

ANNUAL REPORT 2009

May 1, 2010

LETTER FROM THE TRUSTEES

For The Mayday Fund, 2009 represented a year of consolidating ongoing work to move knowledge into practice and supporting projects that enable leading clinicians, researchers and policy experts in the field of pain care to explore new directions and dimensions. Like many of our foundation colleagues, we sought to do more with less, which translated to honoring all of our multiyear commitments and to identifying nimble projects designed to change cultural preconceptions about pain and how it may be treated.

We continue to marvel at the creativity and resilience of the doctors, nurses and pharmacists who are pushing forward an agenda to address the under-treatment of pain and to confront the barriers to better care. From Mayday's vantage point, they are gaining momentum, as they methodically change medical practice by accumulating evidence on how pain is best treated at the bedside.

2009 was a unique year with respect to the intersection of public policy debates about health care reform and responsible advocacy regarding the better care of chronic pain. The Fund chose this opportunity to enable Mayday Pain & Society Fellows and members of the Advisory Committee that directs the Fellowship Program to convene a national panel. The charge was to strategize as to how chronic pain could be treated more responsibly in a reconfigured health care system. In November, The Mayday Fund Special Committee on Pain and the Practice of Medicine issued a white paper, [A Call to Revolutionize Chronic Pain Care in America: An Opportunity in Health Care Reform](#), which has been endorsed by more than 40 health care organizations and medical professional groups.

Key to the recommendations in the paper is the principle that everyone who suffers from chronic pain should have access to care that is timely and evidence-based. While this now exists as a goal, the challenge is still there to turn it into practice. What the process of creating the Special Committee and then the dissemination of the white paper showed us was that there is significant momentum amongst clinicians to advocate for more responsible and timely management of pain. While our grantees and Pain & Society Fellows have shown us this over time, the white paper confirmed that their dedication and determination could be taken to scale.

The grants made in 2009 represent the Fund's ongoing commitment to targeting resources to achieve its mission, 'to alleviate the incidence, degree and consequence of human physical pain.' We continue our support to create networks of researchers as a strategic way to build the field of clinicians who, in their daily practice, treat pain at the bedside and who, in their research, use science to find more effective ways to do this. As the field of pain care grows, we are witnessing

more initiatives to inform the ‘best practices’ of the various medical professions that treat pain. And, we are excited that discussions about the treatment of pain now address the critical role of primary care.

The challenge to conduct translational research and to deliver direct care at the bedside is a key part of many of the grants made in 2009.

In the arena of pediatric pain, the Fund supported a study to explore the genetic factors at play in children who suffer from chronic pain. Comparing genetic data of children and their parents may shed light on which genes – if identified – create pain sensitivity. We continued our support of the team that is testing the possible role that electrode simulated acupuncture may play in relieving needle-stick pain in newborns. And, in its second year, the project to use ‘quality improvement’ tools in the pediatric emergency department holds the promise to show more effective ways to treat pain in this fast-action setting.

It was quite exciting for us to once again underwrite international participation in the Canadian Institutes of Health Research Training Program, PICH: Pain in Child Health: Strategic Training Initiative in Health Research. The impact of the first round of the PICH Program is already evident in the number of trainees who now present at major international conferences on pediatric pain, who regularly publish in peer-reviewed journals, and who now hold academic and professional positions. Collegiality is the hallmark of the PICH program. The network is truly international and promises great strides forward in coordinated research and program development.

As we examine our grantmaking, we find there is often an overlap in projects that target changing practice through research, research designs that advance the science of pain while improving care, and projects that provide resources for immediate use at the bedside. This may be evidence of the progress that the field of pain care is making and also that potential grantees now approach the Fund at the point in their careers when they want to conduct translational research.

Examples of this synergy may be found in an ongoing Chicago-area research project that uses a ‘quality improvement’ strategy and state of the art pain treatment protocols to address the pain of adults who suffer from sickle cell disease. It is also evident in a new study the Fund supported to examine the role of diet in chronic headache pain, a study that introduced Mayday to the complex research that examines biomarkers. We continue to be excited by the potential of an ongoing study to examine the role biofeedback might play in relieving post-amputation pain. And to advance the use of technologies to better measure and map pain, we supported a pilot study to test whether Near Infrared Spectroscopy Systems might add to the armamentarium of pain diagnostic tools.

