ACADEMIC MEDICINE PORTFOLIO

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A. INTRODUCTION TO THE COMBINED PORTFOLIO

The Professorial Promotions Committee requested that I compile a portfolio addressing my impact as both a clinician-educator and program builder. The “Silver Book” describes “The Educator’s Portfolio” as the medium for “faculty who identify education as their primary expertise” to convey “evidence of creative educational scholarship.”¹ There is no companion description for a “program-builder’s portfolio.” After much thoughtful consideration about how best to respond to the PPC’s request, I have created two distinct sections in my portfolio: an educator’s portfolio following the outline provided in the Silver Book and a program-builder’s portfolio that seeks to provide information that parallels the same outline. I have attached a number of evidentiary documents as an Appendix.

The Silver Book states that the Educator’s Portfolio begins with a “Teaching Philosophy” statement. I believe that my professional values and goals form a unified whole, one that underpins my career as a physician scholar and leader in an internationally renowned academic medical center. I therefore introduce this combined portfolio with a single statement of philosophy.

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B. LEADERSHIP IN ACADEMIC MEDICINE PHILOSOPHY STATEMENT

The ultimate goal of academic medicine is to improve the health and well-being of people. Progressive, visionary leaders created the Johns Hopkins Hospital and the Johns Hopkins University School of Medicine more than a century ago to advance this mission through innovation in clinical care, clinical education, and basic and clinical research.² This “tripartite” mission continues to the current day, visible everywhere in the Johns Hopkins Medicine logo. My philosophy as an academic physician is guided always by the goal of improving the health and well-being of the patients who come to Johns Hopkins for help and for all the patients like them the world over. I do this through excellence in clinical care, development and leadership of innovative models of clinical care, facilitation of clinical research that informs best practices in the care of patients, and teaching future physicians and other members of the interdisciplinary health care team to practice and implement best practices that improve patient outcomes.

Health and well-being are not simply the absence of disease.³ Although identifying and treating curable diseases is one strategy to improve health, we practice in an age when there are innumerable chronic incurable conditions that must be effectively managed in a holistic way. Combining expert “medical” assessment and treatment with relationship-centered care⁴ that helps patients to understand and cope with their conditions is essential. I believe that excellence in clinical care requires intellectual rigor, keen observation, empathic communication, an understanding of the context in which the patient lives, and consideration of the individual patient as the center of care.

Providing this type of excellent care, teaching future clinicians how to practice excellence in clinical care, and creating new knowledge about the pathophysiology, diagnosis, and management of new and complex health conditions (our tripartite mission) requires innovative models of care that are responsive to the needs of individual patients and the trends in epidemiology and outcomes of these conditions. I have devoted my career to developing, implementing, and sharing such models. Pediatric and
adolescent HIV infection was one such new and complex health condition that appeared in Baltimore as I began my faculty time at Johns Hopkins. As outlined in my portfolio, I created a comprehensive care clinic based on the scholarly work in academic general pediatrics regarding care for children with chronic conditions, on the scholarly work in nursing regarding interdisciplinary clinical teams and home-based care, on the Hopkins tradition of excellence in clinical research, and on the ethical principle of justice and equal access for vulnerable and marginalized children to clinical trials of promising new treatments for this life-threatening disease. I expanded the scope of my work to specialize in hospice and palliative medicine, a field that embraces my values regarding individualized whole-person care in the context of the family and community, in order to serve as a role model and teacher for colleagues and future clinicians while mentoring junior faculty in their clinical research. Palliative medicine provides the framework for promoting the well-being of patients even as their physical health deteriorates, filling the gaps in disease-directed treatment models in order to achieve our ultimate goal: improving the health and well-being of individuals and those around them.


C. PROGRAM BUILDER PORTFOLIO

C.1. PROFESSIONAL DEVELOPMENT IN PROGRAM BUILDING

My development as a program builder began during my fellowship training in General Academic Pediatrics under the mentorship of strong program leaders at Johns Hopkins. I gained knowledge and skills through one to one mentoring and direct observation of successful strategies and models.

From 1997-2000, my professional development made a major leap while I was a Soros Faculty Scholar in the Project on Death in America. This experience immersed me in learning the emerging field of palliative medicine, created an enduring national network of exceptional colleagues, and launched my program building in pediatric palliative care. I continue to use the resources of this network in my program building, particularly the national conferences on building palliative care programs in academic institutions and the wealth of web-based tools disseminated by the Center to Advance Palliative Care (www.capc.org).

I prepared for and passed the certifying exam offered by the American Board of Hospice and Palliative Medicine (ABHPM) in 2003. 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. I took this exam and became formally certified in Hospice and Palliative Medicine for both adult and pediatric patients.
I am a leader in the physicians’ professional organization, the American Academy of Hospice and Palliative Medicine (AAHPM). I was elected to the Board of Directors for a three year term from 2005-2008. I chaired the Strategic Coordinating Committee for Ethics, Advocacy, and External Awareness from 2008-2010. I chair the Leadership Development Committee, created in 2010 and charged with developing a vision and plan that meets the needs of our diverse 4000 member organization. I rejoin the Board in February 2011, having been nominated and elected to the Executive Committee as Secretary.

C.2. PROGRAM DEVELOPMENT, DESIGN, INNOVATION, LEADERSHIP

1985 to current  Director, Johns Hopkins Pediatric & Adolescent HIV/AIDS Program

C.2.1 Pediatric & Adolescent HIV/AIDS: “Intensive” Primary Care

C.2.2 Research in Pediatric & Adolescent HIV/AIDS: The Impact of the IPC Clinic at Johns Hopkins University

C.2.1 Pediatric & Adolescent HIV/AIDS: “Intensive” Primary Care

I launched my career as an academic general pediatrician in 1984 with a focus on advancing the quality of care and health outcomes for children living with chronic and complex conditions through an enhanced primary care model that crossed diagnostic and subspecialty boundaries. Before the end of my first faculty year, I recognized that Baltimore’s children and families were already in the midst of the newest chronic, complex, and life-threatening condition of childhood – pediatric AIDS. I seized the opportunity and the challenge to develop a new model of primary care for children born in families living with AIDS – one that would serve our local community through excellence in clinical care while simultaneously seeking new knowledge about this little understood disease.

The historical context of AIDS in America did not provide a clear career pathway for me. The AIDS work being done at Johns Hopkins at this time was the groundbreaking Multicenter AIDS Cohort Study (MACS), a longitudinal observational cohort of homosexual men who visited the GCRC “Moore” clinic for periodic research visits. Nationally there were case reports of children with transfusion acquired AIDS and pediatric specialists at Johns Hopkins were beginning to identify a few patients in this risk group. Cases of infants presenting with evidence of immunodeficiency whose mothers had AIDS were being reported in select cities in the US. When I observed that the injection drug epidemic in Baltimore was already spreading HIV to sexual partners and children (the index patient and family for whom I cared in our primary care “well baby” clinic), I encountered disagreement from senior faculty. When I invested my academic time and talents to this new disease, my mentor discouraged my work.

