

December 19,2009
Edward Miller, M.D. Dean, Medical Faculty
The Johns Hopkins University School of Medicine

Dear Dr. Miller:

It is with utmost enthusiasm that I propose that **Dr. Nancy Hutton** be promoted to **Professor of Pediatrics**, full time, with tenure. Dr. Hutton has achieved national and international leadership as a pioneering program builder and clinician-educator in the related interdisciplinary fields of pediatric HIV/AIDS care and pediatric palliative care. She is an international leader in the integration of palliative care into HIV/AIDS care and pediatric medicine.

Dr. Hutton is the founding Director of the Johns Hopkins Pediatric & Adolescent HIV/AIDS Program and its innovative Intensive Primary Care Clinic which cares for more than 250 patients annually, educates students, residents, and fellows, and provides the clinical "core lab" for scores of single and multi-center clinical trials and outcomes research projects. Competitive extramural funding for the clinical components of this program exceeds \$1,000,000 annually. Her national leadership in the field of pediatric HIV is evidenced by her appointment to the DHHS Working Group on Antiretroviral Therapy and Medical Management of HIV-Infected Children, the group responsible for developing and updating US national treatment guidelines. Her international stature is evidenced in her invited participation in training and technical assistance teams to disseminate best practices in pediatric HIV care and research worldwide. She has trained hundreds of pediatricians and other clinicians from nine countries in Africa and the Caribbean through the Pediatric AIDS Clinical Trials Group (PACTG) and the President's Emergency Plan for AIDS Relief (PEPFAR). The World Health Organization has recently requested her participation on an expert panel to develop international pediatric HIV counseling and testing guidelines.

Dr. Hutton is the founding Medical Director of Harriet Lane Compassionate Care, the palliative care program of the Johns Hopkins Children's Center, and Pediatric Hospice Medical Director for the Hopkins-affiliated Community Hospice of Maryland, the only specialized pediatric hospice program in the region. This integrated program provides interdisciplinary education, clinical care and consultation for a rapidly growing patient base, and research projects in health care decision-making, evaluation of the impact on health care professionals of caring for dying children, and evaluation of efforts to improve the quality and outcomes of pediatric palliative care. It provides the clinical infrastructure to develop an ACGME approved fellowship in Hospice & Palliative Medicine, a specialty formally recognized by the ABMS in 2007. Dr. Hutton is a national and international leader in the field of pediatric palliative care. Her national leadership is evidenced in her selection as a prestigious Soros Faculty Scholar in the Project on Death in America, her election to the Board of Directors of the American Academy of Hospice and Palliative Medicine (AAHPM), her recent appointment as a strategic coordinating committee chair for the AAHPM, her recent selection as a Fellow of the AAHPM, her membership on the national task force disseminating the National Consensus Project Guidelines for Quality Palliative Care (NCP), and her membership on the leadership steering committee of the Children's Project for Palliative and Hospice Services (ChiPPS) of the National Hospice and Palliative Care Association (NHPCO). Her international leadership is evidenced by her invited teaching and collaborations to establish pediatric palliative and hospice care integrated with HIV/AIDS care in Africa, Eastern Europe, and the former Soviet Union.

INTRODUCTION

Dr. Hutton attended the George Washington University School of Medicine and Health Sciences where she was member of the national honor society, AOA. She completed three years of residency in Pediatrics at the Johns Hopkins Hospital followed by two years as a Robert Wood Johnson Fellow in the General Pediatric Academic Development Program. During her fellowship she conducted a single-site randomized, placebo-controlled clinical trial of a commonly prescribed cold remedy that was published in the Journal of Pediatrics, receiving much media attention. She was later invited to testify before Congress regarding the outcome of her research.

She was invited to join the faculty in Pediatrics at the Johns Hopkins University School of Medicine in 1984 as Instructor and promoted to Assistant Professor in 1985. In 1998, Dr. Hutton was promoted to the rank of Associate Professor of Pediatrics.

