AOSW NEWS
EXCELLENCE IN PSYCHOSOCIAL ONCOLOGY
VOLUME 23, NUMBER 4 OCTOBER–DECEMBER 2008

Around AOSW

Marcia DeSonier, MSW, LCSW, ACSW, President

As I begin this column, my last as AOSW President, it is still summer. A hurricane is threatening the Gulf Coast. The economy is declining. Gas prices are high. There is much uncertainty in the world. By the time this is printed, there will be a new president of the U.S. and of AOSW. We know Les Gallo-Silver will do an outstanding job of leading AOSW into its 25th year. We will hope the next U.S. President does as well.

A last column by an AOSW President is usually one of reflection, and so it is here. With one year as President-Elect, one as President, and a third as Past-President, the goal is to have continuity of the office while not overburdening the President. I have to say this new 3-year term is very doable. I found it very helpful to become involved as President-Elect and will hope to offer support to Les as Past-President. This year seemed to speed by with some frustration of needing to know more than I felt I did. But we have accomplished a fair amount of getting all our legal affairs in order so we can move forward as an organization.

When Past President Kim Lawson and her task force created the new AOSW structure, it was the beginning of a great deal of change. Now, with a totally redesigned organizational structure, all members of the Board of Directors are elected. The structure is similar to what is familiar to most of us with a Director serving as the chair of the standing committees. The big difference is the role of the Directors at Large (DAL). We are still working to find how they can best serve as the connection to members. There are three DAL positions—one for Regions 1 and 2, one for Regions 3 and 4, and one for Region 5. This structure makes the appointed role of state representative very important. The state representatives will relay issues and concerns to the DAL who will, in turn, bring them to the Board. This is new, and we will continue to massage the roles to serve the members best. We want to keep the link between the members and the Board very strong.

Another big change is having an elected secretary who is charged with keeping all the records and documents secure. AOSW has not done a good job of record keeping and we hope to turn that around. While the secretary does keep the minutes for meetings, this position also signs the legal documents. In

continued on page 2

AOSW's 25th Anniversary Conference

May 6–8, 2009

Savannah, GA

AOSW 25 years
EXCELLENCE IN PSYCHOSOCIAL ONCOLOGY

The Enduring Impact of 25 Years of Advancement in Psychosocial Care

We are delighted to report that this year brought in a record number of abstract submissions—an approximate increase of 30%. Even more to our delight, the caliber of the abstracts was extremely high. We chalk that up to your academic and clinical enthusiasm and desire to share your knowledge with your colleagues—although we realize some of you may just want an excuse to come to Savannah!

In planning the conference agenda, we are keeping multiple goals in mind, including—providing a rich variety of topics, perspectives and authors; ensuring that we offer appropriate and relevant content for all members at all skill levels. Working to meet all of those goals simultaneously is certainly a challenge but one that is well worth it.

We are very excited about the anticipated conference agenda and thank all of you for already making this conference feel like a celebration of AOSW's success and achievement. We look forward to seeing you in Savannah.

The 2009 Conference Committee

David Straseski, MSSW, LCSW, OSW-C (Chair)

Melanie Canetta, MSW

Pamela Jones-Vander Nagel, MSW, LCSW, OSW-C

Barbara R. McLaughlin, MSW, LCSW, OSW-C

Doretta Stark, MA, LICSW

See page 6 for special features!

Also In This Issue

AOSW
ASSOCIATION OF ONCOLOGY SOCIAL WORK
EXCELLENCE IN PSYCHOSOCIAL ONCOLOGY

Association of Oncology Social Work
100 N. 20th Street, 4th Floor
Philadelphia, PA 19103
215.599.6093
215.564.2175 fax

E-mail: info@aosw.org
Web: www.aosw.org

Around AOSW *continued from page 1*

the future, we hope the secretary will know where all the records are. This is obviously a huge job that we need to work on.

And the other big change in the restructuring is terms of office—all are three years. This allows for continuity and also means that at each election only one third of the board is new. Last year those elected were elected for staggered terms. This year's election is the first with a turnover of only one third.

As a result of the new structure, all our legal documents required rewriting and updating. And that is what I have been working to accomplish. All the job descriptions and policies had to be updated to incorporate the new structure. We relied on those currently in the positions to correct and update the job descriptions and policies connected to their positions. Thank you to all the directors who helped complete this task.

One of the most important documents of an organization is the bylaws, which give the organization purpose and structure. They govern the function of the organization. The bylaws have to comply with the state in which the organization is incorporated. AOSW is a non-stock corporation in the state of Delaware; therefore, our bylaws must comply with Delaware law. While the bylaws are very structured according to law, they also are written in such a way that they can accommodate new situations as they arise. We were challenged when the ink was barely dry! Our past president resigned and we had to refer to the bylaws to see how to handle that unforeseen situation. Fortunately, they served us well. The bylaws are now on the Board of Directors page of the Web site, and we will have them on the member section of the Web site soon. All members are welcome to read all our documents at any time.

In addition to our bylaws, we had to rewrite and amend our Certificate of Incorporation with the state of Delaware. The importance of the certificate is that it states the purpose and nature of the activities of AOSW. These are our three purposes:

- To educate the public and increase public awareness of the psychosocial effects of cancer on cancer patients and their friends and relatives.
- To further the study of the psychosocial effects of cancer on cancer patients and their friends and relatives.
- To educate oncology social work professionals to improve the skills and expertise of the profession.

