

THE MAYDAY FUND CELEBRATES
15 YEARS OF GRANTMAKING

T H E

MAYDAY

F U N D

THE MAYDAY FUND IS DEDICATED TO ALLEVIATING
THE INCIDENCE, DEGREE AND CONSEQUENCE OF
HUMAN PHYSICAL PAIN.

THE MAYDAY FUND 2007 ANNUAL REPORT

This special anniversary report examines the work of our grantees over the course of a decade and a half. With it, we hope to call attention to the needs of those in pain. And, we wish to celebrate the amount a small foundation is able to achieve.

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LETTER FROM THE TRUSTEES

January 21, 2008

In 2007, The Mayday Fund furthered its mission to alleviate the suffering caused by human physical pain. The Fund attracted inspired proposals that spanned the human life cycle. Our grantees search for ways to understand and relieve pain in children, pain in adults, and chronic pain across ages and diseases.

A number of our grantees constructed networks that involved multiple sites and professional groups. In the spring, we contributed to a consensus meeting where pediatricians from across the United States met to explore best treatments for children with Complex Regional Pain Syndrome, one of the mystery chronic pain conditions resistant to treatment. Mayday also supported an Illinois Sickle Cell Hospital Network, which brought together teams at three emergency departments to develop treatment protocols and an alert system to address the often too long waits that patients experience during a breakthrough pain episode. In Iowa, the Fund assisted a network of rural emergency departments to advance the timely and effective care of children. And, complementary to the increasing recognition of palliative care as a critical component in the toolbox of medicine, we contributed to a demonstration project to collect evidence of palliative care's impact and effect.

In the arena of pediatric pain, creativity continues to emerge as one of the key components in designing better patient care. For example, Mayday supports a study at the Children's Hospital of Boston on "Headache and Sleep Disruption," where an actigraph, or watch-like activity monitor, is used to measure sleep behaviors. One of our newest projects will study the effectiveness of "Buzzy – the Boo Boo Bee," a distraction device to be used during immunization and venipuncture. In these studies, we hope to explore the role that new technologies might play in both diagnosis and care delivery.

Within the pain field, questions that surround the use of opioids have riveted public attention on the abuse of both drugs and prescribing powers. Counterarguments focus on the relief that opioids provide and the quality of life they make possible. Similarly, breaking news about dangerous side effects and medical liability suits have become factors to be weighed in developing care plans, especially for the chronic pain conditions

that seem to defy diagnosis and treatment. Cultural attitudes that counsel stoicism or the need to “brave it out” factor here, as does a lingering resistance to seeing chronic pain as a public health challenge.

To begin to address these challenges, the Fund made a grant to the “Pharmacy Pain Consensus Project,” under which a forum was created. The intent is to provide an environment where the issues may be more responsibly addressed and where practice guidelines for pharmacists will be developed. And, to help physicians better understand the complexity of the issues involved with opioid prescribing, the Fund contributed to the publication of the book, *Responsible Opioid Prescribing: A Physician’s Guide*. To help the broader public better understand the balance that may be struck between pain relief and concerns about abuse, the Fund made a contribution to the Center for Bio-Ethics “Balance Initiative.”

One of our goals has been to improve the care of pain at the bedside. The nursing home is one place where the dilemmas of prescribing and administering pain medications are quite obvious. Studies indicate that up to 80% of nursing home residents suffer from unrecognized or undertreated pain. When the Center for Medicare Studies polled its state organizations to choose three areas to focus on as they build programs to ensure quality of care, 49 of the 50 states chose pain management as a target. To respond to the educational needs of nurses, we asked if the Fund might join The Atlantic Philanthropies and The John A. Hartford Foundation in their National Nursing Home Collaborative Project. Mayday was responsible for adding a Task Force to the planning stage of this nationwide initiative to develop a reservoir of tools and strategies to improve pain treatment. Our hope is that, by inserting provisions for better pain care at the beginning of the project, we will construct a resource that may be adopted by any long-term care institution.

Another aspect of care at the bedside is the increasing role technology plays in understanding how pain registers in the brain. At the end of 2007, the Fund supported a project at Massachusetts General Hospital to study the use of infrared spectroscopy in the operating room with the aim to identify an objective reading of pain while a person is under anesthesia.

Our multiyear grants from last year continue to probe the complexity of treating pain. The projects tackle issues like cognitive impairment and the challenge it poses to conventional methods of assessing pain, pediatric burn pain, and the difficult question of whether chronic pain is a possible side effect of aggressive cancer treatment. We look forward to

seeing these projects spawn new areas of research and create more effective ways to treat pain. Furthermore, we see the potential of seed monies from Mayday to produce larger grants from government agencies as well as our fellow foundations.

As we begin 2008, we look forward to reviewing the proposals we receive. We anticipate supporting projects that are innovative and have the potential for a high yield in improved pain care. We remain deeply appreciative of the work that our grantees do and continue to encourage them to advocate for those they treat.

2008 also marks an important transition year for us, as William M. Dietel, our trusted advisor for 13 years, becomes emeritus. We wish to thank Bill for his unflagging wisdom, invaluable service and continuing good humor.

Trustees



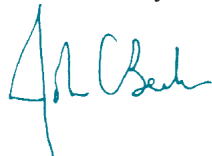
Robert D.C. Meeker, Jr.



Caroline N. Sidnam



Pamela M. Thye



John C. Beck

HISTORY OF GRANTMAKING

Since 1993 The Mayday Fund has awarded 157 discrete grants, representing almost \$12 million.