I persisted. I created my own “private practice” of HIV-exposed or infected infants and children in the Harriet Lane Primary Care Clinic and applied successfully in 1987 for a grant from a local foundation, the Thomas Wilson Sanitarium, to support my effort. It became immediately clear that a solo practitioner could not meet the needs of these children and families. My scholarly focus became the creation of an interdisciplinary primary care practice model. A strong collaboration with a faculty member in the School of Nursing led to R01 funding (1988-1991) that supported an interdisciplinary care team (physician, nurse practitioner, social worker, home visiting nurse) to provide longitudinal primary care for enrolled cohorts of HIV-exposed and at-risk infants. In 1988, Johns Hopkins became a research site of the Pediatric AIDS Clinical Trials Group (PACTG); this grant included salary support for an additional social worker. The Intensive Primary Care Clinic (IPC) was born.
As the number of patients in the IPC Clinic increased steadily, their medical and psychosocial needs became more complex over time. I continued to innovate, shaping the care model in response to the changing demographics and clinical needs of the HIV population of children, youth, and families. Early on, I added a nurse case manager to coordinate patient care and a child life specialist to provide psychological preparation and coping for children, enhancing not only their experience but significantly decreasing our "no show" rate. I co-located specialty services, such as mental health care and dental services, within the primary care clinic to improve access and utilization. As children born with HIV survived into adolescence and increasing numbers of adolescents were acquiring HIV through risky behaviors, I redesigned the model and scope of the IPC Clinic to integrate with the Adolescent Medicine practice. This unique approach stands in contrast to other centers in the US that created separate pediatric and adolescent programs or that assigned HIV care to a specialty-only clinic. Now I am leading our clinical team through the development and implementation of a detailed process to transition young adult patients to adult medicine focused clinics and providers.

Since 1990, I have 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. My program is evaluated rigorously through annual detailed written proposals, annual site visits, quality assurance chart audits, fiscal site visits, and client satisfaction surveys (Appendix A, B, C). The IPC receives excellent reviews in all areas. Extramural awards for the clinical program total more than $11 million since its inception; FY2010 awards totaled $1,059,289. In order to maintain this program funding, I devote substantial effort to writing nine or more grant proposals per year and preparing and submitting quarterly narrative and monthly data program reports that vary in form and format across funding streams and over time (Appendix D).

<p>| Intensive Primary Care Clinic – Extramural Funding for Clinical Services Core (Hutton, PI) |
|---------------------------------|---------------------------------|-----------------|</p>
<table>
<thead>
<tr>
<th>Funding Period</th>
<th>Funding Source</th>
<th>Total Award</th>
</tr>
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<tbody>
<tr>
<td>1990-2011</td>
<td>HRSA (Ryan White)</td>
<td>$ 9,664,860</td>
</tr>
<tr>
<td>1998-2011</td>
<td>State of Maryland</td>
<td>$ 1,589,629</td>
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<tr>
<td>1990-2010</td>
<td>Private Foundations</td>
<td>$ 136,374</td>
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<tr>
<td>TOTAL</td>
<td></td>
<td>$11,390,863</td>
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</tbody>
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A total of 277 clients were served in our clinic-based and outreach programs in CY 2010. One hundred eighty-six have confirmed HIV infection and are enrolled for HIV medical care. Males represent 45%, females 54%, and transgender individuals 1% of the total. Household income is below the Federal poverty level for 80% of clients; 98% fall below 300% of the Federal poverty level. Sixty-nine percent are insured through Medicaid, 3% Medicare, and 18% are uninsured. Of the total population, 86% are Black, 5% are White, and 2% are Hispanic.

The following table shows the IPC Clinic patient enrollment over the past decade by HIV-exposure risk and by age category. From 1998-2008, we doubled our client enrollment. Although the rate of new infections due to perinatal transmission has dropped significantly over the past decade, it has not
dropped to zero, reminding us that HIV programs in the US must maintain pediatric expertise while being vigilant in preventing mother-to-child HIV transmission. The number of clients age 13 years and older increased 16-fold during this same time period due to the improved long-term survival of children born with HIV and the identification of new HIV infections in adolescents and young adults. The decrease in client numbers in 2010 reflects our concerted efforts to transition young adult clients to adult-focused clinics for ongoing care. The population of adolescents in Baltimore continues to be at high risk for HIV through sexual exposure and has become our primary focus for prevention and early identification.

<table>
<thead>
<tr>
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<th></th>
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</thead>
<tbody>
<tr>
<td>HIV-infected patients (0-24 years)</td>
<td>119</td>
<td>141</td>
<td>152</td>
<td>172</td>
<td>194</td>
<td>202</td>
<td>186</td>
</tr>
<tr>
<td>Perinatal</td>
<td>116</td>
<td>128</td>
<td>131</td>
<td>128</td>
<td>139</td>
<td>156</td>
<td>138</td>
</tr>
<tr>
<td>Transfusion</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>4</td>
<td>2</td>
<td>1</td>
<td></td>
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<tr>
<td>Hemophilia</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Heterosexual</td>
<td>8</td>
<td>16</td>
<td>22</td>
<td>23</td>
<td>25</td>
<td>32</td>
<td></td>
</tr>
<tr>
<td>Men sex with men</td>
<td>1</td>
<td>1</td>
<td>15</td>
<td>24</td>
<td>18</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>Injecting drug use</td>
<td>1</td>
<td>1</td>
<td>4</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>0-23 months old</td>
<td>11</td>
<td>5</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>2-12 years old</td>
<td>98</td>
<td>97</td>
<td>70</td>
<td>53</td>
<td>42</td>
<td>35</td>
<td>31</td>
</tr>
<tr>
<td>13-24 years old</td>
<td>10</td>
<td>39</td>
<td>80</td>
<td>117</td>
<td>151</td>
<td>164</td>
<td>154</td>
</tr>
</tbody>
</table>

The IPC staff now consists of a pediatrician/director, adolescent medicine specialists, pediatric and adult infectious disease specialists, two pediatric nurse practitioners, two nurse case managers, two social workers, a part-time psychiatrist, a child life specialist, a youth advocate, and an outreach worker. This team is sensitive to cultural issues with regard to age, gender, race/ethnicity, childbearing decision-making, sexual orientation, and history of substance abuse. The team is comprised of members who reflect the diversity of the clients we serve: women and men; birth parent, adoptive parent, and grandparent; gay/lesbian and straight; African American and Caucasian. The services currently provided by the IPC Clinic team are listed below:

**Ambulatory Primary Medical Care Services (1985), including:**
1. Infant therapies to prevent mother to child transmission of HIV (PMTCT)
2. Pediatric and adolescent HIV diagnostic counseling and testing
3. Comprehensive pediatric and adolescent HIV evaluation
4. Pediatric and adolescent HIV specific therapies (antiretroviral)
5. Pediatric and adolescent prevention therapies (opportunistic infections)
6. Periodic monitoring of disease progression and treatment outcomes (CD4, viral load, resistance testing)
7. Pediatric and adolescent health maintenance care
8. Pediatric and adolescent nutritional screening and counseling
9. Pediatric and adolescent acute illness and injury care
10. 24 hour on call for pediatric and adolescent concerns
11. Adolescent screening, diagnosis, and treatment of sexually transmitted infections
12. Adolescent family planning services
13. Adolescent screening, assessment, and referral for substance abuse treatment
14. Pediatric and adolescent screening and referral for mental health services
15. Pediatric and adolescent adherence counseling