PROGRAM BUILDING

Pediatric & Adolescent HIV/AIDS: "Intensive" Primary Care

Dr. Hutton's vision and leadership are extraordinary. She is a pioneer in designing and funding new programs and models of care that become pillars of the Department of Pediatrics and gain national and international recognition. In 1985, she identified the urgent need for comprehensive pediatric care and research for a newly emerging population of infants and children in Baltimore, those exposed to or infected with the recently identified pathogen causing AIDS. As an academic generalist, she created the innovative interdisciplinary Intensive Primary Care Clinic (IPC), bringing together physician, nurse practitioner, nurse case manager, social worker, and child life specialist professionals as a flexible and responsive care team with continuity of care from outpatient to inpatient to home settings. Dr. Hutton pioneered the integration of clinical trials research into the clinical care site, optimizing access to new investigational treatments for infants and young children while maintaining continuity of care before, during, and after a patient's participation in a clinical trial. The IPC has provided expert clinical care and access to clinical research for over 1000 children and adolescents infected and affected by HIV since 1985. Of these, 187 pediatric patients participated in 39 multicenter clinical trials representing 311 separate study enrollments. Survival for the cohort of perinatally infected patients is 80% over a twenty year period, significantly higher than reported by other domestic sites.

As the needs of patients increased in complexity over time, she funded and implemented the innovative model of co-locating specialty services, such as mental health care and dental services, within the primary care clinic setting. As children born with HIV survived into adolescence and increasing numbers of adolescents were acquiring HIV through risky behaviors, Dr. Hutton redesigned the model and scope of the IPC Clinic to integrate with the Adolescent Medicine practice. This unique approach has gained national recognition and stands in contrast to centers that created separate pediatric and adolescent programs or who separated HIV care into a specialty only clinic.

Dr. Hutton's program has provided a core clinical laboratory for numerous clinical trials of promising treatments for HIV/AIDS and its complications, and a core training site for generations of medical students, pediatric residents, and post-doctoral fellows in general pediatrics, adolescent medicine, infectious diseases, cardiology, and gastroenterology/nutrition.

Evidence of her vision and leadership is the vibrant interdisciplinary nature of the clinical practice model in the IPC Clinic. Dr. Hutton's team members share her passion for excellence. The team has grown from four to ten full-time staff members with high retention despite the challenges inherent in the work. Staff turnover has occurred only for family reasons (marriage, job transfer) over a 20 year span. IPC provides a valuable clinical training site for nursing and social work students and child life interns.

Since 1990, Dr. Hutton has competed successfully for numerous peer-reviewed extramural awards funded by the federal Ryan White CARE Act and administered by the Maryland AIDS Administration and Baltimore City Health Department, continuously funding the expanding IPC Clinic over two decades. Her program is evaluated rigorously through annual written proposals, annual site visits, quality assurance chart audits, fiscal site visits, and client satisfaction surveys. The IPC receives excellent reviews in all areas. Total clinical program funding awards for 2009 - 2010 are higher than ever, totaling more than \$1,000,000 annually.

Pediatric Palliative and Hospice Care: the new pediatric subspecialty

As the pediatric AIDS epidemic worsened, Dr. Hutton's work with dying children led her to develop expertise and leadership in the field of pediatric palliative and end of life care. She is a leader institutionally, regionally, nationally, and internationally in building palliative care programs for patients across diagnostic and age categories.

Dr. Hutton was invited to apply for and was selected as a Soros Faculty Scholar in the Project on Death in America through a highly competitive process. This award provided significant salary support for professional development from 1997-2000 allowing her to become one of the nation's experts in pediatric palliative care and one of only two HIV pediatricians with specialty certification in Hospice and Palliative Medicine.

Dr. Hutton is a leader in the successful development of Harriet Lane Compassionate Care, the interdisciplinary palliative care program for the Johns Hopkins Children's Center. As the only pediatrician in the State of Maryland certified by the American Board of Hospice and Palliative Medicine, she implemented significant changes in clinical care and professional education in the Johns Hopkins Children's Center. This program uniquely focuses on the

education and emotional support needs of health care professionals who care for children with life-threatening conditions. Dr. Hutton is highly regarded by peers and trainees as a mentor, role model, and consultant in palliative care.