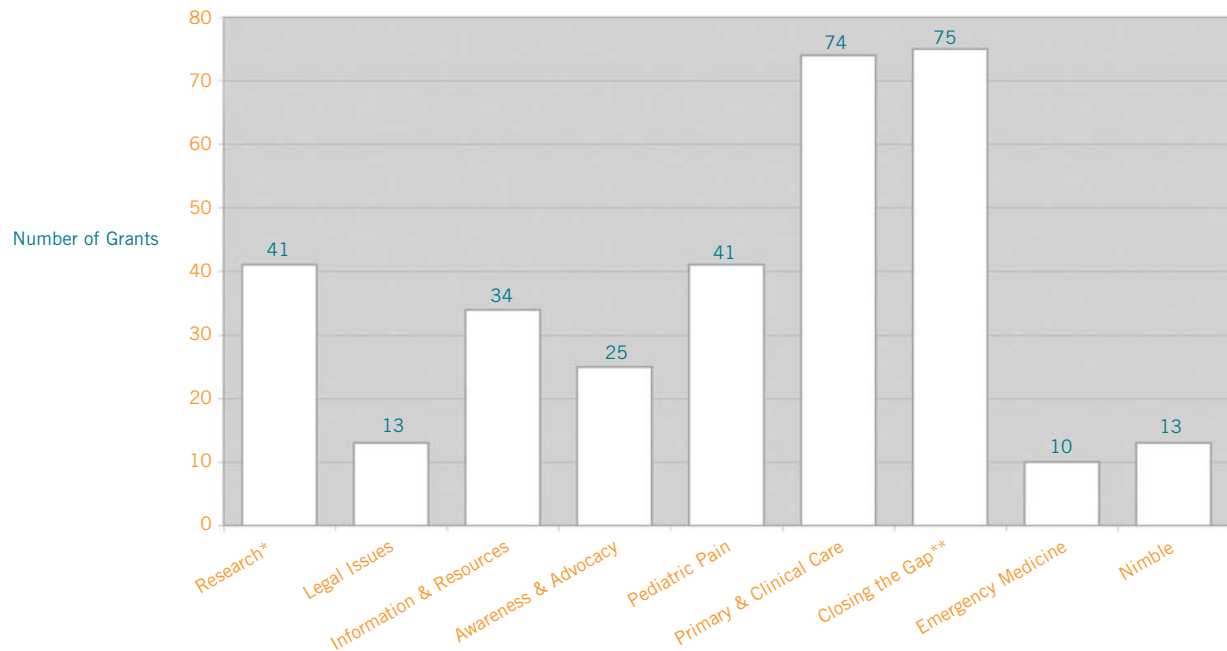
When we reviewed our past grantmaking, we identified nine major themes that characterize arenas in the pain field where our grantees have worked. The Fund has also made grants that we consider nimble; these defy categorization. The graph on the following page is a visual representation of these major themes.

One of the Fund's first initiatives was to commission a national poll to discover and pin-point the gaps in the public's knowledge about physical pain and its care. From this grew a series of programs to document pain and to encourage better treatment. As the Fund moved forward, it began to support new care delivery strategies, leadership models and innovative ways to bring the public's attention to the issues that surround pain. Through the work of its grantees, The Mayday Fund seeks to provide evidence that it is possible to close the gap between knowledge about pain and its care.

In this report, we present snapshots of information about our grants. Last year we requested that past grantees and other friends of Mayday complete an informal survey. We asked them to share past successes, challenges and where they think the future of the pain field will lay. Some of the following quotes, stories and statistics were drawn from this survey.

In 15 years, Mayday awarded 157 discrete grants. 41 were multi-year commitments. In a typical year, the Fund approved 11 new grants and continued support of 3 to 4 ongoing projects.

The graph below shows the range of work Mayday supported. The categories, according to which the grants are sorted, are not mutually exclusive. These overlaps reflect the nature of work in the field; often, many strategies are needed to advance the better care of pain.



*Within Research, there are 2 sub-categories:

Practice-Based Research (32 grants)

Evidence-Based Research (9 grants)

**Closing the Gap between Knowledge and Practice includes:

Changing Institutional Culture (27 grants)

Professional Training (25 grants)

Documenting Pain (23 grants)

“IT’S BETTER TO BE A RIFLE THAN A SHOTGUN.”

“It’s better to be a rifle than a shotgun,” are the memorable words of David E. Rogers, The Mayday Fund’s first advisor and past president of The Robert Wood Johnson Foundation. It is a tricky business, Dr. Rogers told us, to create meaningful change with minimal funding; Mayday would have the greatest impact by setting its sights on a precise target, and aiming for it with all we have. In this spirit, we identified a targeted mission that our resources could have the greatest impact on – the alleviation of the incidence, degree and consequence of human physical pain.

As we write this report, 15 years later, we realize how current Dr. Rogers’ advice remains. A review of Mayday’s grants from 1993-2007 shows the impact a small foundation can have when its focus remains clear.

We offer here a sketch of the types of projects The Mayday Fund has supported and the directions it has taken.

“Pain is something that makes us human – I cannot imagine being interested in people and not in pain.”

Scott A. Strassels

“I have heard so many stories from people who suffer [pain]; how can you turn away?”

Judith A. Spross

A Grandfather in Pain

One of my patients was living at home with his wife and his metastatic lung cancer. His cancer was a demanding member of the household, controlling every move with constant, mind-numbing pain in his back, arms and legs. It was a double blow, having pain take his life moment by moment, as cancer took it day by day ... The answer to his physical torment was deceptively simple: medication, initiation and adjustment. Such a straightforward, clinical intervention, however, masks the true success of the treatment. He relaxed his posture and guard. He lounged on the bed with his grandchildren playing around him. And he held them close when they slipped in to rest against him as small children do. He was restored to his family – and his place in the family.

As told by Joan K. Harrold

DOCUMENTING PAIN & INFORMATION RESOURCES

In 2005, Mayday gave a grant that used a Quality Improvement approach to assess and manage pain in the Neonatal ICU. Today, Brian S. Carter, the lead investigator, reports, "Practice has been changed and excellent pain management is now the expected norm in the NICU."

