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PAIN ADVOCACY COMMUNITY

An E-Newsletter Connecting Those Who Care

SEPTEMBER 2010 PAIN AWARENESS MONTH

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PHOTOGRAPH BY DONALD FOSTER

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FROM THE EDITOR

We join our colleagues working to Conquer Pain Together this September Pain Awareness Month. Congratulations on all your efforts to raise awareness to ensure that people with pain receive appropriate, effective and dignified care!

This summer I had a milestone birthday... no it wasn't 21. There is nothing like getting an AARP card in the mail to make you stop and reflect on what you have experienced to date in your life, and what you yet hope to witness. There are so many experiences and people I am grateful for in my life. I consider myself blessed.

Speaking of being blessed, I am writing this on August 3, 2010, on an early morning flight from New York to Kansas City where I am going to hear one of my mentors and heroes, Kathy Foley, MD, give the Center for Practical Bioethics' Rosemary Flannigan lecture. Kathy is a pioneer and a champion for pain management and palliative care. She is fierce, compassionate, brilliant, and strategic. I am grateful for the encouragement and opportunities for growth that she has provided for me over the years.



Myra Christopher (left), Kathy Foley, MD (center), Pamela Bennett (right)

Another innovator, agitator, convener and role model of mine is Myra Christopher, the CEO for the Center of Practical Bioethics. Myra made a promise to her dying mother, and I know her mother would be proud of all she has accomplished and of those she has mentored along the way. I admire Myra's passion, her grace, and her unwillingness to take "no" for an answer. She challenges me to think differently and to consider and respect all points of view even though I may not agree. The lessons at her feet have served me well over the years. These two women have made and changed history.



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Karen Nichols, DO, (pictured at right) is another woman who made history. On July 17, 2010, Karen became the 114th President of the American Osteopathic Association (AOA), and the first woman to be President of the AOA. It was a joy and an honor to be present as she took her oath of office and was presented with a baton (see photo). This baton embodies Karen's philosophy and leadership style built on mentoring and teamwork. The accolades throughout the three days surrounding the ceremony were not only from her peers, but from state legislators, members of Congress, Cabinet members, and even the President of the United States.



*Karen Nichols, DO, President of the American Osteopathic Association (AOA)
Photo: Dan McCann, AOA Staff Editor*



Dr. Regina Benjamin (back) and Caroline Meyers (front)

medicine. She could hardly believe what she was hearing. A few minutes later, she saw Dr. Benjamin and grinned from ear to ear. I asked her if she would like to meet her and she gave a resounding YES! Surgeon General Benjamin was so gracious and kind, getting on eye level with Caroline before asking her if she wanted to become a doctor. Caroline said, "No, I think a veterinarian". Dr. Benjamin laughed and said, "Caroline, you will make a fantastic veterinarian, doctor, or whatever you choose to become." The moment was captured in the photo above!

During the inauguration ceremony, our United States Surgeon General, Dr. Regina Benjamin, shared some thoughts about Karen and also about healthcare reform. Dr. Benjamin is an amazing leader in her own right, and also has a delicious sense of humor. During her comments she shared how both she and Karen were now "Chicks in Charge"! Sitting with me during the ceremonies was my colleague and friend Carla Duryee, her sister, Kelly Meyers, and her 10-year old niece, Caroline Meyers. I turned to Caroline during the ceremony and said to her, "Today, you are a witness to history." Caroline smiled.

After the ceremony there was a small reception and we shared with Caroline the significance of what she had just witnessed. We explained that one of the reasons this was historic was that it was not too long ago that women were unable to vote or practice



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Caroline was thrilled and I believe that moment will stay with her the rest of her life. These two amazing women are excellent role models. My only wish was that my daughter would have been old enough to have attended and appreciated what she would have witnessed. Then again...I don't want her to grow up too quickly!

We all need mentors, those who inspire us, challenge us, and encourage us. We all can make a difference in the lives of others. Each of us is unique and has special gifts and talents. We need to appreciate, validate, and celebrate the individuality we each bring.

