Building Cathedrals:
PAINS Transition to the Academy of Integrative Pain Management
Introduction

Things in Washington, DC can sometimes move very slowly.

A national cathedral was envisioned by President George Washington in the earliest days of our country. In 1791, Washington asked Major Pierre (Peter) Charles L’Enfant to include it in the master plan for our capital, which he did. However, it wasn’t until 1905 that the site for the National Cathedral was purchased, and not until 1907 that the foundation stone was laid. For the next eighty years, railroad cars and trucks brought limestone from a quarry to build the National Cathedral. It was another president, George H. W. Bush, who was present in 1990, when the final finial was set to dedicate this landmark in our capital. At the dedication, President Bush said, “God speed the work completed this noon and the new work yet to begin.”

Like the architects, builders, stonecutters, stained glass makers and other artisans who built the cathedrals across Europe, those who envisioned the National Cathedral and many who spent their lives working on it knew they would never live to see it finished. Even so, they dedicated themselves to the task because they were inspired by a vision of what could be if their work and that of others who would follow them was done well and also a strong belief that theirs was “worthy work.”

A small group of people who agreed to serve on the Institute of Medicine’s (now the National Academy of Medicine) Committee to Advance Pain Research, Care and Education was also inspired by a vision—that of a cultural transformation in the way pain is perceived, judged, and treated. Their charge was to provide a blueprint for transforming pain care in America and to make specific recommendations about how to accomplish that. Members of the committee knew change was desperately needed and wanted it to happen quickly. Their report, *Relieving Pain in America*, published in June 2011, was founded on the notion that a moral imperative underpinned their work and that effective pain management was long overdue. Members of the committee went so far as to prioritize their sixteen recommendations and to establish a timeline for the completion of each. Their highest recommendation was to “create a comprehensive population health-level strategy for pain prevention, treatment, management, and research,” and they asked the Secretary of the Department of Health and Human Services (HHS), then Kathleen Sebelius, to develop a plan that would include specific goals, actions, timelines and resources and said it should be completed by the end of 2012 (eighteen months after publication of their report). Members of the committee were no cathedral builders. They thought of themselves as change agents and had little patience for or understanding of why comprehensive/integrative chronic pain care was not the standard of care when there had been compelling evidence since the late 1980s that a comprehensive approach to chronic pain not only improved outcomes, but was also cost effective.

Members of the committee were eager for the Department of Health and Human Services to act. Unfortunately, it was not until November 2012 that a workgroup was established to develop what became the National Pain Strategy (NPS). Members of the workgroup were instructed that urgency underpinned their task and they were given a very short timeline (originally April 2014). Their work was completed in June 2014; unfortunately, the National Pain Strategy was not released until March 2016.

Formation of PAINS

In May 2011, the Center for Practical Bioethics (CPB), a freestanding 501(c)3 organization which was represented on the IOM committee, convened a group of national leaders working to improve
pain care to discuss how they could work together to promote the forthcoming IOM report and advance its recommendations, especially the development of a national population health plan—what CPB thought should be a plan to operationalize Relieving Pain in America. Those who gathered included bioethicists, leaders of professional organizations, patient advocates, policymakers, and philanthropists. From that meeting emerged a consortium/project which became the PAINS (Pain Action Alliance to Implement a National Strategy) Project at the Center for Practical Bioethics. The mission of the PAINS Project was lifted from the IOM report—to transform the way pain is perceived, judged and treated. Three initial goals were agreed to:

1. Use the collective influence of those who had gathered and others who would join them later to pressure HHS to develop a national population health plan.
2. Develop a national communication/public education strategy to educate healthcare professionals, policymakers, and the public about chronic pain as a neurologic disease and thereby dispel the stereotypes and reduce the stigmatization of those living with chronic pain.
3. Support and network community-based initiatives committed to improving chronic pain care.

Myra Christopher, the Kathleen M. Foley Chair in Pain and Palliative Care at CPB, agreed to serve as Director of the PAINS Project on a full-time basis, and the Center agreed to support her to do so.

PAINS could not have assumed an initiative of this size and scope without assurances from other organizational leaders that they would stand shoulder-to-shoulder with PAINS. People have been true to those commitments.