One of Mayday's first goals as a foundation was to put pain on the map of medicine. We did this by creating a role model program and supporting projects that ensured basic documentation of pain and its management in medical records. Today, the Quality Improvement movement emphasizes careful review of how patient cases are recorded and handled. Such projects have the potential to further the use of evidence in clinical decision-making and to reduce resistance to managing pain.

In the 1990's, information technology jumped forward, and Mayday advocated the use of newly available tools to document and disseminate information on pain. One project, PainLink, utilized the Internet to create a virtual community of interdisciplinary teams at 75 hospitals in 20 states from 1997-2002. Judith A. Spross, the lead investigator of this project, described the Mayday PainLink project as "ahead of its time with use of the Internet to connect clinicians and administrators who wanted to improve pain management."

Mayday was responsible for creating information resources large and small, both virtual and at the bedside. Many of the web accessible libraries and information sites that the Fund supported remain active today. Closer to the bedside, Mayday allowed for the lamination of a pain assessment card.

- **22% of total grants targeted delivery of information resources; more than half are web-based**
- **15% of grants have addressed the formal documentation of pain**
- **26% of grants were dedicated to research, in both practice and discovery**

RESEARCH: EVIDENCE FOR CLINICAL CARE

In the late 1990s, Mayday began to fund research with the goal of discovery and furthering the science of pain care.

Our intrigue began with the Brain and Central Nervous System and how each could be studied to document pain. For example, mystery pain conditions, like Complex Regional Pain Syndrome, were addressed in grants using fMRI scans and other technologies to map how and where pain acts. More recently, the Fund has begun to explore the effect of headache on sleep. And on next year's agenda is the domain of genetics as well as the challenge of translational research, where the coordination of laboratory and clinic will be critical.

These agendas resonate with the conversations we had with our grantees and other leaders in the field:

- 63% said further research was the top priority in the field
- 50% mentioned genetics as the future of the pain field; an area that may lead to both novel treatments and individualized medicine
- 33% mentioned neurobiology and the brain as areas where more research was needed and headed
- 63% called for new treatments including new agents or drugs as well as multi-disciplinary and non-pharmacological treatments

“The paradigm shift has to be in making pain a priority and the research agenda has to be supported at the highest levels.”

Kathleen M. Foley

“I think it is fair to say that without the Fund, we would not be involved in research at this time.”

David Borsook

Pain on a Friday Afternoon

I got a desperate email from a nurse in the rural Midwest at 3PM on a Friday afternoon. The worst time for a crisis – change of shift, heading into a lower-staffed, less well-resourced weekend – and yet when so many of them occur! The nurse told me about a situation where a psychiatrist had summarily stopped all analgesics because the dying patient (who had bipolar disorder as well as terminal cancer) should not be on “narcotics.” This precipitated a pain crisis for the patient. I put out an email APB to the physicians on the listserve to send an evidence-based email that the staff could use to persuade their colleague to do something differently. Within hours, many leaders in the field had sent material the nurse was able to use and the patient was put back on the regimen that worked for her. The power of Internet communication was so clear.

As told by Judith A. Spross

CHANGING INSTITUTIONAL CULTURE

“Anyone who works with children in the healthcare field can relate to the fear in the eyes of many children as they enter into the examining room and anticipate an injection.”

Neil L. Schechter

“Despite the existence of authoritative guidelines, pain is persistent and too often, under-treated in nursing homes ... One in seven nursing home residents have persistent, severe pain. One in four cancer patients with daily pain are not on any round-the-clock medications for their pain.”

Joan M. Teno

Better care requires change at every level of the health care system. From policy to clinical guidelines, pain needs to be brought into focus. Broad impact requires legislation and regulatory reform. No less important is changing the way both clinicians and patients think about pain.

Projects where pain is unquestionable and where there is consensus for better care are targets of opportunity. These include children with burns and adults with Sickle Cell Disease. More difficult is pain in non-verbal or cognitively impaired populations or persons with limited communication. The pediatric ward and the nursing home are among the places where we strive to meet the needs of these groups. Steven J. Weisman, of Children’s Hospital of Wisconsin, describes the challenge one of these vulnerable populations must face.

“Infants and children with developmental delay remain extremely vulnerable patient populations whose pain can be inadequately managed. These patients often lack the ability to communicate the amount of pain they are experiencing. In addition, they usually do not have the ability to take advantage of self-administered pain delivery pumps. Fortunately, observational pain scales are available.”

At the most rudimentary level, in order to implement change, it is necessary to revise the way medicine is taught. Inserting pain into curriculum is an ongoing project for the Fund. Beth Murinson – a grantee who designed a pain curriculum for the Johns Hopkins University School of Medicine – says that while the prevalence of pain is great, “at this time, there are only three US medical schools – out of 126 – with a required course in pain.” Additionally, “there are currently no federal funding sources devoted to improving medical student education in pain. Thus, foundation support is essential.” Almost 40% of our survey respondents said professional and/or public education about pain is crucial.

Bubbles – Distractions from Pain

One of my first pieces of research was training children to blow bubbles during painful procedures. This behavioral distraction technique was one arm of a multi-pronged treatment regimen. At first, the head nurse refused to allow bubbles in the treatment room. I persisted, and when the staff saw the impact on the child, parent and staff, it was welcomed. Now, bubbles are used everywhere!

As told by Leora Kuttner

FELLOWS & SCHOLARS: PAIN NEEDS A VOICE

One way to support leadership in the field is through Fellows and Scholars programs, where candidates are chosen in a competitive process and where their research or advocacy is given a public forum. This strategy has been in place since the first grants were made and has taken different forms over the years.

First, there were the Role Model Fellows, who became the reference points for responsible pain care in institutions eager to improve clinical practices. Then, Mayday, through the American Society of Law, Medicine and Ethics, supported several cohorts of legal scholars whose work informed decision-making at the national policy level. Currently, Mayday is supporting research fellowships through The John A. Hartford Foundation's "Building Academic Geriatric Nursing Capacity Initiative."

