May 1, 2019

Trustee Letter

The Mayday Fund logo, Morse code for SOS written in dots and dashes, has served the Fund well. To send a 'mayday' is to acknowledge danger and risk. The fields of pain research and medicine face the challenge that the prevalence of pain is great. In 2016 according to the Centers for Disease Control and Prevention, as many as 20.4% of adult Americans experienced chronic pain and 8% experienced high impact chronic pain. At the same time, the tools needed to address pain are limited. In response to this 'mayday call,' it has been the work of The Mayday Fund to responsibly support research, clinical care strategies and networking to provide tools and evidence that pain might be treated and eased.

In 2018 and continuing into 2019, the discourse on pain in the United States and in many other countries has been dominated by the Opioid Crisis and the ravages it has created. With this as a backdrop, the Fund sought projects that have the potential to discover both what pain is and how it works, as well as to aid in the development of evidence-based treatments that respond to real world clinical care of pain, both acute and chronic. Additionally, The Mayday Fund has continued to seek projects that cover pain across the life-span, from the neonate to the geriatric patient.

One target for the Fund has been 'biomarkers,' evidence that there is a signature for pain that can be identified, visualized and potentially corrected. In the last several years, the Fund has supported research in both biochemistry and neuroimaging as ways to advance this evidence. Among the projects supported in 2018 was one on the use of the cornea as a site to diagnose pain and another to clinically evaluate newly identified biomarkers that expedite treatment of multiple chronic pain conditions. A theme running through this work is how to better address the needs of those in chronic pain, a condition/disease that is both complex and mysterious.

Another target is to increase the body of knowledge about pain that might be used responsibly by scientists, clinicians and caregivers. The Fund contributed to two Lancet Commissions on Palliative Care and Pain Control (published in 2018) and on Pediatric Pain Support (in process). It hosted a meeting on "Non-Opioid Management of Chronic Pain: Developing Value-Based Models," at the Banbury Conference Center, where leaders explored strategies to better address how to support pain care as part of larger health care systems.

Pursuant to the Trustees' interests in creating networks to improve the quality of pain care, the Fund contributed to the National Academies of Science, Engineering and Medicine's Roundtable on Serious Illnesses that focused on pain. And, to better serve the pain research community, the Fund continued its commitment to the ongoing work of the Pain Research Forum.² At a more local level and to translate knowledge about pain into coordinated policies, the Fund made a grant to help create the Connecticut Pain Consortium. Led jointly by The University of Connecticut and the Jackson Laboratories, this initiative has the goal to create a network of public and private institutions to improve the quality of pain care across the State of Connecticut.

Since its creation in 1993, The Mayday Fund has been supportive of work done in the field of Pediatric Pain. In 2018, it funded several projects that address clinical care via the use of an app, Virtual Reality and distraction therapies. The Fund has convened a working group to develop "Core Outcomes for Persistent Pediatric Pain (COPPP)" to improve the standards of clinical trials involving children by revising what had become the gold standard for such trial design. To address the need to be certain that

¹ https://www.cdc.gov/mmwr/volumes/67/wr/mm6736a2.htm

² www.painresearchforum.org

³ Formerly known as the IMMPACT Statement

pediatricians more generally are attentive to pain, the Fund contributed to a working group that is developing a Pediatric Pain Fellowship for Pediatricians. Also, in the space of Pediatric Pain, the Fund continued its support of a pain focus in the development of a Pediatric Palliative Care and Pain Curriculum that will be shared internationally.

In the Virtual Reality space of Pediatric Pain, Mayday is supporting the development of new strategies to address pain rehabilitation and is working to develop new designs for using VR in the care of burns, where the burden is high for both the child being treated and the nurses who are delivering care. In the case of burn care, initial work supports the hypothesis that VR is useful and may possibly have an analgesic effect.

Perhaps the most challenging target for Mayday has been to identify projects that address the pain care needs of those who are communication impaired. Because self-report and self-assessment of the severity of pain are presently critical tools in a diagnosis, those who are unable to express their pain are vulnerable. This is as true for a new-born subject to various medical tests and procedures as it is for the older person with Alzheimer's. The search for biomarkers is one response; the need for interprofessional teams attentive to non-verbal cues such as grimace or guarding is another. While a good deal is being learned from animal models, this is an area where there is great need for training to understand what the person is unable to say in terms that are understood by the clinician. In many of the projects mentioned above, the researchers and clinicians who receive Mayday support are asked to be attentive to this issue.

Finally, the Fund will support a conference on the "Cross Species Measurement of Acute Pain" to be held at the National Institutes of Health in the Autumn of 2019. It also was exciting to welcome a new class of Mayday Pain & Society Fellows who actively embraced the task of translating their research into meaningful messages for the general public.

As the work of the Fund is focused on making a contribution to "alleviating the incidence, degree and consequence of human physical pain," we continue to be open to both the challenges and the promise of research as a guide to better care.

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