Since 2011, working with many other organizations, PAINS has made significant progress. Some highlights of those accomplishments include:

- Contributed significantly to development of the National Pain Strategy and effectively pressured HHS to publicly release it.
- Raised awareness among policymakers at both state and federal levels, researchers, and agents of the media about the importance of including the voice and experiences of those living with chronic pain when doing pain-related research, making policy, or reporting.
- Established relationships with those advocating on behalf of people living with substance use disorders to identify common policy interests and to clarify the relationship between prescribing opioids to address chronic pain and the opioid crisis in the U.S.
- Provided well researched information and served as a reliable resource to those living with pain, those caring for them, policymakers, journalists, and other media representatives.
- Routinely convened diverse stakeholders to promote the strongly held belief that integrative pain care improves the lives of millions of Americans living with chronic pain, saves billions of dollars each year and reduces opioid prescribing.
Transition in PAINS Support

At the end of June 2018, after thirty-four years at the Center for Practical Bioethics, Myra Christopher retired from the Center, at which time its board of directors and leadership decided not to continue to support the PAINS Project. Several options for ways to continue PAINS’ important work were explored. Ultimately, it was decided through a non-financial agreement between the Center for Practical Bioethics and the Academy of Integrative Pain Management to transfer the PAINS Project, its resources and collateral materials to AIPM as of August 1, 2018. The Center for Practical Bioethics is enthusiastic about this transition and believes that the timing is right for change.

“The leadership that AIPM has exhibited in the complex arena of pain care treatment ensures that the investment the Center has made over the last decade will continue and flourish. The Academy’s commitment to excellence in interdisciplinary, patient-centered and evidence-based care with virtually every stakeholder group provides the confidence the Center needed in transitioning our work as Myra Christopher retires,” says John G. Carney, President/CEO of the Center for Practical Bioethics.

Since it was founded in 1988, AIPM has been the premier organization supporting the practice of integrative pain management—that is, using every evidence-supported treatment available in an interdisciplinary, patient-centered model to design a unique care plan for each person with pain. Members of AIPM represent virtually every group that cares for people with pain, including physicians, nurses, mental health professionals, dentists, chiropractors, acupuncturists, massage therapists, and many more—a total of more than 30 distinct professions. Through hundreds of live and online educational opportunities, certificate programs for opioid prescribing and nutritional pain management, and the most active policy advocacy program among pain societies, AIPM has been, and is, the leading voice for integrative pain management in the United States. AIPM’s Executive Director, Bob Twillman, has been a member of the PAINS Steering Committee since its inception, and has served as an editor for the PAINS policy and educational brief series.

Carney states, “Those living with chronic pain rely on strong, respected and accomplished organizations to advance person-centered, integrative models of care by uniting clinicians in the fight against chronic pain. AIPM fits that profile and we are pleased and grateful that AIPM has agreed to honor the mission of the PAINS project and the decade-long charitable efforts of the Center in this duty of care to vulnerable patients.”
Clay Jackson, Board Chair of the Academy of Integrative Pain Management, responded. “At AIPM, we are grateful for the tremendous work that has been accomplished by everyone involved in the PAINS Project, and we feel that important milestones such as the publication of the National Pain Strategy would have been impossible to achieve without their commitment to patient advocacy and sound medical evidence.”

“AIPM is uniquely positioned to continue to serve as the central repository of information regarding best practices in integrative pain care...”

“As the only professional organization comprising members of every discipline that treats persons with pain, AIPM is uniquely positioned to continue to serve as the central repository of information regarding best practices in integrative pain care, and as a powerful force for advocating for making those treatments available to all patients,” continued Jackson.

The Opioid Conundrum
When members of the committee that produced the IOM report, Relieving Pain, were given their charge, they were told to focus exclusively on describing the state of pain care in the U.S. and making recommendations about how to improve the status quo. They were specifically told to stay away from the opioid “controversy.” Committee members felt that to avoid the topic entirely would make them appear out of touch or naive. So, they did “tip their hats” to what they referred to as the “opioid conundrum” and described it by saying, “The committee recognizes the serious problem of diversion and abuse of opioid drugs, as well as questions about their long-term usefulness. However, the committee believes that when opioids are used as prescribed and appropriately monitored, they can be safe and effective....”