In 2004, the Trustees created the Mayday Pain & Society Fellowship. To date, 24 Fellows have been trained to work with the media, including print, broadcast and Internet resources, and to brief policy makers at the local, state and national levels. This program is a direct descendent of Mayday's first public education initiative, the commissioning of a public opinion poll to discover and pinpoint gaps in the public's knowledge about physical pain and its treatment.

- **48% of total grants aimed at closing the gap between knowledge and practice, a goal directly mentioned in Mayday's mission statement. One dimension of this category is changing institutional culture, an area that 17% of our grants addressed.**

"Transforming a researcher or clinician into a 'memorable' advocate is a big task, but if it works, it comes with endless opportunities for social change."

Carol Schadelbauer

A Mayday Pain & Society Fellow Finds His Voice

His natural instinct was to speak as an academic. His interviews lacked life, energy and passion; full of statistics and "doctor speak." Finally, at a coffee break, I cornered him: "Tell me why you do what you do." The story of Sarah came to life in the words of his answer. "That's it!" I said, "You've found your voice." After this, he realized the power of telling stories; how the children in the stories made the problem real. Since then, he has published op-eds, given passionate radio and print interviews, and delivered speeches with Sarah's story in the lead.

As told by Carol Schadelbauer

TELLING THE STORY: ADVOCACY, AWARENESS & HOW THE PUBLIC PERCEIVES PAIN

“We still have no organized government support for either centers of excellence in pain research, which could support clinicians and basic researchers in advancing pain therapies, and no institute to create the necessary leadership to advance pain research and policy in America.”

Kathleen M. Foley

Capturing the public imagination, to bring home the message that pain must be diagnosed, treated and managed is a high priority as well as a challenge.

News stories about pain range from pity to crime. Occasional exceptions communicate the excitement of new science or modalities of care. There is the human interest angle, as well, conveying the message of relief from suffering. To be trusted, these news pieces must be based on science and evidence, translated so that a member of the public might understand.

In the late 1990s, Mayday went to Hollywood. The Fund engaged actively in trying to place responsible stories about pain in prime-time television. One famous success was the episode of ER where a child blew on a pinwheel – a recognized distraction technique – while receiving an injection. Two films, “No Fears No Tears” and “When Every Moment Counts,” received support to spread the message that a child’s pain could be treated, as did a news and public affairs program, “To the Contrary.”

The Mayday Pain & Society Fellowship, mentioned earlier, is another way Mayday works to increase the ranks of clinicians who speak directly about pain in a way that the public and policy makers understand. Thirty-seven percent of our survey respondents argued that

Everyday Life as a Cancer Survivor

I get really nervous and scared whenever I have to ask for pain medicine and I absolutely dread every month asking for my latest refill because I have no clue what the doctor’s going to say ... and God forbid I try to ask for something different. It’s really hard for me because I’m used to having to fight for my medicine ... and the mere fact that I need the medication means that I don’t have the strength or confidence to fight. And then, of course, half the time they make me feel like a junkie because of what I do use, but honestly I haven’t found anything yet where I don’t need a pill or lozenge in my mouth every few hours ... and in all honesty, I’ve been afraid to say anything. It’s just so hard, not only the pain, but the guilt and the everything, and then there’s the sleep and tiredness stuff ... it just sucks. And the worst part is that I don’t even want to be ordinary. I want to be extraordinary, I want to change the world, but I can’t even get out of bed.

As told by a patient

more resources should be targeted toward giving pain a voice in public policy debates and regulatory proceedings.

One subject dominates much of the public discourse on pain care in the United States – the use of opioid or narcotic medications for pain relief. The potential for drug abuse with these medicines often overwhelms the discussion about how useful and helpful they are. According to Steven D. Passik, a 2006 Pain & Society Fellow,

“Opioid users run two parallel risks. They run the risk of addiction – if they have a predisposition to addiction or if they have not found a way to communicate their risk to their physician, which includes a previous history of addiction. And, they run the risk that that they will suffer the stigma of addiction even if they are not abusing the drugs.”

Fears of addiction confuse the issue. To respond to the need for balance between medical care and law enforcement, the Fund supported a number of studies aimed at collecting evidence on responsible opioid use and how the public and policy makers might be briefed on both risks and benefits.

- **16% of total grants included aspects of public awareness & advocacy**

“I called on the powerful influence of film to close the gap [between knowledge and practice]. Films with children speaking – displaying their struggles and breakthroughs – directly to [the] camera provide a powerful impact on the viewing pediatric professionals.”

Leora Kuttner

The obstacles are more complicated and inter-related than we first assumed. What really appears to be operating is a complex ecosystem that supports ambivalence, denial, and even suspicion of the circumstances of patients in pain and efforts to treat them.”

Sandra H. Johnson

FOUNDATION CITIZENSHIP

“The Mayday Fund – through its small but important grants – has had a major role in the evolution of pediatric pain management, thus creating a more humane healthcare environment for children.”

Neil L. Schechter

The successes of our grantees are evidence of the Fund’s effect. It is their work and activities that create the public image of Mayday. One quiet aspect of our work, however, is what we call foundation citizenship. To ensure that the work of the Fund respects “best practices” in the field, it is a member of the Council on Foundations and the New York Regional Association of Grantmakers.

We actively pursue partnerships with other foundations and advocate for the benefits that result from collaboration. In partnership, the multiplier effect of the funds granted becomes geometric. It also translates to bringing the message about the science and care of pain to a larger audience, a critical component of Mayday’s mission.

Other evidence of our citizenship is Mayday’s history of supporting multi-year grants. Additionally, in recent years, the Fund contributed indirect costs to some grants, in recognition of how vital capacity-building is for our grantees. The Trustees aspire to be innovative as well as nimble, and so suggest matching grants when appropriate to make a program or project sustainable.

