



PAIN ADVOCACY COMMUNITY

An E-Newsletter Connecting Those Who Care

www.partnersagainstpain.com

February 2007

Pain Management & Public Health Strategy

In this Issue

FROM THE EDITOR

Pamela Bennett, BSN, RN

FIRST PERSON

ADVOCATE Leslie Given,
MPA

IN THE SPOTLIGHT

Centers for Disease Control
& Prevention

HEALTHCARE PROFESSIONAL ALLIANCE OUTREACH

PAIN COMMUNITY CONNECTION

CAREGIVER BOOKBAG

ADVOCACY IN ACTION



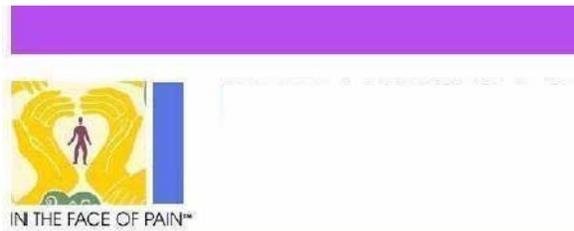
Photograph by Diana Lenkowsky

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FROM THE EDITOR



Last month I spoke to you on a very personal level about my pain advocacy experience with my uncle. Thank you to those of you who sent your thoughts and prayers. Our family was very grateful that my uncle died peacefully at home, with his pain and symptoms managed, and surrounded by his family. As many families who have gone before us, we appreciated that hospice was an available resource.

This month our issue will focus on the intersection between the Pain Management Advocacy Movement and that of Public Health. We are very fortunate to have had the opportunity to interview Leslie Given, MPA. I had the privilege of first seeing Leslie in action at the first meeting of those involved in the cancer control community in Puerto Rico. Her enthusiasm for her work, passion for patient care, ability to bring people and issues together, competence and expertise, and sense of humor, left a tremendous impression on me. In the interview, Leslie provides us with an understanding of public health, ways that those who care about pain management can collaborate with and provide assistance to those in the public health arena addressing cancer and other chronic diseases in meeting their goals, as well as effective practical advocacy tips.

Friends and colleagues of Professor David Niv were shocked and saddened to learn of his untimely death on Tuesday 6th February. David was considered a leading expert in Israel in the field of pain therapy, and was a leading figure in world organizations dealing with pain treatment. He published over 120 articles on pain treatment and therapy in his work and research on chronic pain. Not only was David the director of the pain clinic at Tel Aviv's Ichilov Hospital but he was recognised as one of the leaders in establishing International Pain Day. David was a driving force within the World Institute of Pain and the International Federation of Pain Management and a past President of the European Federation of IASP Chapters. He will be sadly missed by his colleagues, friends and patients.

Dr. Dover's column has some wonderful information including the CDC's new report that includes pain. P.A.N.D.O.R.A. and APHA are the organizations featured in Kim Tiller's column. Included in the P.A.N.D.O.R.A. article is the inspirational story of Marly Silverman. Marly is an example of someone who turned her own challenges into an opportunity to help not only herself but many others!

We appreciate hearing from you about YOUR Pain Advocacy Community e-newsletter. Please send comments or feedback to PatientAdvocacy0@pharma.com.

Kindest regards,

Pamela



FIRST PERSON ADVOCATE

In the Spotlight: Pain & Public Health Strategy

A conversation between Leslie Given, MPA, Vice President, Strategic Health Concepts, and Pamela Bennett, RN, BSN, Executive Director, Healthcare Alliance Development, Purdue Pharma L.P.

Pamela Bennett (PB): Leslie, we first met a few years ago when you were working in a different capacity of public health service. Why don't you talk a little bit about the work you were doing at the Center for Disease Control and Prevention (CDC) in the cancer arena – and about your professional journey in public health.

Leslie Given (LG): When I left CDC in November 2006 I had been there for about eight years in the Division of Cancer Prevention and Control, helping CDC develop their National Comprehensive Cancer Control Program.

The intention of that program is to look at cancer broadly across all disciplines and across the continuum of care from prevention through survivorship. The program works primarily with state health departments and their partners to develop state, tribe, and territory cancer plans. The goal is to build the partnerships that are necessary to actually implement the cancer plans. These are usually five year strategic plans focused on addressing whatever the major cancer issues are in that jurisdiction.

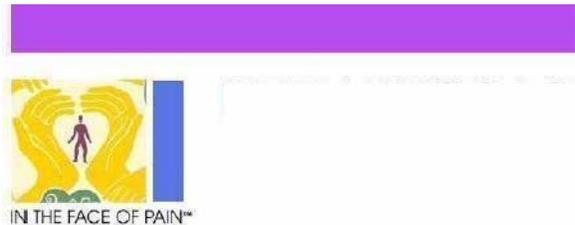
PB: It seems to me the work that you have done at CDC with comprehensive cancer control has been very successful. One of the CDC's partners in this initiative has been C-Change. Can you talk a little bit about how C-Change, the CDC and the other national partners through the Comprehensive Cancer Control Plans became engaged around the issues of pain management and palliative care?

LG: The CDC has been funding comprehensive cancer control plan development and implementation since 1998. Tom Ridge, who was then Governor of Pennsylvania, as a member of C-Change wanted to have C-Change focus on what states could do to address cancer issues.

