access to Quality Care* document. It was endorsed by all national oncology professional organizations, and advocated for high quality, comprehensive care for all Americans with cancer. It was intended for use at both local and policy making levels.

There were a number of issues pertinent at the time. Among them was a request from some AOSW members to write a position statement on Physician-Assisted Suicide and Euthanasia. Under President Susan Stensland, Terry Altilio, Kathy Smolinski, and I were asked to undertake this endeavor. This continued into my tenure as president. Ultimately, we wrote a “White Paper” in an effort to educate AOSW members about the many issues involved in the debate. Ultimately, the AOSW Board voted to oppose Physician Assisted Suicide and Active Euthanasia. This was adopted at the end of my tenure as president, which was particularly challenging as my State of Oregon had just voted to approve Physician-Assisted Suicide (now referred to as Physician Aid in Dying) under certain, very restricted, circumstances (first passed in 1996, then passed again by a larger margin in 1998). While the issues were both professionally and personally challenging, I none-the-less lived in a State that had just legalized this option, while presiding over a professional organization that had voted to oppose the practice. The law, incidentally, has now been in effect in Oregon for 10 years. At the time I knew, as social workers in Oregon, that we would need to find a way to work with this now legal option. It was a challenging, confusing, and bittersweet time. We presented the Position Paper at the Annual Conference in La Jolla, California. It was, not surprisingly, met with controversy. The Washington State, and some Oregon, AOSW members, threatened to drop their AOSW memberships if AOSW adopted a position opposing the issues, as they lived in a part of the country who thought differently about these issues. Others threatened the opposite. We called for written responses: a total of 4 were received, 2 in favor, 2 opposed.

On a different note, one of the events that I felt most proud of during my tenure as president was the adoption as a permanent Special Interest Group, the Diversity Special Interest Group. Pioneered in earlier years by AOSW member, Doretta Stark, it was a tremendous pleasure to see this come to fruition “under my watch”. It was an important step forward for AOSW to address the essential issues of diversity for patients, professionals, and the systems in which we work. We collaborated with NCI to present skills training for social workers at the Annual Conference on discussing Clinical Trials with patients. This was the first of several of these endeavors. We also planned with Cancer Care, Inc., to have both a booth and a “presence” at The March on Washington, in the fall of 1998. Patterned after the “Million Man March”, cancer advocacy groups, professional oncology organizations, and others planned to meet in

Washington DC to advocate to Congress for continued support of cancer research and to increase awareness of the issues facing those with cancer.

The year culminated with a Board meeting in Washington DC, at the March against Cancer. Events included the Board's attendance at the Ribbon of Hope Awards, and I was very fortunate to attend an invited event at then-vice-president Al Gore's home, to continue to advocate for cancer awareness and research. The highlight of the evening was attending a candle-lighting event on the Capitol Mall, on the steps of the Lincoln Memorial, under the leadership of honorary chair General Norman Schwartzkopf, to honor those who had died of cancer, and those living with the disease. Thousands were in attendance on a warm autumn evening in our nation's capitol. (Somehow fitting, in front of me on the steps of the monument, happened to be one of my cancer patients from Oregon.) It was one of those "events of a lifetime" that I will never forget.

I was fortunate to leave office with our financial picture well in hand, primarily because of the generous support of the Genentech grant which began prior to my tenure. We were very excited to be affiliated with other oncology professional organizations, including ASCO, ONS, NCCS, NCI, NASW, ACS, the Leukemia & Lymphoma Society, and others. It appeared that we had "arrived" with regards to being recognized as an important discipline in oncology, and increasingly "at the table" where policy issues were discussed. The following year we held a three-year Strategic Planning Meeting, again furthering and refining the vision and mission of AOSW. Being given the opportunity to preside over this wonderful professional organization, to be entrusted to represent and serve the membership, has been among the greatest professional honors of my career.

Marie Lauria (1998–1999)

Marie Lauria became AOSW President in July 1998. It was a year in which national attention focused on the impeachment of President Clinton. The boom of the 90s was still in evidence in the US and the national deficit was turning into a surplus. Everyone was mastering their computers and use of the Internet. SWON was becoming an essential tool for AOSW members. The world of cancer care was excited by new pharmaceutical and technologic advances and the promise of improving survival rates. Cancer survivors, such as Lance Armstrong, Joe Torre, Darryl Strawberry, and Peggy Fleming, were making news for their accomplishments in sports. Cancer care organizations, AOSW included, were preparing to participate in The March on Washington to advocate for increased federal research funding. The world was just beginning to turn attention to the coming of the 21st century.

The Board of Directors* led AOSW through a busy and successful year. Initial work focused on completing the transition, begun in 1995, from a professional organization (501 (c) 6) to a public charitable one for educational purposes (501 (c) 3). This involved reviewing our status with our attorney, revising by-laws, filing necessary forms, purchasing Directors and Officers Liability Insurance, adopting a Conflict of Interest policy, and designing a formal Board orientation process. AOSW continued to benefit from the generous support of Johns Hopkins' housing of the AOSW Central Office. A Task Force was appointed to begin exploring options for assistance with financial management and other major organizational tasks.

AOSW membership increased to over 1000. A Membership Directory was distributed and a profile of the membership was completed. The Membership Committee began planning to mark AOSW's 15th anniversary. The Task Force on Racial Diversity continued its work. AOSW established a Communications Committee to oversee the organization's multiple ways of communicating with members and the public. The AOSW web page (www.aosw.org) was improved and expanded to include more information for members. The *Journal of Psychosocial Oncology* (JPO), under the direction of Grace Christ and James Zabora, continued

to be an additional means of educating members, other professionals and the public. AOSW News, with Joan Hermann as editor, was redesigned. Membership grew in AOSW's listserv, the Social Work Oncology Network (SWON).

All AOSW regions also experienced growth during the year. Region IV held a two day conference in New Jersey. AOSW also co-sponsored the November educational conference of the Oncology Social Work Organization of Southern California. Talks began with Australian members about creating an exchange program. AOSW's eleven Special Interest Groups (SIGS) continued to function in various ways throughout the year, working to enhance the knowledge and skills of members. AOSW's Social Work Oncology Research Group (SWORG) produced "The Psychosocial Research Kit: Tools for the Practice Evaluation of Oncology Social Work", authored by Elizabeth Smith and Barbara Early. In addition, SWORG facilitated participation by interested members in an inter-institutional study, "Death and the Caregiver's Inner Life", funded by the Nathan Cummings Foundation through Johns Hopkins Oncology Center. Elizabeth Smith and James Zabora were co-principal investigators.