Since publication of Relieving Pain in 2011, this “conundrum” has been described by the Centers for Disease Control and other federal agencies as the opioid “epidemic,” and the attention and energy of policymakers and public health officials has swung away from the tens of millions of Americans who struggle to live with chronic pain and onto the approximately 2.5 million Americans who struggle with opioid use disorders and the associated unintended deaths.

Everyone working with PAINS and all those working to improve chronic pain care are deeply concerned about the opioid crisis and regret that there is little understanding of the relationship to and between these two chronic diseases, i.e., chronic pain and substance use disorders. Advocates for those living with chronic pain regret that these two critically important public health matters have been pitted against one another, to the detriment of both groups, for what many believe has been political gain. In addition, media attention to the opioid problem has fueled political interest in this topic and eclipsed reporting on chronic pain. Clearly, the opioid epidemic pushed implementation of the National Pain Strategy report to the back burner—so much so, that the report wasn’t released until nearly two years after it was submitted for approval, and in the same week as the much more attention-grabbing guideline on opioid treatment for chronic pain issued by the Centers for Disease Control and Prevention. It has also frustrated many of those who worked on either Relieving Pain in America or the NPS or both. However, frustration cannot prevail.
Pain Management Best Practices Inter-Agency Task Force

The second largest Gothic cathedral in the world is in Milan, and it took more than 500 years to construct. The timeline is punctuated by long periods of delay due to lack of money, resources, ideas about how to move forward, wars, and other political upheavals. Efforts to reform chronic pain care since publication of Relieving Pain in America have moved in a similar fashion, i.e., in fits and spurts, which is frustrating to members of the committees who volunteered significant amounts of time to lay the foundation for public health reform. Many believed that the National Pain Strategy would serve as the “cornerstone” for a national public health campaign to transform pain care, but to date, it has not. There are some rays of hope although they are sometimes hard to identify.

On August 25, 2017, Tom Price, then Secretary of Health and Human Services, announced the creation of a new Task Force “to develop best practices for prescribing pain medication and managing chronic and acute pain.” By the time that members of the committee were appointed in May 2018, the press release announcing its first meeting stated the Task Force’s purpose slightly differently. It said, “The Task Force was established to propose updates to best practices and issue recommendations that address gaps or inconsistencies for managing chronic and acute pain.” There was no mention of opioids or pain medication at all, hopefully signaling a slight shift at the federal level from yet another opioid-focused federal initiative to one aligned with at least one section of the National Pain Strategy—Service Delivery and Reimbursement.

The first objective in this section of the report is to “define and evaluate integrated, multimodal, and interdisciplinary care for people with acute and chronic pain, and end of life pain, which begins with a comprehensive assessment, creates an integrated, coordinated, evidence-based care plan in accord with individual needs and preferences and patient-centered outcomes, and is supported by appropriate payment incentives.” To accomplish this as a “short-term strategy,” the committee agreed that a group of expert stakeholders should be convened to develop strategies to address shortcomings in quality pain care and the high costs of current pain treatment approaches, the existence of more effective models, and the steps that can be taken toward achieving high quality care and outcomes.

The authority for the Pain Management Best Practices Inter-Agency Task Force (Task Force) does not come from the National Pain Strategy but rather from the Comprehensive Addiction and Recovery Act of 2016. Its charter states that “unless extended by Congress, the Task Force shall be terminated on July 22, 2019,” which is slightly more than one year after its first meeting which occurred on May 30, 2018. Dr. Vanila Singh, who serves as the Chief Medical Officer for the Office of the Assistant Secretary for Health at the U.S. Department of Health and Human Services, chairs the Task Force and reports to the Secretary.

“The Task Force was established to propose updates to best practices and issue recommendations that address gaps or inconsistencies for managing chronic and acute pain.”

Dr. Singh is well qualified to lead this effort. She graduated from George Washington University’s Medical School, completed a medical internship at Yale, a residency at Cornell Medical Center in New York, and after doing a fellowship in pain management at various locations, she was board certified in both anesthesia and pain medicine. She served as a clinical assistant professor at UCLA Medical Center and then became a clinical associate professor at Stanford University Medical School for anesthesiology, perioperative and
Pain Management Best Practices Inter-Agency Task Force Members

The following individuals have been named to serve on the Pain Management Best Practices Inter-Agency Task Force.