Two of the Fund’s ongoing projects that were targeted to specifically change practice culminated in 2009. The Nursing Home Pain Task Force launched the website, www.geriatricpain.org. This free site is designed to provide nurses in nursing homes with the tools they need to better assess and manage pain in an environment where resources are scarce and the need for training in pain management is enormous. The National Consensus Project on Pain and Palliative Care Education for Pharmacists held its capstone meeting and is now disseminating the findings, which will provide key curriculum resources for pharmacy schools.

Near the end of the year, the Fund supported projects that reflect the Fund’s continuing commitment to remain ‘nimble’ in response to key opportunities. For example, to call attention to the widespread non-availability of pain medications for those suffering from late stage cancer, we

contributed to a documentary film project, *“The Real Thing”* or *“Aside from the physical suffering, nothing is real.”* As with the Special Committee Report, the opportunity to engage a broader public audience to be better informed about pain and its care is one we feel advances our mission.

A second ‘nimble’ project is the grant made in partnership with [The Patrick and Catherine Weldon Donaghue Medical Research Foundation](#) to support the implementation of a “Stepped Care” model of pain management in the West Haven, Connecticut VA Hospital. The Donaghue Foundation has among its goals to “promote knowledge uptake of health research into the realms of health care delivery, practice and policy.” Donaghue and Mayday agreed to jointly fund one of Donaghue’s Research Leadership awards that combined interests in knowledge uptake with those in pain management. It is hoped that as the work on this grant moves forward it will prove useful to the Veteran’s Health Administration as it implements the ‘stepped care’ model system wide. We are particularly enthusiastic regarding this grant as it helps us to achieve an ongoing goal of working with fellow foundations to place pain more centrally in the delivery of medical care and it enables the Fund to provide support for the veterans who are in need of better pain care.

Our third ‘nimble’ project was to contribute support to the creation of “The Mitchell Max Neuropathic Pain Research Endowed Award,” offered by the American Academy of Neurology. This award to honor Dr. Max’s contribution to the field and to recognize his extraordinary leadership at the same time directs attention to pain research within Neurology. The first award will be made in 2011.

As we begin to shape the program of Mayday in 2010, we are excited by the number of new projects that are submitted and by the progress that many of our current grantees report. We continue to be deeply appreciative of the work that our grantees do and look forward to seeing the impact of their work as greater public attention is being paid to pain care.

TRUSTEES

Robert D. C. Meeker, Jr.
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A THOUGHT ABOUT PAIN AND ITS IMPACT OF THOSE WHO SUFFER – FROM THE REPORT BY THE MAYDAY FUND SPECIAL COMMITTEE ON PAIN AND THE PRACTICE OF MEDICINE

COMMITTEE RECOMMENDATIONS

The Mayday Fund Special Committee on Pain and the Practice of Medicine was co- chaired by Russell K. Portenoy, MD, chair of the Department of Pain Medicine and Palliative Care at Beth Israel Medical Center in New York City and Professor of Neurology and Anesthesiology at the Albert Einstein College of Medicine; and Lonnie Zeltzer, MD, Director of the Pediatric Pain Program at Mattel Children’s Hospital, University of California, Los Angeles (UCLA), and Professor of Pediatrics, Anesthesiology, Psychiatry and Biobehavioral Sciences at the David Geffen School of Medicine at UCLA.

After reviewing data and discussing the current status of pain management in the United States, the Special Committee recommends that:

- Every American who suffers from chronic pain should have **24/7 access to a well-trained primary care provider** who can offer—and coordinate—pain care that is high-quality, equitable, and cost-effective.
- Every American with chronic pain who needs sophisticated or high-tech treatment, or whose pain has not responded to best practices in the primary care setting, should have **access to evaluation and treatment by a pain medicine specialist**.
- **Every patient should expect to have pain managed in a manner that translates the best evidence into appropriate treatments**, and then coordinates these treatments into a plan that is likely to be effective in controlling symptoms and promoting function, while minimizing the risks associated with treatment. At the same time, such a plan should reduce the costs associated with duplicative and ineffective treatments.