During 1998–1999, AOSW issued two position papers, one with ONS titled "End of Life Care" and another, the "AOSW Position Paper on Euthanasia and Assisted Suicide". Work on both had begun under the presidency of Susan Hedlund. In September, the AOSW Board met in Washington and staffed a booth with Cancer Care at The March. They joined other cancer organizations for a candlelight vigil for survivors at the Lincoln Memorial and attended a dinner hosted by the National Coalition of Cancer Survivorship (NCCS). This dinner saw the launch of the Genentech funded Cancer Survival Toolbox, a joint project of NCCS, AOSW and the Oncology Nursing Society (ONS). Additional Genentech funding enabled further development of the Toolbox throughout the year, notably a Spanish version, and one for geriatric survivors.

Michael Fife, President-Elect, and Marie met in Washington with representatives of 48 other Social Work organizations at the National Summit called by the National Association of Social Workers (NASW) as part of its 100th anniversary celebration. Participants identified their organizations particular social justice concerns. One outcome involving AOSW was creation of a Coalition of Social Work Health Care Organizations to address common issues and advise NASW on health matters. The National Dialogue on Cancer was formed in November and Marie was invited to be a charter member and Collaborating Partner. The group, facilitated by the American Cancer Society, with Barbara & George Bush as honorary co-chairs, brought together leaders from corporations, non profits, professional organizations, voluntary health care organizations, patient advocacy groups, government agencies, and the media to set a national agenda for eradicating cancer.

The Board held a retreat in February 1999, facilitated by Elizabeth "Betsy Clark", to craft a Mission Statement and begin a strategic planning process. It culminated in "Focus 2002: AOSW's Three Year Strategic Plan". The plan called for new initiatives in professional management, leadership development, marketing, public and professional educational efforts, research activities, and public advocacy. To help address our main mission of educating about the importance of quality psychosocial care for survivors, families and caregivers, AOSW, with support from Novartis, joined with Cancer Care and the National Cancer Institute (NCI) to present two national teleconferences on clinical trials. In partnership with NCI and ONS, AOSW also participated in the development and implementation of the Cancer Clinical Trials Education Program (CCTEP) and planned "training the trainer" sessions for the 1999 AOSW conference. During the year, eleven members represented AOSW by presenting on managed care and the psychosocial aspects of cancer care in nationwide seminars "Defending Quality Oncology Care" sponsored by the Association of Community Cancer Centers (ACCC).

In June, Dr. Richard Klausner, then NCI Director, invited AOSW officers to meet with him and key NCI staff (including Past President, Deborah Dozier-Hall) to discuss issues of importance to AOSW. Marie, Michael and Joyce Herschl traveled to Washington to review collaborative projects and explore new opportunities for working with NCI. The 1999 annual conference, chaired by Linda Diaz, was held in New Orleans, May 26–29. Its theme was “New Visions: Expanding Opportunities”. AOSW’s 15th anniversary was celebrated by reviewing highlights from AOSW’s past at a reception honoring AOSW past presidents. Susan Hedlund won the Oncology Social Work Leadership Award, sponsored by the American Cancer Society. Rene Barrat-Gordon was named Oncology Social Worker of the Year, an award underwritten by The Leukemia Society of America. The National Brain Tumor Award for Brain Tumor Social Worker of the Year went to Charlene Amato. Dr. Jimmie Holland was given an AOSW Special Recognition Award for her outstanding contributions to psychosocial oncology. Marcia DeSonier and her committee began planning for AOSW’s first international 2000 conference in Vancouver, B.C., and its first of the 21st century.

The challenges of 1998–1999 for AOSW were many, particularly in regard to our organizational identity, but most were addressed successfully. Our presence on the national stage continued to expand and AOSW’s contributions to the quality of cancer care gained increasing recognition. We achieved a clearer sense of what it means to be a charitable, non-profit organization as we crafted a first-ever Mission Statement, and outlined in “Focus 2002” our plan for moving confidently into the future. There were several other “firsts”: issuing position papers, presenting educational teleconferences, joining in the launch of the Cancer Survival Toolbox, creating the “The Psychosocial Research Kit”, increasing our collaborative efforts with other cancer care organizations, and producing AOSW’s first Annual Report. It was a full and exciting year.

Michael Fife (1999–2000)

Remember Y2K? The fall of 1999 brought us, not only cooler days and colorful trees, but also speculation that all our computers would crash at midnight! Fortunately, the doomsday predictions did not materialize, and we faced instead, a brand new century full of promise. AOSW had grown and matured as an organization, with increasing relationships with other national and international oncology organizations. This growth and maturity was made possible by the commitment and hard work of AOSW’s membership and previous leadership.

Following the blueprint of *Focus 2002: Three-Year Strategic Plan for AOSW*, the Board began a process of assessment and revision to provide organizational support and management support to insure that AOSW would continue to grow and flourish. The increase in special projects and grants, such as *The Cancer Survival Toolbox*, a collaborative effort with AOSW, ONS, and NCCS funded by a major continuing education grant from Genentech, brought fiscal soundness. However, the complexity of effective management of the funds involved in these projects had grown beyond what AOSW could reasonably expect from a volunteer MSW treasurer, and the Board elected to contract with a professional association management company to assist with financial services and database management.

One of the important Priority Goals of Focus 2002 was the expansion/enhancement of educational activities. The Board voted to establish an Education Committee and Carolyn Messner willingly accepted to job of chairman to define and develop this important committee which will work with regional conferences and other educational efforts so critical to AOSW’s mission.

In 1998, I had the honor and pleasure of chairing AOSW’s annual conference, *Celebrating Diversity*, in La Jolla California. We explored diversity in all aspects: culturally and clinically to broaden our understanding of ourselves and the needs of our patients/families. President,

Susan Hedlund, created the Committee on Diversity, initially chaired by Doretta Stark; they had their initial meeting at the LaJolla conference and again at the New Orleans conference. In February, 1999, The Diversity Task Force submitted an application to become the Diversity Special Interest Group. Their application was received with enthusiasm and accepted unanimously. This new SIG, coordinated by Gayle Harper and Evaon Wong-Kim, provided a very visible focus for AOSW's foundation of respect for the individual and appreciation of the richness, as well as the challenges, that diversity brings.

Responding to an increasing awareness of the deficiencies in care at the end of life and the growing conviction that steps to improve care are essential, AOSW joined with the Oncology Nursing Society (ONS) in issuing a joint Position Statement on End-of-Life Care. The position of AOSW and ONS is that people with catastrophic, potentially fatal illness and those close to them should be able to expect and receive reliable skillful and supportive care. It must be recognized that suffering is an interpretive process, framed within a cultural context, and unique to each individual. Elizabeth Smith represented AOSW in the development of this important position statement.