**Chair**
Vanila M. Singh, M.D., MACM, Chief Medical Officer, Office of the Assistant Secretary for Health, U.S. Department of Health and Human Services.

**Public Members**

Amanda Brandow, D.O., M.S., Associate Professor of Pediatrics in Hematology/Oncology, Medical College of Wisconsin, Milwaukee, Wisconsin.

Renée Campos, Retired U.S. Navy, Commander, Senior Director of Government Relations, Military Officers Association of America, Alexandria, Virginia.

Jianguo Cheng, M.D., Ph.D., Professor of Anesthesiology, Director of the Cleveland Clinic Multidisciplinary Pain Medicine Fellowship Program, Cleveland, Ohio.

Daniel Clauw, M.D., Director, Chronic Pain and Fatigue Research Center; Professor of Anesthesiology, Medicine (Rheumatology) and Psychiatry, University of Michigan, Ann Arbor, Michigan.

Jonathan C. Fellers, M.D., Medical Director, Integrated Medication-Assisted Therapy, Maine Medical Center; Medical Director, Maine Tobacco Help Line, Maine Health Center for Tobacco Independence, Portland, Maine.

Howard L. Fields, M.D., Ph.D., Professor Emeritus, Departments of Neurology and Physiology, University of California at San Francisco, San Francisco, California.

Rollin M. Gallagher, M.D., M.P.H., Clinical Professor of Psychiatry and Anesthesiology and Critical Care, Director for Pain Policy Research and Primary Care, Penn Pain Medicine, University of Pennsylvania, Philadelphia, Pennsylvania.

Halena M. Gazelka, M.D., Assistant Professor of Anesthesiology and Perioperative Medicine, Mayo Clinic College of Medicine and Sciences; Chair, Mayo Clinic Opioid Stewardship Program; and Director of Inpatient Pain Services, Division of Pain Medicine, Mayo Clinic, Rochester, Minnesota.

Nicholas E. Hagemeyer, Pharm.D., Ph.D., Associate Professor of Pharmacy Practice, Gatton College of Pharmacy, East Tennessee State University (ETSU); Research Director, ETSU Center for Prescription Drug Abuse Prevention and Treatment, Johnson City, Tennessee.

Michael J. Lynch, M.D., Medical Director, Pittsburgh Poison Center; Assistant Professor, University of Pittsburgh, Department of Emergency Medicine, Pittsburgh, Pennsylvania.

John J. McGraw, Sr., M.D., Medical Director, OrthoTennessee; County Commissioner, Jefferson County, Tennessee.

Mary W. Meagher, Ph.D., Professor and Coordinator of the Clinical Health Psychology Program at Texas A&M, College Station, Texas.

John V. Prunskis, M.D., Founder, co-Medical Director, Illinois Pain Institute, Elgin, Illinois.

Mark Rosenberg, D.O., M.B.A., Chairman, Emergency Medicine, and Chief Innovations Officer, St. Joseph’s Health; and Board of Directors, American College Emergency Physicians, Paterson, New Jersey.

Molly Rutherford, M.D., M.P.H., Certified Addiction Specialist, Founder, Bluegrass Family Wellness, PLLC, Crestwood, Kentucky.

Bruce A. Schoneboom, Ph.D., Chief Learning Officer, American Association of Nurse Anesthetists, Park Ridge, Illinois.

Cindy Steinberg, National Director, Policy and Advocacy, U.S. Pain Foundation; Policy Council Chair, Massachusetts Pain Initiative, Lexington, Massachusetts.

Andrea Trescot, M.D., Interventional Pain Physician; Director, Pain and Headache Center, Eagle River, Alaska.

Harold K. Tu, M.D., D.M.D. Associate Professor and Director, Division of Oral and Maxillofacial Surgery, School of Dentistry, University of Minnesota; Chairman, Department of Dentistry, Fairview Hospital, University of Minnesota Medical School, Minneapolis, Minnesota.

Sherif Zaafaran, M.D., President, Texas Medical Board, Austin, Texas.