Speaking of those who inspire, challenge and encourage us, I hope you enjoy the columns this month from my colleagues. Dr. Kristi Dover's column focuses on the regulatory environment and pain care, and Gina Barbarotto brings a new twist to Pain Awareness Month with her ingenious crossword puzzle. Our summer intern, Jessica Belardo shares her parting thoughts (Thank you Jessica for all your hard work this summer!). Last but not least, Kimberley Tiller shares the inspiration surrounding Reflex Sympathetic Dystrophy Syndrome Association's "Achilles Walk for Hope & Possibility". This column is a shining example of the difference that one person can make.

Much has been accomplished since the first September Pain Awareness Month, yet there is much left to do. It will take those skills that Karen Nichols, DO, embodies – leadership and teamwork, as well as each one of us using our unique gifts and talents. As Aristotle says, "Where your talents and the needs of the world cross, lies your calling." I believe that if you are reading this e-newsletter today, that you are called to be part of the solution to ensure that people with pain no longer needlessly suffer in silence. Thank you for your caring and your service to others.

In closing, a special thank you my mentors, and also to Caroline Meyers. Caroline, you inspire me with your curiosity and sense of wonder...I encourage you to never lose that as you grow. Always remember Surgeon Benjamin's words to you...you can be and do whatever you set your mind on and work hard to achieve. Most importantly, have fun along the way...life is good!

