

## **Proposal for 2004-2005 Common Fund Grant**

Project: Medicine and Humanities Working Group

Project Title: Beyond Measure: Accounting for Suffering in the Context of  
Illness

Submitted by:

David W. Markham, M.D., Duke University School of Medicine (Co-Principal Investigator)

Deborah Pope, Ph.D., Department of English (Co-Principal Investigator)

Frances A. Neelon, M.D., Duke University School of Medicine

Nikki Vangsnes, Associate Director, Center for the Study of Medical Ethics and  
Humanities

### **Introduction**

A barrier is easily discernible between the medical institutions of our society and departments of liberal arts. By and large, practitioners of medicine do not engage in any sustained way with their counterparts in literature, philosophy, history, and art, to name just a few divisions of liberal arts in the university. While some few, exceptional programs have begun to explore cross-field interests in these areas, it is our observation, especially at our Duke, that these paths do not regularly intersect. We cannot help but wonder what might result if bridges were built between the various fields of science and the humanities. Our proposal seeks to diminish this institutional and professional divide, and explore the untapped potential. As an example, one might consider the nature of medical training in basic sciences and clinical methods. Increasingly smaller amounts of time are spent learning about modern cultural trends, the importance of spirituality, end-of-life care, or even the part of the interview -- much less literature or ethics or philosophy, though all potentially hold great meaning for the practice of medicine today. Conversely, how might the study of humanities be altered by increased knowledge of the medical context and advances in science? What would the mapping of some common ground reveal? What interdisciplinary partnerships might ensue around pressing – yet ageless—issues in ethics, aging, empathy, nature of self, quality of life, and end of life?

In this proposal we offer a model for a pilot program to consider these interrelationships in a focused, thematic way, with the eventual goal of a long-term interdisciplinary program in medical sciences and humanities. Among the significant faculty and university results we see from such as initiative are (1) innovative cross-field and cross-professional interaction; (2) positive impact on specific practices of care; (3) essential groundwork for faculty research and publication; (4) a lively forum for sifting university dialogue on complex, contemporary issues; and (5) not least of all, it further signals Duke's stake in an emergent medical/humanities movement shaping scientific and cultural inquiry. As E.O. Wilson has written, "the greatest enterprise of the mind has always been and always will be the attempt to link the sciences and

the humanities [because] when we have enough unified knowledge, we will understand who we are and why we are here.”

Our commitment to this project and our belief in its rich potential originates in work we have done this past year and a half on the planning board for the pioneering conference on poetry and medicine, “Vital Lines/Vital Signs.” Bringing together as it did just such a group of diverse Duke Faculty, with no previous connection, this undertaking has succeeded far beyond what we could have foreseen. In its collaborative workings and synergistic energies, in the productivity of research plans, new curricula, and professional development, this experience has spurred us to take the next step of extending our interdisciplinary inquiry to a wider, more sustained university presence. The Center for the Study of Medical Ethics and Humanities sponsored the conference, and Nikki Vangsnes, Associate Director, has offered the Center as an administrative and coordinating hub for the proposed Medicine and Humanities Working Group. This endorsement and assistance is a crucial aspect of our ability to carry through the logistical and practical demands of our proposal.

### **Proposal**

As we have noted, few sustained, institutionally supported opportunities exist for physicians and educators in the liberal arts to discuss ideas and learn from each other. Informative as intermittent lecturers and speakers might be, these events are not commensurate with the kind of multi-layered, interactive, developing dialogue that we envision arising from the program we propose. Therefore, we seek Common Fund support for the initiation of a Medicine and Humanities Working Group -- an extracurricular investigational group to bring together Duke Faculty, medical students, and graduate students for the investigation of important topics. The group will have the opportunity to learn from each other and pursue projects over the course of a year. Faculty from diverse departments will commit to full participation in the program, provide direction for projects, mentoring to the graduates, pursue related research interests of their own, and be responsible for assessment and evaluation.

Since we intend this forum, once instituted, to become a long-term feature of medical/humanities dialogue and collaboration, we see a number of issues and topics arising as guiding points for in-depth study on a serial basis. For this first year, the topic we have selected is *suffering*, specifically suffering in the context of illness. We have chosen this topic in part because of the frequency of proposals related to suffering submitted to the poetry and medicine conference, and also for its clear resonance across a number of humanistic and medical circumstances, technologies, materials, attitudes, and practices.