**Federal Members**
Steven Davies, M.D., Senior Medical Officer, Office of the Chief Medical Officer, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services.

Scott Griffith, M.D., Director, National Capital Region Pain Initiative and Program Director, National Capital Consortium Pain Medicine Fellowship, U.S. Department of Defense.

Sharon Hertz, M.D., Director, Division of Anesthesia, Analgesia, and Addiction Products, Center for Drug Evaluation and Research, Food and Drug Administration, U.S. Department of Health and Human Services.


Fredheim Sandbrink, M.D., Acting National Program Director, Pain Management Specialty Care Services, Veterans Administration Health System; and Director, Pain Management Program, Department of Neurology, U.S. Department of Veterans Affairs.

Cecelia Spitznas, Ph.D., Senior Science Policy Advisor, Office of the Director, Office of National Drug Control Policy.
pain medicine. Not only does she have exemplary qualifications, Dr. Singh is also deeply committed to this initiative, as are members of the Task Force.

“The Pain Management Best Practices Inter-Agency Task Force is firmly focused on the narrow charge to propose updates to best practices and issue recommendations that address gaps or inconsistencies for managing chronic and acute pain. In the end, our goal is to improve patient-centered care and improve health outcomes for individuals who suffer from a variety of different and challenging pain syndromes,” says Singh.

Dr. Singh also understands the importance of including those who live with chronic pain in the work of the Task Force. PAINS was pleased to be asked by Dr. Singh to help her identify one of its Citizen/Leader Advisors along with three other people living with chronic pain to speak at the beginning of the May 30th meeting.

Jonathan Bell, who lives with Sickle Cell Anemia and is one of the PAINS-KC Citizen Leaders, served in that capacity. Mr. Bell said, “Growing up with a debilitating disease like sickle cell disease and feeling like you almost never get heard, having a chance to be a part of PAINS-KC and the Pain Management Best Practices Inter-Agency Task Force, I now know that I not only have a voice but I am being heard. I am helping people who are making decisions and laws for people who live with chronic pain. I am also able to speak and be a face for others who live with chronic pain—individuals who may never be able to voice their opinions about what we live with on a day-to-day basis. I know our work is making a difference in the way people judge and perceive pain.”

Their stories set the tone for a very productive first meeting which can be viewed at http://bit.ly/2mZAI5.
Ongoing work: Integrative Pain Care Policy Congress

With financial support from PAINS, the Integrative Health Policy Consortium (IHPC), and the Alliance for Balanced Pain Management, AIPM convened the first Integrative Pain Care Policy Congress in October 2017. This first-of-its-kind meeting brought together more than 75 participants from more than 50 organizations, representing professional societies covering the full scope of licensed and certified healthcare providers, patient advocacy organizations, governmental agencies, private payers, and other important stakeholders. In a monumental task, these disparate parties agreed on a consensus definition of comprehensive integrative pain management, one that closely mirrors a definition previously offered in a PAINS policy brief: "Comprehensive Integrative Pain Management includes biomedical, psychosocial, complementary health, and spiritual care. It is person-centered and focuses on maximizing function and wellness. Care plans are developed through a shared decision-making model that reflects the available evidence regarding optimal clinical practice and the person’s goals and values."

Congress participants also established workgroups focused on efforts to promulgate this definition widely, as well as identifying and overcoming barriers preventing nationwide adoption of integrative pain management as the predominant model of care for people with pain.

PAINS and IHPC will again serve as co-sponsors with AIPM of the second Integrative Pain Care Policy Congress meeting in November 2018. This second Congress meeting will build upon the efforts of the workgroups and will include even more participants, from a wider array of participating groups, including:

- key leaders from federal executive branch agencies such as the Department of Health and Human Services, Centers for Medicare and Medicaid Services, the Substance Abuse and Mental Health Services Administration, and more;
- non-governmental organizations representing a variety of policymakers;
- multiple private health plans that provide both specialty coverage for integrative and complementary treatments as well as broad coverage for traditional medical services;
- healthcare professional societies representing both integrative/complementary professions and traditional medical professions;
- pain patient advocacy groups;
- health policy researchers; and
- coalitions of healthcare purchasers.