We have a registered agent in the state of Delaware who is our contact with the state. We also have to file papers in the state of Pennsylvania because our management company is located in Philadelphia. If we change our address or tax status, we have to let Delaware know. The Certificate of Incorporation also gives the Board of Directors the right to govern the organization and to amend or appeal the bylaws as needed to manage AOSW.

The third really important document is our tax exempt status. We are incorporated as a tax exempt corporation under Section 501(c)(3) of the Internal Revenue Code of 1986, which has been amended from time to time. This status is very important to our purpose and all our activities. We are an educational charity organization. We are not a professional organization as many may think. Our purpose is to educate professionals, the general public, and cancer patients, their families and friends. When we deal with professional standards we must approach them from the point of view of educating other social workers to provide the highest standards of care to the cancer patient. As an example, with the IOM report, we have an incredible opportunity to provide education to other professionals as well as the general public about psychosocial care for the whole patient. This is what we have done for 25 years and we, better than any other profession, can provide that education.

The final document that helps us know a direction for programs and activities is our strategic plan. We are completing the plan for 2005-2008. In February, we began work on our next plan for 2009-2011. The plan is complete and will begin to be

continued on page 3

Around AOSW *continued from page 2*

implemented in 2009. Actually, activities that have already been started in the summer of 2008 will continue under the 2009-2011 Strategic Plan. In this plan, we have tried to take into consideration the issues affecting the profession as a whole and also allow for new issues that might arise in the next three years. All plans are ambitious, which is good. All goals are not reached, which is also okay. That you try to reach a goal is important, but to recognize that sometimes they aren't possible is also important. The new plan is somewhat conservative, with recognition of the economy at the forefront. There are basically four areas around which all goals are based. Those goals are:

- 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.

Again, by keeping the goals fairly simple, we allow ourselves the ability to take advantage of opportunities as they arise. We can also be creative and attempt things that we had not envisioned when the plan was put to paper. So as the bylaws are structured in such a way to allow room to govern, the strategic plan is written to allow growth where it is possible and activities that occur as AOSW moves forward. One last word about the strategic plan. While the Board of Directors creates the plan for the next three years, it depends on the entire organization to help achieve the goals. We know the range of talent and skills in AOSW is without comparison. Together we will achieve our goals.

In closing, I want to thank AOSW for the opportunities it has given me. Not just this year, but for all its 25 years of support for an oncology social worker in a small town in Florida. Through my professional organization, I have created a parallel life that has enabled me to learn from so many talented and skilled oncology social workers in this incredible profession. In a job I love and have been in for 25 years, my world has been broadened and enriched through all the wonderful people I have met through AOSW. It has been my privilege to serve as your president. I hope I been able to give back a little of what AOSW has given me. One last word to all the young oncology social workers: Become involved in AOSW, volunteer for committees, work on a conference, run for office, become a leader in AOSW. It is an incredible opportunity that will add to your professional growth! And—it is great fun!

Author contact: president@aosw.org

SWORG Report

AOSW at IPOS

Brad Zebrack, PhD, MSW, MPH

SALUDOS! In the best interests of promoting AOSW's mission—*To advance excellence in the psychosocial care of persons with cancer, their families, and caregivers through networking, education, advocacy, research and resource development*—I share with you notes from the International Psycho-Oncology Society (IPOS) meeting in Madrid, Spain in June. Several social work faculty from AOSW and APOSW presented papers at the meeting. Julianne Oktay, PhD, from the University of Maryland School of Social Work, reported on what she learned at the meeting and thought you would be interested to hear a little about what is going on around the world. Barbara Jones, PhD, MSW, University of Texas at Austin; Karen Kayser, PhD, Boston College; and Matt Loscalzo, MSW, City of Hope National Medical Center, Duarte, CA also were in attendance and contributed to this report.

Comprehensive Psychosocial Oncology Services

As the U.S. moves into a more systematic approach to integrating psychosocial services into oncology settings (and for oncology patients and families in community settings), we can look to the experience of our colleagues in other parts of the world who are far ahead of us in developing national or regional systems for psychosocial oncology services (and research). The Europeans and Australians have developed systems to screen all oncology patients for psychological distress, and to provide services to those whose screen indicates high scores.

Role of social work. One thing you realize when you come to an international conference like this is that the U.S. is really different in many ways from other countries with respect to social work. There were very few social workers at this conference, and this reflects the fact that social workers in Europe are more like our BSWs, or even something more like an AA (vocational) degree. They generally focus on practical things and they do not do counseling. The "clinical" work in Europe is done by psychologists and psychiatrists. In other countries, "psycho-oncology" is rapidly growing as a field, and many of the oncology centers and educational programs are offering special training for health professionals in "psycho-oncology." I was very happy to see that these programs are interdisciplinary. I met several European physicians at this conference who have taken that training and who are working to provide more psychosocial oncology services in their centers. (These are oncologists—not psychiatrists!)

Screening process. Screening patients (and families) for psychosocial needs is an essential component of a comprehensive psycho-oncology program. There were many papers on screening tools at the IPOS conference. Many are using the "distress thermometer." Several studies compared the results of the distress thermometer with other longer instruments, and found outcomes as good—one study used only two questions and had comparable results. Another screening instrument was from Matt Loscalzo, called "How Can We Help You and Your

continued on page 4

continued from page 3

Family?," which he has in a touch screen format that is easy to use. It has the advantage of including many social issues such as finances and transportation that are not covered in the distress thermometer. The disadvantage, of course, is that it is a longer instrument (it takes 6 minutes to complete). It needs more testing, too. Some feedback shows that it gets larger numbers of "positive screens," since it screens more broadly than other instruments that look only at emotional distress.