A team was created within C-Change, the State Cancer Plan Team, now called the Comprehensive Cancer Control Team. CDC is an obvious partner with C-Change in focusing on that work, because CDC is the federal agency that actually funds the infrastructure for these state, tribe and territory coalitions, including the staff to coordinate implementation of their plans.

Because plans address the whole continuum of care, they include issues that people face in treatment and as they go through stages of survivorship - and obviously one of these issues is pain control and palliation.

I am certain that every cancer plan - and every state now does have a cancer plan - contains something that addresses pain control and palliation.



FIRST PERSON ADVOCATE

There are various things the comprehensive cancer control coalitions might do about pain control. They determine what policies need to be enacted, what legislation needs to be pursued, the different methods of public and provider education about cancer pain control that need to be focused on, as a few examples.

PB: It sounds very encouraging - that the states, tribes, and territories include pain management and palliative care as part of their plans. Many of our readers are people who are actively engaged in the pain community who may not know how to become involved. How would they go about offering their expertise or get engaged in the comprehensive cancer control effort in their area?

LG: One of the first things would be to understand who's involved in comprehensive cancer control in the state, tribe or territory. The easiest way to find that out is to go to a web portal - Cancer Control PLANET (<http://cancercontrolplanet.cancer.gov/>). The site is jointly sponsored by CDC, the National Cancer Institute (NCI), and the American Cancer Society, as well as the Agency for Healthcare Research and Quality (AHRQ), the Substance Abuse and Mental Health Services Administration (SAMHSA), and the Commission on Cancer (CoC).

The portal includes contact information for people who are currently involved with comprehensive cancer control in each state and some tribes and territories. In addition, someone who is unfamiliar with what's happening in comprehensive cancer control in their state can find the state cancer plans on PLANET. They can get a sense of what the plan's objectives are, as well as contact information for the program directors in each state.

PB: I think that it's so wonderful that our government and our states are really working to look at cancer care in a continuum. Because we know that as we do a better job with earlier diagnosis and screening and treatment we're going to have more and more survivors. There are two interesting aspects of pain as it relates to cancer. The first is that those people who do have the benefit of early screening, diagnosis and treatment, are often left as survivors with residual problems of persistent pain or other chronic symptoms –lifelong quality of life problems that these folks need help with throughout their survivorship.

Secondly, as you pointed out, there are still many disparities in care. Many populations are not receiving adequate screening or treatment. Oftentimes, unfortunately these people are diagnosed with late- stage disease and often are facing end-of-life care decisions, where pain management and palliative care are critical in helping them transition through that process. It is encouraging to me that this is being addressed in a thoughtful and comprehensive manner through the efforts of comprehensive cancer control.



FIRST PERSON ADVOCATE

CDC has recently released a report that includes information on pain management [available at: [http://www.cdc.gov/nchs/data/06.pdf#highlights](http://www.cdc.gov/nchs/data/hus/06.pdf#highlights)]. Historically CDC has looked at infectious diseases such as HIV/AIDS, and they've looked at chronic disease states such as arthritis, diabetes, cardiovascular disease, and cancer. Recently they have begun to look at issues like obesity which cross many different disease states. Can you share any insight about how they are starting to look at pain or what you think their approach may be to address the public health issue of pain in the future?

In answering my question, I realize you're not speaking as a representative of CDC, but would rather be drawing on your knowledge of public health and your knowledge of how government works. The other caveat I am aware of is that government only tends to do what they have funding to do. However, I would be very interested in hearing your perspective of what this report means, how you see it fitting in the larger picture of the public health agenda, and how does this impact the public health community?

LG: I believe what is significant here is that I think it's the first time there has been a focus on pain control within this CDC report. To me, and this is classic public health theory, public health organizations have some basic core functions and one of those is to assess and monitor health and health conditions.

I think that this report from CDC is the first step – it's recognition from a major federal agency that pain control is an issue that needs to be addressed. And the first step is to understand it – to understand the prevalence and to understand the impact.

There are basically three core functions of public health: monitoring, ensuring appropriate care for the greatest number of people, and then regulating and formulating policies about health issues.

I think individual states have probably been ahead of many national organizations in what they've done to address pain control, but this report from the CDC can be seen as one of the first steps.

Beyond this new report CDC's Division of Cancer Prevention and Control has been looking across the continuum of care and through comprehensive cancer control working with their public health partners to address survivorship issues such as pain control.

In 2002, the Lance Armstrong Foundation and CDC came out with A [National Action Plan for Cancer Survivorship](#). It was really the first of its kind. The plan focuses on cancer survivorship as a public health issue. And I believe you can easily translate in this plan into what the role of public health in pain control might be.

PB: That's great. Many of our readers are not in public health. If I'm a pain management advocate, be that a patient, caregiver, or practitioner, and now we



FIRST PERSON ADVOCATE

have this CDC report that is the first step to put pain on the public health agenda, how would you, as an expert in advocacy and public health, advise us about how we could impact the public health agenda?

LG: I think it's just being involved. The great thing about comprehensive cancer control is the partners who are coming together to address cancer as a major health issue. The coalitions are made up of anywhere between 50 and 500 individuals. Multiply that by every state (and many tribes and territories), and you really have this powerful core of people who are focused on doing something significant to lessen the impact of cancer on individuals.

What pain control advocates can gain by contacting these comprehensive cancer control coalitions and getting involved is they can put their issue, pain control, on a larger agenda that's about cancer.