In the fall of 1998, AOSW in collaboration with ONS and NCCS launched a new survivorship resource called the *Cancer Survival Toolbox: Building Skills that Work for You*. It was a set of six audiotapes, available free to patients, families and professionals, to help patients and families learn self-advocacy skills. This year, *The Toolbox* was translated into Spanish (audio) and into Chinese (available in hard copy). Two new modules were added to the Basic Toolbox, including "Finding Ways to Pay for Care" and "Topics for Older Persons", which was launched at the annual scientific Meeting of the Gerontological Society of America. This invaluable patient/family educational resource has been generously funded by several unrestricted educational grants from Genentech, Inc. Future modules are planned to address the needs of caregivers and an interactive program for adolescents with cancer. AOSW members who have contributed to the Toolbox were: Betsy Clark, Carol Marcusen, Katherine Walsh-Burke, Naomi Stearns, and Yvette Colon.

AOSW received another non-restricted educational grant from Genentech, Inc. to develop another Toolbox called "*Oncology Social Work Toolbox: Building Advocacy Skills*. The goal is to further educate oncology social workers about the *Cancer Survival Toolbox* and the importance of helping survivors learn essential self-advocacy skills. An advocacy-training workshop was presented at the Vancouver conference with plans to develop a web-based learning program through the AOSW website. *The Oncology Social Work Toolbox* will cover the advocacy continuum from personal/self-advocacy to institutional advocacy through community and political advocacy. The Project Core Team members were Elizabeth Clark, Carol Marcusen, Katherine Walsh-Burke, and Marie Lauria.

The annual conference, *Psychosocial Oncology 2000 and Beyond: Past Lessons, Future Directions*, chaired by Marcia DeSonier, was a landmark in two ways. It was our first international conference meeting in picturesque Vancouver, British Columbia and we were joined by the Canadian Association of Psycho-Oncology and the American Society of Psychosocial and Behavioral Oncology/Aids. Ross Gray, PhD and his drama, "Handle with Care?" opened the conference and AOSW presenters were joined by featured speakers including David Spiegel, MD, Timothy Quill, MD, and Mark Spiegel, DMIN. The poster session was presented in a reception format with refreshments and libations, a welcome addition.

My personal AOSW journey began in 1985 as a participant/presenter at the Houston conference winding through the St Petersburg conference to Colorado and Detroit; then to San Antonio, as local arrangements chair for Carol Marcusen and on to La Jolla where we reversed roles.

Throughout this journey, I have been continually impressed by the sensitivity and creative spirit of oncology social workers. Just as our “core muscles” provide the foundation and structure for our individual physical strength, an organization needs a strong core to survive and flourish. While the heart and soul of AOSW is our membership, AOSW has been blessed with a dedicated core group of leaders who have created a unique professional organization that “truly serves the membership” and have shepherded that organization from a fledgling group of dedicated oncology social workers to an internationally respected professional organization.

As I was gathering my notes and thoughts for this chapter, I found myself remembering how helpful three women had been to me personally and how much they had meant to AOSW. Joan Hermann, whose labor of love AOSW News, kept us all informed and up to date (and on deadline) and Marie Lauria, whose steady hand and eloquent writing made projects flow smoothly, were both Charter Members when AOSW was formed in 1984 and both remain active contributing members today. Two of the most fulfilling, not to mention labor intensive, projects I have done in AOSW were the San Antonio conference 1995 and the LaJolla conference 1998. Carol Marcusen taught me about organizing a conference and I taught her about Texas... then we reversed it in California. Her strong principles and commitment to the standards of AOSW are unwavering and her organizational skills make even the most daunting task doable. As my mother always said, “it is always appropriate to say thanks”.

Joyce Herschl (2000–2001)

My term as president of AOSW, from 2000 to 2001, occurred during the first full year of database management under Association Management Center (AMC). Many changes had taken place and with the decision to dissolve the central office and move operations to AMC, I found myself having to step back and evaluate where we had been and where we were going. There were many challenges. But communication issues, both with the board and the membership came to the forefront.

With a goal of fostering communication, I established weekly online reports, on the AOSW Board Listserv, along with weekly telephone calls to the account administrator from AMC. I also met on site, in Chicago, with the staff of AMC, along with Mary Turney and Karlynn BrintzenhofeSzoc to discuss ongoing concerns about management issues. AOSW and AMC did not always share the same goals for the organization. This was all occurring at a time when my professional career was going through an upheaval due to major changes in the workplace and subsequent job responsibilities. Thus, effective communication became even more of an issue as the contract with AMC was limited to 30 hours per month, resulting in AOSW primarily remaining a volunteer led organization. The role of president was often an overwhelming responsibility and could not be done without all of the dedicated members who voluntarily took on roles of leadership within the organization.

Recognizing that a great deal of the business of AOSW was being conducted online on the Board Listserve, I became concerned about the legality of the decisions that were being made. After researching my concerns, also done online, I subsequently drafted Intent to Amend the Bylaws to include electronic meetings. The by-laws were then amended at the fall, 2001, board meeting along with policies and procedures for conducting electronic board meetings.

During the 2000–2001 terms, Karlynn BrintzenhofeSzoc developed a Membership Survey to evaluate the then current membership benefits. The annual conference, the *Journal of Psychosocial Oncology* (JPO) and Social Work Oncology Network (SWON) were determined to be the most valuable member benefits. However, much discussion took place throughout my term as president as to the relevance of JPO as a member benefit. Although JPO was described as the “gold standard” of psychosocial oncology research, many members expressed

concern, as evidenced in the Membership Survey, that the research-based publication did not meet the clinical needs of those working in the trenches. Subsequent concerns were addressed with James Zabora, co-editor of JPO with a request for an increase in translational research and more clinically-based articles. A Letter of Agreement was subsequently revised by Haworth Press, and signed for an additional one year period of time with no increase in cost.

After countless volunteer hours and the subsequent resignation of both John Sharp and Neil O'Connor who managed the AOSW web site and SWON, a board decision was made to hire Jon Day, Next Generation Communication, to revamp the web site and serve as Web Editor. This moved AOSW from volunteer management of communication to a professional/business level.

The 2001 AOSW annual conference, appropriately titled "2001: An Odyssey: Redefining State of the Art in Psychosocial Oncology, in Cleveland, Ohio, was both well attended and well received. Charlene Amato was the Conference Chair and Kim Day was the Abstract Chair. The first ever Oncology Social Work Leadership Training Program was held prior to the start of the Cleveland conference, thanks to a generous grant from Genentech BioOncology. Project leaders directing the institute were Elizabeth Clark, Carol Marcusen, Marie Lauria and Michael Fife.

AOSW also launched the Oncology Social Work Toolbox at the annual conference during a poster session which was sponsored and hosted by Genentech BioOncology. Attendees received copies of the Toolbox thanks to an unrestricted grant from Genentech. The content was developed by Elizabeth Clark, Michael Fife, Carol Marcusen, Marie Lauria and Katherine Walsh Burke. Following the conference, Karlynn BrintzenhofeSzoc prepared a detailed analysis of the overall conference evaluations and individual sessions. The total mean scores indicated that the 2001 AOSW conference was "very successful." The report was submitted to the Board and the 2002 conference planning committee to assist with future conference planning.