Providing psychosocial services in a comprehensive system. When there is universal screening, a large number of people come up as needing further assessment or services. Studies are also looking at whether all positive screens actually need services. Many do not respond to outreach, saying that they will handle it on their own. Also, lack of manpower makes it impossible (at this point, anyway) for social workers or others (psychologists, psychiatrists) to see everyone who screens positive. One direction (much seems to be coming from Australia) is to develop materials such as decision aids and educational materials that provide psychosocial services with minimal staff. Decision aids, for example, provide a great deal of information and guide the patient through treatment decisions such as genetic testing. In the U.S., similar materials could be developed and tested for financial problems, etc. Other ideas being tested are tele-counseling and distance support groups. This may be the direction of the future, with social workers seeing the most severe or complex cases and many with psychosocial problems getting some kind of "lite" service.

Another way some systems are dealing with this issue is through training all staff in the oncology center (including nurses aides, even janitorial staff) in psychosocial skills, such as making a referral (if a patient is crying, for example, or a couple fighting), or just listening skills, avoiding inappropriate remarks (e.g., false reassurance).

I imagine the recommendations of the new Institute of Medicine report will soon work their way into practice standards, and oncology centers will need to demonstrate that they meet them. Social workers have an opportunity here to influence how this will be done, and we need to think about solutions that are more realistic than "everyone needs to see a social worker."

Support Groups

There were several papers asking questions about support groups. The field has moved past the basic question of "Do They Work?" and is now looking into questions on what type of group works best with what type of patient. Several seemed to be suggesting that patients with particular coping styles (e.g., "fighting spirit") were more interested in socio-emotional support groups than patients with a more avoidant or hopeless/helpless coping style.

I gave a paper based on my work at Mercy Medical Center with Susan Scarvalone (some of you may know her from pediatric social work oncology when she used to work at Hopkins). We are working in a program to help breast cancer survivors who have persistent fatigue after treatment is over. My paper was based on our 10 session mind-body medicine group, which has good results using before and after measurements. We also presented some preliminary findings from our current study comparing the fatigue program to a similar program that involves family members.

There was a whole session on fatigue at IPOS. Most of the papers were looking at questions like "How many women have fatigue…when do they have fatigue… before treatment? During treatment? After treatment?" and "What do we know about what works to combat or prevent it?" (Findings are conflicting.)

Services for caregivers, partners. I went to one interesting session that Matthew Loscalzo organized on gender and oncology services. Several of the papers went over the data showing that women consistently come out more distressed than men, whether they are the patient or the caregiver. For prostate cancer patients, the wives tend to come out more distressed than the patients. Matt provided an explanation based on basic gender differences in how men and women respond to stress. He and Mark Heyison have developed a program for male caregivers (Men Against Breast Cancer) that helps couples identify ways to be more helpful to each other based on this model. Another paper reported success with support groups for men with sexual dysfunction after prostate cancer, but admitted that it is was very hard to recruit men. Matt's technique is to present the program as the man's responsibility—his "mission"—and then not do a touchy-feely thing, but focus on problem solving —something men are comfortable with.

Karen Kayser (another social work researcher) recently published a book, *Helping Couples Cope With Women's Cancers: An Evidence-Based Approach for Practitioners* (Springer, 2008). While emotional support from an intimate partner is vital to a woman's adjustment to cancer, often the partner is experiencing a high level of distress at the time of the diagnosis and during the treatment. There has been a lack of psychosocial interventions that focus on how both patient and partner cope together with cancer. The book describes a protocol of a couple-based intervention that was tested in two randomized control trials in the United States and Australia.

Other Topics

There were a number of papers and symposia on pediatric psycho-oncology. These lectures represented the wide diversity of pediatric services being provided in different parts of the world—from Ireland, where they are seeking collaborators as they develop their programs, to Canada and Spain, which have well-established pediatric psycho-oncology services. Additionally, there were papers focusing on adolescents, including Barbara Jones' paper on the meaning of survival for Hispanic/Latino adolescents, which highlighted the importance of family, faith, and community.

This was an exciting conference, and if you get the opportunity to go to a future one, don't miss it. It's an opportunity to hear what your international colleagues are doing. Thanks to Julie, Barbara, Karen, and Matt for representing social work at this worldwide venue. AOSW will continue to be a lead organization in demonstrating the unique and valuable contribution that oncology social workers make to patient and family care. Meanwhile, it is apparent that we have much to learn from our colleagues and collaborators all around the world.

Author contact: zebrack@umich.edu

Co-Pay Assistance Programs

Lauralea Cox, MS, LBSW, IPR
Texas Oncology, Longview, TX

Is this not a wonderful time of year? The birds are heading for their winter home, a nice northern breeze is gently blowing through the trees, and many foundations are in a brand new fiscal year with new money to pay out. There are several foundations as well as many pharmaceutical company patient assistance programs that will help with co-pay. Here are some co-pay assistance programs I have found that work well for our patients.