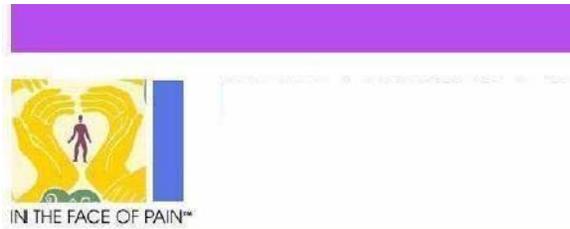
Each coalition is looking at a range of issues— whether it is a specific cancer, a piece of the continuum of care (like survivorship) or a functional issue like policy change. Keep in mind that you might have to help someone else – say an advocate for breast cancer screening work on their issue -but you can be assured they're going to turn around and help you deal with your issue. You may also find that the coalition has not been able to focus on pain control issues yet. Your ideas, contacts and expertise that you bring to the coalition may just be the catalyst for moving something forward. I think just offering to help in some way is the best thing to do, just jump right in and get involved.

PB: Outside of the cancer world – since this CDC report really looks at broader pain management issues - pain management in long term care, or chronic or persistent pain issues – are there ways advocates can get involved – what recommendations would you have about how they can make their voices heard?

For example, I don't think the American Public Health Association (APHA) has ever focused on this issue. Are there are other areas within the public health community where pain management advocates can make their voices heard?

LG: I think APHA is a good idea. Other good possibilities are some of the organizations that directors of state health departments are involved with such as ASTHO, the Association of State and Territorial Health Officers (<http://www.astho.org>). Another idea is to make contact with the individual Director of the State Health Department as they are a very powerful person within the state government.

Another organization affiliated with ASTHO is the National Association of Chronic Disease Directors (<http://www.chronicdisease.org/>). One of the key members of that organization, Dr. Phil Huang, is also a member of C-Change. Because pain is associated with many chronic diseases I think making contact with the Chronic Disease Director within a health department may open up dialogue or opportunities for you.



FIRST PERSON ADVOCATE

PB: I totally agree with you. If you're a healthcare professional you may be looking within your practice or within your association, if you're a patient you're looking a lot at the patient associations that either serves your disease or your condition, or in the case of pain, a disease and/or a symptom. So I think this is extremely helpful for our community, the pain community, to understand the public health community and to understand where there may be intersections and opportunities to become engaged and to make some changes.

From being in the roles you've been in, and I know you've worn a lot of different hats from state government work to federal government work – are there any suggestions you would give to an advocate about the best and most effective ways to communicate with folks who are in the public health roles you're talking about – or ineffective ways, things to avoid or things to embrace that would make your message more clearly heard and available.

LG: I think when you're talking about working with folks in public health you have to remember these are civil servants, they have a lot of things on their plate. For example, Directors of Health Departments are concerned with everything that is related to health: from communicable diseases to chronic diseases to emergency response and bioterrorism. Because they don't have a lot of time, my advice would be to think of them in the same way as legislators.

I know you have information in the Pain Management Advocacy Toolkit (<http://www.partnersagainstpain.com/painadvocacycommunity/>) about how to speak to your legislator about your issue and I think pain advocates might want to take the same approach and apply the same principles with public health folks. Because they don't have a lot of time, they like getting to the point quickly. So it's important to say what you have to say succinctly, to hit on the key messages, and to tailor your key message to their area of expertise.

Directors of Health Departments are very much involved in policy change – it's one of the major things that they do on a regular basis, they're in front of state legislators all the time – and so treating them the same way as you might a legislator is a good approach.

PB: If an advocate does arrange a meeting, do you think it's helpful to leave something behind and, if so, is it helpful to leave something like the CDC report? What kind of leave-behind would you suggest that people in the public health world would appreciate having?

LG: I think it would be good to leave something behind that's not a huge report but perhaps there's a summary or a key graph or table out of that report – there may be something else like that that lays out the impact of the particular pain issue they



FIRST PERSON ADVOCATE

want to focus on. Simple-to-read, succinct documents would be good to leave behind that you can tailor to the issue and the person you're talking to.

PB: Can you tell me more about what you're doing now that you have left CDC and how people can contact you should they want additional information??

LG: Strategic Health Concepts has been around for a long time – they've worked with over 100 different clients over the past 10 years, including virtually every state health department on health related issues including tobacco control, cancer and other chronic diseases. Karin Hohman is the President and I'm very pleased to be her new business partner.

In addition to working with government agencies we work with non-profit organizations like C-Change and the American Cancer Society, as well as a variety of for-profit corporations. We are focused on helping healthcare leaders with a number of issues, including strategic planning, organizational development, leadership development – essentially problem-solving and analysis. We assist organizations with special studies whether related to cancer, tobacco, emergency response, or other health issues. We also have a lot of experience in developing, implementing and evaluating programs. For example, we're working right now on developing a document and set of tools with support from C-Change that will lay out the access to cancer care issues for comprehensive cancer control programs and coalitions, to give them ideas, data, tools that they might use to address their own access issues.

Please feel free to have your readers contact me at leslie@shconcepts.com should they need any additional information.

PB: Thank you Leslie for your wonderful work on behalf of patients and caregivers.