Warmest regards-

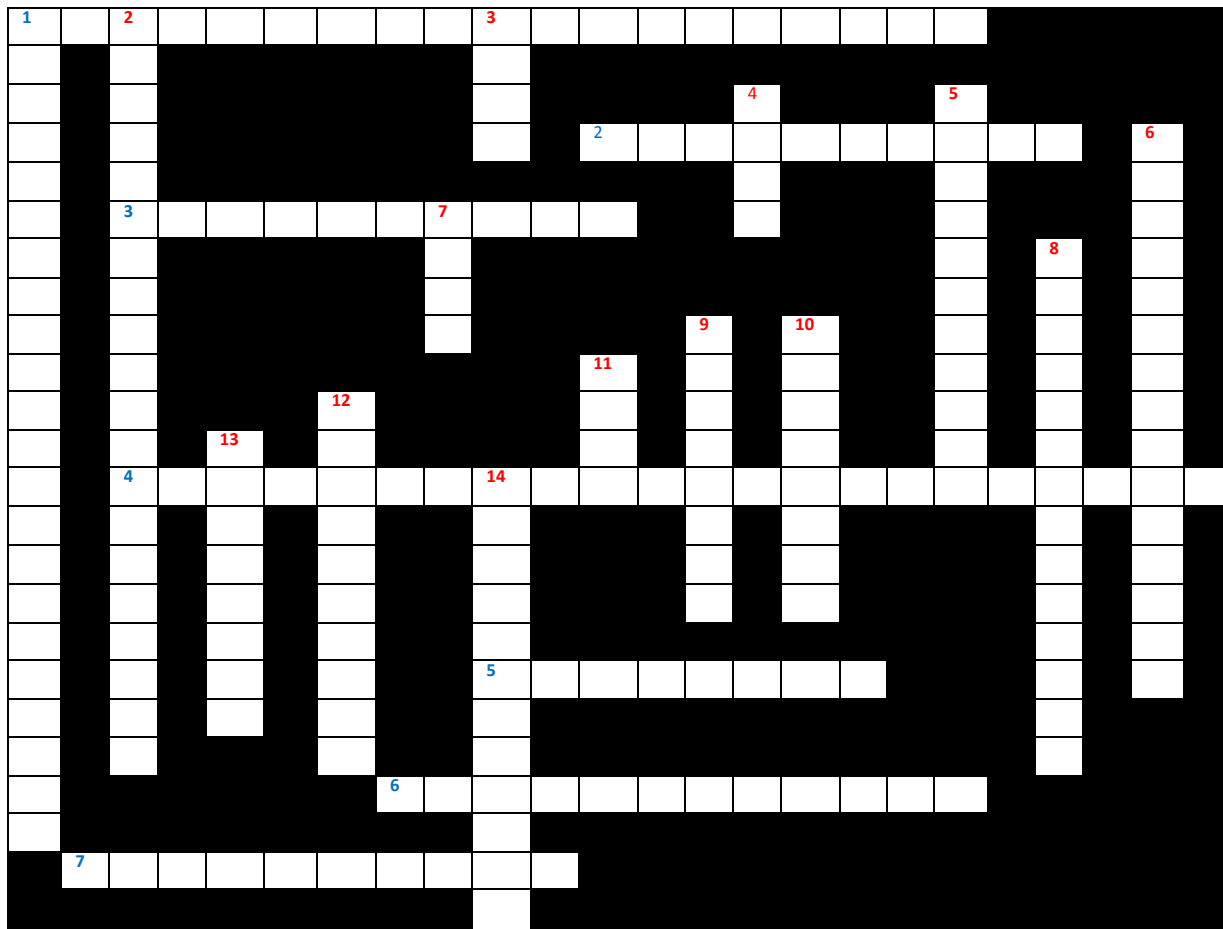
Pamela



By Gina M. Barbarotto, MS, MBA, Associate Director, Healthcare Alliance Development

In honor of Pain Awareness Month and to respectfully acknowledge those individuals who live fully despite their pain, I thought it might be interesting to recognize several common pain conditions through a unique (and maybe enjoyable?) activity. Test your knowledge of some common pain conditions in the crossword puzzle below. Answers are on the final NETWORK page (no cheating). 😊

Pain Awareness Month Crossword Puzzle





Pain Awareness Month Crossword Puzzle

ACROSS

1. This chronic pain condition affects the nerve that carries sensation from your face to your brain; mild stimulation of your face may trigger a jolt of excruciating pain.
2. A form of arthritis caused when the body's own defense system don't work properly; affects joints, bones and may also affect internal organs.
3. In this inherited blood disorder, red blood cells are destroyed rapidly causing anemia, jaundice and the formation of gallstones.
4. This complicated disorder is characterized by extreme exhaustion that may worsen with physical or mental activity, but doesn't improve with rest.
5. This vascular pain condition in the head is characterized by pulsating and may last from 4 to 72 hours; symptoms include nausea, vomiting, increased sensitivity to light, and increased sensitivity to sound.
6. A rare genetic disorder of the connective tissue that causes joints to be hyper-flexible; this syndrome can vary from mild to life-threatening.
7. A chronic condition of the female genital organs; affects approximately 6 million women.

DOWN

1. A condition involving inflammation in and around this joint; often leads to pain in the joint and/or facial muscles and may cause difficulty with opening/closing and chewing.
2. Of the estimated 1 million Americans with this urinary bladder condition, up to 90% are women; also called "painful bladder syndrome."
3. This disease has an estimated 225,000+ new cases each year and is transmitted by the bite of an infected deer tick.
4. This type of pain can be one of the most intense and prolonged types of pain; however, in the most severe cases, it may be painless.
5. This common musculoskeletal disorder affects 80% of people at some point in their lives.
6. Each year, approximately 185,000 Americans undergo amputation of a limb; this pain often accompanies the loss of a limb.
7. Typical features of this chronic pain condition include dramatic changes in the color and temperature of the skin over the affected limb or body part, accompanied by intense burning pain, skin sensitivity, sweating, and swelling (abbreviation; also called RSD).
8. The most common form of arthritis; usually develops with age and most often affects the fingers, knees, and hips.
9. This infection invades the nerve and the area of skin around it; caused by the same virus that causes chickenpox.
10. High blood sugar can injure nerve fibers throughout the body, but this neuropathy most often damages nerves in the legs and feet, sometimes causing altered perception of pain.



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THE NETWORK

11. A type of arthritis caused by crystals that build up in the joints causing pain.
12. This type of cancer is sometimes called a "silent killer" because it may often grow without any symptoms at first; in 80% of patients the tumor has already spread and cannot be completely removed at the time of diagnosis.
13. Estimated deaths from this type of male cancer in the United States in 2010 are 32,050, according to the NIH.
14. A chronic disorder characterized by widespread muscle pain, fatigue, and multiple tender points.