Inpatient Care (1985) for pediatric and adolescent patients

Social Work Services (1988), including:
1. Psychosocial screening and assessment
2. Supportive counseling
3. Crisis intervention
4. Child abuse and neglect evaluation and referral
5. Caretaker support group
6. Referral of adult family members to medical care
7. Referral of adult family members for financial and housing assistance
8. Permanency planning

Case Management (1990) for those without Medical Assistance
1. Intake and assessment
2. Care plan development in collaboration with client
3. Monitoring of goals
4. Referrals to needed services

Care Coordination (1990) for those with Medical Assistance, including:
1. Referral of eligible patients to the REM Program
2. Linkage with REM case managers
3. Referrals for home care services
4. Prescription refills to assure adherence

Child Life Services (1993), including:
1. Developmentally appropriate psychological preparation and support for medical care interventions
2. Support for HIV disclosure
3. Teaching about HIV and medications
4. Peer support groups and social gatherings
5. Therapeutic camping programs

Mental Health Services (1997), including:
1. Psychiatric evaluation, diagnosis, and treatment planning
2. Psychotherapy
3. Pharmacotherapy and monitoring
4. Family therapy

Substance Abuse Assessment and Intervention Services (1997), including:
1. Assessment by interdisciplinary substance abuse team
2. Intervention by substance abuse counselor
3. Referral for inpatient treatment
4. Support groups for children and youth of substance abusing parents

Adherence Services (1999), including:
1. Adherence assessment at each visit
2. Collaborative treatment planning with client and family
3. Specific medication adherence strategies and supplies
4. Referral for intensive outpatient behavioral psychology as needed
5. Referral for intensive inpatient adherence rehabilitation as needed
6. Intensive home-based adherence support
7. Directly observed therapy

Buddy Program (2000), including:
1. One-to-one relationships between interested clients and volunteer medical students
2. Monthly group social or recreational activities
3. Individual mentoring regarding peers, school, career

Outreach Services (2001), including:
1. Community-based HIV counseling, testing, and referral
2. Clinic-based rapid HIV testing
3. Outreach for missed appointments
4. Partner notification of exposure to HIV and other sexually transmitted infections
5. Risk reduction counseling for HIV positive clients

Legal Services (2003), including:
1. Assistance with standby guardianship and health care proxy
2. Legal advocacy

Oral Health Services (2005), including:
1. Complete dental examination
2. Teeth cleaning
3. Basic restorative dental procedures

Transitions Program from Youth to Adult (2006), including:
1. Anticipatory guidance regarding future transfer of care
2. “Med-Peds” trained physicians as primary providers
3. Assist clients in identifying adult clinic
4. Practice self-efficacy skills

HIV care and treatment within the framework of the Intensive Primary Care (IPC) model has resulted in a remarkable track record for our patients. Despite the social and behavioral risks of our IPC client population, we have achieved impressive health outcomes, including
  o 80% survival over a twenty year period
  o 88% of clients with CD4 count greater than 200
  o 66% of clients with undetectable viral load

C.2.2 Research in Pediatric & Adolescent HIV/AIDS: The Impact of the IPC Clinic at Johns Hopkins University
Shortly after I started the IPC Clinic, a faculty member in pediatric infectious diseases received a supplement to the newly created AIDS Clinical Trials Unit (ACTU) housed within the adult infectious diseases division. He came to me seeking access to patients for research specimens and for clinical trial enrollment. In collaboration with University of Maryland pediatric immunology program, we
successfully competed as a site in the newly created network, the Pediatric AIDS Clinical Trials Group (PACTG) in 1988.

As director of the IPC Clinic’s comprehensive care program, I pioneered the integration of clinical research, especially the PACTG’s clinical trials, into our 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. This approach maximizes the identification, enrollment, and retention of eligible study subjects in several ways. The clinical care team is always aware of open research protocols and the eligibility and exclusion criteria. Wary parents or adolescents learn from trusted clinicians about the safeguards and ethical principles that are the foundation of any clinical research. Subjects who miss research appointments are seen when they come for clinical appointments to minimize “missing data.” Whenever possible, clinical and research appointments are coordinated on the same day and in the same location. The IPC wraparound support services minimize practical barriers to participation in research so that subjects are free to make informed choices based on the merits of the research proposed. The IPC Clinic is the “clinical core” of a rich research program. More than 50% of IPC patients participate in one or more clinical research studies.

This integrated approach has facilitated the conduct of clinical research, the career development of junior investigators, and new lines of research for senior investigators in the Johns Hopkins University Schools of Medicine, Nursing, and Public Health. Examples include:

- Thomas Quinn – laboratory search for infant early diagnostic test (1 publication)
- Deborah Persaud – laboratory discovery of latent reservoir of HIV-infected cells in children (16 publications)
- Arlene Butz – developmental and social outcomes of HIV-infected infants (7 publications)
- Ann Kavanaugh-McHugh – echocardiographic study of cardiomyopathy in HIV-infected children (2 publications)
- Robin Henderson – nutritional research in HIV-infected children (5 publications)
- Jose Saavedra – gastrointestinal bacterial overgrowth in HIV-infected children (1 publication)
- Ruth Faden, Nancy Kass, & Andrea Gielen – ethical treatment of women and children with HIV (2 books, 28 publications)
- George Siberry & Allison Agwu – observational cohort studies of HIV-positive children and youth (24 publications - including 9 from the HIV Research Network [169 IPC subjects enrolled] and 16 presented abstracts from the CDC LEGACY study [143 IPC subjects enrolled])
- Annie Michaelis – doctoral dissertation, transition of perinatal survivors from pediatric to adult medical care (dissertation completed)
- Morgan Philbin – doctoral dissertation, qualitative study of youth newly infected with HIV (research in progress)

According to my Collexis Research Profile (http://www.researchprofiles.collexis.com/jhu/, accessed 01/08/2011), I have authored 42 indexed publications with a network of 87 co-authors, 29 internal to JHU and 58 external.

The largest and most sustained research effort was and continues to be made in multicenter clinical trials in the Pediatric AIDS Clinical Trials Group (PACTG 1988-2007), the International Maternal Pediatric Adolescent AIDS Clinical Trials (IMPAACT) Network (2007-current), and the just-awarded Adolescent Trials Network (ATN). As described above, the IPC Clinic team collaborates actively with the research team to optimize enrollment and retention in clinical trials. Despite the intensive effort to make clinical
trial participation accessible for all IPC patients, research protocols have become increasingly selective thereby excluding many of our patients. Our response as a research site has been to open as many protocols as possible in order to hit enrollment targets. This approach is remarkably labor-intensive given how few subjects can be enrolled in many of the protocols. From 1986-2006, we opened 51 protocols but were able to enroll subjects in only 42. Our site’s study enrollments totaled 376 during this period (Appendix E). This experience is shared by other centers, emphasizing the need for multiple sites contributing even small enrollments to answer pediatric-specific hypotheses. Our IMPAACT site currently has 25 IRB-approved protocols for which I am co-investigator, 11 protocols open to enrollment, and 25 IPC patients enrolled as subjects in active follow-up.