IN THE SPOTLIGHT

Centers for Disease Control and Prevention (CDC) *Health, United States, 2006*

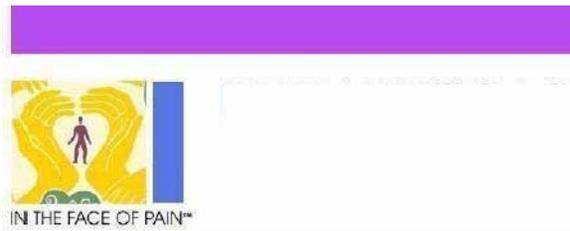
The 2006 Chartbook on Trends in the Health of Americans, released by the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics, focuses on selected determinants and measures of health. Although this is the 30th report in the Chartbook's history, the 2006 edition is the first to include a special feature on pain.

"We chose to focus on pain in this report because it is rarely discussed as a condition in and of itself – it is mostly viewed as a byproduct of another condition," said lead study author Amy Bernstein. "We also chose this topic because the associated costs of pain are posing a great burden on the health care system, and because there are great disparities among different population groups in terms of who suffer from pain."

The following is excerpted from the 2006 Chartbook's Highlights/Executive Summary, available at <http://www.cdc.gov/nchs/data/hus/hus06.pdf#highlights>

"Pain affects physical and mental functioning, and can profoundly affect quality of life. In addition to the direct costs of treating pain—including visits for diagnosis and treatment, drugs, therapies, and other medical costs—it can cause loss of productivity and concentration. Patterns of self-reported pain vary considerably by age, sex, race and ethnicity, and poverty.

- In 1999–2002, more than one-quarter of Americans (26%) 20 years of age and over reported that they had a problem with pain in the past 30 days that persisted for more than 24 hours.
- Nearly 60% of adults 65 years of age and over who reported pain lasting more than 24 hours stated that it lasted for one year or more compared with 37% of young adults 20–44 years of age who reported pain in 1999–2002.
- In 2004, more than one-quarter of adults 18 years of age and over reported experiencing **low back pain** in the past 3 months.
- In 2004, 15% of adults 18 years of age and over reported experiencing **migraine or severe headache** in the past 3 months. The percentage of young adults 18–44 years of age who reported migraine or severe headache was almost three times the percentage for adults 65 years of age and over.
- In 2004, almost one-third of adults 18 years of age and over and one-half of older adults 65 years of age and over reported joint pain, aching, or stiffness (excluding the back or neck) during the 30 days prior to interview. The knee was the site of joint pain most commonly reported in all age groups.



- In 2003, the percentage of adults 18 years of age and over who reported severe joint pain increased with age. Women were more likely to report severe joint pain than men (10% compared with 7%).
- In 2003–2004, 50% of ED visits for persons with a severe pain recorded had narcotic analgesic drugs prescribed, or provided during the visit. Among visits with severe pain recorded, those made by children under 18 years of age and adults 65 years of age and over were less likely than visits by persons in other age groups to have a narcotic drug provided in the ED.
- The percentage of adults who reported using a narcotic drug in the past month increased from 3.2% in 1988–1994 to 4.2% in 1999–2002 (age adjusted). This increase has been driven largely by an increase in narcotic drug use among white non-Hispanic women and women 45 years of age and over.
- Between 1992–1993 and 2003–2004, the hospital discharge rate for **knee replacement** among adults 65 years of age and over increased by nearly 90%, from 39 to 73 discharges per 10,000 persons. Knee replacement was more common among older women than older men.
- Between 1992–1993 and 2003–2004, the hospital discharge rate for **hip replacement** among adults 65 years of age and over (excluding those performed for fractured hips) increased almost 60% from 25 to 40 discharges per 10,000 population. Nonfracture hip replacement rates were similar among older men and women.
- In 2002–2003, 3.5% of adults 18 years of age and over had ambulatory care visits or prescribed medicine purchases to treat **migraines or other types of headache** during the year. Their **average annual expenditure** for these treatments was \$566 (in 2003 dollars).
- In 2004, 28% of adults 18 years of age and over **with low back pain** in the past 3 months said they had a **limitation of activity** caused by a chronic condition, compared with 10% of adults who did not report recent low back pain. People with recent low back pain were almost five times as likely to have **serious psychological distress** as people without recent low back pain."

Health, United States, 2006, With Chartbook on Trends in the Health of Americans With Special Feature on Pain. 559 pp. (PHS) 2006-1232. GPO stock number is 017-022-01602-8. This report may be purchased from the [Government Printing Office](http://www.gpo.gov) at <http://www.cdc.gov/nchs/hus.htm>



HEALTHCARE PROFESSIONAL ALLIANCE OUTREACH

By Kristi R. Dover, PharmD

Addressing the Public Health Issue of Pain in the United States

The recent Centers for Disease Control and Prevention special report on pain underscores the growing need for better approaches to pain care. <http://www.cdc.gov>

Another US government agency, the Agency for Healthcare Research and Quality provides mechanisms for systematically addressing knowledge gaps that limit current approaches to treating pain. Below is a description of the latest developments in the agency's research programs and opportunities for engaging the process.

Recommend Future AHRQ Research Projects and Comment on Draft Reports

The Agency for Healthcare Research and Quality (AHRQ) is offering new opportunities to provide input on the direction of current and future research projects at the agency.

In late 2005, AHRQ launched the Effective Health Care Program. The goals of the program include assimilation of existing evidence and generation of new scientific data to support evidence-based decisions and optimal clinical outcomes. Determining the comparative effectiveness of various pharmacologic and non-pharmacologic treatment options is the primary research focus. The program employs comparative effectiveness reviews (CERs) from the agency's Evidence-based Practice Centers (EPC) Program and generates new data through its DEcIDE Research Network. The findings are then used to develop resources for both clinicians and patients. For more information on DEcIDE, see the next topic heading.