And, in 2007, the Trustees resolved to dedicate its entire required payout to its charitable grants budget, assuming responsibility for program-related costs as an added expense.

Compared to organizations such as the National Institutes of Health (NIH), Mayday’s budget is small. We take pleasure in providing seed monies to studies to collect preliminary or pilot data. One of our achievements is when a grant turns our seed money into a more substantial study. One example is a Mayday grant of \$72,000 that led to one of \$3.1 million from the NIH.

- **26% of total grants were multi-year commitments**

CONCLUSION

As we review our work and listen to our grant recipients, we are impressed by how many see the need to change the health care system as an important step in addressing pain. Their work is directly influenced by public policy and the economics of health care. To effectively treat pain, many in our survey identified as important: changes in access and delivery of care, recognition and reimbursement for pain treatments, strategies that put pain forward as a public health issue, and creating federally funded Centers of Excellence for Pain Care.

In response to the magnitude of these recommendations, it is important to remember that Mayday is a family foundation. Its success reflects that of a family working together, debating direction, and weighing the difficult decisions about what areas to support and how to best guide the Fund. Because Mayday is small, the Trustees have worked hard to maintain their focus.

The Trustees are unanimous in the opinion that Mayday is a fitting tribute to the spirit of philanthropy entrusted to them. With Dr. Rogers' advice in mind, they have set their sights on pain and they have aimed almost \$12 million at changing how it is cared for.

"Mayday has been a consistently positive force and has been especially good at encouraging creative thinking and promoting projects that have the potential to drive interest and catalyze innovation."

Russell K. Portenoy

"We depend on the sufferer of pain for all information about its amount and its quality. A subtle essence has to be translated into words: the words themselves are used in different senses by different people."

John Kent Spender, 1874

REFLECTIONS ON THE PAIN FIELD

Marcia L. Meldrum is a historian of the field of pain medicine. She has compiled oral histories of many of the leaders of the field and has worked with The Mayday Fund in a number of ways, including helping to organize the archive of materials the Fund contributed to the John C. Liebeskind History of Pain Collection at UCLA. As the Fund moves forward, we thought it would be useful to ask Marcia for her thoughts on what is important in the pain field – at the “bird’s eye view.” In response to our questions, “where is the field now, where was it 15 years ago, and where do you sense it is going,” she shares these reflections.

Chronic pain has been the subject of creative research in the interdisciplinary pain field for 35 years.¹ Today we have a richer and more complex understanding of both its physiology and its holism. We have mapped many of the pathways by which the periphery and interior of the body send signals to the brain, observed the multiple biological and chemical events triggered by inflammation or neural trauma, and perceived the crucial roles played by tiny glial cells and by the cortex of the brain.

We have come to understand pain as biopsychosocial in ways that Engel and Fordyce only suggested.² We have observed that men and women, through their own thought patterns and behavior, can meld pain into their lives and structure their days around the pain, the fear of making it worse, the dependence on whatever keeps it even a fraction below the unendurable. And we have seen, too, that men and women can retrain their thoughts, restructure their behavior and remake their lives again, still living daily with pain but no longer under its tyranny.

We have discovered new pharmacological weapons against some kinds of pain and imagined many ways to use the old and the new: through transdermal patches, through slow-release formulas, through patient-controlled pumps, through nasal sprays. But none of the drugs we have are without flaws. The safest work best on mild, transient, pain. The best drugs we have for severe, chronic pain carry high costs for the patient – if not a loss in mental acuity, then the risk of stigma and ostracism – and for the prescribing physician, the risk of professional sanctions and, in some cases, prosecution.

¹ The interdisciplinary pain field dates from the Issaquah symposium organized by John Bonica in May, 1973. There was, of course, much creative research in the years immediately preceding.

² Engel George. Psychogenic pain and the pain-prone patient. *American Journal of Medicine* 26 (June 1959): 899-918. Fordyce Wilbert E., Fowler Roy S. Jr., and DeLateur Barbara. An application of behavior

We seek deeper and deeper in the body for more clues: we hunt proteins, peptides, monoamines, genes. We use advanced imaging techniques to map blood flow and oxygenation, so we can visualize the brain's activity when we feel pain. We make new and interesting measures to see how the chronicity of pain is associated with anxiety, or anxiety sensitivity, or somatization, or alexithymia, or self-efficacy, or self-competence, or functional disability. We can see now what pain is, we can watch what it does, we can measure its parameters.

But we are always conscious that there is some fundamental essence of pain that is only reachable through direct experience. The work of the American Pain Society (APS), the International Association for the Study of Pain (IASP), The Mayday Fund and patient support groups have given that unexpressible essence a voice. Patients write, they talk, they paint, they draw, they sing and dance, they show us and tell us their pain. We learn still more and understand still less. As one patient wrote on the American Pain Foundation site, "I have no words for the pain. Or perhaps I have too many."³

There are perhaps too many meanings for pain and they confound one another. At a very early stage in our evolution, pain warned of body damage and triggered cellular and behavioral mechanisms to protect the injured site. That pain is easy to understand and even to respect. But we evolved into a more complex species and pain branched out within our repertoire of learned behaviors. We learned to call on pain to hide from emotions we cannot face at the moment or to punish ourselves for not being perfect or to give ourselves a respite from stress. Or we learned to become so attuned to warnings that they sounded continually, beyond the need for protection. And those lessons became encoded in our nervous systems.

Beyond these meanings, pain is still part of the human condition. The body grows old or tired or less active and pain pulls at its nerve strings, no longer as a warning, but as a lament. To treat pain, we may need to silence the redundant warnings, to relearn the behaviors, to soothe the laments, and maybe all three in succession or all at once.

