

# **Changing the Face of Pain in Missouri: A Strategic Planning Initiative Sponsored by the Missouri Pain Initiative and the State Advisory Council on Pain and Symptom Management**

November 25, 2006

## **Background**

A United States Congressional mandate declared 2000 - 2010 the Decade of Pain Control and Research. More than half the decade has passed, and more than 50 million Americans still live with chronic pain. Another 25 million experience acute pain as a result of injury or surgery. Pain remains the number one reason people seek medical help. The National Institutes of Health estimate that pain costs the U.S. economy over \$100 billion every year due to medical expenses and lost work days. Of course, the cost to the pain sufferer is even steeper: it interferes with sleep, social activities, hobbies, sex, and even how a person thinks. Recurring and unresolved pain isolates a person and takes away his or her dignity and hope.

Pain in all of its forms is a problem no matter where one lives, and the state of Missouri is no exception. In a recent survey, 31% of Missourians reported that during the past month, pain made it hard for them to do usual activities, such as self-care, work, or recreation. Eleven percent reported experiencing significant pain for 15-30 days that month. (Source: Missouri 2005 Behavioral Risk Factor Surveillance System survey).

### ***Missouri Advisory Council on Pain and Symptom Management***

To help address the problem of Missourians living with undertreated pain, the Missouri state legislature in 2003 established the Missouri Advisory Council on Pain and Symptom Management (Council). The Council, chaired by a designee of the Director of the Department of Health and Senior Services in which it is housed, is comprised of 19 members including an individual who has been diagnosed with chronic pain; health professionals; a representative of the Pharmaceutical Research and Manufacturers of America; legislators; an advocate representing voluntary health organizations or groups with an interest in pain management; and a designee of the state attorney general. The Council's duties are outlined in statute and include reviewing guidelines; making recommendations on acute and chronic pain management treatment practices; suggestions as to how pain and symptom management can be integrated into the customary practice of health care professionals; analyzing statutes, rules and regulations; and examining the needs of targeted populations.

In 2004, the Council conducted town hall meetings across the state to obtain input from persons experiencing severe or chronic pain, as well as the health care providers who care for them. Based on their testimony, a number of barriers to effective pain management and assessment in Missouri were identified: inadequate training of health professionals to diagnose and treat pain, exaggerated fears on all sides of side effects and addiction related to taking pain medication, lack of communication between patients and health care providers, limited access to care in the rural and urban core, the low priority of pain management in the health care system, and health professional fears of regulatory scrutiny. Additional information about the Council, including the town hall meetings, is available at:

<http://www.dhss.mo.gov/PainManagement/>

## **Missouri Pain Initiative**

Incorporated in 2004, the Missouri Pain Initiative (MOPI) is an independent nonprofit 501(c)3 organization dedicated to removing the barriers to effective pain assessment and management in the state of Missouri through professional and patient education, advocacy, and changes to the health system. MOPI's priorities include:

- Educating the general public, health care professionals, policymakers, and the media about pain and pain management treatment options by serving as the central statewide clearinghouse and resource center.
- Promoting self-advocacy of better pain assessment and management through community education and engagement efforts like the Power Over Pain © campaign.
- Supporting healthcare provider practice improvement through continuing education opportunities presented throughout the state.
- Collaborating with other pain partners to share resources and knowledge, mobilize efforts to ensure timely and effective access to pain care, and support each other's pain-related priorities and activities.