Visit the *In the Face of Pain*® website (www.IntheFaceofPain.com) and the links to organizations below to find out more information about the conditions in the crossword puzzle you successfully completed above.

- Reflex Sympathetic Dystrophy Syndrome Association: www.rsds.org
- Arthritis Foundation: www.arthritis.org
- American College of Rheumatology: www.rheumatology.org
- Sickle Cell Disease Association of America, Inc.: www.sicklecelldisease.org
- Chronic Fatigue and Immune Dysfunction Syndrome Association of America: www.cfids.org
- MAGNUM, The National Migraine Association: www.migraines.org
- Ehlers-Danlos Syndrome Network C.A.R.E.S.: www.ehlersdanlosnetwork.org
- Ehlers-Danlos National Foundation: www.ednf.org
- National Vulvodynia Foundation: <http://www.nva.org>
- The TMJ Association: www.tmj.org
- Interstitial Cystitis Association: www.ichelp.org
- American Lyme Disease Foundation: www.aldf.com
- American Pain Foundation: www.painfoundation.org
- American Chronic Pain Association: www.theacpa.org
- Disabled American Veterans: www.dav.org
- Pancreatic Cancer Action Network: www.pancan.org
- Prostate Net: www.prostate-online.com
- National Fibromyalgia Association: www.fmaware.org

Let's keep the momentum of Pain Awareness Month moving forward long after September has past. Let's "Conquer Pain Together" one day at a time...and through many loud voices!



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HEALTHCARE PROFESSIONAL ALLIANCE
OUTREACH



By Kristi R. Dover, PharmD

Dr. Dover is a Senior 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.

Can we recognize September as *Pain Awareness Month* without acknowledging the elephant in the room? You might ask which elephant? The answer may depend on your practice setting, or maybe not. Until the dust settles, it will be difficult to tell the actual size of the herd and whether it's elephants or woolly mammoths.

Allegories aside, the regulatory environment of pain care is in a state of evolution. In the meantime, there are patients in need of care.

Daily Practice Resources & Professional Development

The two DVDs, listed below, were recently developed to inform healthcare professionals about the health benefits of integrative therapies as presented from a scientific, medical perspective. They are available free of charge to U.S. based healthcare professionals. Copies can be ordered via Purdue's Medical Education Resource Catalog Online at: www.PurduePharmaMedEdResources.com

Harmony in Motion: The Science of Tai Chi

Looking for a practical, evidence-based bridge between Eastern and Western therapeutic approaches?

The physical health benefits found in the ancient martial art of tai chi have been evident for centuries. Only recently, however, have the medical underpinnings, rationale and particular techniques of the practice been subjected to the clear lens of science.

Stillness in Thought: The Science of Meditation

Are you seeking ways to deepen self-understanding and enhance spiritual awareness?



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Recent ground-breaking studies have revealed meditation to be a proven stress-reduction and therapeutic strategy. This program will investigate the growing body of evidence supporting the practice of meditation.

Calls for Comment from FDA and DEA

REMS Comment Period

The Food and Drug Administration (FDA) public comment period is open until October 19, 2010 Available online at:

<http://www.regulations.gov/search/Regs/home.html#documentDetail?R=0900006480a44cce>

Comment Period Closed for Dispensing of Controlled Substances to Residents at Long Term Care Facilities

While the comment period for the DEA ended August 30th, this continues to be a topic of interest for health care professionals and patient caregivers alike. Stay tuned...

✓ Relevant Readings

Effect of Telecare Management on Pain and Depression in Patients with Cancer: A Randomized Trial.

Kroenke K, Theobald D, Wu J, Norton K, Morrison G, Carpenter J, Tu W. *JAMA*. 2010 Jul 14;304(2):163-71.

Gender Differences in the Correlation Between Symptom and Radiographic Severity in Patients with Knee Osteoarthritis.