In addition to my role as leader of the IPC clinical core, I served as site principal investigator for several PACTG studies, including the highest enrolling protocol at our site, PACTG 219/219C Late Outcomes Study and the second highest enrolling antiretroviral treatment study, ACTG 128, an early study that confirmed equivalent efficacy with improved safety of lower dose zidovudine (AZT) compared to standard dose in the treatment of children with mild-moderate HIV disease. My contributions to PACTG publications are described on pages 15-16 below and in Appendix J.

**2000 to current  Medical Director, Johns Hopkins Pediatric Palliative Care Program:**

| C.2.3 | Hospice & Palliative Medicine – a new medical subspecialty |
| C.2.4 | Johns Hopkins Medical Institutions |
| C.2.5 | Johns Hopkins Children’s Center |
| C.2.6 | Regional Pediatric Hospice & Palliative Care |
| C.2.7 | Pediatric Palliative Care Research at JHU |

**C.2.3 Hospice & Palliative Medicine – a new medical subspecialty**

During the second decade of the AIDS epidemic in the US, the death toll from HIV hit its peak. The IPC Clinic was a microcosm of the suffering and death experienced by children and parents, and the helplessness experienced by health care providers to alter this outcome. I worked closely with the Johns Hopkins Children’s Center pediatric home hospice nurse to assure comfort-focused care for my dying patients in the hospital and at home. I “hit a wall” – I saw no way to innovate our way out of this inexorable loss. In 1996, while desperately trying to treat my pediatric patients with a promising new protease inhibitor approved for use in adults, I learned about the growing Palliative Care movement in the US. This movement expanded on the principles of hospice care and called for a new approach to care of seriously ill people. Modern breakthroughs in technology, surgery, and medicine were saving lives but also sentencing people with incurable and terminal conditions to be tethered to life support in intensive care settings as they died, rather than being in the presence of loving family with care focused on the relief of pain and suffering. I recognized my own core values as a physician in this new field – values that emphasize the patient and family as the center of care, the relief of suffering and promotion of quality of life, the recognition that when cure is not possible caring must continue, and the right to self-determination throughout one’s lifespan. I applied to a new, highly competitive program and was awarded a three year grant, becoming a Faculty Scholar in the Soros-funded Project on Death in America (PDIA). This faculty development experience changed my career.

**C.2.4 Johns Hopkins Medical Institutions**

At the Johns Hopkins Medical Institutions, there was a concurrent groundswell of interest in improving care at the end of life for patients and their families. I volunteered to co-chair the institution-wide
Palliative Care Task Force with Dr. Michael Carducci in Oncology from 1998-2000. We met with all department directors to assess the need for palliative care and to ask for their support of our initiative. Our interdisciplinary and interdepartmental task force developed a business plan for Johns Hopkins Medicine leadership. In response to this proposal, a pilot program was implemented in the Department of Medicine to support palliative care consultation. We also directed the annual Palliative Care Lecture Series: Promoting Quality of Life in Chronic and Terminal Illness from 1998-2005, bringing national leaders in the field to address the Hopkins community.

C.2.5 Johns Hopkins Children’s Center
In the Johns Hopkins Children’s Center, Dr. George Dover appointed a committee in 1997 to improve end of life care in Pediatrics. As a founding member of that committee, I worked with a diverse group of health professionals representing the full range of disciplines, specialties, and settings involved in the care of children with serious and life-threatening illness at Johns Hopkins. We discussed and debated gaps and barriers and recommended that a formal palliative care program be created for the Children’s Center. Dr. Dover agreed and in 2000 appointed me as the Medical Director of this new program, Harriet Lane Compassionate Care (HLCC).

My impact is evident in the design and growth of this program; it mirrors my approach to building the HIV/AIDS program. We used the committee’s clinical needs assessment to identify high priority goals for change. I counseled that we should learn from the early experience of the Task Force in initiating a palliative care consultation team in Medicine where health professionals with frontline responsibility for patients resisted a new team inserting itself at critical decision points. I recognized that the culture of Johns Hopkins – to give the best possible care by being the best prepared and hardest working professional – and the culture of pediatrics – to protect one’s vulnerable patients from unwanted or unhelpful intrusions into care – needed to be acknowledged and embraced as we developed our model program. We specifically observed that the confluence of these cultures in the Children’s Center was leading to professional burnout behaviors, such as angry assumptions about the intentions or work quality of other teams or units when children were dying. We therefore designed a model unlike any other program at the time (adult or pediatric) in that we did not begin by creating a traditional medical consultation team. We specifically chose to focus first on recognizing the excellence, expertise, and commitment that all Children’s Center professionals brought to their work with patients. We did this through education, clinical teaching rounds, facilitated patient care conferences, and counseling and support for staff following the death of their patients (see Teaching Activity Report on pages 20-22).

The HLCC approach has changed the culture of care in the Children’s Center (Appendix F, G, H). We have integrated the principles of palliative care into the fabric of our pediatric hospital. All professional staff members receive some degree of training in palliative care knowledge and skills and can provide basic support from their discipline’s perspective. This has created a demand for specialist level consultation and support for more complex clinical situations. Of note, it appears that the palliative care field has “caught up with us.” Current program innovations nationally are focusing on the integration of basic palliative care in intensive care settings with triggers for specialty level consultation. (http://www.capc.org/ipal-icu/)

In preparation for this anticipated need for specialty level care, I became certified in Hospice & Palliative Medicine (HPM) in 2008. I initiated a palliative medicine consultation program in 2009. Once again, I sought and obtained seed funding from the local Thomas Wilson Sanitarium to support my effort for this startup, assessing the level of demand, the intensity of effort required, and the potential for third party reimbursement. In the first year, without advertising this service, I was consulted for 21 patients,
provided 47 face to face clinical consults, and 107 other clinical encounters (eg. advice to the primary physician) for patients in the ICUs, acute inpatient units, the emergency department, outpatient clinics, and in the home. In October 2009, I began convening weekly interdisciplinary palliative care rounds to discuss patients seen by me in consultation as well as those cared for by other Children’s Center professionals in attendance.

I am currently leading a strategic planning process to identify short and long-term goals and activities for HLCC in its second decade. Sustainable funding is critically important. I am working with professionals from across the institutions to build a strong and comprehensive clinical program, a vibrant research program, and a strong educational program including a Fellowship Program in Pediatric Palliative Medicine.

C.2.6 Regional Pediatric Hospice & Palliative Care
In 2004, I proposed and helped plan and convene a Maryland State Summit for Pediatric Palliative and End of Life Care that brought together a diverse group of stakeholders, including health care professionals, parents, and agency representatives to discuss palliative care for children. Sponsored by Harriet Lane Compassionate Care, we prepared and disseminated a summary report outlining the challenges and opportunities to improve pediatric palliative care in our state (Appendix I). This document serves as a foundation for program building by a number of local organizations, including Joseph Richey Hospice and its pediatric program Dr. Bob’s Place, Gilchrist Kids pediatric home hospice program, Johns Hopkins Harriet Lane Compassionate Care, and the Maryland Pediatric Palliative Care Coalition. The Coalition was formed to continue the collaboration and synergy among participants in the Summit.