Patient Advocacy Foundation (PAF) Co-Pay Relief

http://www.copays.org/eligibility.html

- Autoimmune Disorders
- Breast Cancer
- Colon Cancer
- Diabetes
- Kidney Cancer
- Lung Cancer
- Lymphoma
- Prostate Cancer
- Sarcoma
- Macular Degeneration

Healthwell Foundation

http://www.healthwellfoundation.org/index.aspx

- Anemia Associated With Chronic Renal Insuffiency and Chronic Renal Failure
- Chemotherapy-Induced Anemia or Neutropenia
- Colorectal Carcinoma
- Head & Neck Cancer
- Iron Overload
- Moderate to Severe Asthma
- Multiple Myeloma
- Myelodysplastic Syndromes
- Non-Hodgkins' Lymphoma
- Non-Small Cell Lung Cancer
- Psoriasis
- Psoriatic Arthritis
- Rheumatoid Arthritis
- Secondary Hyperparathyroidism

Patient Access Network Foundation

https://www.patientaccessnetwork.org

- Anemia
- Ankylosing Spondylitis
- Breast Cancer
- Chemotherapy-Induced Nausea and Vomiting
- Colorectal Cancer
- Cutaneous T-Cell Lymphoma
- Cystic Fibrosis
- Gaucher's Disease
- Growth Hormone Deficiency
- Multiple Myeloma
- Multiple Sclerosis
- Myelodysplastic Syndrome
- Non-Hodgkins Lymphoma
- Non-Small Cell Lung Cancer
- Oncology Cytoprotection
- Pancreatic Cancer
- Patient Access Network
- Plaque Psoriasis
- Psoriasis
- Respiratory Syncytial Virus
- Rheumatoid Arthritis

AOSW's 25th Conference

May 6 – 8, 2009 • Savannah

Additional Features:

- We have invited the Mayor of Savannah, Otis Johnson, who is also a social worker, to give the welcoming address
- Matthew Loscalzo will deliver the opening keynote address
- Dr. Patricia Ganz, the Director of the UCLA-Livestrong Survivorship Center will give the closing keynote
- Building on last year's success, the Leadership Institute will provide more training with higher levels of specificity in content areas
- NASW will be conducting a 3-hour risk management workshop that will fulfill the requirement for 3 CEUs on ethics
- Staff from *A Lion in the House* will offer a 2-hour workshop that will focus on the training and testing around the use of the Childhood Cancer Survivorship Stories Module

Patient Services Incorporated (PSI)

http://www.uneedpsi.org/index.cfm

- Alpha1-Antitrypsin Deficiency – Lung Disorder
- Asthma
- Bone Health – Bone Metastases
- Chronic Myeloid Leukemia or Chronic Myelocytic Leukemia
- Chronic Renal Insufficiency – Kidney Failure
- Crohn's Disease – Fabry Disease – Enzyme Deficiency Disease
- Gastrointestinal Stromal Tumors
- Growth Hormone Deficiency – Endocrine Disorder
- Hemophilia – Blood Clotting Disorder
- Hepatitis C – Infectious Liver Virus
- MPS-1 – Hurler/Scheie – Enzyme Deficiency Disease
- Plaque Psoriasis
- Primary Immune Deficiency – Immune System Disorder
- Rheumatoid Arthritis
- Solid Organ Transplant Anti-Rejection Therapy

Chronic Disease Foundation

http://www.cdfund.org

- Adult Growth Hormone Deficiency
- Ankylosing Spondylitis
- Asthma
- Pediatric Growth Hormone Deficiency
- Psoriasis
- Psoriatic Arthritis
- Rheumatoid Arthritis
- Myelodysplasia

National Organization for Rare Disorders (NORD)

http://www.rarediseases.org

- Intrathecal Therapy for Pain Management: *800.459.7599*
- Advanced Renal Cell Carcinoma: *866.828.8902*
- Hodgkin's Lymphoma: *800.999.6673*

It is always a good idea to check these Web sites to make sure they are funded for the diagnosis you are working with.

Author contact: Lauralea.Cox@USOncology.com

The "Lone Ranger" Perspective of Oncology Social Work

Katherine K. Jefferson, LCSW, OSW-C
Little Rock Hematology/Oncology Associates, Little Rock, AR

Each year at AOSW, during our SIG/Ambulatory Care sessions, the topic of fee for service arises, and each year we come to the same conclusion — the majority of oncology social workers in private practice settings or outpatient ambulatory care centers cannot bill for their services.

It is always interesting to hear everyone's description of their job, and very exciting to hear about a social worker who actually does bill for counseling services. Overall, the mutual feeling of our SIG is that there are many of us out in the "hinterlands" who provide excellent psychosocial services and many who are the only social worker or the "lone ranger" in that area of practice.

I left the oncology hospital setting six years ago to work for a private practice group of eight oncologists who work in two separate office buildings on the campus of a large medical center. Burned out from hospital politics and the frustration of working understaffed, I was thrilled to take on the challenge of being the sole social worker in a very busy practice. With no job description other than my own AOSW practice guidelines, I was faced with justifying to the clinic staff exactly why the physicians hired me. Nurses know what a social worker can do for patients, but try to explain to insurance and support staff what your role is in what I best describe as a very dysfunctional work family. It took me many months to convince our insurance department that I was not a Medicaid caseworker or a friendly visitor to the patients, or even worse, the person who talked to patients about their past due accounts.

My role has evolved over the past years and I must admit that I surprise even myself at my knowledge of resources and oncology reimbursement issues. I sometimes feel like the information desk at the public library! I have learned all the preferences of each physician and nursing staffs. I have learned how to advocate for my patients even when I risk the negative reaction of the physician. I have learned how to be a diplomat and facilitate new policies in our clinic that impact our patient care. And I have obtained rounding privileges at both major hospitals in our city so I can problem solve some of our more difficult discharges.

Through AOSW and our annual conferences, I have learned to be creative in my practice and to network with other "lone rangers" in oncology settings. I am challenged, I am busy, but I still go to work each day excited about my profession and my patients.