To put it another way, much of the research evidence suggests that pain mechanisms are woven deeply into the physiological fabric. Take, for example, glial cells, the specialized non-neuronal cells sometimes described as the "glue" of the central nervous system. Since the 1990s, we have come to understand that these fascinating little cells contribute to the

We can see now what pain is, we can watch what it does, we can measure its parameters. But we are always conscious that there is some fundamental essence of pain that is only reachable through direct experience.

modification technique to a problem of chronic pain. *Behavior Research and Therapy* 6 (1968): 105-107.

³ "allison", at: www.painfoundation.org/ManageYourPain/Creativity/PainArtContestWinners07.pdf, accessed 12/03/07. The patient art and writing on this site is worth viewing and pondering.

When we asked grantees about critical issues in the field of pain, 1 in 3 spoke of the need to dismantle the myths about the nature of pain and who it affects.

development and persistence of chronic pain. But they perform multiple other functions which are critical to the smooth and healthy operations of the central nervous system. So removal or inactivation of the glia are not therapeutic options; instead, we face the more complex task of finding a way to selectively inhibit their pain regulatory activities.⁴ As we learn more, we see more clearly that pain is a difficult challenge even for our sophisticated science.

In 35 years, the science of pain has taught us a great deal about our bodies and minds. But the most critical lesson we have needed to learn is empathy. Experiments with mice have shown that even these small animals exhibit sensitivity to the pain of their cagemates, but not to strangers.⁵ Yet chronic pain has often made the human sufferer a stranger even to his or her own family. We have seen those in pain as weak, lazy, over-anxious, masochistic, hypochondriacal, malingerers, overstressed, unable to cope. We have paid attention to some complaints of pain, but listened less attentively to the cries of women, to the aged, to people of color.

The complex mechanisms that can generate chronic pain are common to all of us. More than one-quarter of Americans report pain of extended duration.⁶ Those who suffer severe chronic pain are not different from us; they are not strangers. By learning from them and helping them, we will learn to help ourselves.



Marcia L. Meldrum, PhD

Co-Director, Liebeskind History of Pain Collection at UCLA

⁴ Watkins Linda and Maier Steven P. Glia and pain: past, present, and future in Merskey Harold, Loeser, John D., and Dubner Ronald. *The Paths of Pain* 1975-2005. Seattle: IASP Press (2005): 165-176.

⁵ Langford DJ, Crager SE, Shehzad Z, et al. Social modulation of pain as evidence for empathy in mice. *Science* 312 (June 30, 2006): 1967-1970.

⁶ National Center for Health Statistics. Health, United States, 2006 With Chartbook on Trends in the Health of Americans. Hyattsville, MD: 68-71

PEDIATRIC PAIN

Sleep Disruption in Adolescents with Chronic Daily Headache

Children's Hospital Boston, Boston, MA. A pilot project to address a gap in research about the interaction of pain and sleep problems. It targets chronic headache pain and will examine how “insufficient sleep and feelings of fatigue may increase pain sensitivity and interfere with an individual’s ability to cope with pain and perform daily tasks.”

Contacts: Navil F. Sethna, Jennifer Scott-Sutherland

Grant: \$64,088.50 – Final payment of a two-year grant of \$125,591

Outcomes and Parent Satisfaction Associated with Parent/Nurse Controlled Analgesia (PNCA) in Pediatric Patients with Developmental Delay

Children's Hospital of Wisconsin, Milwaukee, WI. The study addresses the challenge that children, who are unable to clearly communicate their pain experience, are at risk for sub-optimal pain control. It will provide recommendations regarding optimal pain management for this very high-risk pediatric patient population. Contacts: Steven J. Weisman, Michelle Czarnecki, Antonella Ferrise, Lynn Rusy, Jaya Varadarajan, Yvonne Anderson

Grant: \$120,842 – Final payment of a three-year grant of \$344,528

Development of Systems for Evidenced Based Management of Pain, Anxiety and Itch in Children with Burn Injury

University of Texas Medical Branch, Galveston, TX. A database with ongoing monitoring allows more timely review and speeds improvements in pain and anxiety treatments to injured children.

Contact: Walter J. Meyer

Grant: \$60,000 – Final payment of a three-year grant of \$180,000

Consensus Meeting to address Juvenile Complex Regional Pain Syndrome

Lucille Packard Children's Hospital, Palo Alto, CA. Contact: Elliot J. Krane

Grant: \$12,500

Buzzy – the Boo Boo Bee: Two Pilot Studies

Georgia State University, Atlanta, GA. A grant to clinically test a hand held vibrating and cold device placed on the skin to mechanically decrease or eliminate intravenous needle pain in two studies, one involving immunization, the other venupuncture.

Contacts: Amy Baxter, Lindsey L. Cohen

Grant: \$64,662.50 – First payment of a \$129,325 grant

The Child Kind Initiative: Preventing Childhood Pain Worldwide

Connecticut Children's Medical Center, Hartford, CT. Support for a consensus meeting to design an initiative to improve the quality of pain control for children. Child Kind will designate and accredit institutions that implement specific policies known to promote pain reduction.

Contacts: Neil L. Schechter, G. Allen Finley

Grant: \$50,000

Over the past 15 years, one in four grants awarded by The Mayday Fund has addressed pain in children.

“Infants and children in pain have no organized and insistent voice. They cannot lobby for themselves and their cries of pain are often ignored.”