Cho HJ, Chang CB, Yoo JH, Kim SJ, Kim TK. *Clin Orthop Relat Res*. 2010 Jul;468(7):1749-58.

Effect of Glucosamine on Pain-Related Disability in Patients with Chronic Low Back Pain and Degenerative Lumbar Osteoarthritis: A Randomized Controlled Trial.

Wilkens P, Scheel IB, Grundnes O, Hellum C, Storheim K. *JAMA*. 2010 Jul 7;304(1):45-52.

Comment in:

Glucosamine and the Ongoing Enigma of Chronic Low Back Pain

Avins AL. *JAMA*. 2010 Jul 7;304(1):93-4.

Supplementing Relaxation and Music for Pain after Surgery

Good M, Albert JM, Anderson GC, Wotman S, Cong X, Lane D, Ahn S. *Nurs Res*. 2010 Jul-Aug;59(4):259-69.



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PAIN COMMUNITY CONNECTION



By Kimberley Tiller, RN, MPH, Associate Director, Healthcare Alliance Development

Although September is Pain Awareness Month and most of us in the “Pain” world make a special effort to get the message of the need for safe and appropriate pain management out in the community, the reality is that many pain advocates work tirelessly all year long. This month I want to bring attention to the Reflex Sympathetic Dystrophy Syndrome Association (RSDSA) and one of their advocacy efforts.

Team RSDSA has participated in the “Achilles Walk for Hope & Possibility” for six years, and the past three years have seen tremendous growth in participation and fundraising. This year, through social media, word of mouth, as well as traditional means, they recruited almost 300 participants—100 more than last year—who were physically present in addition to 165 “virtual walkers.” The virtual participants, who purchase a team T-shirt and celebrate the walk any way they can, were spread out all over the world, but they were together in spirit. Some walked 5K, others walked to the end of their driveways, while others wore the t-shirt to show their support.

The essence of the event was captured beautifully by Mary Beth Kenny Ludington, Patient Representative, and Vice President of the RSDSA Board of Directors. Here are her words:

“On the beautiful, bright Sunday morning of June 27, 2010, I was in Central Park for the aptly titled ‘Achilles Walk for Hope and Possibility.’ The air literally seemed to vibrate with the energy of more than 6,000 participants, well-wishers, and volunteers. This was the Reflex Sympathetic Dystrophy Syndrome Association’s (RSDSA) sixth time participating in this inspiring event. At nearly 300 people strong, ‘Team RSDSA’ was ready to spread awareness of complex regional pain syndrome (CRPS) and raise funds to support RSDSA’s mission.

“Achilles International states that walk “celebrates life, community, achievement and the power of the human spirit.” Nowhere was this spirit more evident than in Team RSDSA! We were second in size only to the New York Road Runners Club. Our co-chairs Marsha Tyszler and Jaci Drake led our members as we walked, ran, or rode through the park. Volunteers enthusiastically encouraged us along the way. Each year, I become emotional as we approach the finish line, an achievement of Herculean proportions for many. Equally important is the sense of community engendered by sharing our stories with one another. Pain can be isolating, but the Achilles Walk banishes that isolation and forges life-long friendships.

“Members come from all over the world for this spectacular occasion. Our largest fundraiser, Rajinder Purewal, traveled from England, while documentarian Patty Micheletti, her husband and friend made their second trip from Canada. Our virtual team enabled another 165 people to participate from all across the US and internationally.



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“Jim Broatch, the RSDSA’s executive director, says ‘We see the Achilles Walk as a great opportunity to create awareness of our syndrome and also to let people know that it can be disabling. Perhaps even more important, though, is the way the walk brings together people with CRPS, their friends and family members, and lets them participate in funding awareness and research for better treatment and, hopefully, a cure.’

“The presence of a number of celebrities helped generate increased awareness this year. Both Heather Mills and Trisha Meili addressed the runners before the race. Governor David Paterson of New York ran, as did Cindy and Meghan McCain. Prince Harry of England, who served in Afghanistan, walked with 34 members of the Freedom Team of Wounded Vets.