In response to a board decision to develop a conference scholarship fund, named in honor of our founding president, Naomi Stearns, I worked with AMC to draft and develop policies and procedure, a brochure, application and rating form. Announcement of the scholarship was made in the summer of 2001. Katherine Walsh Burke, Project Leader, of a grant with Project on Death in America, developed an internet based curriculum for oncology social work continuing education credits on the AOSW web site. This project was launched through Dynamic Learning, Inc. Liaison activity continued to flourish as AOSW was represented and/or partnered with many organizations such as the Association of Community Cancer Centers, the National Dialogue on Cancer, Oncology Nursing Society, National Cervical Cancer Coalition and the Cancer Clinical Trials Educational Program Leadership committee, just to name a few.

AOSW was and continues to be a dynamic organization whose mission could not be accomplished without its many dedicated volunteers. My thanks to the following: Carol Marcusen, President Elect, Michael Fife, Immediate Past President and Kathryn Smolinski, Secretary.

Carol Marcusen (2001–2002)

During my presidency, AOSW's Board was experiencing some new growing pains and struggles. We were completing *FOCUS 2002: AOSW's Three-year Strategic Plan*. The board was not completely satisfied with the current management company's progress towards our goals. We were being invited to the table of many important and influential organizational efforts, and we wanted to be collaborative, but maintain our individuality. These important

issues generated much discussion and differing opinions from the different board members. We learned to process these differences and come out the stronger for it all.

Kathy Smolinski, Secretary, created an organizational manual that was reviewed and updated. It included the Articles of Incorporation, Bylaws, recent annual financial reports, relevant legal documents, current contracts, letters of agreement with other organizations, policies and procedures, key publications, and board meeting minutes. AOSW's five Regions continued to grow under the leadership of the Regional Directors: Lori Worden, Region 1; Lisa Marquette, Region 2; Jan Erbrecht, Region 3; Karen Atkin, Region 4; and Terry Baker, Region 5. Regional newsletters, reports in the AOSW NEWS and on the website, contacts with local Social Work Oncology Groups (SWOGS), as well as online communication via AOSW's online network, (SWON) facilitated networking and provided mentoring to oncology social workers around the globe.

The exchange program continued with the Victoria Oncology Social Workers Group (VOSWG), a special interest group of the Victoria branch of the Australian Association of Social Workers (AASW). Receptions for international members and for new members to AOSW were held at the annual meeting in Atlanta. Through AOSW's eleven Special Interest Groups, members maintained contact and shared information focusing on specific areas of practice or special issues. A number of presentations at the Atlanta conference were presented by SIG Group Leaders and members, providing opportunities for more focused learning to all conference attendees. Examples include: "Pain and Symptom Management Workshop: Ensuring Care for All" and "Transitions, Time and Training – Blood and Marrow Transplant: Support for Patients and Caregivers Over Time." Additional networking opportunities were available at the SIG Group meetings, held at the Atlanta conference, with the groups sharing resource information and discussing common issues.

AOSW's 18th annual conference, Exploring The Dream was held in Atlanta, Georgia on May 4–7, 2002. Lynn Behar, conference chair, and her conference planning committee provided a rich educational opportunity for attendees. Special features included keynote speakers Congressman John Lewis and Mr. Hamilton Jordan, the First Annual Quality of Life In Cancer Lecture by Dr. Elizabeth Clark, sponsored by the American Cancer Society, and the offering of Specialty Tracks in Leadership, Bone Marrow Transplant, Pain Management, and End of Life Care. A special general session included a panel of speakers that spoke to "The World Trade Center Tragedy: The Oncology Social Work Response and the Lessons Learned." AOSW provided a 6-hour workshop at the annual conference in Atlanta devoted to clinical trials. This workshop was funded through a special conference grant from NCI. AOSW also provided a Leadership Tract at the annual conference in Atlanta. This was funded through the 2002 Genentech sponsored grant.

The *Journal of Psychosocial Oncology* was current with the publication of four issues and membership continued to receive the issues as a membership benefit. JPO continued to be a well-respected journal focusing on psychosocial oncology research. Editors, Grace Christ and James Zabora continued to do an excellent job. Cancer Care and AOSW co-sponsored the development of a Teleconference 4-part Series on Innovative Approaches to Caring for Lung Cancer Patients, Their Families and Caregivers. Three web courses for continuing education were offered for continuing education credit. They were: (1) The Social Work Survival Toolbox: Advocacy Training for Social Workers in Oncology and Related Fields; (2) Social Work and End of Life Care; and (3) Social Work and End of Life Care: II. Members of AOSW received free registration for the first 6 months on each of these three courses. These web courses were funded through grants from Genentech and The Robert Wood Johnson Foundation, Death in America.

AOSW significantly strengthened its role in psychosocial oncology over the year through continued and new relationships with key oncology and healthcare related organizations. Continuing liaison relationships included: the Association of Pediatric Oncology Social Workers, Oncology Nursing Society, National Coalition of Cancer Survivorship, National Cancer Institute, American Cancer Society, Leukemia and Lymphoma Society, Association of Community Cancer Centers, National Brain Tumor Foundation, American Federation of Clinical Oncologic Societies, Intercultural Cancer Council, the Wellness Community, Winship Cancer Institute, and Children's Healthcare of Atlanta. American Society of Psychosocial & Behavioral Oncology/Aids, the National Dialogue on Cancer, and the National Association of Social Work.

AOSW also worked with the corporate community to support our goals of education and advocacy. Genentech provided continued funding for the *Cancer Survival Toolbox* and for a continuation grant for the *Social Work Toolbox*. The Robert Wood Johnson Foundation/Death in American provided support through a grant for two web courses on end of life care. Conference 2002 corporate support included: Amgen, Aventis Pharmaceuticals, US, AstraZeneca, Illuminations, Novartis, OrthoBiotech, NCS Assessments, Precision Therapeutics, Inc., and US Oncology. Other support came from Angel Flight America, Apria Healthcare, Cancer Care, Inc., Cancer Hope Network, Georgia Cancer Foundation, Kidney Cancer Association, and the Komen Foundation.

AOSW was asked to be present at the Social Work Summit on End of Life, the President's Retreat for ACCC, the leadership meeting for the Society of Social Work Leadership in Health Care, and at various other meetings. Sean Hebbel joined the AOSW Board of Directors as Chair of Development. During my presidency proposals were developed and submitted for web expansion and redesign and also for funding an Executive Director position for AOSW. A continuation grant to Genentech was also submitted for 2003.