Hospice care for children in Maryland has evolved over the past 25 years. A Johns Hopkins pediatric nurse practitioner pioneered the first such program in our region, taking on the role of hospice nurse for children in the late 1980’s with support from Dr. Frank Oski, the chair of Pediatrics. I was a member of the Children’s Center Hospice Advisory Board from 1988-1992. With the creation of the Johns Hopkins Home Care Group, Johns Hopkins created its own home hospice team for adult patients and this team ultimately incorporated the pediatric team as well; I served as the assistant pediatric hospice medical director for this program from 2000-2003. In 2003 the Home Care Group negotiated with the Washington Home and Community Hospices to take over the hospice program, including pediatrics. I became the Pediatric Hospice Medical Director for Community Hospice of Maryland. During the six years of my leadership of this team, its census rose from two patients to an average of ten patients on service. Referrals increased significantly from all pediatric hospitals in the region as well as case managers working with special needs children. Most significantly, parents whose children died under our care began referring friends to our program.

During this same period, I worked with and learned from visionary pediatric nurses to improve palliative care for children with cancer. Negative myths and concerns about hospice care were expressed by families of children with cancer, presenting barriers to accessing this supportive care. These nurses worked for years to develop a program that would provide hospice-like care at home for children who no longer wanted to be in the hospital, but for whom the term “hospice” meant “giving up”. When a competitive funding opportunity presented itself, I worked closely with them to craft a successful grant application to the Lance Armstrong Foundation for the Butterfly Connection in 2006. This three year innovative project sought to provide home-based pain and symptom management for children with cancer in the central Maryland area. I guided the planning group to anchor this program in the community with the Maryland Pain Initiative as the grantee, Pediatrics at Home (part of the Johns
Hopkins Home Care Group) as the pediatric home health agency, and Community Hospice of Maryland as the home hospice provider. The three pediatric oncology practices in Baltimore (Johns Hopkins Hospital, University of Maryland, and Sinai Hospital of Baltimore) were linked to these home-based programs through established referral relationships. We initiated routine formal assessment of pain and symptoms for all children with cancer admitted to a home health care program regardless of prognosis, provided feedback to oncology providers and collaborated in patient care planning, and implemented a weekly Butterfly clinical team meeting via conference call. These activities improved the quality of care through the sustainable integration of structured patient assessment and communication among health professionals. Expanding the scope and impact of this model beyond the oncology population was the logical next step.

Pediatrics at Home was therefore poised to take the lead in filling the sudden gap in home-based care for children with terminal conditions when Community Hospice abruptly discontinued its pediatric program in January 2010 due to fiscal problems. I worked closely with the director of Pediatrics at Home to assure continuity of palliative home care for our hospice patients. Pediatrics at Home has provided excellent end of life home care, including supporting families at the time of death of their children, throughout 2010. I serve as a consultant and clinical resource to the Pediatrics at Home senior palliative care nurse and we “team” her patients during our weekly clinical palliative care rounds in the Children’s Center.

With the close of Community Hospice’s pediatric program, I immediately began working with Gilchrist Hospice Care to plan for a pediatric hospice team within their organization. They opened Gilchrist Kids on July 1, 2010. I am now a consultant for this program and serve on their Pediatric Advisory Committee.

Private foundation grants have provided the extramural funding to build the clinical palliative care program thus far:

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<th>Total Award</th>
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<td>2006-2010</td>
<td>Private Foundations</td>
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<tr>
<td>TOTAL</td>
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C.2.7 Pediatric Palliative Care Research at JHU
Harriet Lane Compassionate Care is committed to advancing the science of pediatric palliative care domestically and internationally. HLCC investigators represent multiple professional disciplines and cross departments and schools within JHU:

- Janet Serwint, MD
- Nancy Hutton, MD
- Cynda Rushton, RN, PhD
- Renee Boss, MD, MHS
- Pamela Donohue, ScD
- Elizabeth Keene, MA, CTC
- Deena Levine, MD
• Benjamin Lee, MD, MPH
• Cora Welsh, CCLS

At least fourteen research papers have been published thus far, with newly funded projects getting under way.

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<th>Funding Period</th>
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<td>2010-2011</td>
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<td>Private Foundations</td>
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<td>TOTAL</td>
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C.3. NATIONAL & INTERNATIONAL IMPACT - TREATMENT AND PRACTICE STANDARDS

C.3.1 PACTG and IMPAACT – multicenter HIV clinical trials
C.3.2 Pediatric HIV Treatment Guidelines – United States
C.3.3 Palliative Care Quality Guidelines – United States
C.3.4 International Palliative Care Initiative
C.3.5 President’s Emergency Plan for AIDS Relief (PEPFAR)

C.3.1 PACTG and IMPAACT – multicenter HIV clinical trials
Under my leadership as a team scientist, the IPC Clinic has contributed to groundbreaking advances in the prevention and treatment of pediatric HIV infection, changing the course of this epidemic worldwide. Scientific areas of inquiry and illustrative protocols include:
• Preventing HIV transmission from mothers to infants
  o PACTG 049 (safety and pharmacokinetics of zidovudine in infants)
  o PACTG 076 (placebo controlled trial of zidovudine to prevent mother to child transmission (PMTCT) of HIV; dramatic benefit at first DSMB-changed the standard of care worldwide)
  o PACTG 316 (attempted to determine added benefit of nevirapine for PMTCT in women already taking antiretroviral therapy; due to potency of available highly active combinations, the transmission rate in control group was <2% and sample size too small to show difference)
• Treating HIV infection
  o PACTG 043, 051, 128 (early zidovudine trials)
  o PACTG 144 (early didanosine trial)
  o PACTG 152 (proved that dual nucleoside therapy better than monotherapy)
  o PACTG 245 (superior efficacy of non-nucleoside RT inhibitor)
  o PACTG 377 (phase 1/2; dual vs. triple class therapy)
• Preventing opportunistic infections
  o PACTG 254 (atovaquone prevents PCP)
• PACTG 265 (safety, immunogenicity of varicella vaccine in HIV-infected children)
• P1057 (safety and immunogenicity of FluMist influenza vaccine in HIV-infected children)
• Identifying and managing co-morbidities and late complications
  • PACTG 219/219C (late outcomes, quality of life)
  • PACTG 247 (nutritional intervention to improve growth)
  • PACTG 367 (pregnancy and infant outcomes)
  • P1028 (prevalence of hepatitis C co-infection)
  • P1045 (prevalence of metabolic abnormalities)

These studies span the history of HIV treatment in children from mono to dual to triple drug therapy. Our IPC clinic model provided the perfect framework for our contribution to the extraordinary results of PACTG 076, the first study to prove that antiretroviral medication could prevent the transmission of HIV from mother to infant. We tested medications and vaccines to prevent opportunistic infections. Our IMPAACT team continues to focus on prevention of mother to child transmission, the testing of new antiretroviral agents in children and adolescents, and the comparison of treatment strategies for effectiveness, tolerability, and durability in the context of a global research network.