MOPI's membership includes physicians, pharmacists, nurses, social workers, occupational therapists, physical therapists, academicians, practitioners specializing in complementary therapies, and Missourians who live with chronic pain. More information about the Missouri Pain Initiative is available at: <http://www.missouripain.org>

## **Joining Efforts to Build an Alliance**

In late 2005, representatives from the Council and MOPI met to discuss their mutual interest in improving pain education, assessment, and management. It was decided that MOPI and the Council would jointly convene a series of meetings of interested partners across the state to develop a collective strategy to address the barriers to care identified in the Council's 2005 legislative report and incorporate the recommendations contained in the Council's report related to assessment, treatment, and education. It was intended that the end product of this effort would be the development of a ready to implement 2-year strategic plan complete with identified tasks and resources, action steps, timelines, and areas of responsibilities. The following outcomes were identified as crucial to a successful collaboration:

1. Development of a viable collaborative strategic plan that includes plans for:
  - a. a more comprehensive system for data collection to better understand consumer needs;
  - b. improved access to effective pain care;
  - c. consumer education and engagement; and
  - d. integrating professional education into practice.
2. Incorporation of the Power over Pain © (POP) campaign into the strategic plan.
3. Clarification of MOPI and Council roles in helping to shape education, advocacy, and policy around pain management issues.
4. Development of a model that other state pain initiatives might use relative to how to engage in a collaborative strategic planning process.

## **Launch**

In the spring 2006, a group of approximately 80 individuals, agencies, and organizations identified as having a potential interest in pain were invited to attend an initial meeting on June 13<sup>th</sup> in Jefferson City (See attachment A for a complete list of invitees and Attachment B for the letter of invitation). The primary goals for the day were identified: 1) to discuss how attendees might collectively combine their interests, knowledge and resources to better understand and improve pain care in Missouri, and 2) to take initial steps towards establishing an ongoing alliance among like-minded organizations. It was hoped there would be sufficient collective interest in developing a short-term action plan for a variety of activities to be implemented during Pain Awareness Month in September. The invitees completed an on-line pre-meeting survey (Attachment C), the purpose of which was to determine areas of common interest and glean a better understanding of their views on the barriers to effective pain assessment and treatment, and priorities for addressing those barriers.

Of the 80 possible attendees, 40 were represented at the June kick-off meeting (agenda is outlined in attachment D). The meeting began with an overview of the Council and MOPI roles in and priorities for improving pain care in Missouri, and with a summary of the current state of affairs in pain assessment, treatment and policy. After individual group introductions in which attendees described their organization's mission, priorities, and sources of support, the entire group brainstormed possible advocacy and education activities for National Pain Awareness Month in September 2006.

Following that discussion, attendees were invited to participate in one of following three breakout sessions to begin dialoguing about how these priorities might be incorporated into a longer term plan:

- Public Policy/Systems Change – Discussed legislative and non-legislative strategies to ensuring pain policy in Missouri is responsive to emerging needs.
- Provider Practice Improvement – Discussed the realities of and opportunities for bridging the gap between the existing global knowledge base regarding effective pain assessment and treatment and current practice in Missouri.
- General Public Education – A brainstorming session on sharing resources and planning collaborative public education activities beyond Pain Awareness Month.

The general session then reconvened with each breakout group summarizing their discussion and recommendations. After next steps were identified, including the development of a Pain Awareness Month Action Plan and a pledge for the newly formed collaborative to meet again after September, the summit was adjourned.

## **Pain Awareness Month**

The Pain Awareness Month brainstorming session generated a bounty of ideas for education and advocacy activities, coupled with pledges of collaboration. The ideas were grouped into the four focus areas identified during the brainstorming session and incorporated into a draft action plan that was sent out to the collaborative members for their review and comment. Given the tight timeline between the June meeting and September, the activity list was prioritized, with priority given to activities for which resources and pledges of support or interest were readily available.

The plan focused on the following areas:

- Public Education:
  - Goal - educate consumers to become empowered advocates for more effective pain assessment and treatment.