In keeping with our mission of advocacy and education, the AOSW Board established the Naomi Stearns Scholarship Fund and the Nancy Denton Memorial Fund. These were well received by the membership. Kelly Johnson was the first recipient of the AOSW Naomi Stearns Scholarship Award. Kelly was from the Regional Cancer Center in Greensboro, North Carolina. In May 2001, AOSW launched the *Oncology Social Work Toolbox*. AOSW was able to fund the production of the Toolbox from an unrestricted educational grant from Genentech. The Toolbox includes Building Advocacy Skills, a training manual on oncology social work advocacy in various arenas' AOSW's Standard of Practice, Scope of Practice, and position papers; Questions and Answers about Oncology Social Work, and other tools for practice. Building Advocacy Skills was also an on line course for continuing education credit, free to members through November of 2001 at the AOSW website. All members received a copy of the Toolbox.

Virginia Vaitones (2002–2003)

My first day as the President of AOSW started off with a bang, there was no honeymoon period for anyone on the board. Two days prior to the official start, July 1, 2002, we learned that our management company was terminating their contract in ninety days. This was the company that handled our membership, data base and paid our bills. There had been a few board members, including me that were unhappy with the management company and wanted to replace them. We met with a representative from the company in May to discuss the issues. I thought the meeting had gone well, but suspected that we would be looking for a new management company, someday 'on our terms. That was not to happen.

After an emergency conference call with the AOSW Board members*, President-elect Karlynn BrintzenhofeSzoc and I started the search for a new management company. A Request For

Proposal was written and sent out to a number of management companies. One of the criteria for the company was to have experience managing professional health care organizations. One of the companies identified was the management company, Resource Management Plus (RMP). They had just started managing the Society of Health Care Leaders. I had met them at the society's conference in March. We ended up with two excellent choices and in the end selected RMP, now known as Fernley & Fernley, the present management company. Contacts were signed, bank accounts and membership data was transferred from Chicago to Philadelphia with only days to spare. That over, we could move on to planning the fall board meeting, work with the conference planning committee and do research on how AOSW could offer an oncology social work certification program.

At the Fall board meeting we reviewed the AOSW Strategic & Business Plan which went into effect July 1, 2002. There were four goals: 1, Increase revenue to sustain growth for AOSW; 2, Increase the visibility of AOSW and its mission; 3, Provide quality member services and educational products; and 4, Redesign a management structure to support our organizational needs. By October, we had accomplished the fourth goal by hiring RMP. Besides the every day management of our membership data base and paying our bills, RMP would be handling all the management of running the annual AOSW conference except selecting the workshops and fund raising. This would take a tremendous burden off of the conference planning committee.

We had three guest speakers at the fall board meeting. The first speaker was a non-profit development director that addressed the fundamentals of fund raising. The second speaker was our attorney, who specialized in non-profits. He addressed the legal issues which impact non-profit groups like AOSW. After listening to the lawyer, the board voted to explore re-establishing a 501-c-6 (business and membership) to help us carry out the goal of starting an oncology social work certification program. For a nonprofit organization, it is beneficial and allows flexibility to have a 501-c-3 and 501-c-6 tax status. A third day had been added to the board meeting to allow for leadership training. This program was funded by a grant from Genentech. Ten members from AOSW plus the board were lead through leadership exercises and learned how leadership styles impact on how the group functions. Marie Lauria and Carol Marcusen had secured the funding for the grant and Sondra Van Sant from North Carolina lead the exercises.

As President, I was invited to attend two "Summits", one sponsored by Oncology Nurses Society (ONS) and the other by National Association Social Workers (NASW). The first summit "Health Policy Partners" I attended was sponsored by ONS, held at their new offices in Pittsburgh. Other groups in attendance were American Society of Clinical Oncology (ASCO), US ONCOLOGY (a leading healthcare services network), National Coalition Cancer Survivors, American Cancer Society, and Association of Community Cancer Centers. The second summit was sponsored by NASW, "Building a Positive Image and Greater Influences for the Social Work Profession through Social Work Advocacy, Practice, Education and Research.

"The Journey Shared" was the conference theme for 2003. The conference held in Salt Lake City, Utah from April 9–11, 2003. The keynote speakers selected were Hester Hill Schnipper, Rachel Naomi Remen and Jonathan Young. Late in the fall, Carolyn Russell had to step down as conference chair due to a family tragedy. Kim Day, Education Chair stepped in and kept all the conference planning on tract. There were 330 AOSW members in attendance. This was the first AOSW conference that our management company, under the leadership of Jessica Widing, took care of the details of working with the hotel, exhibitors and food.

Being President of AOSW is like having a 2nd job or additional family member that requires constant attention. All summer and fall, I felt that I could not run fast enough to keep up with the needs. Just before Christmas, AOSW received a present from the American College of Surgeons, Commission on Cancer (ACSCoC). Association of Oncology Social Work had been asked to become a member of the American College of Surgeons, Commission On Cancer. The present, one that I had wished for, was now to be a reality. We were going to be sitting with the others at the “big table”. This organization, ACSCoC sets standards and gives accreditation to cancer programs. It was an organization that influenced the role we played in cancer programs. It was an honor to be elected to the Commission on Cancer and I recently began my second three year term. During 2007–2008, I had the opportunity to review and recommend changes to the Facility Information Profile System (FIPS), the information shared with the American Cancer Society. For the first time there would be a question about oncology social workers and an increase in the number of psychosocial services provided at your hospital. This information is part of the data base that consumers can access when comparing cancer programs in their area. There will be continued opportunities in 2009 for my direct involvement that could have lasting impact on oncology social work as we develop new standards for accreditation.

It is good to periodically step back and assess the structure of the Board of Directors. As our organization evolves, I believe that the board should grow with it. The structure of the board should be compatible with the progress, needs and growth of the organization. After adding RMP to our lives, it seemed time to critically evaluate the board structure. The AOSW Board had grown larger as compensation for having a part-time management company. A subcommittee, headed by President-elect Karlynn BrintzenhofeSzoc was formed to assess the board structure and make recommendations to the full board. The following changes were approved:

1. the past president and secretary position be eliminated
2. the president and president-elect would each serve two years
3. the regional directors would serve 3 years
4. the marketing and development committee chairs were eliminated
5. Region 5 would have its own regional director
6. the remaining committee chairs would reflect the AOSW mission –legislative/ advocacy, education, networking(communication), research(SWORG), and resource development(membership)

The terms for president, president-elect and regional directors were increased based on the needs of the positions and continuity to finish projects. The number of international members was increasing and it was an area the AOSW board identified a need to nurture the growth. The other positions were eliminated as RMP was contracted to assume those areas of responsibilities.

The last piece of business that was created by the AOSW Board of Directors during my Presidency was oncology social work certification. The AOSW board gave the seed money to create this certification which meant establishing a separate board of directors and a 501-c-6 corporation. The idea for certification came through membership, spearheaded by a survey conducted by Avis LaGrange and Johanna Schutte. Oncology social work certification” will demonstrate and support the value of the specialized social work services provided by oncology social workers in the care of oncology patients and their family. Board members were Virginia Vaitones, Kim Day, Avis LaGrange, Johanna Schutte and Jamie McDonald. The certification program will celebrate its 6th birthday November 2008.