My scientific contributions to PACTG publications are detailed in Appendix J. In recognition of my unique expertise as an HIV primary care pediatrician and co-investigator, the 219 protocol team chair asked me to join the national protocol team in 2000 during the expansion and revision from 219 to 219C as a hypothesis-driven longitudinal study. I participated in monthly team conference calls monitoring enrollment and data collection, reviewing new work concept sheets, and approving lay summaries for study participants. The study team has published 24 journal articles in the past eight years; I personally co-authored two of these publications in areas of particular expertise: palliative and end-of-life care and HIV diagnosis disclosure to children. I co-authored the publication that resulted from ACTG 128. My work as a “team scientist” is acknowledged in at least 9 recent PACTG/IMPAACT publications for which I served as the lead investigator at the Johns Hopkins site, enrolling and retaining subjects in study, performing study procedures, reviewing laboratory data, and overseeing research staff.

C.3.2 Pediatric HIV Treatment Guidelines – United States
The results of clinical trials must be translated into treatment recommendations that are broadly implemented in order for research efforts to have any impact on individual or public health outcomes. Based on my expertise in the clinical management of children with HIV infection, I was invited to become a member of the DHHS Working Group on Antiretroviral Therapy and Medical Management of HIV-Infected Children in 2001. This group of sixteen clinicians, researchers, community advisors, and representatives of government agencies is responsible for developing and continuously updating US national treatment guidelines for pediatric HIV infection; formal updates are published at least annually. I am one of two generalist pediatricians in this group and as such contribute unique perspective “from the field” regarding the practical implications of our recommendations. I participate in monthly conference calls, review/comment/approve guideline updates, and take primary responsibility for assigned sections of the guidelines (reviewing literature/evidence, revising section, presenting to working group). I am working to incorporate palliative care principles into the next revision with a focus on management of symptoms and side effects during antiretroviral therapy. I also serve on the membership subcommittee, reviewing current member participation and nominations for new members. My membership has been renewed every three years based on my active participation and contributions. The guidelines have been updated 13 times during my ten year membership (CV pages 11-12). A copy of the most recent edition of the Guidelines is found in Appendix K; a hard copy is also included with this portfolio.
C.3.3 Palliative Care Quality Guidelines – United States
As a leader in the field of Hospice and Palliative Medicine, particularly regarding the care of children and people living with HIV/AIDS, I am sought after to join national and international committees and working groups to develop and disseminate best practices in the field. I participate in several initiatives that promote quality palliative care for patients of all ages. My unique contributions represent the needs of children and families, the needs of persons living with HIV/AIDS, and the perspective of clinical practice in an academic medical center, an outpatient clinic, in home care, and home hospice.

Robert Wood Johnson Promoting Excellence in End of Life Care
As one of two experts in pediatric HIV/AIDS and pediatric palliative care in the US, I 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. I contributed specific recommendations and case scenarios for this report to highlight the inclusion of children and adolescents throughout the document. (Appendix L - electronic and hard copy)

National Consensus Project for Quality Palliative Care (NCP)
The NCP is comprised of the four leading national organizations in hospice and palliative care: the Center to Advance Palliative Care (CAPC), the American Academy of Hospice and Palliative Medicine (AAHPM), the Hospice and Palliative Nurses Association (HPNA), and the National Hospice and Palliative Care Organization (NHPCO). This expert group released evidence-based Clinical Practice Guidelines for Quality Palliative Care in 2004 that were intended to apply across a full range of clinical services, settings, and patient populations. The AAHPM leadership asked me to represent the organization in the dissemination phase of this project in 2005. I participated in monthly conference calls, contributed to the development of a dissemination plan, and reviewed and approved the second edition. As the only pediatric representative and the only member with HIV/AIDS expertise, I led the effort to elicit feedback on the guidelines document from representatives of the pediatric palliative care community and the HIV palliative care community and to advise the revision process in response to these constituencies. The revised second edition of the guidelines was released in 2009. (Appendix M – electronic and hard copy).

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.

Position Statements of the American Academy of Hospice and Palliative Medicine
During my first term as an elected member of the Board of Directors of the AAHPM, I was appointed the liaison to the academy’s Ethics Committee. In this role I contributed my expertise to the evidence review and revision of the organization’s position statements regarding palliative and end of life care listed below, particularly regarding their applicability to children and adolescents.
http://www.aahpm.org/positions

- Statement on Artificial Nutrition and Hydration Near the End of Life
- Statement on Palliative Care Research Ethics
- Statement on Palliative Sedation
- Physician-Assisted Death
**Children’s Project on Palliative/Hospice Services (ChiPPS)**

Based on my expertise as a hospice & palliative medicine pediatrician, I was invited to join the pediatric steering committee of the National Hospice and Palliative Care Organization (NHPCO) in 2006. This committee develops and disseminates national pediatric standards for hospice/palliative care and pediatric-specific educational resources and curricula. It advocates for full access to palliative care for children with life-threatening conditions and their families in national and international arenas. Recent products of this committee are Pediatric Standards for Hospice and Palliative Care (2009) and Pediatric Palliative Care Online Training (2011) [http://www.nhpco.org/i4a/pages/index.cfm?pageid=3409](http://www.nhpco.org/i4a/pages/index.cfm?pageid=3409).

**C.3.4 International Palliative Care Initiative**

The International Palliative Care Initiative is one of the Public Health Programs of the Open Society Institute and Foundations. Because of my work as a PDIA Faculty Scholar, I am their “go to” person for international pediatric palliative care expertise, especially for HIV affected populations and regions. At their invitation, I have traveled to present at palliative care training seminars in Kiev, Ukraine; Salzburg, Austria; Tbilisi, Georgia; and Mexico City, Mexico (CV pages 32-34) and to participate in international policy and program development panels held in Bethesda, Boston, and Geneva, Switzerland listed below (CV page 35):

- Consultation on Pain and Palliative Care in Resource-Limited Settings, NIH/NIDA/Clinton Foundation, Bethesda, Maryland (11/16-17/2009)
- Appreciative Inquiry Summit: Creating Effective Partnerships to Advance Palliative Care Education and Research Capacity in Africa, FSSHA/Diana Princess of Wales Memorial Fund, Boston, Massachusetts (08/04/2010)
- Peer reviewer, WHO Guidelines on Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses (10/2010)

I collaborate with international colleagues as a member of the International Children’s Palliative Care network (ICPCN) and the African Palliative Care Association (APCA). I nominate Ethiopian physician colleagues for professional development opportunities in pain and palliative care through OSI and the AAHPM.

**C.3.5 President’s Emergency Plan for AIDS Relief (PEPFAR)**

PEPFAR is the major US government funded effort to support the care and treatment of people living with HIV internationally. Although the primary focus is on identifying individuals with HIV infection and initiating antiretroviral treatment, the design of this program explicitly includes palliative care as a core component. This integration of HIV treatment and palliative care fits my expertise perfectly. In 2005, I helped one of the prime grantees, Catholic Relief Services (CRS), to provide training and technical assistance in pediatric HIV and palliative care at a ten-day conference in Kenya. Currently I am assisting the lead CRS pediatric advisor in assessing the need for transition planning for perinatal HIV survivors graduating to adult care clinics based on our IPC Clinic model.