Her vision of building a comprehensive regional network of palliative care services for children and adolescents is an extension of her success in innovative program development and implementation. In her dual role as medical director for the Johns Hopkins pediatric palliative care program and as the pediatric hospice medical director for the Community Hospice of Maryland, she has initiated several regional activities. She proposed and helped facilitate the first State Summit for Pediatric Palliative and End of Life Care in 2004, leading to the formation of the Maryland Pediatric Palliative Care Consortium. She collaborated with the State Office of the Attorney General and the Maryland Health Care Commission in their report on pediatric palliative care access in the state.

In 2006, she successfully partnered with the Maryland Pain Initiative to obtain funding from the Lance Armstrong Foundation to implement a program to improve pain and symptom management at home for pediatric oncology patients in central Maryland. This model project brings together hospital based oncology programs at Johns Hopkins, University of Maryland, and Sinai Hospital with home health care through Johns Hopkins and home hospice care through Community Hospice. Evaluation of program outcomes and effectiveness is planned so that successful components can be extended to other patient populations and disseminated to other regions of the country.

Dr. Hutton is leading a regional consortium composed of tertiary, specialty, and community hospitals, home health care, and hospices to develop and fund a model demonstration of perinatal and neonatal hospice and palliative care in Maryland. She is working with the leadership of Pediatrics at Home, the Johns Hopkins Home Care Group, and regional hospices to expand access to quality pediatric hospice care to all eligible children in Maryland.

The American Board of Medical Specialties (ABMS) recognized Hospice and Palliative Medicine (HPM) in 2007. Ten specialty boards, led by the American Board of Internal Medicine and including the American Board of Pediatrics, sponsored the first certification exam in 2008. Dr. Hutton sat for this exam and is now board certified in HPM for both pediatric and adult patients. She plans to develop a fellowship training program that meets ACGME approval.

Integration

Dr. Hutton brings these two fields together in her domestic and international work. Domestically, the IPC Clinic cohort represents the leading edge of the epidemic of long-term survivors with medically complex HIV disease and minimal social support; they are now experiencing disease progression and death and require expert palliative care. She leads the effort nationally to incorporate palliative care principals into US national treatment guidelines.

Internationally, HIV causes substantial suffering and death. Antiretroviral therapy is the best palliation for this life-threatening condition and is most effective when provided within a supportive care program that recognizes the multidimensional needs of this population. Dr. Hutton is recognized as a leading pediatrician with both HIV and palliative care expertise in the world. Dr. Hutton was an invited participant in the recent summit meeting on Pain and Palliative Care in Low Resource Settings sponsored by the Clinton Foundation and NIDA. As a collaborator in the PEPFAR-funded JHU TSEHAI program in Ethiopia, she leads the effort to establish a pain and palliative care program with the Faculty of Medicine of Addis Ababa University. Ethiopia currently ranks as the country with the lowest per capita use of opioid analgesic medication in the world. For example, children undergoing abdominal surgery at the premier teaching hospital receive only acetaminophen for pain relief, and only if the family can afford to pay. The impact of this pain initiative will change the practice of medicine and medical training in Ethiopia and disseminate effective models for change in Africa and throughout the world.

RESEARCH SCHOLARSHIP

In the field of pediatric HIV/AIDS, Dr. Hutton developed the first prospective cohort of HIV exposed and infected

children in the US and has provided continuous leadership in expanding and strengthening this clinical research program. This cohort has provided the pool of eligible participants for both observational and experimental clinical trials for over 20 years.

Dr. Hutton has been a productive investigator in the NIH funded multi-center Pediatric AIDS Clinical Trials Group (PACTG) since its inception in 1988 and she continues as Co-Investigator in the new International Maternal Pediatric Adolescent AIDS Clinical Trials (IMPAACT) Network. She is instrumental in the successful conduct of pediatric clinical trials at Johns Hopkins, contributing to groundbreaking knowledge in pediatric antiretroviral treatment, the prevention of mother-to-child transmission of HIV, and the prevention of opportunistic infections and other complications. Evidence of her leadership are the 187 children and adolescents representing 311 enrollments in 39 clinical trials over a 20 year period.