In January, the Effective Health Care Program posted the new clinician guide, *Choosing Non-Opioid Analgesics for Osteoarthritis*. A companion consumer guide is also available on the AHRQ website.

The first projects of the Effective Health Care Program focused on 10 priority conditions that were identified through public testimony and a steering committee representing AHRQ, Centers for Medicare & Medicaid Services, the Food and Drug



HEALTHCARE PROFESSIONAL ALLIANCE OUTREACH

Administration and the Health & Human Services Office of the Secretary. Conditions were chosen with the needs of the Medicare patient population in mind.

This year, the program launched a new web-based form which allows clinicians and organizations to nominate additional priority conditions for Comparative Effectiveness Review. A corresponding webpage outlines information needed for condition nomination and the parameters used during the selection process. Program plans include widening the priority conditions category to include the medical needs of the Medicaid and SCHIP¹ patient populations, in addition to that of the Medicare population. Collectively, these patient categories represent a sizeable portion of the US population.

AHRQ's website offers extensive information regarding the progress of current research projects being conducted by the Effective Health Care Program as well as a means for posting comments regarding draft reports published on the site. <http://effectivehealthcare.ahrq.gov/>

Additional research and reports are available in the EPC section of the AHRQ website. <http://www.ahrq.gov/clinic.epcix.htm>

The Agency for Healthcare Research and Quality is a significant national resource which first produced pain-related clinical references 15 years ago. Future contributions may be guided by input from the healthcare professionals who struggle to provide optimal pain care in the presence of current knowledge gaps.

DEcIDE Research Network

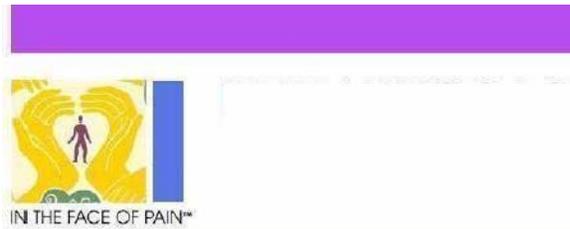
Developing Evidence to Inform Decisions about Effectiveness

The DEcIDE Network is a group of 13 research centers brought together by AHRQ, in 2005. The Network employs electronic health information databases to conduct rapid turnaround research examining comparative clinical effectiveness, safety and clinical outcomes. This allows for examination of research questions where randomized controlled trials cannot be utilized or may be complicated by ethical debate. For more information on the network, view the downloadable slide presentation available on the AHRQ website.



Dr. Dover is an Area Director in Purdue's Medical Liaison Department where her focus is Alliance Outreach Initiatives. Her pharmacy practice experience includes post-doctoral oncology residency, faculty committee appointment, inpatient oncology, ambulatory pain clinic and clinical research. Dr. Dover's office is based in North Texas.

¹ SCHIP – State Children's Health Insurance Program



PAIN COMMUNITY CONNECTION

By Kimberley Tiller, RN, MPH



Kimberley Tiller, RN,
MPH, Assistant
Director, Healthcare
Alliance Development

Patient Alliance for Neuroendocrineimmune Disorders Organization for Research and Advocacy Inc. (P.A.N.D.O.R.A.)

P.A.N.D.O.R.A. Inc. mission is to be one strong voice for many© . . .

- Creating and raising awareness
- Advocating for quality of life Issues
- Providing support and educational resources
- Establishing partnerships in our worldwide community
- Supporting scientific research
- Encouraging creation of empowerment groups
- Organizing educational conferences

These goals will assist patients with Neuroendocrineimmune Disorders and their families in leading productive and fulfilling lives.

In the fall of 1998, Marly Silverman (founder of P.A.N.D.O.R.A.) was diagnosed with chronic fatigue syndrome (CFS) and fibromyalgia (FM). Her year long personal health struggles with these illnesses made her realize the need for a well organized patient advocacy effort to ensure persons with chronic fatigue syndrome and fibromyalgia would fare better in their local communities. Her earlier advocacy efforts led her to founding P.A.N.D.O.R.A. in June 2002. P.A.N.D.O.R.A. is a 501 c 3 charitable organization that was built on hope, is strong on advocacy and works tirelessly to find a cure for neuroendocrineimmune disorders such as CFS, FM, Gulf War syndrome and multiple chemical sensitivities.

I asked Marly how her role as an advocate evolved and this was her answer:

"I started in the advocacy movement shortly after I was diagnosed with CFS/FM. In March 2000 I attended an advocacy summit in DC sponsored by the Arthritis Foundation which highlighted fibromyalgia. Shortly after that I connected with an informal group for FM and CFS in Plantation. I then attended the first National Fibromyalgia Association F.A.M.E. conference in Los Angeles in 2000 and I realized that we needed to be more organized in Florida.

"In 2002 I co-founded a group at Memorial Hospital West, Pembroke Pines, Florida, with Dawn Broksch a former and founding board member of P.A.N.D.O.R.A. With this group we sponsored and hosted our very first annual conference in 2001. Once P.A.N.D.O.R.A. was incepted, we sponsored annual conferences in 2002, 2003 and in 2004. Hurricane Wilma cancelled our 2005 conference, but we went right back to "work" on 2006 and most recently the one in January 2007.