Karlynn BrintzenhofeSzoc (2003–2004)

When I began my term in July of 2003 I expected to be the first AOSW president to hold office for two years since Grace Christ (1988–1990). I believed that a two year term would allow presidents to see projects we started to completion. As an Assistant Professor Catholic University of America I felt confident I would be able to balance the two full-time jobs – teaching and research and president of AOSW. Part of my confidence came from the benefit offered by my Dean, James Zabora, of release time from teaching to have time to lead AOSW. I was, and continue to be very aware and grateful to be in an academic environment where leading an international social work organization was seen not only a benefit to the profession but also seen as a benefit to my school. To jump to the end first – it turned out I wasn't very good at balancing my career in academia with the AOSW presidency. In February I received a letter from the Provost of the University reminding me to submit my application for promotion and tenure during the Fall semester of 2004. This is the biggest step in a professor's career, and there was no way I could give either the tenure packet or the presidency the appropriate focus. Thus, what was to be the first two year presidency in over a decade would turn out to be held by Kathy Walsh as she stepped in a year early after I stepped down at the end of June to focus on promotion and tenure – which by the way I received in June 2005.

Despite my abbreviated term as president, there were a number of initiatives and accomplishments during my year. AOSW was successful in getting its name and logo, as well as content review, on an important brochure entitled *About Your Screening Mammogram*. This brochure is the outcome of a collaborative project with the Y-Me National Breast Cancer Organization, R2 Technology, Inc., Diagnostic Imaging, NABCO and AOSW. Content was reviewed by AOSW members Susan Everly, Kim Day, and Louisa Daratsos and based on feedback from the board they insured that the issue of mammography for woman with breast implants was addressed.

We signed a collaboration agreement with the American Cancer Society to co-brand *I Can Cope*, the educational program developed by two oncology nurses in 1976 and adopted as an official ACS program in 1979. In the co-branding the AOSW logo is displayed on every module of *I Can Cope*. A number of AOSW members, including myself, worked on and continue to work on updating the material and making the program more user friendly. We also offer *I Can Cope* facilitator trainings at every AOSW annual conference followed by a train-the-trainer training. This opportunity offers AOSW members the skills and resources to provide educational sessions in their home settings without needing to find space in their office for that big yellow box (the old *I Can Cope* container) since all material is available online.

In the Winter of 2004 AOSW purchased its first exhibit booth for display at our conferences as well as at conferences we are invited to. This was exciting but over time we learned that exhibit booths are difficult to travel with and put together correctly after not seeing the booth for a couple of months. It was a good investment and got the AOSW Board thinking creatively at getting AOSW visible. After the inaugural use of the exhibit booth at the AOSW conference in DC it was shipped to Quebec for the 4th International Conference on Social Work on Health and Mental Health. Ivan Hochberg, Roeliena Van Zanten, and I went to represent AOSW and to begin discussions with this group about AOSW's involvement in the 5th International Conference. This was the beginning of a wonderful relationship with the organizers of the International Conferences and resulted in AOSW coordinating the Psychosocial Oncology, Hospice, and Bereavement Track in Hong Kong in December 2006.

Like every president before me and after me membership was a major focus. Lynn Behar led the charge of updating all our marketing materials for membership recruitment and retention.

This resulted in step sheets that inform a potential member of all the benefits of being a member of AOSW.

As a native of Washington, DC I was very excited that the 20th annual conference would be held in DC and that it would include, for the first time, an advocacy campaign. The conference committee was chaired by Nancy Boyle – who by the way did a fantastic job of pulling off two conferences in one. The first conference was the one we all have come to expect and love – three days of educations and networking. The second conference was a half day trip to Capitol Hill that allowed AOSW members to meet with their federal legislators and let them know that oncology social workers were passionate about issues related to health care, Medicare, quality of care of people with cancer ... and we were just getting warmed up! It turned out that nearly half of the conference participants went to the Hill for this visit.

The advocacy of AOSW as an organization and as individual members continued to grow and develop. At the conference site, to prepare for the visit to Capitol Hill we had a number of speakers educate the membership on what impact we individually held and how to secure time in with our federal legislators. We had a wonderful keynote speaker, Illisa Halpern, who talked to us about the power one voice, has in the lives of our patients and their families by sharing our stories and their stores as a means of teaching Congress about the day to day challenges associated with having cancer. We had a panel of lobbyists talk about the current hot issues that may impact oncology social work and cancer patients in the future. I can still see this training and trip to the Hill in action on SWON when someone will remind us to contact our legislator about a new or recurring issue that keeps a patient from getting the care he or she needs.

One other exciting event regarding the annual conference began this year. We started online conference registration. Member and non-members were able to register for the conference, select what workshops and presentation they would attend, and pay for it all online. This saved time and resources for both AOSW and the membership.

After a very successful conference, a full and busy year with the board of AOSW (who occasionally told me I overwhelmed them with information) I stepped down on June 20, 2004, one year early. I still look back on this year as one full of growth for both AOSW and me, and fun – the board and all the committee members had and still have a great sense of humor, and a continued commitment to keeping AOSW vibrant for all the oncology social workers who follow.

Katherine Walsh (2004–2006)

The rewards and challenges of a career in Oncology Social Work are mirrored by the rewards and challenges of serving on the Board of Directors of AOSW, and in particular, the presidency. The continuous task of assessing needs, developing a plan, integrating information to guide decision-making, making adjustments as unanticipated life events and environmental factors exert their influence, and maintaining hope as well as understanding that desired outcomes are not always achievable, despite everyone's best efforts, are part of our daily professional lives as well as our volunteer service in a professional organization. The continuous process of advocacy has perhaps been the greatest hallmark of AOSW's history. While AOSW has gained increasing recognition through the efforts of all boards and members, continuing to enhance the organization's name recognition, branding, and public understanding of how oncology social workers help and the expertise required to provide this help to persons affected by cancer was the main focus of the board during [the tenure of Katherine Walsh] my tenure, which was the first two-year presidency (2004–2006) since Naomi Stearns' initial term from 1984–86.

On the operational side, the transition in the management company from AMC to RMP, initiated during Ginny Vaitones' presidency was completed during Karlynn Brinznhofeszoc's presidency, and then in 2006 RMP merged with Fernley & Fernley, increasing both resources available to AOSW and capacity, but also increasing expenses! Raising dues was one method of increasing revenue for operations, as it had been in previous years, and continuous grant writing activities along with fundraising for a successful Annual Conference were ongoing with the assistance of Jessica Widing as Executive Assistant, who transitioned with AOSW from RMP to F&F.