She was invited to join the national protocol team of the Pediatric Late Outcomes Study, PACTG 219/219C in 2000. This hypothesis driven, observational study has enrolled over 4000 subjects throughout the US. Dr. Hutton is a masthead author on 3 PACTG publications and is a study team member and/or site investigator for 30 additional publications. These publications document the profound impact that this clinical research has had on the health and survival of children. The rate of mother-to-child transmission of HIV has dropped from 25% to less than 2% in the US. Use of highly active combination antiretroviral therapy has decreased the mortality rate in children by 85%.

Her research collaboration and mentorship have resulted in 29 research and policy publications from the IPC clinical cohort. She mentored Dr. George Siberry in his development as an independent investigator in the CDC-funded Legacy Study & the development of the IPC cohort database that contributes to the multicenter HIV Research Network.

Dr. Hutton has been a strong advocate for the inclusion of children and minorities in clinical research and for equal access for children to cutting edge treatments for life-threatening conditions. Most recently she provided leadership in defining the ethical approach to enrolling foster children in clinical research, assisting the institution in its response to OHRP.

In the field of Pediatric Palliative Care, Dr. Hutton has co-authored 12 peer-reviewed articles. She mentored Dr. Renee Boss in her development as an independent investigator through an institutional K12 award. Dr. Boss has received numerous national awards as a junior investigator in palliative medicine. Dr. Hutton is creating a palliative care core in the Pediatric Outcomes Research Center as a means to promote rigorous evaluation and dissemination of best practices derived from the model programs she has developed.

Additional evidence of her impact are her authorship of 14 invited book chapters, development of two web-based curriculum modules on pediatric HIV palliative care, her role as the pediatric editor for a book on HIV palliative care for sub-Saharan Africa, and the recent publication of her revision of the AAHPM's pediatric self-study guide. She has given 124 invited lectures regionally, nationally, and internationally in the fields of pediatric HIV/AIDS and palliative care.

EDUCATIONAL SCHOLARSHIP

Dr. Hutton has a long history of training and mentoring fellows in General Academic Pediatrics, Adolescent Medicine, Pediatric Infectious Diseases, and Pediatric Gastroenterology & Nutrition in the area of HIV/AIDS. These mentees have gone on to faculty positions at Johns Hopkins, other US medical schools, and medical schools in India and South America, and to the NIH. More recently, she has mentored fellows in palliative care from the Divisions of Neonatology, Pediatric Oncology, and Pediatric Critical Care. All have gone on to academic faculty positions that combine their specialty with palliative care.

She is an active teacher of pediatric residents through inpatient attending rounds, outpatient clinic-based teaching,

didactic and experiential learning. In response to repeated requests from pediatric residents, she offers interdisciplinary electives in HIV care and in palliative care.

She has taught medical students in the Patient, Physician, and Society course over several years as a small group leader and teacher of palliative care through lectures and a highly regarded palliative care selective. The evaluations of this selective are outstanding. She is one of three core faculty developing the palliative care intersession for the new Genes to Society curriculum. She is the founding faculty advisor for the Big Buddy Little Buddy Program, a volunteer service program in which first year medical students are paired with a patient from the IPC Clinic for a longitudinal relationship of mentoring and social support. Approximately 40 students and 40 patients have been paired each year during the decade since its inception. Students graduating from the Buddy program attribute invaluable learning in professionalism to this experience.

She lectures in the School of Public Health annually about pediatric & adolescent HIV. She served on the dissertation committee for Annie Michaelis, a doctoral candidate in Health Policy & Management, mentoring her in the design and conduct of a qualitative study of a critical emerging issue, young adult survivors with perinatal HIV infection and their transition from childhood to adulthood. Dr. Michaelis is now a Research Associate for Monitoring & Evaluation at the Clinton Foundation after being selected in a highly competitive process.

She is committed to the interdisciplinary and interprofessional training and practice of pediatric palliative care, providing didactic and experiential training for Children's Center nurses, social workers, child life specialists, and chaplaincy residents. She leads the annual daylong palliative care educational retreat for Children's Center staff and is an invited physician faculty facilitator for regional trainings in palliative care.