In order to improve access to appropriate, high-quality, and cost-effective pain care in the United States, the following action steps should be taken:

- 1. Government, health care payors, and health care providers should develop and utilize coordinated health information technology (IT) systems to track pain disorders, treatments, and outcomes as a mechanism to improve pain care. Quality indicators and performance measures should be developed and applied, and the public should gain access to information on the performance of hospitals, doctors and other health care providers.
- 2. State medical and osteopathic boards, deans of medical and other health professional schools, directors of residency training programs in specialties and subspecialties that provide primary care, professional societies and other stakeholders should make sure that every trainee and health practitioner in the health professions has the skills to assess and treat pain effectively, including chronic pain. Licensing examinations should include assessment of clinical knowledge related to appropriate pain care.
- 3. The Health Resources and Services Administration (HRSA) should expand funding for pain training programs that address competencies in pain assessment and management aimed at pediatric and adult primary care physicians, as well as other health professionals who manage pain, such as nurses, pharmacists, psychologists, physical therapists, social workers and other providers.
- 4. The Department of Health and Human Services (HHS) should establish an independent

- commission to reform the reimbursement practices for chronic pain. At present, Medicare and Medicaid maintain fee for service systems that incentivize procedures and inadequately compensate professionals for the time required to assess, counsel and educate, and coordinate the care of chronic illnesses like persistent pain. This commission should explore outcome-based payments for a team approach for selected cases, revision of the disparity between non-procedural and procedural pain treatments, and parity for mental health services. Ongoing complex chronic pain management should be treated, when possible, with an interdisciplinary, rehabilitation-oriented, team approach with reimbursement for the team, rather than fee-for-service for specific individuals within the team.
- 5. The National Institutes of Health (NIH) should increase funding for pain research to a level that is commensurate with the size of a public health problem that affects millions of people. The research should put an emphasis on emerging therapies and translational research, comparative effectiveness trials, bio-behavioral treatments, and health services research, as well as basic science. More research should focus on ways to prevent acute pain from developing into a chronic illness and to prevent childhood chronic pain from becoming a lifelong condition.
 - 6. The Agency for Healthcare Research and Quality (AHRQ) should expand funding for studies aimed at finding a set of best practices that could be used to treat specific types of chronic pain. Providers and policymakers could use such information to develop and promote high quality pain management models.
 - 7. The U.S. Surgeon General should make public education about pain, especially chronic pain, a high priority. Such a campaign could educate the public about the risks of untreated and undertreated pain in children and adults as well as promote preventive strategies that can enhance wellness and reduce the risk for the development of chronic pain.
 - 8. Health care providers, insurers and government should work to eliminate disparities in access to pain care related to race, ethnicity, gender, age (e.g. children and the elderly), and socioeconomic status so that chronic pain for all individuals in need is recognized and treated without delay.
 - 9. Federal, state and local agencies should publicly adopt a balanced approach to the regulation of controlled prescription drugs, particularly opioids. The clinical decisions of prescribers should not be inappropriately influenced by fear of regulatory scrutiny. Research has shown that state laws continue to harbor requirements that are outdated or reflect poor medical practice. A balance must be achieved between the legitimate need to protect public safety and public health through efforts to reduce drug abuse and diversion, and the imperative to address the public health problem of unrelieved pain. Policies and actions intended to reduce abuse or diversion must also include a comprehensive public analysis of these actions on access to quality and equitable pain care, including access to medications required for legitimate pain management.

Conclusion

Reducing the burden of uncontrolled chronic pain is a societal necessity, a medical challenge and an economic requirement. Chronic pain, if not recognized and treated as a chronic illness, takes an enormous personal toll on millions of patients and their families, and leads to increased health care costs. Chronic pain can also compromise the productivity of the U.S. workforce. Although the impact of pain on patients and on society is among the most serious of public health concerns, chronic pain has been largely left out of the current national debate on health reform. The nation must take the necessary steps to re-define chronic pain as a unique chronic illness and must immediately address this public health crisis.