Meanwhile ongoing activities of the Board included implementing two successful annual conferences, (Austin 2005, chaired by Ginny Vaitones and Minneapolis 2006, chaired by Ann Myers) and grant writing to support education and research activities, as directed by the existing Strategic Plan: Focus 2003. Conference sites and chairs were determined for 2007 and 2008, and international outreach efforts highlighted by Ivan Hochberg's election as Region V director. A task group composed of Board members Kimberly Barrio (Lawson), Lori Worden and Terry Baker was formed to study a proposal that had been part of the 3 year ACS organizational grant secured by Carol Marcusen in 2002, to hire an Executive Director for AOSW. Their recommendation to the Board was that an Executive Director be hired to both raise funds and serve as "the face" of AOSW at national and international meetings of cancer related organizations, which were steadily increasing in number.

A major task of the 2005 board was to develop Focus 2008, the next strategic plan, which we constructed at a self-led retreat in February. The remainder of the 2005 and 2006 Presidency was focused on implementing the strategic plan to continue to achieve the 5 goals of AOSW, Networking, Education, Advocacy, Research and Resource Development. Major 2006 achievements of the goals identified in Focus 2008 included:

Goal 1: Maintain AOSW as a fiscally responsible and sound organization

To insure the fiscal stability of AOSW each committee developed a budget and business plan (with identified funding) for each product/project they planned to complete. Following Ginny Vaitone's initial communications with the Lance Armstrong Foundation as Chair of the Austin Conference, a Cooperative Agreement was signed with LAF under which AOSW would provide expertise (for example in authoring content for LiveStrong) and receive \$85,000 to improve AOSW's capacity, improve the AOSW web site, and develop the POWER directory.

Goal 2: Increase visibility of AOSW and its mission

With permission from the Australian OSW Association, *Excellence in Psychosocial Care* was added to the AOSW logo. In collaboration with NASW's Public Education Campaign, an outstanding advertisement was developed featuring oncology social worker Alicia Hughes from MD Anderson and one of her clients and was placed in national magazines including the March issue of O magazine gaining perhaps the highest visibility available in the print media. Visibility was also enhanced by the participation of the President, ED and BOD in many major national and international meetings including ongoing participation in meetings hosted by C-Change, the InterCultural Cancer Council, the National Patient Advocate Foundation, National Coalition for Cancer Survivorship, NCI and many other organizations. Participation in these meetings was crucial, particularly because of the emergence of Patient Navigator programs and legislation, and the importance of oncology social work in this realm of patient care. AOSW was also represented by Katherine Walsh and other members at the historic first NASW Congress and Katherine Walsh provided testimony on the psychosocial needs of Cancer Survivors to the President's Cancer Panel, urging inclusion of Oncology Social Workers.

Goal 3: Establish a fiscally sound international research and education strategy

AOSW Collaborated with NCI on their National Practitioner Survey, designed to identify and develop methods practitioners can use to translate research to practice. Ivan Hochberg, Karlynn Bryntzenhofeszoc and Cecilia Chan led AOSW in the co-sponsorship of the International Psychosocial Conference in Hong Kong in 2006.

Goal 4: Improve and expand member services

AOSW undertook its first member survey, administering it electronically through survey monkey as well as US mail. Brad Zebrack, SWORG chair, assisted with the survey design and analysis of the data which was gathered to both provide evidence of the scope of oncology social work practice and identify member interests and needs. The format of the Annual Meeting was significantly changed to specifically present evidence to the membership of the Board's progress in achieving strategic plan goals as well as to present the traditional report on finances and operations of the organization. The design of the searchable POWER directory to showcase AOSW members' expertise was initiated as well as a member's only section of the AOSW web site.

Goal 5: Improve and expand educational products

With the LAF cooperative agreement funding, a complete redesign of the AOSW web site was undertaken to provide more specific information for the general public on psychosocial issues and cancer and the roles and functions of Oncology Social Work. AOSW members collaborated in the construction of the NASW free online course Understanding Cancer and contributed articles to both NASW's HelpStartsHere web site and the LiveStrong site to which the AOSW site was linked. A member's page was created for the site and the POWER directory was initiated.

Goal 6: Create and support organizational culture of legislative advocacy

Capitalizing on the training provided to participants at the 2004 Washington DC Conference, Bettye Bradshaw and the Legislative Advocacy committee continued legislative alerts, attended conferences on advocacy and responded to coalition requests from organizations sharing AOSW's mission and goals to advance psychosocial care.

Goal 7: Establish Executive Director of AOSW and integrate with current management structure

The 3rd year of grant funding from ACS was used to hire Kathryn Smolinski, MSW, into the Executive Director position. Kathy, a seasoned oncology social worker, brought to the organization an understanding of and commitment to, the profession and spent 2005–2006 establishing herself as a liaison to funders, other national organizations, the BOD and F&F, the management company.

It was a most rewarding two years of building on both the solid foundation and prior achievements of the organization and its dedicated leaders and forging new collaborations to continue to achieve the mission of AOSW; to advance the psychosocial care of persons affected by cancer. The reins of leadership were then placed in the capable hands of Kimberly Lawson.

Kimberly Lawson (2007–2008)

It was truly one of the greatest honors of my career to serve AOSW as President. The Presidency from 2006–2007 was an exciting time of innovation and change for our organization. This included many "firsts", as well as opportunities for evaluation and reflection regarding organizational and leadership function, as the Board of Directors (BOD), along with AOSW's

first Executive Director and its management company, endeavored tirelessly to strengthen the organization.

A committed and focused group of volunteers, including the Board of Directors and others, as well as employees, realized several accomplishments. Many of these were directly related to the continued successful implementation of the Lance Armstrong Foundation (LAF) grant projects. The LAF projects included a significant web site enhancement for AOSW, the publication of the organization's first oncology social work brochure with downloadable capabilities, and the launching of AOSW's POWER directory - Psychosocial Oncology Worldwide Resource Network - the first-of-its-kind database allowing worldwide access to the "power" of oncology social work. Additionally, recognizing that the sustainability of oncology social work services for cancer patients and families is rooted in the strength and development of future oncology social work leaders, the LAF grant also gave birth to the AOSW Leadership Work Group, which convened for the first time in April 2007. This Work Group initiated planning for what would become a highly successful 2008 AOSW Conference Leadership Initiative. All these projects were of primary focus during this term of office for the Board of Directors, countless other AOSW member-volunteers, the Executive Director and AOSW's management company, Fernley and Fernley.