- How accomplished - distribute Power Over Pain materials and/or message to and through a number and variety of venues, including community education presentations and the media.
- Success measured by - the number and variety of venues where materials are distributed, and the volume of materials distributed
- Media Advocacy:
  - Goal - use the media as an education and advocacy tool to increase awareness during PAM.
  - How accomplished – pitch ideas to and through all media venues, especially the larger markets in Missouri
  - Success measured by – the number and variety of media venues thru which the pain messages are delivered.
- Professional Education:
  - Goal - enhance provider knowledge and practice.
  - How accomplished - use existing information sources and systems to distribute education pieces to provider groups and highlight continuing education opportunities.
  - Success measured by – the number and variety of venues thru which the education pieces and curriculum are delivered.
- Public Policy:
  - Goal - begin to build relationships with policy makers so that in the longer-term we will be able to proactively influence pain policy within the state of Missouri.
  - How accomplished – meet with elected officials on Pain Advocacy Day and distribute a targeted pain message.
  - Success measured by - the number of volunteers who participate in the Pain Advocacy Day activities, and the number of legislator offices visited.

For more detail, including timelines, identified resources, etc., please refer the Pain Awareness Month Action Plan and Breakout Discussion Summary, Appendix E.

The implementation of activities during Pain Awareness Month in Missouri reflected the success of the above enterprise. Members of the collaborative organized and convened over 20 community presentations across the state. Thousands of pieces of pain education materials were disseminated through a number of avenues which included outpatient clinics, Meals on Wheels, and public libraries. Various pain experts were featured in print, radio and television in both the small and larger media markets across the state. Pain advocates converged on the State Capital on September 13 for Pain Advocacy Day, making visits to elected officials and offering free pain information. Advocates also attended the Governor’s Proclamation signing ceremony declaring September as Pain Awareness Month in Missouri. Seventy-five health care professional attended the September joint conference of the Missouri Pain Initiative and the St. Louis and Kansas City Chapters of the American Society for Pain Management Nursing, which featured regional and national experts in the field of pain management. (See Attachment F for a detailed Summary Report for Pain Awareness Month).

What proved key to the successful implementation of the action plan was to have a project coordinator (MOPI’s Executive Director) who took responsibility for coordinating the communication, ensuring deadlines were met and assignments carried out, and completing unassigned tasks.

## Looking Ahead – Developing a Two-Year Plan

On October 4, the collaborative convened a second meeting (agenda found in Attachment G) for the purposes of evaluating the Pain Awareness Month outcomes, reassessing the collaborative's longer-term priorities and developing a 2-year strategic plan, complete with focus areas, outcomes, strategies, and action steps. The aim in doing so was to maximize resources and exposure available to the various collaborators, minimize duplication and forge interdependent relationships that will ultimately result in better assessment and treatment of pain among our fellow Missourians.

While less well attended than the June meeting, the October meeting was quite successful. The framework for a 2 year strategic plan was drafted. It was distributed to the entire invitee list for their review and accompanied by a questionnaire (Attachment H) designed to solicit an indication of each organization's or individual's intentions to be involved in the implementation phase of this plan. What follows is a synopsis of the plan.

### ***Public Engagement and Self-advocacy***

*Discussion:* We want to move from a passive orientation whereby raised awareness is translated into increased public action. Thus, we are changing the name of this target area from "Public Education" to "Public Engagement and Self-advocacy". We also want to guard against using the word "consumer" and instead use the word "public" as this term is inclusive of pain sufferers and their caregivers. We want to encourage ongoing exploration of and discussion about the message(s) we use so that we have a better understanding of the linguistics, tools, and motivations behind the message. For example, what is more likely to motivate the public - fear or anger? We also want to ensure our outreach efforts reach the poor/working poor and under served populations and find ways to include more minority organizations in this effort.

*Goal:* Educate and engage Missourians to become empowered self-advocates for more effective pain assessment and treatment.