PAIN COMMUNITY CONNECTION

"In 2000, I was twice featured in the Sun-Sentinel in regards to creating awareness for CFS/FM and as the recipient of the Millennium Award from Memorial Hospital West. Other local community newspapers also profiled the work of P.A.N.D.O.R.A. In 2002, I was interviewed by the local Fox – Chanel 7 Affiliate that resulted on a health segment titled- 'Fibromyalgia, An Invisible Illness.'

"I attended the first Leaders Against Pain seminar hosted by the NFA in 2005. I fell in love with the advocacy program lay out and the seed was planted. Right there inspired by this program, I knew I had to develop an outstanding and more organized advocacy program for P.A.N.D.O.R.A., which finally happened in January 10-14, 2007 during the International Association for Chronic Fatigue Syndrome Bi-Annual Conference hosted by P.A.N.D.O.R.A. in Fort Lauderdale, Florida

"Meanwhile, Rebecca Artman and I continued to "lobby" on behalf of P.A.N.D.O.R.A. on Capitol Hill and presented testimonies to the CFS to the CFS Advisory Committee in Washington DC. We represented P.A.N.D.O.R.A. on meetings sponsored by the Florida Arthritis Partnership, attended yearly lobby days with the CFIDS Association, and have joined the Florida Pain Initiative as well as the Power Over Pain program with the American Pain Foundation. Our grass roots initiatives included the ongoing "Pediatric Pennies" campaign for CFS and FM pediatrics, the Florida Neuroendocrineimmune Institute (Center of Excellence), awareness programs like our international Video contest for CFS and FM and the P.A.N.D.O.R.A.'s Box Art Auction Project. and much more.

"Since then I have attended 4 advocacy leadership training programs, including one with the American Pain Foundation, APF, and the last one being the Advocates Extraordinaire! ©Advocacy and Leadership Training – one that I participated and graduated to as one of the program guest speakers. One golden and proud moment for or P.A.N.D.O.R.A. culminated in the appointment of Rebecca Artman to the CFS Advisory Committee, a congressional committee under the Secretary of Health. I am very proud of her accomplishments!

"Although, I had some media exposure before I attended the first advocacy and media training, the additional and specific tools I learned have given me additional skills to keep me focused, to be more organized, and it has provided me with additional assertiveness, poise and confidence. It has greatly improved the overall results of our advocacy program, which have added additional momentum regarding P.A.N.D.O.R.A. congressional grass roots initiatives.

"If you go to <http://www.pandoranet.info/press.html> , you will see some of the most recent media exposure of P.A.N.D.O.R.A. One article written by Nancy McVicar, a health reporter from the "Sun-Sentinel" was actually published in 33 cities in the US. If you click on <http://www.pandoranet.info/advocacyactionalerts.html> and or <http://www.pandoranet.info/advocacy.html> you will become familiar with our grass roots initiatives.



PAIN COMMUNITY CONNECTION

"In the media, the most recent edition of *Miami Living Magazine* has an article on Dr. Nancy Klimas with our picture, and it lists P.A.N.D.O.R.A. as a resource for CFS and FM. This magazine has a local distribution in Miami Dade, Broward and Palm Beach Counties as well as in Europe.

"We have also taken the first steps to begin a community outreach program in the local Hispanic community with the aid of the Hispanic Media with articles in the "El Nuevo Herald", (the Spanish publication of the "Miami Herald" as well as a segment in the show "Al Rojo Vivo con Maria Celeste" on the cable network Telemundo 51 and an interview with Canal 41 (a local cable channel in Miami Dade County).

"Two weeks ago, I shared my personal story with Melanie Haiken, a health writer for *Health* magazine (www.health.com) and we hope it will be published soon. I am also hoping that a major cable station in the US might be interested in doing a segment on P.A.N.D.O.R.A. on their morning show. So stay tune!

"All of this could not have happened if I did not have some great 'mentoring.' Now it is my turn to mentor others."

Marly and Rebecca Artman, who is currently serving on P.A.N.D.O.R.A.'s board in an advisory capacity due to her new position as one of the member of the congressional Chronic Fatigue Syndrome Advisory Committee in Washington, D.C., have worked tirelessly to build a team to fulfill P.A.N.D.O.R.A.'s mission. I had the pleasure of experiencing this firsthand when I attended the P.A.N.D.O.R.A./IACFS (International Association for Chronic Fatigue Syndrome) 8th international bi-annual patient/medical conference in Fort Lauderdale, Florida from Jan 10-14, 2007.



From left to right: Marly Silverman and Rebecca Artman.

The main purpose of the program 2007 Advocates Extraordinaire! © Advocacy and Leadership Training was to teach, empower, and motivate patients, caregivers and friends and to become "agents for change".

All presentations were designed exclusively to better understand the difficult health issues persons with CFS/FM are faced with daily. Advocacy and leadership training by professionals in the area of political lobbying, marketing, media (TV, newspapers, and radio) were presented. Advocates had the opportunity

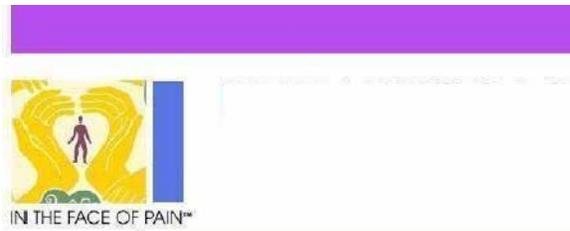


PAIN COMMUNITY CONNECTION

to attend a session on “how to” speak, write, and address congressional representatives in state and federal legislatures and how to contact members of the media in order to create awareness about chronic fatigue syndrome, fibromyalgia and related conditions. It included being interviewed “live” on camera with feedback from media professionals and from the audience.