Author contact: kjefferson@lrho.org

A Day in the Life of a "Lone Ranger" Oncology Social Worker

Peggy Jarrell, LCSW
Methodist Estabrook Cancer Center, Omaha, NE

When I came to this position a year ago I left a social work department of 11 co-workers. It had crossed my mind that I might miss the collective wisdom and camaraderie of this group, but I was eager to pursue my career in oncology social work in an outpatient setting. What I have found in the last year has been a supportive, interdisciplinary environment that has allowed me to stretch my skill level and be open to new ideas. And, of course, SWON has been my lifeline to my profession!

Our cancer center is affiliated with a hospital health system and houses both system-owned and private clinics. We have a breast clinic, lung clinic, a large head and neck surgical office, GYN oncology office, radiation therapy department, infusion clinic, and two private oncology offices. Although I am the only oncology social worker, we have an established behavioral health office with an on-site psychiatrist and two fulltime therapists. This enables me to refer patients or family members for longer, more in-depth counseling than I have time to provide. I still work closely with them on issues of patient and caregiver resources; and financial, insurance, and vocational support.

As is the case across the country, financial stress referrals are rampant and I get many calls about this area. I've gotten to know the billing managers for the hospital and various clinics quite well and find them grateful for any resources or assistance I can provide for patients. I've been able to avoid having to manage prescription-assistance referrals, as those are handled by the individual offices. I am well aware of the large amount of time and follow-up required for those referrals and find I am lucky to have others in the system able to provide this service.

My referrals come to me in various ways. I am able to attend any of our multidisciplinary treatment planning conferences and often become aware of patients through this venue. Some referrals come directly from the staff of the clinics or offices here at the cancer center, and some are referred to me from the social work staff at the hospital. Oh yes, I still get to talk with them occasionally and this has facilitated much better follow through with services!

I've tried to establish name/title recognition with the various MDs and make myself visible in the clinics. I get many calls from patients or family members who are looking for help with psychosocial issues. My other wonderful onsite resources are a

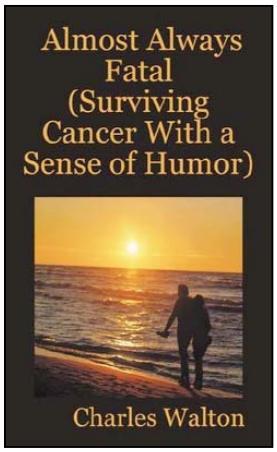
continued on page 8

Continuing Education Telephone Workshop

CancerCare, in collaboration with AOSW, offers telephone workshops on a variety of cancer-related topics. The following program is free and provides continuing education credit for participating social workers. For details, and to register for a workshop, call 1.800.813.HOPE, or visit the CancerCare Web site at www.cancercare.org/tew.

- **December 17, 2008 —** The Latest Developments Reported at the 31st Annual San Antonio Breast Cancer Symposium

Almost Always Fatal (Surviving Cancer With a Sense of Humor)



Charles Walton
KC Creations, Inc., 2006, 196 pages

Reviewed by Rita Gingrich, LCSW
PNI Counselor
Center for Cancer Care
Goshen, IN

Stage four metastatic melanoma is no laughing matter. But Charles ("Chuck") Walton is able to lighten his spirit and the spirits of those around him with his amazing sense of humor. "Take massive doses of the medication we call laughter!" is his wise counsel to chase away negative thoughts, feelings, and influences. In his story, he doses himself and others with refreshing humor and lightness.

Chuck was 33 years old in 1986 when he first experienced, in his words, "the spotting of the spot." The "spot" was given little attention over the next 3-4 years, with three different doctors finding no cause for concern. His life was full — with his truck driving job, a divorce from his first wife, the purchase of and running a deli, running a trucking business, financial challenges, and marrying the love of his life, Kathy, in 1989.

Fast forward to 2004. The business was sinking and the "spot" was rising. At the insistence of his wife, Chuck saw a dermatologist and within a week he underwent tests, procedures, and two surgeries. The final verdict was given by the surgeon: "Stage 3 melanoma, which is almost always fatal." Almost always fatal??? Not good news! Chuck was self-employed and had not purchased health insurance. Finances were being drained and medical bills were mounting. And, of course, fears and uncertainties were clamoring. There was not much to laugh about.

But Chuck has the gift of finding humor even in a grave situation. With bare truth and entertaining wit he relates the challenges of undergoing rigorous IL2 treatment. Chuck also describes how he was able to tap into his spirituality, connect with his soul, and give back to others. He is quick to attribute his ability to cope to the genuine care and support of Kathy, his family, and even his dog Elvis. Chuck does not escape the fright and alarm of a cancer diagnosis and treatment, but with comic relief he is remarkably able to move from ugly thoughts to a place of peace and hope. What a gift to share with readers!

Reviewer contact: rgingrich@goshenhealth.com
ISBN: 978-0-6151-5361-2

A Day in the Life

continued from page 7

fulltime dietician, genetic/risk assessment RNs, smoking cessation program and physical wellness program counselors. I also am involved with our support group programs and work interactively with the Pastoral Care Department and behavioral health staff on staffing some of those. So, I am the Social Work Department (wo-hoo, I'm a Department Head!) but feel pretty well connected most of the time.

I do get those referrals that no one else wants — e.g., find a kennel for a patient's dog, talk to the patient who is "borrowing" all the toilet paper/supplies from the restrooms in the building, find money *today* for someone's pain medicine or supplies not covered by insurance, or no source of insurance or income at all. But that appears to make me more "indispensable," which isn't always such a bad thing in today's environment of staff reductions.

I have a wonderful boss who is very supportive of social work (yes, she is an administrative nurse) and encourages me to do program development and build my position. I also have good support for continuing education opportunities and conferences like AOSW's.