*Strategy:* Education of the right things (i.e. - what the public needs to know to become self-empowered) said the right way (i.e. - how the message is delivered)

*Success measured by:*

- number and variety of venues through which pain message is delivered to the public
- volume of printed materials distributed
- number of POP presentations made
- growth in the American Pain Foundation's Power Over Pain Action Network (in Missouri)
- amount and variety of media coverage during the two-year period

*Action Steps:*

- Create a listserv, for the purpose of fostering responsive two-way communication on pain-related matters among the collaborating agencies
- Identify targeted activities for Pain Awareness Month (PAM) in September 2007 and September 2008 and develop an action plan that identifies resources needed, responsibilities, timelines, and outcomes to measure success.
- Continue to solicit and train Power Over Pain (POP) community education presenters, polling collaborators on their interest in training public education presenters from within the ranks of their specific groups/organizations.

- Continue to identify and solicit venues through which to distribute a new MOPI/Advisory Council pain brochure and APF POP materials.
- Continue to solicit, schedule, and maintain a calendar of POP community presentations.
- Add a component to POP presentations that provides specific advice on how to communicate with their health care provider, including what information they need to bring with them for discussion (e.g. - pain diary).
- Use the media as an education and advocacy tool to help spread the pain message, especially during PAM 2007 and 2008.
- Print a laminated card with the pain care bill of rights on one side and resources on the other for distribution at community education and advocacy events.

### ***Provider Practice Improvement***

*Discussion:* Again, we want to move from a passive orientation of education to one in which the providers demonstrate they are incorporating effective pain assessment and treatment into their practice. Thus, we are changing the name of this target area from “Professional Education” to “Provider Practice Improvement”. The group quickly decided that the analysis of the recent professional education survey sent out by MOPI should be used as the road map for developing our action plan for this target area. The survey analysis should be completed by the end of 2006. We discussed the importance of continuing to look for opportunities to develop strategic provider practice partnerships, with Occupational Medicine Nurses and Primaris receiving specific mention.

*Goal:* Effective pain assessment and treatment is incorporated into the practice of health care providers.

*Strategy:* Develop an action plan based on the professional education survey findings that addresses identified curriculum development and delivery system needs.

*Success measured by:* to be determined once the action plan is completed in early 2007.

*Steps:*

- Analyze survey data and report to collaborative on findings.
- Schedule a conference call for the collaborative in early 2007 to identify new provider practice improvement strategy and develop an action plan for this target area. Use the discussion from the initial meeting (June 2006) as a starting point for planning.
- Incorporate steps for developing strategic partnerships with groups/organizations that are focused on health care delivery system improvement into the plan.
- Use the data to develop expansion of any future DHSS Behavioral Risk Factor Surveillance System survey to include more pain-related questions.

### ***Public Policy/Systems Change***

*Discussion:* Our end in mind is that we want to have state pain policies and statutes which support effective pain management. In order to accomplish that we need to continue to build relationships with policy makers and, hopefully, identify some legislative champions who will work with us. We also need to look for common ground with those who influence policy who may not currently support our goal and strategy.

*Goal:* To have state pain policies and statutes which support effective pain management.

*Strategy:* Establish an in-state policy guidance action network and use it to champion a) language change consistent with suggestions in Pain Policy Studies Work Group report card and Advisory Council workgroups, and b) improved access to effective pain assessment and treatment in Missouri.

*Success measured by:*

- Successful removal of ambiguous or negative language from Intractable Pain Treatment Act and the Controlled Substances Act
- Improvement in our 2008 Pain Studies Work Group report card
- Any prescription-monitoring bill, if passed, is balanced such that while minimizing risks of abuse and diversion of medications, it will not negatively impact access to care for legitimate patients with pain.
- Increasing access to pain care through passage of legislation authorizing advanced practice registered nurses to prescribe schedule II, III, IV, or V controlled substances under a collaborative practice agreement.