Speakers for this empowering patient conference included the IACFS Board, nationally and internationally recognized scientific researchers in various CFS/FM healthcare fields, officials from governmental health agencies, and nationally recognized professionals in fields relevant to the CFS/FM patient community.

P.A.N.D.O.R.A. is a great resource for the thousands of people around the world who suffer from CFS/FM! For more information about P.A.N.D.O.R.A please call 954-783-6771 or visit their website at: www.pandoranet.info



PAIN COMMUNITY CONNECTION

American Pharmacists Association (APhA)

About APhA

The American Pharmacists Association, founded in 1852 as the American Pharmaceutical Association, represents more than 60,000 practicing pharmacists, pharmaceutical scientists, student pharmacists, pharmacy technicians, and others interested in advancing the profession. APhA, dedicated to helping all pharmacists improve medication use and advance patient care, is the first-established and largest association of pharmacists in the United States.

The Association is a leader in providing professional information and education for pharmacists and an advocate for improved health of the American public through the provision of comprehensive pharmaceutical care. APhA has also been very active in the pain management arena.

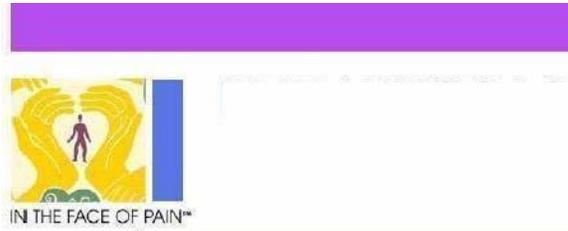
Vision:

APhA is the organization whose members are recognized in society as essential in all patient care settings for optimal medication use that improves health, wellness, and quality of life.

Major Initiatives:

APhA offers a multitude of pain management materials through their pain management partnership activities. For more information please visit the following link:

<http://www.aphanet.org/AM/Template.cfm?Section=Search&template=/Search/SearchDisplay.cfm&Display=1&Criteria=pain%20AND%20management&Interests=&Sections=&DocTypes=&SearchComponents=CM&StartDate=&EndDate=&Summary=Y&Refresh=0>



PAIN COMMUNITY CONNECTION

Medication Therapy Management Programs (MTM): Although pharmacists routinely provide patient education, they are finally recognized providers of MTM services. This service has tremendous potential to enhance patient care in the community. Please visit the following link to learn more about MTM programs.

http://www.aphanet.org/AM/Template.cfm?Section=Search§ion=MTM_Services&template=/CM/ContentDisplay.cfm&ContentFileID=1376

Annual Meeting and Exposition

Attend APhA2007—held March 16-19, 2007 at the Georgia World Congress Center in Atlanta. Headquarter hotel is the Hyatt Atlanta.
[Registration, housing, and tour reservations now open!](#)

Contact Information:

American Pharmacists Association
1100 15th Street NW, Suite 400
Washington, DC 20005-1707
1-800-237-APhA (2742)

<http://www.aphanet.org>

<http://www.pharmacist.com>



CAREGIVER BOOKBAG

National Comprehensive Cancer Control Program

For more information about the CDC's National Comprehensive Cancer Control Program, please click links below to abstracted articles from a Special Supplement. *Cancer Causes and Control* (Vol. 16, October 2005).

[In conclusion: the promise of comprehensive cancer control.](#)

Cancer Causes Control. 2005 Oct;16 Suppl 1:79-88.

[The evaluation of comprehensive cancer control efforts: useful techniques and unique requirements.](#)

Cancer Causes Control. 2005 Oct;16 Suppl 1:69-78.

[Examining advocacy and comprehensive cancer control.](#)

Cancer Causes Control. 2005 Oct;16 Suppl 1:61-8.

[Cancer survivorship: a new challenge in comprehensive cancer control.](#)

Cancer Causes Control. 2005 Oct;16 Suppl 1:51-9.

[Cancer-related disparities: weathering the perfect storm through comprehensive cancer control approaches.](#)

Cancer Causes Control. 2005 Oct;16 Suppl 1:41-50.

[Translating research into improved outcomes in comprehensive cancer control.](#)

Cancer Causes Control. 2005 Oct;16 Suppl 1:27-40. Review.

[Using data to motivate action: the need for high quality, an effective presentation, and an action context for decision-making.](#)

Cancer Causes Control. 2005 Oct;16 Suppl 1:15-25.

[Collaborating to conquer cancer: a comprehensive approach to cancer control.](#)

Cancer Causes Control. 2005 Oct;16 Suppl 1:3-14.

Kaiser Family Foundation :Live Webcast – Today's Topics in Health Disparities

On Friday, March 2, 2007 at 1:00 p.m. ET, the Kaiser Family Foundation will launch a new series of live webcasts addressing issues relating to health and health care disparities in the U.S., featuring panel of experts tackling current issues and answering questions from viewers. Join us for the first discussion in the series, "Is the U.S. Making Progress in Reducing Disparities in Health Care Access and Quality?" Send questions to TodayTopics@kaisernetwork.org.