As our patient numbers continue to rise, and more physicians come into the center, I hope to see another position created for this department. In the meantime, I will continue to try to set boundaries for referrals and educate colleagues about what oncology social workers can provide to this center. I think time will tell how the department will grow in the future. In the meantime, I'll be the social worker "Lone Ranger"— but I sure wish I had that beautiful white horse!

Author contact: Peggy.Jarrell@nmhs.org

Nonprofits, 990s, and Tax Exemptions (in a Very, Very Small Nutshell)

Leora Lowenthal, LCSW, OSW-C
New York University Cancer Institute
New York

If you follow SWON, you may have noticed recent questions related to the "vetting" of a new resource or finding information on an old one. Ordinarily this would *not* inspire me to write an article and I certainly wouldn't have been motivated to write one this quickly. But, as luck would have it, Margo Neal (our Managing Editor) tricked me and suddenly I find myself writing about a topic that is anything but entertaining.

Specifically, I'm going to address the topic of nonprofit organizations and how to learn more about them. The information here is the "generalized" version with many missing details and over-simplifications galore, and it pertains only to organizations within the United States. Still, I think it might help get you started if this is new material for you. And, even if you think this sounds deeply, profoundly boring, I recommend at least a surface familiarity with the subject. Oncology social workers live and breathe in a nonprofit world and that is a world with very particular, occasionally quirky, rules.

So again, the general version: From the perspective of the Internal Revenue Service, there are multiple forms that a "nonprofit" or "not-for-profit" organization (NPO) can take. Some examples include: religious organizations such as the Catholic Church; educational organizations such as Harvard University and perhaps your neighborhood pre-school; member organizations such as NASW; labor unions; political organizations such as The Democratic Party; private foundations such as The Rockefeller Foundation; social service providers such as The Wellness Community or Planet Cancer; some hospitals and clinics; and many small grassroots organizations with names such as *Kathy's Koala Refuge*.

Most of these organizations are entitled to specific tax exemptions under the Internal Revenue Code Section 501(c)(3), and within that code are referred to as "charitable organizations." Among other important regulations, organizations applying for 501(c)(3) status must have a purpose as described in the code:

"The exempt purposes set forth in section 501(c)(3) are charitable, religious, educational, scientific, literary, testing for public safety, fostering national or international amateur sports competition, and preventing cruelty to children or animals. The term charitable is used in its generally accepted legal sense and includes relief of the poor, the distressed, or the underprivileged; advancement of religion; advancement of education or science; erecting or maintaining public buildings, monuments, or works; lessening the burdens of government; lessening neighborhood tensions; eliminating prejudice and discrimination; defending human and civil rights secured by law; and combating community deterioration and juvenile delinquency."

In addition, a 501(c)(3) organization cannot be what is called an "action organization," meaning it cannot *"attempt to influence legislation as a substantial part of its activities and it may not participate in any campaign activity for or against political candidates."* This is a big deal and is complex but there are important reasons for it. Two of my favorites: It promotes the separation of church and state, and political organizations are held to different standards and are entitled to different tax exemptions than 501(c)(3) organizations. If you have ever wondered why AOSW does not (and cannot) endorse a presidential candidate, this is your answer.

In exchange for offering certain tax exemptions to nonprofit organizations, the government has attempted to create guidelines for accountability and transparency to the public. One such guideline is the mandate that with only a few exceptions, tax-exempt organizations file a special tax return called a 990. The 990 provides information about the mission, programs, and finances of an organization, and when this return is filed it is considered public information. While 990s are usually not available until well after the actual tax year, they can give you an excellent snapshot of an organization's structure and finances. Sometimes included on an organization's Web site, 990 forms are available in many other ways (I'll get around to that eventually).

Nonprofit organizations that do *not* have to file 990s include the following: religious and/or faith-based organizations; NPOs with incomes of $25,000 or less (although 501(c)(3) private foundations must file at any income level); NPOs that have not received tax-exempt status from the IRS; and subsidiary organizations.

And as you are surely wondering why you would ever want to look at a 990 form, here are a few good reasons (this part is more amusing):

1. You are applying for a job as Program Manager at a nonprofit community service agency. In this financial climate you are aware that donations may be limited and you want to know what alternate resources this agency has. You can look at the 990s to see from where the agency has historically gotten its income. And, you can see if they tend to operate at a deficit or a profit. You can see quite a bit.

2. You decide you want the job and you're going into salary negotiations. You really want to know what the person before you was making but don't know how to find out. Well, as it happens, the 990 will list the top five salaries paid along with the names and titles of the employees. Because you're fabulous and important, you're obviously applying for one of those well-paid positions so your predecessor's slightly out-of-date salary is probably on the 990.

3. You're just a curious person and like to know stuff.

4. You're considering making a donation to an organization (like AOSW) and you want to know what the heck they spend all their money on. Have they been buying matching velour tracksuits for the Board of Directors? (The answer is no, our President Marcia DeSonier nixed the velour, calling it "too trendy.") And while you wouldn't find that level of detail in

continued on page 10

Nonprofits

continued from page 9

most 990s, you can see what portion of their income is spent on actual services and programs.

If you happen to be intimidated by tax returns, the Foundation Center Web site offers an online lesson, walking you through every step of understanding the information on a 990 form. It's fantastic. Actually, that entire Web site is pretty fantastic.