I am both the pediatric HIV and the palliative care consultant for the Johns Hopkins School of Public Health PEPFAR program in Ethiopia, initiated under the direction of Dr. Andrea Ruff in 2005. The Technical Support for the Ethiopian ART Initiative (TSEHAI) is responsible for developing capacity and rolling out antiretroviral treatment for HIV positive people living in Addis Ababa and the rural regions of SNNPR, Gambela, and Benshangul. I travel to Ethiopia approximately twice per year to provide teaching and technical assistance. These activities are described in more detail on pages 20-22, 24-25 below.
My impact is visible in the development of the pediatric antiretroviral therapy (ART) clinics supported by TSEHAI. I have worked closely with the TSEHAI lead pediatric advisor to adapt IPC Clinic tools and clinical practices to fit within the national framework and promote excellent pediatric HIV assessment, treatment, and monitoring, particularly for medication adherence. This model is disseminated to 63 clinics across the four regions. In the second phase, I asked the child life specialist from the IPC Clinic to travel with me to Addis to assess readiness for, plan, and train staff at the highest functioning pediatric sites for HIV diagnosis disclosure to older children, to create supportive and educational environments within the clinics, to learn approaches to preparation and coping with medical procedures such as phlebotomy, and to initiate and run youth support groups for children who are aware of their HIV diagnosis. This interdisciplinary, comprehensive model is currently rolling out at 4 clinics (2 in Addis, 2 in SNNPR). I look forward to engaging my Ethiopian colleagues in planning for the long-term survival of children born with HIV and the need to transition their care to adult HIV clinics; I anticipate that the IPC Clinic model will once again inform the design and implementation at TSEHAI.

My impact is also evident in TSEHAI’s efforts to promote the safe use of opioids for pain management, a core component of palliative care. According to the International Narcotics Control Board, Ethiopia ranks last in per capita consumption of morphine equivalents among the 150 countries who report data to this body. My initial assessment revealed several reasons for this. The primary barriers at the federal government level are being addressed through amendments to regulations about importation and the publication of national Pain Management Guidelines. But practical barriers of supply and cost continue in this impoverished country. PEPFAR has been instrumental in adding opioids and adjuvant analgesics to the Opportunistic Infection (OI) Essential Drug List in Ethiopia, making them available at no charge in HIV pharmacies. Yet when I speak with physicians in hospitals and clinics, they incorrectly assume that morphine is illegal or unavailable. Therefore my focus has been on the training of clinicians to screen and assess pain and the training of physician prescribers in the safe use of analgesics for adults and children. I have brought together Johns Hopkins experts in pain medicine and palliative nursing to provide on site consultation and training to build capacity at Black Lion Hospital, the national referral and teaching hospital of the Medical Faculty of Addis Ababa University.

C.4.  HONORS AND AWARDS IN CLINICAL PROGRAM BUILDING
I have been recognized for my work as a pediatrician caring for children and adolescents with HIV and as a palliative medicine specialist.

1994  The Johns Hopkins Children’s Center Champion Award
1996  Mayor's Citation for Public Service, Baltimore, Maryland
1996  Presidential Award, Maryland Coalition for Healthy Mothers, Healthy Babies
1997  Faculty Scholar, Project on Death in America, Open Society Institute
1999  Thomas Ferciot Memorial Award, Baltimore Association for Retarded Citizens (BARC)
2002  Recognition Award, Baltimore Pediatric HIV Project
2008  Fellow, American Academy of Hospice and Palliative Medicine
2011  Secretary, American Academy of Hospice and Palliative Medicine

C.5.  ADVISOR AND MENTOR
I have mentored JHU TSEHAI technical advisors in Ethiopia:
• Dr. Berhanu Gudeta, Pediatrics Clinical Advisor - pediatric HIV diagnosis, treatment, adherence, disclosure, chronic care model (2005-current)
D. CLINICIAN - EDUCATOR PORTFOLIO

D.1. PROFESSIONAL DEVELOPMENT IN EDUCATION

Much of my learning to teach has been drawn from my observations and experiences as a life-long student. Throughout my career, structured learning experiences have included my fellowship in General Pediatric Academic Development, educational workshops at professional meetings, a faculty development program in substance abuse, the Soros Faculty Scholars Program in palliative care, and palliative medicine fellowship directors summits. As an educator, I recognize the need for continuous learning. I enthusiastically embrace the changes in Johns Hopkins undergraduate and graduate medical education and look forward to participating in two Johns Hopkins educational retreats this year, one for Graduate Medical Education (3/1/2011) and one for the Genes to Society curriculum (6/17/2011).

D.2. TEACHING ACTIVITY REPORT

Lecture:
- Physician and Society: Introduction to Palliative Care for Year 2 Medical Students (2 hours weekly for 3 weeks per year, 4 years);
- Johns Hopkins Bloomberg School of Public Health course “HIV Infection in Women, Children, and Adolescents” for Masters and Doctoral graduate students (2 hours per lecture, 50 students per class, 1 lecture per year for 7 years);
- Pediatric Residency Noon Conferences – present Pediatric Hospice and Palliative Medicine topics (1-6 times per year, 8 years);
- Harriet Lane Compassionate Care (HLCC) Network Day- lecture on pediatric palliative care topics for interdisciplinary Johns Hopkins Children’s Center clinician audience annually for 7 years (30 participants per year);
- Continuing medical education for community clinicians – 29 JHU CME lectures on Pediatric and Adolescent HIV topics (1-3 lectures per year for 16 years); 4 lectures on Pediatric Hospice and Palliative Medicine topics (current year thus far);
- Invited lectures regional, national, and international – 77 domestic and 26 international presentations on topics related to Pediatric HIV/AIDS and Pediatric Palliative Care over 23 year period; includes Grand Rounds, Visiting Professorship, international trainings sponsored by the Pediatric AIDS Clinical Trials Group (PACTG) and the President’s Emergency Plan for AIDS Relief (PEPFAR), national and international professional conferences;
- Management of Pediatric HIV/AIDS in Resource-Limited Settings – video recorded with power point presentation, 9 topics, archived for on line access in international settings (see Curriculum #1 below on page 23-24).

Small group:
- Physician and Society – small group leader for Year 2 Medical Students (2 hours weekly for 6 months per year, 3 years, 10 students per year)
- Healer’s Art – small group leader for Year 2 Medical Students (4 hours weekly for 6 weeks per year, 1 year, 5 students per year)
- Patient, Physician, and Society: Selective in Palliative Care for Year 2 Medical Students (18-30 students/year, total 92 students selected this course, 2 hours weekly for 4-5 weeks per year, 4 years; see Curriculum #5 below on page 27-28)
- Death and Bereavement Seminar – small group leader for PGY-2 Pediatric Residents to learn communication skills using Standardized Patient methodology (8 hour day per year, 12 years, 5 residents per year)
- Harriet Lane Compassionate Care (HLCC) Palliative Care Teaching Rounds – small group clinical case discussion monthly on 3 inpatient units in the Children’s Center (PICU, NICU, Pediatric Oncology) (10 years, 60 participants per year)
- Initiative for Pediatric Palliative Care (IPPC) retreats – lead topical breakout discussion sessions of small interdisciplinary groups of clinicians and parents of pediatric patients over two and a half day retreats (1 regional retreat per year for 3 years, 10 participants per group)
- Harriet Lane Compassionate Care (HLCC) Network Day – lead small group discussions throughout this annual daylong educational event for Johns Hopkins Children’s Center clinicians from multiple disciplines (8 participants per small group, 8 years)
- Intersession in Palliative Care – new course in 2010, Genes to Society Curriculum for Year 2 Medical Students who have just completed their first clinical block rotation (see Curriculum #6 below on page 28), small group leader throughout 3 day course.