These participants will discuss progress made since the inaugural Congress meeting and outline next steps to be taken to maintain and enhance the momentum toward making comprehensive integrative pain management the standard of care for people with pain.

The missions of both AIPM and the Policy Congress align with the mission of PAINS, and through PAINS’ affiliation with both, there is potential to bring about rapid and dramatic change in the nature of care provided for people with pain. The legacy of PAINS as a convener and facilitator is unparalleled and will be carried forward through the new relationship with AIPM.
Conclusion

Much progress has been made toward transforming the way pain is perceived, judged and treated since *Relieving Pain in America* was published seven years ago. However, the work has been slower than had been anticipated, and there is significant work to be done before all people living with chronic pain receive patient-centered, multi-modal/comprehensive, quality care. Many pain care reformers are frustrated, and people living with chronic pain are losing hope. For those who struggle every day for relief from persistent disabling pain, the analogy to cathedral building provides no comfort.

Historians and authors have written volumes about lessons learned from the cathedral builders. Perhaps, some of these lessons will encourage advocates working to transform the way pain is perceived, judged, and treated to continue their work with the necessary strength of conviction and determination.

For example, those who worked on the great cathedrals:

1. Were inspired by a vision and believed it was worthy work.
2. Knew that no single architect or craftsman could ever have done this work. It required a civil society.
3. Recognized patience as essential to progress.
4. Were undaunted even though the work was not comfortable or easy.
5. Recognized the need for external support when their project was at risk of collapsing inward upon itself.
Although our healthcare delivery system and policymakers have failed the chronic pain patient population, there are rays of hope in the movement to transform chronic pain care from a biomedical model to a comprehensive/integrative approach. One of the most promising is consumer self-advocacy; people living with chronic pain speaking out, talking to the media, presenting at Congressional hearings, and participating in continuing medical education programs. Another promising sign is recognition by policy makers that the voices of people living with chronic pain and those who care for them must be heard to formulate meaningful policy and to create the political will necessary for change. These signs of promise reflect the success of PAINS’ No Longer Silent initiative.

Jonathan Bell’s story and those of the three other panelists who kicked off the first HHS Task Force meeting in May by telling their compelling stories set a tone for the two-day meeting that followed. It is hard to ignore intelligent, brave individuals like those who shared their personal stories with Task Force members and people around the country who watched the meeting via the internet. Their stories are paradigmatic of the courage and conviction of millions of Americans living with unrelenting chronic pain day-after-day-after-day and denied care that will benefit them.

PAINS’ six-year experience with its Citizen/Leaders Advisory Group demonstrates the strength of character, stamina, and ingenuity of chronic pain sufferers and their family caregivers. Those who have advised leaders of the PAINS Project are not only committed to helping themselves but also to helping others who cannot engage in reform efforts because of physical limitations—those who are often isolated, stigmatized and falsely accused of being drug seekers. This perception must change. As recent media coverage is beginning to tell stories of chronic pain sufferers as well as those of people living with opioid use disorders which have dominated media coverage for several years, stereotypes are beginning to be dispelled, and ultimately these narratives will fuel reform efforts. As President George W. H. Bush said to those who had dedicated themselves to building the National Cathedral, “Godspeed the work completed… and the work yet to begin.”

There is a moral imperative to address pain and suffering when it is possible, and eventually comprehensive chronic pain care will be provided to those who have been afflicted with this terrible disease, but it will take much more work—work that some may not see finished.
The Pain Action Alliance to Implement a National Strategy (PAINS) is a consortium of leaders from professional societies, patient advocacy organizations, policy groups, consumers, third-party payers and the private sector collaborating to achieve a common vision and mission.

Learn more at painsproject.org

The Academy of Integrative Pain Management a diverse community of healthcare providers representing more than 30 distinct disciplines who are dedicated to using all appropriate therapeutic approaches to reduce pain, and achieve optimal health and healing.

Learn more at integrativenpainmanagement.org

This brief is a product of the Pain Action Alliance to Implement a National Strategy (PAINS) and the Center for Practical Bioethics. The entire series is available at painsproject.org and may be downloaded for free.

For further information about PAINS or this policy series, visit painsproject.org.

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