For the task of quickie-vetting a resource, it may feel excessive to read through a 990. And in fact there are a number of organizations (nonprofits, natch) that already exist to provide ratings and reports on most categories of NPOs. Their Web sites often provide direct links to an organization's 990 forms. Here are a few (thank you, Patty Bledsoe and Kevin Francis, for your postings on SWON):

American Institute of Philanthropy: www.charitywatch.org

Better Business Bureau (BBB) Wise Giving Alliance: www.us.bbb.org/charity

Charity Navigator: www.charitynavigator.org/

Guidestar: www.guidestar.org

If you still can't find the 990 and you need it, you may want to call the agency and ask. Assuming they have filed one (remember, it is not necessary for every NPO), that information should be available.

For those of you who may not know, AOSW is a nonprofit organization with 501(c)(3) status and proud of it. You can find us on Guidestar. And on that note, I give you our very own mission statement:

"To advance excellence in the psychosocial care of persons with cancer, their families, and caregivers through: networking; education; advocacy; research; and resource development."

We are so cool.

Common Beliefs and Possible Misconceptions About Nonprofits

Belief. A NPO is not allowed to make a profit.

Reality. A NPO is allowed to make a "profit," but any income and/or profit must be used to further the mission of the organization. No private party or shareholder can be the beneficiary of a NPO's income, unlike for-profit organizations that may benefit private parties and often distribute profits among shareholders.

Belief. If I make a donation to a NPO, I am entitled to take a tax deduction.

Reality. Actually, it's not so simple. Generally speaking (really generally), donations to NPOs with 501(c)(3) status are deductible. On the other hand, donations to some other categories of NPOs, such as political organizations, are not deductible. If you are planning to itemize your deductions, and this is important to you, make sure you double-check an organization's status *before* you make the donation.

Belief. An organization that has not legally formed as a NPO or applied for tax-exempt status is out to make money, scam people, and cannot be trusted.

Reality. Being a legally sanctioned do-gooder involves a great deal of paperwork and time, and not everyone is up to the challenge. Then again, the world is full of con artists. There is no simple response to this "belief" but my advice to clients (and to myself) is — always be careful and use due diligence. For example, a group of neighborhood parents raising funds for local children having BMTs might not go to the trouble of legally defining themselves as a nonprofit entity and/or applying for tax-exempt status. The money they raise may indeed go to a great cause and perhaps more quickly than if they stopped to deal with bureaucracy. On the other hand, they won't have to follow the many stringent guidelines and reporting measures established for NPOs with tax-exempt status, and that makes fraud much easier. It's tricky.

Want to Know More?

If you are interested in learning more about nonprofit organizations, philanthropy, management, and, yes, tax codes, these are a few Web sites you could check out:

Chronicle of Philanthropy: www.philanthropy.com

Foundation Center: www.foundationcenter.org

Idealist.org (section on nonprofit FAQs): www.idealist.org/if/i/en/npofaq

IRS tax codes for nonprofit organizations: www.irs.gov/charities/nonprofits

Nonprofit Quarterly: www.nonprofitquarterly.org

Author contact: Leora.Lowenthal@nyumc.org

AOSW LEADERSHIP

BOARD OF DIRECTORS

PRESIDENT
Marcia W. DeSonier, MSW, LCSW, ACSW
Baptist Cancer Institute
Pensacola, FL • 850.469.2224
president@aosw.org

PRESIDENT-ELECT
Les Gallo-Silver, ACSW, LCSW-R
LaGuardia Community College,
City University of New York
New York, NY • 215.599.6093
jillino@aol.com

SECRETARY
Joyce Hendershott, MSW, LISW, ACSW
James Care for Life
Columbus, OH • 614.293.6903
joyce.hendershott@osumc.edu

TREASURER
Roeliena L. Van Zanten, MSW, ACSW, OSW-C
Private Practice
Bainbridge Island, WA • 206.842.1476
rvzstern@aol.com

ADVOCACY DIRECTOR
Tammy Weitzman, LCSW
Dana Farber Cancer Institute
Boston, MA • 617.632.4353
tammy_weitzman@dfci.harvard.edu

COMMUNICATIONS DIRECTOR
Kevin Francis, MSSW, LCSW, OSW-C
Scott & White Hospital & Clinic
Temple, TX • 254.724.5918
kdfrancis@swmail.sw.org

EDUCATION DIRECTOR
Leora Lowenthal, LCSW, OSW-C
NYU Cancer Institute
New York, NY • 212.731.5141
leora.lowenthal@nyumc.org

MEMBERSHIP DIRECTOR
Pam Murph, LCSW
Private Practice
Knoxville, TN • 865.216.6693
p.murph@att.net

SWORG DIRECTOR
Brad Zebrack, PhD, MSW, MPH
University of Michigan
Ann Arbor, MI • 213.821.3111
zebrack@umich.edu

DIRECTORS-AT-LARGE
Tony A. Cheung, MSW, Dip. HCA, OSW-C, RSW
Providence Healthcare
Toronto, Canada
416.993.9930
tacheung@rogers.com

Kerry Irish, MSW, LCSW, OSW-C
Central Maine Comprehensive Center
Lewiston, ME
207.795.7118
irishke@cmhc.org

Alison Mayer Sachs, MSW, OSW-C
Eisenhower Lucy Curci Cancer Center
Rancho Mirage, CA
760.674.3612
asachs@emc.org

2009 CONFERENCE COMMITTEE

CHAIR
David Straseski, MSSW, LCSW, OSW-C
dstraseski@oncologyalliance.com

COMMITTEE MEMBERS
Melanie Canetta, MSW
canettam@yahoo.com

Pamela Jones-Vander Nagel, MSW, LCSW, OSW-C
pjones@emc.org

Barbara R. McLaughlin, MSW, LCSW, OSW-C
bareg@earthlink.net

Doretta Stark, MA, LICSW
wrussian@comcast.net

SPECIAL INTEREST GROUP (SIG) COORDINATORS

AMBULATORY CARE/ FEE FOR SERVICE
Melissa Panszi Riebe, LMSW, OSW-C
St. Vincent's Comprehensive Cancer Center
New York, NY
212.804.6012
mprmojaz@aol.com