She has provided extensive Continuing Medical Education for local and national audiences about pediatric HIV and pediatric palliative care.

CLINICAL SCHOLARSHIP

Dr. Hutton is heavily involved in patient care in all settings. She supervises the clinical care provided in the Pediatric & Adolescent HIV/AIDS Program, encompassing outpatient, inpatient, rehabilitative, and home-based care for over 250 patients. Her leadership has resulted in extraordinary survival for IPC enrolled patients, with 80% surviving over a twenty year period. She maintains an active clinical practice in the IPC Clinic, providing direct HIV primary care for patients with complex medical and psychosocial needs. She provides clinical supervision for nurse practitioners, pediatric residents, and fellows in the IPC, Adolescent, and Harriet Lane Clinics and the inpatient service.

Dr. Hutton provides clinical consultation to primary and specialty physicians regarding hospice and palliative care. She is developing a consultation service for the Johns Hopkins Children's Center in response to demand for HPM specialty care. She successfully competed for funding from the Thomas Wilson Sanatorium to initiate this service. Her inpatient consultations have

already reduced length of stay while improving patient, family, and staff satisfaction with care. During her leadership of the pediatric home hospice team, quality of care and satisfaction improved, resulting in a dramatic increase in referrals.

ORGANIZATIONAL and ADMINISTRATIVE

Dr. Hutton is a dedicated citizen in the Department of Pediatrics and the School of Medicine. Her active and committed participation on the Search Committee for the Directorship of the Department of Dermatology is strong evidence of her citizenship. She has also served on the Intern Selection Committee for the Department of Pediatrics and continues to meet with applicants with interest in HIV and/or palliative care.

Dr. Hutton's administrative duties as program director for the Pediatric and Adolescent HIV/AIDS Program encompass responsibility for program planning, budget planning, data management and reporting, and personnel supervision for the IPC clinic. As medical director for pediatric palliative care and for the pediatric hospice program,

she is responsible for promoting a continuum of quality care that meets the unique needs of children and families in organizations oriented to adult care.

NATIONAL and INTERNATIONAL LEADERSHIP

Dr. Hutton is highly regarded among her peers nationally and internationally for her exceptional care and teaching in the fields of pediatric HIV/AIDS and pediatric hospice and palliative care. She is a pioneer, defining the cutting edge of innovation in comprehensive clinical care models for vulnerable patient populations that incorporate interdisciplinary health professional education and the conduct of seminal clinical research.

Dr. Hutton's national reputation in palliative care is evidenced by her election in 2005 to the Board of Directors of the American Academy of Hospice and Palliative Medicine (AAHPM). In addition, she was appointed as Board liaison to the Academy's Ethics Committee that is charged with developing and updating the organization's position statements. She has served on the program planning committee and the scientific subcommittee for the Academy's Annual Assemblies in 2006 and 2007. In 2008, she was appointed as chair of a new Strategic Coordinating Committee of the AAHPM, charged with oversight of two standing committees on Ethics and Public Policy and two new task forces charged with building collaboration with domestic and international professional groups and awareness of this new medical specialty among health professionals and the general public. This role has taken on even greater importance during the current national health care reform process, with advocacy for health professional training, research funding priorities, and health care coverage and reimbursement. She was selected as a prestigious Fellow of the AAHPM in 2009 through a rigorous peer-review process.

Her appointments to key cross-cutting national committees are further evidence of her leadership. She was nominated by AAHPM leaders to join the National Consensus Project for Quality Palliative Care (NCP) task force, providing both pediatric expertise and HIV/AIDS expertise as this group works to disseminate its clinical care guidelines. The NCP Guidelines formed the basis for the Framework and Preferred Practices for Quality Palliative Care released by the National Quality Forum in 2007. It is anticipated that accrediting organizations, such as the Joint Commission, will utilize the work of the NQF to develop standards for palliative care in hospitals in the US, including a planned certificate program.