### *Participants and Structure:*

The faculty listed on this proposal will constitute the core group, with several additional faculty to be added. In this regard, we note that Reynolds Price (James B. Duke Professor of English), by any measure one of the real luminaries of our university, has expressed a strong interest in collaborating, as has Dr. Wesley Kort (Chair, Department of Religion). We have begun to recruit interested faculty from the university as a whole.

We envision an eventual core group of approximately ten faculty participants to serve as the Working Group. They will meet monthly to discuss issues regarding suffering and its context in illness and health care. **The primary function of this group will be to develop topics and issues for discussion, research, and collaboration.** They will also act as mentors for a group of medical and graduate students that will participate in monthly meetings. One of the distinctive components of this program is to extend inclusion in the seminar to selected, top students from medicine and the humanities. They will thus be encountering, at key points in their training and professional directions, perspectives and individuals with the potential for decisive intellectual and philosophical impact.

Thus, this program will bring together faculty and students from diverse backgrounds to discuss and learn about the nature of suffering in our modern age of medicine. The faculty, through both interactions with students and other professors from a wide variety of backgrounds, will have a unique opportunity to develop new lines of research and investigation. The Center for the Study of Medical Ethics and Humanities will serve as a key component to this project. Their conference room will house the meetings, and selected visiting professors invited by the Center will participate in the programs of the Working Group. Most importantly, the Center has a long-term commitment to developing programs such as this, and it is our hope that members of the Center can form relationships and collaborative programs through its involvement in this proposal.

*Projects:*

Both the faculty and the students will be responsible for projects within the seminar:

1) Faculty: The entire faculty involved in the Working Group, but particularly the core group submitting this grant proposal, will attend to the ongoing documentation and assessment of the program. The Working Group will develop research (initial examples are listed below), but the program is designed so that new areas of research can be discussed and enacted through the efforts of the Working Group:

A) Including information on suffering in the patient interview: This effort will examine how suffering might best be assessed in the physician-patient interview. No current method exists for evaluating a patient's expectation of his/her illness. We hope to begin developing questions that a physician might ask of a patient to most accurately define his/her level of suffering, including how disease affects family and work, how illness is perceived with regard to life expectancy, and how a doctor might help them through the course of their treatment. The Working Group will explore the possibility of fundamentally changing how the patient's history is collected and recorded to more accurately reflect past and current physical, emotional, and spiritual issues.

B) Assessing pain and suffering: Throughout modern medical times, various scales of pain have been developed to assess levels of pain in both adults and children. These scales are studied and included in protocols of pain control. There is, however, a great need to revise measurements of pain and to include suffering. Fully understanding

quantity and quality of pain and suffering may lead to a narrower gap between the patient and physician and improved expectations in this relationship.

C) Using poetry for teaching empathy and cultural awareness on the medical wards: The core group is initiating a project to study medical interns randomized to either study poetry or scientific journals during the first year of residency. The development of this project through planning and discussion of the Working Group might lead to a novel method for training young physicians and assessing their interactions on patients. Funding of this project could be a focus of members of the Working Group, and certainly there is the potential for non-medical faculty to have unique interactions with young physicians as this project develops.

In addition to the above projects, the faculty will produce a report on the program, not only relating what occurred during the course of the year, but also how the ideas arose and developed, and how discussing suffering may (or may not) have eventuated in changes with personal and/or professional relevance.

2) Medical and Graduate Humanities Students: Each student will identify a mentor and regularly meet with him or her to define and carry out a topic of research. Given the diversity of students it is likely that projects will cover a spectrum of interests and approaches. Students might develop a clinical project related to an aspect of suffering, or undertake some substantial creative project, or do produce a scholarly paper. The experience of direct collaboration will be important experience in establishing ways to frame common understandings and communicate across distinct professional cultures.