Mary Keeney, MSW, LCSW
Capitol Comprehensive Cancer Care
Columbia, MO
573.893.6406
keeneyblue@aol.com

BLOOD & MARROW TRANSPLANT
Tammy Weitzman, LMSW
Dana Farber Cancer Institute
Boston, MA
617.632.4353
tammy_weitzman@dfci.harvard.edu

Jane Dabney, MSW, LISW
Cleveland Clinic
Cleveland, OH
216.445.8423 • dabneyj@ccf.org

BRAIN TUMOR
Harriet Patterson, MPH
National Brain Tumor Foundation
San Francisco, CA
800.934.2873 • patterson@braintumor.org

Jillann Demes, MSW, CSW, OSW-C
American Brain Tumor Association
Chicago, IL
847.827.9910 • jillann@ABTA.org

CHILDREN & CANCER
Nancy Cincotta, MSW
Mt. Sinai Medical Center, New York, NY
212.241.7168
nancy.cincotta@mountsinai.org

Mary E. Turney, LCSW
H Lee Moffitt Cancer Center
and Research Institute
813.979.7247 • mary.turney@moffitt.org

COMPLEMENTARY/ ALTERNATIVE MEDICINE
Rosemarie Ampela, LCSW, OSW-C
North Shore - LIJ Health System
Lake Success, NY
516.734.8814 • rampela@nshs.edu

Joan Framo Runfola, ACSW, LCSW
Joan Knechel Cancer Center
Hackettstown, NJ
908.441.1503 • JRunfola@hch.org

DIVERSITY
Alycia Hughes, LMSW
M.D. Anderson Cancer Center
Houston, TX
713.792.0762
ahughes@mdanderson.org

Holly Randall, LCSW, OSW-C
Angelina Radiation Oncology Associates
Lufkin, TX
936.639.7620
hollyr@cancer.org

END-OF-LIFE CARE
Marta Metz, MPH, LMSW-C
Henry Ford Health System
Detroit, MI
313.916.3975 • mmetz1@hfhs.org

ETHICS
Tracy S. Borgmeyer, MSW
Saint John's Regional Medical Center
Joplin, MO
417.625.2492 • tborgmey@stj.com

Leora Lowenthal, LCSW, OSW-C
NYU Cancer Institute
New York, NY • 212.731.5141
leora.lowenthal@nyumc.org

PAIN & PALLIATIVE CARE
Yvette Colón, PhD, ACSW, BCD
American Pain Foundation
Ypsilanti, MI
410.783.7292 ext. 223
yvette@painfoundation.org

RADIATION THERAPY
Gina DiVincenza, LCSW, OSW-C, NSW
North Shore-Long Island
Jewish Hospital System
Manhasset, NY
516.562.2825 • gdivince@nshs.edu

Randi A. Goldfarb, LCSW, OSW-C
North Shore-Long Island
Jewish Hospital System
New Hyde Park, NY
718.470.7033 • rgoldfarb@lij.edu

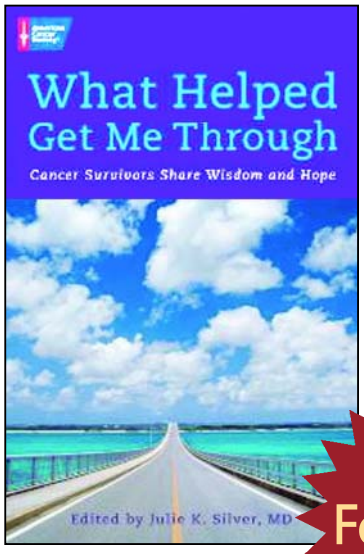
SPIRITUALITY
Debra Mattison, LMSW, ACSW, BCD, OSW-C
University of Michigan Hospitals
Ann Arbor, MI
734.936.4637
debmatt@med.umich.edu

THE AOSW MEMBERSHIP DIRECTORY IS AVAILABLE ON THE WEB SITE. GO TO WWW.AOSW.ORG

AOSW MEMBERS: BE SURE TO UPDATE YOUR CONTACT INFORMATION IN THE MEMBERS SECTION ON THE WEB SITE OR THROUGH THE MAIN OFFICE VIA E-MAIL AT: INFO@AOSW.ORG

SPECIAL WEB ONLY OFFER!

American Cancer Society Book Promotions for AOSW Members and Their Patients



NEW Featured Title!

All AOSW Members:
Receive a 40% professional discount off list prices on all ACS books.

For Your Patient and Family Members:
30% discount off list prices on all ACS books.

Go to the members' area of the AOSW website **www.aosw.org/members/html/main.php** for additional information and links to the book specials.

These offers are good through December 31, 2008, while supplies last.

American Cancer Society®

Thank You!

AOSW thanks our sponsors for their financial support of the 2008 24th Annual Conference in Louisville, Kentucky

GOLD SPONSORS

Bayer Healthcare
Gilda's Club Worldwide
Lymphoma Research Foundation
National Marrow Donor Program
Sanofi-Aventis

SILVER SPONSORS

Amgen
Celgene
The Leukemia & Lymphoma Society

BRONZE SPONSORS

Genentech, Inc.
Lance Armstrong Foundation