The Board of Directors also undertook for the first time in many years a detailed assessment and evaluation of board structure and function much as our own employers do periodically. This assessment required the BOD to offer significant introspection and assessment of the function of each Board position, the goal of which was to ensure optimal and efficient utilization of both volunteer and employee hours toward carrying out AOSW's mission and strategic plans. It resulted in a restructuring of the Board of Directors. Many positive changes resulted as the Board Restructuring Task Force undertook this effort. These included the addition of a recording secretary and Members-at-Large to the Board, and the implementation, for the first time in AOSW history, of Board term limits. This latter alteration to the structure of volunteerism on the AOSW Board of Directors will hopefully serve the organization well for many years to come. It optimizes time spent in Board volunteerism, preserving valuable Board member time and energy while maximizing their opportunities for organizational contributions. The new term limits also serve to foster new member engagement in Board of Directors service, while assuring an ongoing balance of both seasoned and new Board member contributions toward the success of each organizational strategic plan.

Disappointments were also realized during this Presidency, particularly as the nation's economy began to experience recession. Grants and grant renewals were not received, and concern for the sustainability of several projects as well as AOSW's operational structure weighed heavy on Board members' minds, becoming the primary focus of much BOD time in the initial development stages of the next three-year strategic plan. Concern for sustaining, if not growing, AOSW's place in cancer care, and therefore our members' places in cancer care, was a significant priority for this term's Board of Directors.

It is said, though, that from such experiences we become stronger and often grow. Indeed, great strength, garnered from many, saw the AOSW Board of Directors, working together with the organization's employees, the 2008 Conference Planning Committee and devoted AOSW members, including many former leaders, devised plans of all sizes, great and small, to aid AOSW during this time. A major focus was the creation of a newly structured management plan that transitioned many organizational functions to volunteer Board Members. A plan for renewed operational efficiency was developed with volunteers and employees alike, with all involved committed to ensuring the best possible financial sustainability plan for AOSW. Volunteers were beckoned and they came, and delivered. To their credit, the "greatest of all" - many of AOSW's Past Presidents and other committed leaders - came together to deliver a

highly successful –and entirely volunteer - conference leadership initiative. Although a challenging time of transition, the Board, AOSW employees and volunteer's alike demonstrated remarkable commitment to ensuring AOSW's operations were managed in the most fiscally sound manner possible while delivering quality services to our members. Indeed, it was remarkable.

As President of AOSW during this time I will be eternally grateful for this incredible commitment from each remarkable person with whom I worked. It is with enormous pride that I served AOSW as President from 2006–2007 and that I am an oncology social worker.

Marcia DeSonier (2008–2009)

As the newly restructured Board took office in January, 2008, our first task was to bring all our governance documents in line with the new organizational structure. First, the bylaws required extensive rewriting to fully serve the newly restructured organization. With the help of the attorney with knowledge of Delaware law, the new bylaws were presented to the Board and approved. They served us well when they were tested by the resignation of the past president, Kim Lawson. Because of personal issues, Kim had to resign the very position she had felt was so important to the board early in the year. The by-laws were able to guide us through this event and we were able to continue without appointing someone to serve since there technically was no one qualified for the position.

Once, the bylaws were in place, we then had to amend and restate the certificate of incorporation in the state of Delaware. Since the bylaws state that we have a registered agent in the state of Delaware, we needed to find that agent. Much to our surprise, we found that our agent was there but, had not been paid since the late 1990's when the AOSW office was moved from Baltimore. Fortunately, the same company was there and agreed to continue as our agent without paying for the past 10 years! The Certificate of Incorporation is significant because that is where the purpose of AOSW is set forth. Again, we relied on the attorney to guide us in Delaware law to restate the certificate to cover us well. The new Certificate of Incorporation was signed and sealed and delivered in October, 2008.

In, February, 2008, at a meeting hosted by the American Cancer Society (ACS) at their National Home Office in Atlanta, GA, the new board met to develop the Strategic Plan for 2009–2011. The ACS staff generously provided us with a facilitator who led us in the process. Betsy Clark, Executive Director of NASW, was able to attend and bring us the latest update on the profession of social work in the world today. The release of the Institute Of Medicine report in the fall of 2007 was as very important as we looked at where AOSW needed to direct its attention over the next three years. Also of major importance in shaping the strategic plan was the financial picture of the organization. AOSW had not been able to obtain any grants similar to those awarded several years ago. That resulted in having passed a budget for 2008 that required reaching into reserves to address expenses for the remainder of the year. So, the newly developed strategic plan had four major goals for AOSW:

- Psychosocial Standards – Information and guidelines for professionals, institutions, and the consumer public
- Psychosocial Development – Maximize education and training opportunities
- Membership – Maximize member recruitment and retention
- Financial Management – Maximize financial health

We have begun orienting our Board activities to these four goals to enable us to begin thinking in terms of fitting all activities of AOSW into the framework of the new Strategic Plan. We will track our activities through this framework for the next three years. Another approach is

to be sure that there is financial backing for any new endeavors in place before activities begin. Even though the plan does not technically begin until 2009, there are activities directed at developing staffing standards and to improving the website for members as well as the public. Two task forces are already working on these projects.

In May, the 24th Annual AOSW Conference was held in Louisville, Kentucky. The conference was an overwhelming educational success and was a financial success as well. The wonderful content and speakers contributed to outstanding evaluations. There were 134 new oncology social workers there for the first time which is more than ever before. This is great for the profession as well as the organization. One of our foremost leaders in oncology social work, Joan Hermann, was the recipient of the ACS Quality of Life Lecture and Award. There was very successful Pain Plenary with our three experts, Terry Altilio, Yvette Colon, and Shirley Otis-Green sharing their expertise on the latest in pain management. In addition, the AOSW Leadership Institute was launched based on the work of Susan Hedlund, Vicki Kennedy, Carolyn Messner, Lisa Porat, and James Zabora. But perhaps the most intriguing speaker was Dr. Adewale Troutman of Louisville, who spoke on advocating for equity and access in health care. He described how without housing, there can never be health. This message is the same as Dr. Richard Cabot wrote about in his book, *The Art of Healing*, in 1909. One of the first oncology social workers, Ida Cannon, worked with Dr. Cabot in a world far different from today's world. But, as Dr. Troutman noted in his talk, some things have not changed.

As this year in AOSW draws to a close, there is more hope for AOSW than I would have thought possible just 10 months ago. The very successful conference has allowed us to get through our budget year without going into the reserves as we had anticipated. The elections have one-third of the board being replaced with new leaders. Carolyn Messner, a long time leader in our field, joins the board as president-elect. The board is working together to address the needs of ACS for patient navigator training for all of their ACS Patient Navigators. AOSW has been invited to many national tables and is participating as fully as possible. Two board members recently were invited to a new IOM Forum addressing the coming shortage of professionals in oncology care. A board member will attend the 10th Anniversary meeting of C-Change. We continue to work the American College of Surgeons and the Association of Community Cancer Centers. A board member is an invited director on the American Psychosocial Oncology Society's Board of Directors. As opportunities to work with other organizations involved in psychosocial oncology, we will avail ourselves of those opportunities. There is much to do as AOSW begins its 25th Anniversary and we are excited to begin the work.

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