#### *The Ongoing Nature of the Program:*

We see this as a program Duke is exceptionally positioned to offer, with its obvious strengths as a medical center and a top-level humanities and research institution. Of no small importance, as well, is the alignment of the seminar's vision and purpose with the mission of Duke itself, that is, to "help those who suffer," "engage the mind," and "elevate the spirit." Therefore, our proposal is presented with every hope and intention that it will become a long-term effort. With a foundational year in place, we foresee an ongoing structure with rotating faculty, graduate students, and others convening in successive years around additional issues. Future topics might address aging, the relationship of science and peace, mental illness, healing, creativity in art and science, to suggest but a few among the many compelling possibilities.

Based on the outcome of this inaugural offering, we see several plausible routes for the transition, financially and administratively, to a self-sustained program. One possibility would be a more permanent program under the auspices of the Center for Medical for the Study of Medical Ethics. Another logical transition might be toward incorporation into an established curricular offering in the Medical School. This bodes well as an auspicious moment for this given the substantial reconfiguring of curriculum recently implemented. We could approach the prospects of affiliation with existing university bodies such as the Kenan Institute for Ethics and the Franklin Center. Additional routes might be sponsorship through private organizations, government grants, etc. It is also entirely possible, given the selection of focus in a given

seminar that we would seek funding from agencies specifically committed to fostering work on the topic.

### **Applicants' Biographical Sketches**

**David W. Markham, M.D.** is currently a senior fellow in the Division of Cardiology, Department of Internal Medicine at Duke University Medical Center. He has trained at The University of Texas Southwestern Medical Center at Dallas, University of Virginia, and Emory University School of Medicine. Being involved in the humanities and medicine courses and programs at each of these institutions, he has a strong background in teaching humanities to medical students and medical education in general. A program of medical humanities was initiated under his direction at UT Southwestern that has had growing influence and participation. His clinical interests include heart failure, cardiac transplantation, and general cardiology. Dr. Markham is a Faculty Associate at the Center for Study of Humanities and Medical Ethics. Email: [david.markham@duke.edu](mailto:david.markham@duke.edu). Phone: 970-1326.

**Deborah Pope, Ph.D.** is a Professor of English at Duke University. She serves on the Editorial Board of the literary magazine Free Verse, and is currently the chair of the Committee on Creative Writing at Duke. She received her Ph.D. from the University of Wisconsin-Madison and has published three volumes of poetry, which have been nominated for numerous awards. Her other books include A Separate Vision: Isolation in Contemporary Women's Poetry (LSU, 1984) and Ties That Bind: Essays on Mothering and Patriarchy (University of Chicago Press, 1990). She is currently teaching a course in poetry and the healing arts. Dr. Pope is a Faculty Associate at the Center for Study of Humanities and Medical Ethics at Duke University. Email: [dpope@duke.edu](mailto:dpope@duke.edu). Phone: 684-2899.

**Frances A. Neelon, M.D.** is emeritus professor of Endocrinology, has been a Fellow of the National Genetics Foundation and an editor for Diabetes Care. He is Editor of the North Carolina Medical Journal and was previously acting Director for Duke University School of Medicine's Clinical Research Unit. Dr. Neelon has published over one hundred articles in the North Carolina Medical Journal and other medical journals, numerous commentaries on medical practice and social issues as well as scientific investigative pieces. He is author of A Syllabus of Problem-Oriented Patient Care (Boston: Little, Brown & Co.) and has produced several book chapters on endocrinology. Dr. Neelon has long been interested in the role of literature in the formation and development of clinical practice. For the past 12 years he has been a regular supporter and instigator of the "Osler Literary Roundtable." Dr. Neelon is a Faculty Associate at the Center for the Study of Medical Ethics and Humanities.

**Nikki Vangsnes** is the Associate Director of the Center for the Study of Medical Ethics and Humanities. She directs the Center's Humanities in Medicine Lecture Series and oversees conference and symposia planning efforts. She currently chairs the planning committee for the upcoming conference "Vital Lines, Vital Signs: A Conference on Poetry and Medicine". She is also responsible for the research and development of new educational initiatives, strategic planning, and day-to-day management and administration at the Center. Prior to working at Duke, she worked for over nine years at the American Social Health Association (ASHA) where she was responsible for training and operations for the Centers

for Disease Control's National AIDS Hotline. Ms. Vangsnes holds a BA in Liberal Arts from the University of Minnesota.