“Everywhere I looked I was inspired and uplifted. The entire event seemed to embody the words of Martin Luther King: ‘We must accept finite disappointments, but we must never lose infinite hope.’”



Team RSDSA 2010 in Central Park

This is truly Advocacy in Action!

---The Reflex Sympathetic Dystrophy Syndrome Association (RSDSA) is a not-for-profit organization established in 1984 to raise awareness of Complex Regional Pain Syndrome (CRPS), educate the general public and the medical community, and fund research. Since 1992, RSDSA has funded more than \$1 million in fellowships and research grants. For more information about CRPS and RSDSA, visit www.rsd.org.



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FIRST PERSON ADVOCATE

By Jessica Belardo, Intern, Healthcare Alliance Development



Though this summer internship is coming to a close, it seems like I just started! I am confident saying that I have appreciated every single learning experience throughout this summer, as I have been able to learn and take guidance from others. It's a bit sad to realize that the summer is almost over.

It is good to know that I spent the summer working in a department that exposed me to the fact that pain management is essential for those who need it. In particular, I have become quite familiar with the enormous number of organizations that are advocating for pain management. Whether it is a cancer patient or a person suffering from severe migraines, everyone is entitled to receive proper pain

care. During these months of working with the Healthcare Alliance Department I became much more aware of the people around me who may be dealing with pain.

On a national basis, the thought of knowing that there are organizations that have been able to create change is quite powerful. I've read through stories of individuals dealing with pain who became associated with these organizations in order to feel like a part of a community that shares in their suffering. I look at my life as I experience it on a daily basis and see the many blessings I have, from having supportive parents to being able to earn an education, but most importantly the fact that I still am in good health. I admire these organizations that are willing to work together in the hopes of helping others. For example, The American Pain Foundation, an individual nonprofit organization that is committed to improving pain policy in this country, has done work from aiming to improve the Health Care Reform Bill to reaching out to those who suffer from pain in the military. In other words, many of these organizations deal with more than one aspect of pain management.

As I see the efforts being put forth to improve pain management, I only hope that it continues to the point where those millions of individuals who suffer from pain today will one day receive the proper pain care that they need.



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IN THE NEWS-ADVOCACY IN ACTION

The American Pain Foundation Action Network is pleased to announce:

A Virtual March on Washington and the 10,000 Voices Campaign to Improve Pain Management!

Uniting Our Voices, Conquering Pain Together

September Pain Awareness Month (PAM) provides an opportunity for organizations and individuals to come together to raise awareness in communities across the country to bring positive change to the management of pain.

As part of PAM, the American Pain Foundation has announced details of its Virtual March on Washington – an online event to unite, empower and rally those who care about people living with pain and be part of making a difference in pain policy and practice.

According to APF, “2010 marked an enormous victory for pain management. Provisions in the National Pain Care Policy Act passed with the Health Care Reform bill after 7 years in the making! We’ve garnered awareness and momentum around pain and the challenges it creates for millions of people but there is still so much work to do. The majority of people with pain still do not receive the pain care they deserve. JOIN US and make the difference!”

For more information about the Virtual March on Washington, the 10,000 Voices Campaign and how YOU can get involved, PLUS the Pain Awareness Month Advocacy Toolkit, visit:
<http://www.painfoundation.org/take-action/action-network/>



National Institutes of Health (NIH) Implements New Pain Committee

The NIH has announced the establishment of an “Interagency Pain Research Coordinating Committee.” According to the Federal Register, the Patient Protection and Affordable Care Act requires the committee to:

- (a) Develop a summary of advances in pain care research supported or conducted by Federal agencies relevant to the diagnosis, prevention and treatment of pain and diseases and disorders associated with pain;
- (b) identify critical gaps in research on the symptoms and causes of pain;
- (c) make recommendations to ensure that the activities of the NIH and other Federal agencies are free of unnecessary duplication of effort;
- (d) make recommendations on how best to disseminate information on pain care; and (e) make recommendations on how to expand partnerships between public and private entities to expand collaborative, cross-cutting research.

Duration of this committee is two years from the date the Charter is filed.