Dr. Hutton was invited to join the steering committee for the Children's Project in Palliative Hospice Services (ChiPPS) of the National Hospice and Palliative Care Organization (NHPCO). This group develops and disseminates national pediatric standards for hospice and palliative care; educational resources and curricula to build capacity to provide pediatric-specific hospice services, and advocates for full access to palliative care for children with life-threatening conditions.

As one of two experts in pediatric HIV/AIDS and pediatric palliative care in the US, she was invited to participate in the HIV/AIDS Workgroup of the Robert Wood Johnson Foundation funded program, Promoting Excellence in End of Life Care, resulting in a monograph calling on leaders in government and health care to renew commitment to integrating palliative care with HIV care and treatment in the era of highly active antiretroviral therapy. This message was incorporated into the President's Emergency Plan for AIDS Relief (PEPFAR), mandating the inclusion of palliative care in HIV care programs in PEPFAR countries.

Dr. Hutton's work has improved the care and treatment of children, youth, and families with HIV/AIDS worldwide. She is sought after as a colleague and collaborator nationally and internationally in the field of HIV and palliative care. She is an invited member of the United States DHHS Working Group charged with developing and updating national pediatric HIV treatment guidelines. She has provided specific consultation and training to HIV care and research programs in South Africa, Kenya, Uganda, Tanzania, Zambia, Zimbabwe, Guyana, and Haiti as part of the President's Emergency Plan for AIDS Relief (PEPFAR) and the Pediatric AIDS Clinical Trials Group (PACTG). She provides teaching and technical assistance regarding palliative care and pediatric HIV care for the PEPFAR-funded JHU TSEHAI project in Addis Ababa and three rural regions of Ethiopia. Her HIV clinical care model is being replicated

there, including the development of peer support and coping activities to enhance adherence to treatment. She mentors physicians there in pediatric HIV and in palliative care. She is leading the development and implementation of the pain and palliative care initiative at model centers in Addis Ababa for dissemination throughout the country.

Due to her reputation as an outstanding HIV pediatrician with demonstrated ability to work respectfully with diverse people and bring teams together, she was invited by the Office of the Global AIDS Coordinator in the US Department of State to work with African pediatric professionals in the development of pediatric content for the Clinical Guide for Supportive and Palliative Care for HIV/AIDS in sub-Saharan Africa, published for open access on the internet in 2006.

She was invited as the pediatric HIV and palliative care expert to join a delegation to Ukraine to meet with health professionals from the Former Soviet Union under the auspices of the Open Society Institute in 2004. She served as a core faculty member for the Pediatric Palliative Care Conference in Salzburg, Austria and the satellite conference in Tblisi, Georgia in 2007. She was an invited member of the scientific planning committee for the 2nd African Palliative Care Association meeting in Nairobi in 2008. She presented workshops on HIV palliative care topics with African and US collaborators at the XVII International AIDS Conference in Mexico City and at the 17th International Congress on Palliative Care in Montreal in 2008.

In summary, Dr. Nancy Hutton is an outstanding member of the Hopkins community whose pioneering creativity and dedication have produced novel programs with worldwide impact in two new and emerging areas of medical care and rigorous inquiry. Her unique contributions have made Johns Hopkins a world leader in pediatric and adolescent HIV/AIDS care and research. Her research in the prevention and treatment for pediatric HIV has resulted in worldwide changes in the care of children and families. Her innovations in the newer field of Hospice and Palliative Medicine have changed the way medicine is practiced in this discipline, including infants, children, and adolescents in palliative care programs, palliative care research, and palliative care policy in the US and throughout the world.

She has successfully mentored numerous young professionals in medicine, public health, nursing, social work, and child life who in turn have had global impact in the fields of pediatric and adolescent HIV/AIDS and pediatric hospice and palliative medicine.

As a result of her outstanding and groundbreaking clinical skills and deep compassion, she has nurtured a generation of young people who were expected to die, but who are alive today in no small part because of her commitment to excellence, her tenacity in the face of numerous barriers, and her vision of patient care as the core mission that gives meaning to research and education.

Sincerely,

George J. Dover, M.D.