For Information, visit the Kaiser Family Foundaiton website at:
http://kaisernetwork.org/daily_reports/rep_disparities.cfm



CAREGIVER BOOKBAG

Amputee Coalition of America's Online Library

The Amputee Coalition of America's National Limb Loss Information Center (NLLIC) houses a comprehensive library collection pertaining to limb loss. The NLLIC contains full-text articles, research abstracts, training videos, books, inspirational stories, online resources and organizations. The online library catalog has recently been redesigned with users' needs in mind. State-of-the-art searching capabilities allow users to narrow their search and get better results:

- Choose from either a Basic Search for quick searching or an Advanced Search for narrowed results.
- Download and e-mail search results.
- Click *Common Keywords* for automatic search.
- Search ACA publications only with just the click of a button.

Visit www.amputee-coalition.org/catalog for more information.

Cancer Survivorship: Living With, Through & Beyond Cancer

CancerCare, in collaboration with the National Cancer Institute: Office of Cancer Survivorship, Office of Education and Special Initiatives and Cancer Information Service, Lance Armstrong Foundation, Intercultural Cancer Council, Living Beyond Breast Cancer and National Coalition for Cancer Survivorship, will present a three-part telephone education workshop series, beginning April 17. This free series offers cancer survivors, their families, friends and health care professionals practical information to help them cope with concerns and issues that arise after treatment ends.

Part I, which takes place on April 17, is entitled **Neuropathy and Joint Aches: New Post-Treatment Challenges**. The faculty for this program include: Julie Silver, MD, Cancer Survivor, Assistant Professor, Department of Physical Medicine and Rehabilitation, Harvard Medical School and Nessa Coyle, NP, PhD, FAAN, Pain and Palliative Care Service, Department of Neurology, Memorial Sloan-Kettering Cancer Center.

Part II, **My Treatment is Over: Why Do I Feel So Alone and Sad?** will take place on May 15.

Part III, **Finding Hope and Meaning After Treatment**, will take place on June 19.

All of the teleconferences are scheduled from 1:30 to 2:30 p.m., Eastern Time.

These workshops are free - no phone charges apply. However, pre-registration is required. To register, simply go to the CancerCare website, www.cancercare.org/TEW



ADVOCACY IN ACTION



National Directory of Non-Profit Community Based Cancer Control Organizations

Enrollment Survey



The Intercultural Cancer Council (ICC) is creating a national directory of non-profit community based organizations (CBOs) that work to reduce the unequal burden of cancer among minorities and the medically underserved. This directory will facilitate national, regional, and local efforts promoting comprehensive cancer control.

If you work with a non-profit CBO involved in cancer control, please take a few moments to provide information about your organization using the online survey form at:

<https://websurveyor.net/wsb.dll/16315/ICC-NN-CBO-Survey200701.htm>

Pending approval by an authorized member of the organization, ICC will include the organization in our National Directory of Non-Profit Community Based Cancer Control Organizations. This Directory will be posted on the ICC Website.

National Cancer Institute's Teleconference Series

The National Cancer Institute's (NCI) Office of Liaison Activities (OLA) is continuing its "Understanding NCI" teleconference series again this year. The monthly teleconference is designed to inform the advocacy community and the general public about NCI research and scientific initiatives, as well as featuring an advocate's perspective on the topic. The Schedule of upcoming teleconferences is below:

March 7, 2007 from 1:00 p.m. - 2:00 p.m. (EST)

How the Patient Navigator Program Helps Cancer Patients

Topic: NCI's Patient Navigator Research Program. Featuring Dr. Roland Garcia, Program Director, Patient Navigator Research Program, Center to Reduce Cancer Health Disparities, NCI and Dr. Beth Calhoun, Co-Principal Investigator, Patient Navigator Research Program, Chicago Program

*USA Toll-Free: 1-800-857-6584
Passcode: PNP*

Through April 7, 2007 toll-free playback will be available at 1-800-873-2035.



**April 24, 2007 from 1:00 p.m. - 2:00 p.m. (EST)
Resources for Understanding Cancer Risk**

Topic: How to understand your risk for cancer. Prior to the call please view NCI's website: [Cancer Risk - Understanding the Puzzle](#). Featuring Ms. Felicia Solomon, Public Health Advisor, [Office of Education and Special Initiatives](#), NCI and Dr. Mitchell Gail, Chief, Senior Investigator, [Biostatistics Branch](#), Division of Cancer Epidemiology and Genetics, NCI

*USA Toll-Free: 1-800-857-6584
Passcode: RISK*

Through May 24, 2007 toll-free playback will be available at 1-866-434-5268.

**Thursday, May 17, 2007 from 2:00 p.m. - 3:00 p.m. (EST)
NCI's Intramural Clinical Trials Program: A National Resource for Patients**

Topic: How to take part in [clinical trials at NCI](#). Featuring Dr. Lee J. Helman, Scientific Director for Clinical Research, [Center for Cancer Research](#), NCI

*USA Toll-Free: 1-800-857-6584
Passcode: CCR*

Through June 17, 2007 toll-free playback will be available at 1-866-442-1776.

**Tuesday, June 5, 2007 from 1:00 p.m. - 2:00 p.m. (EST)
NCI Cancer Centers Program**

Topic: [NCI-Designated Cancer Centers](#). Featuring Dr. Linda Weiss, Chief, [Cancer Centers Branch](#), NCI

*USA Toll-Free: 1-800-857-6584
Passcode: CENTER*

Through July 5, 2007 toll-free playback will be available at 1-800-839-2204.

For more information, visit the NCI website at:
<http://ola.cancer.gov/activities/teleconferences>