For more information: <http://edocket.access.gpo.gov/2010/pdf/2010-17261.pdf>

3rd Annual Women in Pain Conference: “Gender Matters—Raising the Curtain on Pain”

Free to all women in pain and their caregivers!

For Grace, an organization dedicated to ensuring the ethical and equal treatment of all women in pain, is hosting their 3rd Annual Women in Pain Conference: Gender Matters – Raising the Curtain on Pain!

The conference will be held on September 17, 2010 at the California Endowment’s Center for Healthy Communities in downtown Los Angeles.

This empowering event will feature keynote speakers, celebrities, legislators, workshops, breakout sessions, live performances, and a patient/doctor dramatization that will focus on the interconnection between the mind, body and spirit.

The conference will focus on Integrative Medicine and the Creative Art Therapies. Throughout the day, dance, theatre, music, visual arts and standup comedy will be staged to paint literal and metaphorical murals of the pain experience.

Women in pain and their caregivers can attend the all-day conference **free** of charge. Registered nurses in attendance are eligible to receive **five** CEU credits. For those unable to attend, the conference will be broadcast live via worldwide webcast.

For more information and to **register**, please visit the conference website at:

<http://forgrace.org/women/in/pain/C248>



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ON THE HORIZON

September 2010

Southern California Cancer Pain Initiative

19th Annual Pain Resource Nurse (PRN) Course

September 1-3, City of Hope, Duarte, CA

<http://sccpi.coh.org/PRN19%20.htm>

PAINWeek

September 8-11, Las Vegas, NV

<http://www.painweek.org/>

American Academy of Pain Management

September 21-24, Las Vegas, NV

<http://www.aapainmanage.org>

American Society of Pain Management Nursing

September 22-25, Minneapolis, MN

<http://www.aspmn.org>

American Academy of Family Physicians

September 29 - October 2, Denver, CO

<http://www.aafp.org>

October 2010

American Society of Anesthesiologists

October 16-20, San Diego, CA

<http://www.asahq.org>

American College of Nurse Practitioners

October 20-24, Tampa, FL

<http://www.acnpweb.org>

National Community Pharmacists Association

October 23-27, Philadelphia, PA

<http://www.ncpanet.org>

American Osteopathic Association

October 24-28, San Francisco, CA

<http://www.osteopathic.org>



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November 2010

American Academy of Physical Medicine & Rehabilitation

November 4-7, Seattle, WA

<http://www.aapmr.org>

American College of Rheumatologists

Nov. 6-11, Atlanta, GA

<http://www.rheumatology.o>

American Society of Consultant Pharmacists

November 10-13, Orlando, FL

<http://www.ascp.com>

Spotlight: Alliance of State Pain Initiatives 21st Annual Meeting

A Decade of Change: The 21st Annual Meeting of the Alliance of State Pain Initiatives (ASPI) will be held October 21-23, 2010 at the InterContinental Hotel in Atlanta, Georgia. This unique, interdisciplinary national forum brings together leaders involved in efforts to address the diverse challenges that impede effective pain control.

The 2010 meeting focuses on a decade of pain care, looking back and moving forward and is designed to highlight the actions essential to overcoming the organizational, societal, regulatory, attitudinal, and clinical barriers that contribute to the undertreatment of pain.

Pri-Med East

November 18-21, Boston, MA

<http://www.pri-med.com>

American Society of Regional Anesthesia and Pain Medicine

November 18-21, Phoenix, AZ

<http://www.asra.com>

December 2010

American Society of Health-System Pharmacists

December 5-9, Anaheim, CA

<http://www.ashp.org>

Participants will be able to share resources and expertise, network with one another, and gain the knowledge and motivation to develop and implement programs to improve the care of persons in pain. For more information please visit

Target Audience: Physicians, nurses, pharmacists, physician assistants, social workers, physical and occupational therapists, complementary medicine practitioners, health care administrators, psychologists, educators, advocates, policy makers, and all other individuals interested in improving pain management are invited to attend.

For more information: <http://aspi.wisc.edu>