*Steps:*

- Inventory all collaborators regarding their willingness to:
  - include pain in their current advocacy activities
  - become active in a state policy guidance action network and be willing to send e-mail and letters or make phone calls and visits to policymakers, or even testify should the occasion arise.
- Distribute pain fact sheet to newly elected legislators
- Solicit volunteers to meet with selected Committees (e.g. – Health Care Policy, Aging, Families, Mental and Public Health) prior to the beginning of the 2007 legislative session.
- Formulate wording changes for the Intractable Pain Treatment Act and the Controlled Substances Act and forward them to the network.
- Ask collaborative members to co-sign a letter addressed to the Boards of Healing Arts, Nursing, and Pharmacy, encouraging them to officially endorse the Joint Statement developed by the Advisory Council in support of pain management as a healthcare priority.
- Schedule and plan a Pain Advocacy Day for the legislative session 2007 and 2008.
- Identify and engage a legislative champion with the interest and clout to move an agenda for change forward.
- Secure a Governor's proclamation for Pain Awareness Month for September 2007 and September 2008.

More detail for the plan, including activity status, timelines, and individual or organizational pledges of support, can be found in Attachment I.

### **Next Steps – Funding and Implementation**

The plan is now ready for implementation and there are several action items for which sufficient manpower and resources have been pledged to enable the collaborative to proceed with their implementation. However, the successful implementation of the Pain Awareness Month action plan has demonstrated to the collaborative how valuable and essential is it to identify, name, and secure the resources to retain a project coordinator who will oversee the implementation of the strategic plan in its entirety over its two-year timeline. This individual needs to demonstrate successful management of similar projects and have a working knowledge of the collaborative and its membership.

At this time, the collaborative lacks sufficient resources to retain the services of a project coordinator. The Advisory Council and Missouri Pain Initiative also lack the resources to provide the needed level of support and oversight to the effort. Thus, the ability to successfully implement the strategic plan as currently outlined is dependent on the collaborative's ability to identify and seek the support of potential funders who see and value the merits of our plan and are willing to provide the monetary resources needed to hire a coordinator. Finding and securing funding now becomes the next priority action item for the Council, MOPI, and the entire collaborative.

### **Outcomes**

As indicated earlier, the Council and MOPI established outcomes by which the success of the planning phase of the Changing the Face of Pain in Missouri collaborative initiative would be measured (see page 2). How have we performed?

With plans to expand the future DHSS Behavioral Risk Factor Surveillance System survey to include more pain-related questions we have addressed the outcome aimed at developing a more comprehensive system for data collection to better understand consumers. The Power over Pain campaign was successfully integrated into our 2006 Pain Awareness Month action plan and remains a key feature of our consumer education and engagement efforts over the coming years.

Convening the two meetings and going through the process of building the collaborative has heightened the awareness of both the Missouri Pain Initiative and the Advisory Council and has clarified our respective roles in helping to shape education, advocacy, and policy around pain management issues. The Missouri Pain Initiative is viewed as the convener, the centralized clearinghouse for information and resources related to raising awareness in both the public and provider sectors, and the craftor of the media message on pain. The Advisory Council is viewed, quite appropriately, as the public policy force through which efforts to eliminate ambiguous statute language, secure a Joint Statement highlighting the support of pain management as a healthcare priority, prepare policy briefs, and dialogue with licensing boards about pain education needs are channeled. Both groups are seen as alliance builders and a joint guiding force in the development of appropriate pain management standards. A serendipitous outcome has been the forging of a more interdependent relationship between the two groups.

Since our strategy for Provider Practice Improvement hinges on yet-to-be released data analysis of the MOPI sponsored professional education survey, it may be premature to evaluate the success of our plans for improved access to effective pain care and integrating professional education into practice. We will have to leave it up to the other state pain initiatives and to the Alliance of State Pain Initiatives to determine whether or not we serve as a model on how to engage in a collaborative strategic planning process.

### **Acknowledgements**

The collaborative wishes to thank the Alliance of State Pain Initiatives, the Missouri Advisory Council on Pain and Symptom Management, and the Missouri Pain Initiative for their funding and operational support, without which, this effort would not have been possible.