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

GRANTS 2009

PEDIATRIC PAIN

- ***Genetics and Chronic Pain - UCLA Pediatric Pain Program, Los Angeles, CA.*** A research grant to study genetic patterns in children who suffer from chronic pain and their parents. Contacts: Lonnie Zeltzer and Jennie Tsao
<http://www.mattel.medsch.ucla.edu/pedspain/home.php>
Grant: \$105,375 – Second and final payment of two-year grant of \$208,597
- ***Acupuncture for Relieving Pain in Newborns - Arkansas Children's Hospital Foundation, Little Rock, AR.*** A grant to study the effect of electrode simulated acupuncture to relieve the pain of heel sticks in newborns. Conducted in conjunction with the Stanford University Lucille Packard Children's Hospital. Contacts: K.J.S Anand, R. Whit Hall and Brenda Golianu
<http://www.archildrens.org/foundation/about/>
Grant: First payment of two-year grant of \$401,884 made in 2008. The final payment will be made in 2010
- ***PICH: Pain in Child Health: Strategic Training Initiative in Health Research - IWK Health Centre, Halifax, NS, Canada.*** A grant to support participation by international trainees in a Canadian Institutes of Health Research training program with goal of creating an international network of pediatric pain researchers. Contact: Barb Brown
http://paininchildhealth.dal.ca/pich/cgi-bin/view_page.pl?pageToView=content_main_WelcometoPICH!
Grant: \$50,300 – First payment of a three year grant of \$150,900

PAIN & EMERGENCY MEDICINE

- ***Improving Pain Management in the Pediatric Emergency Department -- Quality Improvement Initiative - Cincinnati Children's Hospital Medical Center, Cincinnati, OH.*** A grant to design and monitor quality improvement projects for pain in the pediatric emergency department. Contact: Srikant Iyer
<http://www.cincinnatichildrens.org/>
Grant: \$104,255 – Second and final payment of two-year grant of \$197,695
- ***Illinois Emergency Department Pain Management Collaborative - Department of Emergency Medicine and the Institute for Healthcare Studies, Northwestern University, Chicago, IL.*** A grant to support the project, "Improving Pain Management Through Surveillance and Quality Improvement – The Illinois Emergency Department Pain Management Collaborative: Project 1: Sickle Cell Disease, Acute Pain Episodes." Contact: Paula Tanabe
Grant: \$114,079 – Third and final payment of three-year grant of \$302,035

CHANGING PRACTICE

- **Task Force on Nursing Home Pain - The Sigma Theta Tau International Foundation for Nursing, Indianapolis, IN.** A collaboration with the John A. Hartford Foundation and The Atlantic Philanthropies to create educational resources for nurses who provide care in nursing homes. In 2009, the website: www.geriatricpain.org was launched. Contact: Keela Herr
<http://www.geriatricpain.org>
Grant: \$31,231.84 – Final payment of \$153,594 grant (Year 1 refund credited from 2008)
- **National Consensus Project on Pain and Palliative Care Education for Pharmacists - Southern Illinois University at Edwardsville, Edwardsville. IL.** A grant to support a pharmacy specific pain and palliative care consensus summit of leaders in the field of pain and palliative care pharmacology. Contact: Chris Herndon
<http://www.pharmacypainsummit.com/>
Grant: \$46,509 – Second payment of three-year grant of \$152,490

INFORMATION & RESOURCES

- **The John C. Liebeskind History of Pain Collection - University of California, Los Angeles, Darling Biomedical Library, Los Angeles, CA.** Contact: Marcia Meldrum
<http://unitproj.library.ucla.edu/biomed/his/pain.html>
Grant: \$5,250
- **Palliative Care Film Project, “The Real Thing” or “Aside from physical suffering, nothing is real” - International Association for the Study of Pain (IASP), Seattle, WA.** This 52 minute television documentary will focus on the global crisis in pain relief and the work of the International Union Against Cancer to advocate with leaders of the United Nations, the pharmaceutical industry, and governments to provide equitable access to the essential medicine that it is estimated over 600 million people will need to avoid needless suffering. Contact: Kathy Kreiter
<http://www.iasp-pain.org//AM/Template.cfm?Section=Home>
Grant: \$30,000

