

The Mayday Fund Annual Report 2019



May 14, 2020

As we review the grants made by The Mayday Fund in 2019, it seems they represent a different world than the one we now inhabit in the climate of Covid-19. That world was one of sustained commitments to addressing the needs of those in pain in the service of Mayday's mission of "alleviating the incidence, degree and consequence of human physical pain." In this world, we recognize that support for the public health initiatives caused by the pandemic eclipse most other medical needs. Still, it seems to us that the needs of those in pain remain pressing and critical.

We know from our grantees that the challenge for the pain field now is to both sustain their work on the science and treatment of pain, while trying to anticipate how new strategies will be needed to address the pain caused by the pandemic. On this we have great respect for the work that our clinical grantees are doing to deliver medical care in a time of great crisis.

The 2019 grants offer a view into the complexity of addressing pain and suffering. As you will see in the list of grants made, The Mayday Fund supports research, both basic and clinical, that seeks to identify what causes pain and how it might best be treated. These grants allow exploration and experimentation at the pilot or 'proof of concept' level with the intent to improve evidence-based care.

New to our grantmaking in 2019 was support for patient registries for Early Stage Genetic Small Fiber Neuropathy and Fibrous Dysplasia/McCune Albright Syndrome. Registries have emerged as an essential way to study rare diseases because no one doctor sees enough patients to gather a sufficient sample size to be statistically valid. Researchers use registries to track the life history of how people with specific disease conditions change over time. They also allow scientists to more easily collaborate on shared diagnostic and therapeutic goals. By systematically collecting data, more will be known about the pain burden these people sustain. At the same time, it is hoped that having enough data will catalyze the development of new treatments.

The Mayday Fund also supports meetings and convenings that encourage collaboration across institutions. The goal here is to accelerate momentum through the use of networks. In the context of medicine as a whole the pain field is relatively small, so the possibility of creating working groups and cross institution research paradigms is more easily done. We have been able to support some of these efforts in the context of pediatric pain care and the rewards are promising. And, with Mayday's support, the "Pain in Animal Workshop, 2019" was hosted at the National Institutes of Health, resulting in an engaging and well attended conference where cross-species work on pain (including humans) was shared, and areas of opportunity to learn from pain research in different species were identified.

Among the treatments that The Mayday Fund has explored, Virtual Reality therapies seem to have captured the imagination of those delivering pain care in the clinic. In 2019, this research continued Mayday's long-standing interest in the role of distraction in treating procedural pain, especially in children. One grant explored how VR might enhance pain rehabilitation. Initial research indicates that playing in a VR world enables a child who feared movement due to the pain of injury to disregard that fear, and walk and play unencumbered. The question of whether VR might have an analgesic effect is now also on the research agenda.

A continuing key challenge in the pain field is to explain and communicate with the broader public about pain, what causes it, and how it might be treated. The Mayday Fund in 2019 sent 12 pain experts to communications training with the goal to empower them to share their knowledge and research beyond their existing professional networks. The Mayday Pain and Society Fellowship trains applicants, who are working on research and evidence-based approaches, to advance what is known about pain and how to best alleviate it.

While The Mayday Fund's grantmaking continued on an even course during 2019, it faced a challenge as a foundation when its reputation was called into question. In the context of the opioid epidemic, a report was issued by United States Representatives Katherine Clark and Hal Rogers, "Corrupting Influence: Purdue and the WHO," which among others named The Mayday Fund. At issue were grants made to the WHO in support of a pediatric pain project, the Mayday Fellows Program, and the American Pain Society. All agree that over-prescribing opiates has had adverse consequences for public health. However, The Mayday Fund itself takes no public positions on government policy, nor does it endorse one form of pain treatment over another. Mayday has never had any collaborative relationships with, nor has it taken funding from or given funding to pharmaceutical companies. Above all, we value the importance of evidence-based clinical care and continued research to help patients who may be in severe pain.

As we reflect on the work of The Mayday Fund in 2019, especially in light of the opioid epidemic and the deaths of despair that resulted, we are acutely aware of how challenging it is for our grantees to work in the field of pain medicine. There is still so much that needs to be discovered about the evolution and mechanisms of pain, as well as to identify and implement better models of care. We recognize that the boundaries between medical practice and society are malleable and that all we do is subject to both scrutiny and interpretation. At the same time, especially in the midst of the current Covid-19 pandemic, we realize the importance of supporting work in the pain field. Rigorous research and reasoned advocacy provide the hope that is needed in environments of turbulence and uncertainty.

Sending a mayday call for those in pain seems pressing now, perhaps more so than ever.

Yours,

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