Patrick J. McGrath &

Lynn M. Breaux

PAIN & EMERGENCY MEDICINE

Iowa Pediatric Pain Rural Emergency Department Network

University of Iowa, College of Nursing, Iowa City, IA. A grant to further pediatric pain assessment and management in rural emergency departments. Contact: Charmaine Kleiber
Grant: \$90,000 – First payment of a two-year grant of \$120,814

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: \$77,266 – First payment of a three-year grant of \$302,035

PAIN AT THE BEDSIDE – PRIMARY & CLINICAL CARE

PainCARE

UCSF Pain Management Center, University of California at San Francisco, San Francisco, CA. A matching unrestricted grant to the UCSF Pain Management Center for UCSF PainCARE, which began in 2004. PainCARE’s programs include a free grand rounds series and an online program based on the IASP’s Core Curriculum for Professional Education in Pain. Contacts: Pamela P. Palmer, Laurie E. Snyder
Grant: \$59,800 – Final payment of a three-year grant of \$179,400

National Consensus Project for Quality Palliative Care

Pittsburg, PA. Support for a demonstration project on the effectiveness of palliative care. Contact: Ken Zuroski
Grant: \$30,000 – Complete payment of a two-year grant

CHANGING PRACTICE

Task Force on Nursing Home Pain

American Academy of Nursing, The Building Academic Geriatric Nursing Capacity Coordinating Center, Washington, DC. A collaboration with The John A. Hartford Foundation and The Atlantic Philanthropies to create educational resources for nurses who care for pain in nursing homes. Contact: Pamela Dudzik
Grant: \$85,661 – First payment of a two-year grant of \$153,594

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 invitation-only consensus summit of leaders in the field of pain and palliative care pharmacotherapy. Contact: Chris Herndon
Grant: \$48,667 – First payment in a three-year grant of \$152,490

“The clear fact that nursing home residents need better pain assessment and management is being recognized by a growing number of organizations, including regulators and policy makers. This increasing awareness contributes to both internal and external pressures to implement evidence based strategies to improve practice.”

Cornelia Beck

INFORMATION & RESOURCES

The John C. Liebeskind History of Pain Collection

University of California, Los Angeles, Darling Biomedical Library, Los Angeles, CA.

Contact: Marcia Meldrum

Grant: \$5,000

The Center for Practical BioEthics

Balanced Pain Policy Initiative, Phase II – Kansas City, MO. A grant to address the regulatory environment and law enforcement involved in the practice of pain medicine, including advocacy for a more balanced policy to avoid the “chilling” effect on prescribing practices.

Contact: Myra J. Christopher

Grant: \$7,500

Educare: Redesign of The Mayday Pain Project Website

Fond du Lac, WI. Contact: Tim Havican

Grant: \$19,025

Federation of State Medical Boards Research and Education Foundation

Eules, TX. A grant to support the New Mexico distribution of the publication, *Responsible Opioid Prescribing: A Physician’s Guide.* Contact: Lisa Robin

Grant: \$10,000

RESEARCH

Vitamin D and Nocturnal Leg Cramps

University of Wisconsin, School of Pharmacy, Madison, WI. A grant to support the study “Nocturnal Leg Cramps in the Elderly: Randomized Controlled Trial of Ergocalciferol (Vitamin D2) for a Painful and Distressing Problem.” Contact: Mary E. Elliott

Grant: \$12,872

Finding an Objective Index of Pain in the Operating Room

General Hospital Corporation, Massachusetts General Hospital, Boston, MA. A grant to support research using the CW6 with Real Time Control Near Infrared Spectroscopy Systems. This study will further ongoing work in measuring pain. Contact: David Borsook

Grant: \$176,400

“I hope the Pain Specialist of the future will serve a transitional role in assisting major medicine in returning to its roots of curing when we can but treating suffering always. This pain specialist will be the role model assisting all physicians from all clinical fields to integrate care of pain and suffering into standard practice.”

Scott M. Fishman

THE PREVALENCE OF PAIN IN CANCER SURVIVORS

Pain in Cancer Survivors

Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center, New York, NY. A study to identify the prevalence of pain in adult cancer survivors and to examine the characteristics of their pain. A second aim is to compare health-related quality and psychological distress in adult cancer survivors with and without pain, when controlling for the effects of medical and socio-demographic variables, distressing physical symptoms other than pain, hopelessness, social support, and stressful life events. Contacts: Steven D. Passik, William S. Breitbart, Lara K. Dhingra

Grant: \$99,228 – Final payment of a two-year grant of \$194,286

“The Mayday Fund has a disproportionate influence on pain in the United States and around the world. By means of strategic investments that are quite modest, the Fund is training a whole generation of policy and public relations spokespersons, is seeding new ideas and leveraging other research dollars and training the next generation of researchers.”

Patrick J. McGrath

FOUNDATION CITIZENSHIP

New York Regional Association of Grantmakers

New York, NY. – \$850

The Council on Foundations

Washington, DC. – \$2,680

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. Contact: Carol Schadelbauer, Burness Communications

TOTAL GRANTS PAID IN 2007: \$1,097,042

FINANCIALS

The Mayday Fund has assets of almost \$30 million and a charitable grants budget of approximately \$1.1 million. The financial information for The Mayday Fund is available on the website www.maydayfund.org.

THIS IS THE STORY OF MAYDAY THROUGH THE EYES OF THE PEOPLE
WHO DREAMED ITS CONCEPT AND CARRY FORWARD ITS MISSION.

THE MAYDAY FAMILY STORY

In February of 1986, Shirley Lazo Steinman Katzenbach wrote a letter to her three children regarding her will and her wishes with respect to her estate ...

“The new scheme is to ... use this part of my money to create a charitable fund for you to distribute as you like. I like this plan because it allows you to become personally in control of how the money is used ... I hope this plan will provide some extra pleasure for you.”

Shirley always knew what she wanted and was quietly resolute in going after it. In her philanthropic endeavors, she did not simply write checks. Shirley researched her causes, became actively involved in specific projects within organizations, and garnered great satisfaction from doing so. As she once noted, “There’s a lot of fun to be derived from such individual giving.” The memories I have of my grandmother, Shirley, are limited, as she passed away when I was seven. So, to write about her influence on the creation of The Mayday Fund, I rely on the memories of her children and friends.

Shirley had a lifelong passion for medicine and the health sciences. Coty Sidnam, Shirley’s younger daughter, recalls: “Although my mother was not a doctor, her subscription to JAMA was as basic to the household as those to Time and Life. Had she been born in another era, I am confident she would have gone to college and medical school instead of secretarial school.”