RESEARCH

- **Analysis of Biofeedback as a Therapeutic Intervention for Post Amputation Pain - Center for Pain Studies, Rehabilitation Institute of Chicago, Chicago. Ill.** A research project to test the effectiveness of new treatments for post amputation pain. Contact: R. Norman Harden
<http://www.ric.org/research/centers/pain/index.aspx>
Grant: \$79,507.92 -- Second payment of three-year grant of \$251,669.63
- **Proof of Concept Study using NIRS technology – Massachusetts General Hospital, Boston MA.** A grant for research using the CW6 machine with Real Time Control Near Infrared Spectroscopy Systems. The support is targeted to a small defining project that may provide a critical proof of concept to identify an objective index of pain to further ongoing work in measuring pain, and that may lead to further funding from private and public sources. Contact: David Borsook
<http://www.imagingpain.org/team.html>
Grant: \$29,370
- **Exploratory Analgesic Dietary Intervention for Chronic Daily Headache – Program on Integrative Medicine, University of North Carolina, Chapel Hill, NC.** A grant to support a translational research study to investigate a

multifaceted dietary strategy designed to address fundamental biochemical derangements believed to play central roles in the initiation, amplification and perpetuation of human pain. Contacts: Douglas Mann, Christopher Ramsden and Susan Gaylord

<http://www.med.unc.edu/phyrehab/pim/research>

Grant: \$119,988.85 – First payment of a two-year grant of \$239,985.96

RESEARCH AND CHANGING PRACTICE

- ***Implementation of a VA Stepped Care Model of Pain Management - Yale University School of Medicine and the West Haven VA Hospital, New Haven, CT.*** A partnership with The Patrick and Catherine Weldon Donaghue Medical Research Foundation to support transdisciplinary teams to conduct research while exploring the best ways to move knowledge into practice – Donaghue’s deep commitment to ‘knowledge uptake.’ This project is designed to include - as the name suggests - different steps in pain care. It starts with all-inclusive access to pain assessment and treatment services within primary care clinics. It continues with readily available secondary consultation services offering specialized pain care. The final ‘step’ is tertiary interdisciplinary pain care services offering pain consultation and evaluation by an interdisciplinary team. The invitation to work with The Donaghue Foundation on its Program For Research Leadership has enabled Mayday to make progress towards three goals: closing the gap between knowledge and practice, sharing the Fund’s mission to advance the better care of pain with fellow foundations, and making some meaningful contribution to the Veterans Health Administration.
Contacts: Robert D. Kerns and Patricia Rosenberger
The Donaghue Foundation: http://www.donaghue.org/about_donaghue/knowledge_uptake.php
<http://medicine.yale.edu/index.html>
Grant: \$100,000 – First payment of a four-year grant of \$400,000 matched equally by The Donaghue Foundation

FOUNDATION CITIZENSHIP

- ***The Council on Foundations***
Arlington, VA. -- \$2,440
- ***Philanthropy New York***
New York, NY. -- \$950

NIMBLE ADVOCACY GRANTS

- ***“The Mitchell Max Neuropathic Pain Research Endowed Award”- American Academy of Neurology Foundation, St. Paul, MN.*** A one-time contribution to help create the award to commemorate Dr. Max’s contribution to the field of pain management. Contact: Susan Dunlop
<http://www.aan.com/go/foundation>
Grant: \$7,000
- ***The Healthcare Chaplaincy, New York, NY.*** A contribution made in lieu of an honorarium for peer review.
<http://healthcarechaplaincy.org/>
Grant: \$1,000

PROGRAM RELATED PROJECT

The Mayday Pain & Society Fellowship: A Media & Policy Initiative was designed to equip physicians, nurses, social workers, scientists, and ethical and legal scholars with the skills to become effective advocates and spokespeople about pain issues in the United States. The Fellowship was established to build a community of experts in the pain management field that can effectively communicate to the public and policymakers. The Fellowship is steered by an advisory committee made up of some of the nation's leading experts in the pain management field.

In 2009, the Mayday Fund created the Mayday Fund Special Committee on Pain and the Practice of Medicine. This 22-person Committee released [*A Call to Revolutionize Chronic Pain Care in America: An Opportunity in Health Care Reform*](#), a report with recommendations to improve the treatment of pain in the United States.

Contacts: Carol Schadelbauer, Burness Communications

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

TOTAL GRANTS PAID IN 2008: \$827,226 net of refunds or repayments

FINANCIALS

The Mayday Fund Financial Statements are published on the website: <http://www.maydayfund.org>

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