Pamela Thye, Shirley’s older daughter, tells the story of Shirley’s work in the Lenox Hill Emergency Room during WWII: “She was allowed to do procedures – stitching wounds, giving injections – which today would be unheard of for a laywoman, but it confirmed her fascination with medicine.”

“Pixie-like” is how John Beck, a Mayday trustee and friend, describes Shirley. He recounts how intelligent, bright, irreverent, persistent and effective she was. And Dr. Kathy Foley, another friend, shares a favorite memory of Shirley’s pragmatic nature: with great wealth at her disposal, Shirley refused to take taxis, preferring instead to walk or take public transportation. After all, the money might be put to better uses.

When Shirley died in 1991, her children agreed that her true wish was for them to work together, even though her will left the final decision of forming one fund or three up to them. Bob Meeker, Shirley's son said, "The responsibility thrust upon us was truly intimidating. Clearly [it] was to be a philanthropic learning tool, and the challenge was thought provoking."

In 1992 Pamela, Bob, and Coty created The Mayday Fund; a single foundation with a targeted mission. All agreed the pain field was an area in great need of resources as well as an issue closely tied to their mother's interests. Selecting a name for the foundation took some time, though once arrived at, seemed a "no-brainer." Not only was Shirley's birthday May 1st, but "Mayday" is the international distress call for help.

My own introduction to Mayday was through stories I heard around the dinner table. My mother would come home from trustee meetings so excited about what she had just learned. Her face would light up when she talked about new ways to map pain in the brain or advanced techniques of measuring pain in children. As I got older, I jumped on opportunities to attend these meetings as both a "next generationer" and a fascinated bystander.

Mayday has been extremely successful in recruiting superb talent for its advisors and directors. When they started the Fund, Pamela, Bob and Coty were all quick to admit that they knew almost nothing of the pain field. For that reason they have always been extremely open to information and advice from every arena: scientists, doctors, lawyers, philanthropic experts and more have all sat down at Mayday's table and many have been adopted into Mayday's extended family.

William Dietel, a former president of the Rockefeller Brothers Fund and a current advisor to The Mayday Fund, describes his experience: "At times I think I was a kind of outsider who was needed as a cheerleader. Just because they were small did not mean that they couldn't be philanthropic entrepreneurs. The kit bag available to them to do new and different things with their passion was bigger than they seemed to realize and it was really quite good fun to help them understand their potential and how good they were."

"The positioning and success of The Mayday Fund is attributable," Bob says, "to the knowledge, enthusiasm and professionalism of the directors we have been so fortunate to have." Fenella Rouse, trained as a lawyer and the first of Mayday's two outstanding directors, knew Shirley from their work together in the "Right to Die" movement. Her background and prior friendship with Shirley made Fenella an invaluable addition to Mayday.

No less credit goes to Christina Spellman, the current director. When Christina started in 2001, she brought a fresh approach to the work of the Fund that stemmed from her

background as an academic in the social sciences. Under both of its directors, The Mayday Fund has flourished tremendously.

Additionally, both directors have been adroit in their ability to carry forward Shirley's wishes. As Pamela points out, "It is interesting to visualize both Fenella and Christina (who Mother never knew) so accurately representing Shirley now: Fenella bringing into being all that Mother had hoped to achieve and Christina's intuitive intellect and refreshing curiosity," which has brought an ever evolving maturity to the Fund's work.

The newest member of the Mayday family is scientific advisor Dr. Robert Cook, the General Director of New York City Zoos and Aquarium for Wildlife Conservation Society (WCS). Trained in veterinary medicine, he too knew Shirley from her philanthropic work. "Shirley provided the funding for my residency training that brought me to WCS," then known as the New York Zoological Society. In Shirley's description of the gains and satisfactions of working with the Society, her enthusiasm was apparent. "Fascinating trips, talks, films and people. Visits to [the] animal hospital, especially the nursery and operating theater. Watching a gorilla have a scan! The best parties in town!"

Over the past 15 years, the original \$13 million has more than doubled and the Fund has already given close to \$12 million in grants. I believe Bob speaks on behalf of everyone at Mayday when he says, "The success of the Fund, its recognition within the foundation community, and therefore its empowerment to be continually more productive, bespeaks all the goodness that can be said of it."

As a pro-active and nimble foundation dedicated to helping those suffering from pain, Mayday represents the ideals Shirley Lazo Steinman Katzenbach stood for. Coty, when asked why she continues to participate in Mayday, responded, "Because it is important, because it is interesting, and because it is our legacy and promise."



Emma X Sidnam Pucci

MISSION, PRINCIPLES & GUIDELINES

The Mayday Fund was established in 1992 to further Shirley Steinman Katzenbach's commitment to social and medical causes. The Trustees decided to adopt Mrs. Katzenbach's special interest in the treatment of pain as the Fund's mission. The name Mayday commemorates the date of her birth and is the international word signaling a cry for help, taken from the French "m'aidez" or "help me."

MISSION

The Mayday Fund is dedicated to alleviating the incidence, degree and consequence of human physical pain

PRINCIPLES

It is better to be a rifle than a shotgun

Mayday understands that creating meaningful change with modest funding is a formidable challenge.

It is necessary to close the gap between knowledge and practice

Excellent research has already led to a wealth of information about the treatment of pain, but existing knowledge still needs to be effectively used.

APPLICATION GUIDELINES

Mayday's current grant-making targets are:

- projects that result in clinical interventions to reduce the toll of pain
- pediatric pain
- pain in non-verbal populations
- pain in the context of emergency medicine

The Trustees of The Mayday Fund wish to remain nimble in order to respond as special opportunities are identified.

TRUSTEES

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Caroline N. Sidnam

Pamela M. Thye
John C. Beck

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