Teleconference:
- Ethiopia case conference – prepare and present teaching discussion in response to pediatric HIV clinical cases prepared and presented by Ethiopian pediatricians via live video conferencing (2 hour conference, 8 conferences per year, 25 participants per conference, see Curriculum #2 below on pages 24-25).

Clinical teaching:
- Harriet Lane Clinic – pediatric resident (PGY 1, 2, 3) continuity clinic preceptor half day per week for 10 years; initiated weekly small group didactic teaching sessions on general pediatric topics followed by supervision of individual patient care (4-6 residents/clinic group/year)
- Intensive Primary Care (IPC) Clinic – preceptor for medical student sub-interns(3-4 months per year, 15 years), faculty advisor for Big Buddy Little Buddy program which matches graduate students in medicine, nursing, and public health with HIV affected children and youth with dual goals of mentoring for children and building professionalism for graduate students (40 students per year for 15 years), pediatric resident continuity clinic (half day per week, 5 years), pediatric residents on elective (0-3 months per year, 20 years), general pediatric and adolescent medicine fellows(10 years), pediatric infectious diseases fellows (22 years), general pediatric and adolescent medicine faculty as needed (10 years), weekly case review and discussion for interdisciplinary clinical team (22 years)
- Harriet Lane Compassionate Care – pediatric residents on palliative medicine consultation service elective (1-6 half blocks per year, 3 years); PICU interdisciplinary team at Goals of Care Conference (1 hour weekly, 2 years); NICU interdisciplinary team at weekly Goals of Care Conference (1 hour weekly, 1 year); Children’s Center interdisciplinary clinical team members at weekly Palliative Care Rounds (1 hour weekly, 2 years)
**Bedside Clinical Teaching**
- Hawassa Regional Hospital, Ethiopia – pain screening, assessment, and treatment for Pediatric Ward Rounds and Adult Medicine Ward Rounds (4 hours)
- Johns Hopkins Children’s Center – inpatient general pediatric attending teaching pediatric residents and medical students (1-2 months per year, 26 years); hospice & palliative medicine pediatrician teaching physicians (attendings, fellows, residents, students); nurses, social workers, child life specialists, chaplains integration of palliative care with disease directed therapies for inpatients, outpatients, and children in the home setting (1-10 hours per week, 2 years).

**Evidence for Teaching Effectiveness**
- Pediatric Resident evaluation (E-Value scale 1-5)
  - 4.93 (2010 palliative care elective)
- Medical Student evaluations (PPAS Selective in Palliative Care 2007):
  - “Selective fulfilled stated goals & objectives” 94% agree mostly or completely
  - “Leaders organized; I understood requirements from the beginning” 100% agree or strongly agree
  - “Leaders had appropriate expertise” 94% agree or strongly agree
- JHU CME Course Director feedback (13th Annual Clinical Care of the Patient with HIV, 2003)
  - “As always, your presentation was fresh, highly informative, brimming with compassion and highly inspirational. I am always amazed with the great energy and sense of commitment you bring to the task and am grateful for your continued willingness to share your wonderful perspective with us.” Dr. Richard E. Chaisson, Professor of Medicine, Epidemiology, and International Health, 4/23/2003
- JHSPH Graduate Course Director feedback (HIV in Women, Children, and Adolescents, 2008)
  - “Your insights as a clinician and caregiver are incredibly valuable to the class, as was apparent by their many questions and keen interest in your lecture. Not all physicians have as holistic an approach as yours, and we are very lucky and grateful to have you working in Baltimore and willing to share your work with our students.” Sabina Haberlen, 4/17/2008
- Community based interdisciplinary clinical education participant feedback (Gilchrist Kids Hospice Team, 10/1/2010)
  - “I enjoy Dr. Hutton's speaking style. She is knowledgeable but able to explain in simple terms.”
  - “Excellent - loved real-life examples. Very knowledgeable presenter (Dr. Hutton).”
  - “I liked that it was interactive. It gave the opportunity for audience participation and work through individual cases makes it more of an experience than just a lecture. Thank you.”

**D.3. CURRICULUM DEVELOPMENT & INSTRUCTIONAL DESIGN**

1. Management of Pediatric HIV/AIDS in Resource-Limited Settings
2. HIV Clinical Care Discussions in Ethiopia
3. Pediatric HIV/AIDS Palliative Care Module
4. U8: The Hospice and Palliative Care Approach to Caring for Pediatric Patients
5. Patient, Physician, and Society Course - Palliative Care Selective
6. Palliative Care Intersession – Genes to Society
Course Directors: George Siberry, MD, MPH and Nancy Hutton, MD
Johns Hopkins Center for Clinical Global Health Education (CCGHE)

Background/Need: This course was designed to provide comprehensive clinical training in the care and management of HIV exposed infants and HIV infected children in resource-limited settings. Dr. Robert Bollinger, Professor of Medicine at JHU and Director of the Center for Clinical Global Health Education (CCGHE), asked Dr. Siberry and me to create this distance learning curriculum for his collaborating sites in India. Participants earned a Certificate of Achievement for completing the course and testing.

Learning objectives: Specific learning objectives were prepared for each course topic.

Educational strategies: Individual lectures were video-recorded with simultaneous power point presentation and then uploaded to the internet accessible platform. Each lecture was limited to 18-20 slides and 20-25 minutes of presentation in order to facilitate ease of viewing by busy clinicians. The course consisted of 29 lectures by experts at Johns Hopkins and took place over 6 weeks. A live videoconference Question and Answer session was offered with the course directors. Multiple choice pre- and post-testing corresponding to learning objectives was done for each topic.

Instructional materials: Course Table of Contents is listed below. Lecture materials created and presented by Dr. Hutton are found in the Appendix N.

Unit 1:  HIV Epidemiology and Prevention of Maternal-Child Transmission
(1) Global Epidemiology of Pediatric HIV Infection
(2) Epidemiology of Pediatric HIV in India
(3) PMTCT and Care of the HIV-exposed Infant
(4) Diagnosis of HIV Infection in Infants and Children
(5) Anatomy of a Pediatric Clinical Visit*

Unit 2:  Management and Monitoring of HIV-Infected Infants and Children
(6) Confirming HIV Infection and Clinical Staging in Children*
(7) OI prophylaxis
(8) Immunizations
(9) Monitoring Nutrition and Growth*
(10) Laboratory monitoring
(11) HIV & TB Co-infection

Unit 3:  HIV Infected Children, Their Families and Their Communities
(12) Disclosure of HIV Diagnosis to Children
(13) Neurocognitive Development
(14) Adherence
(15) Palliative Care*
(16) Myths and Realities: Can I Get HIV From This Child?*

Unit 4:  Antiretroviral Therapy
(17) Initiation of Antiretroviral Treatment and Dosing
(18) Adverse Effects and Toxicities
(19) Drug Interactions
(20) Changing Antiretroviral Treatment
(21) Immune Reconstitution Inflammatory Syndrome (IRIS)

Unit 5:  Organ System Illness and Assessment
(22) Skin Complications*
(23) Neurologic and Ophthalmologic Complications
(24) Cardiac Complications*
(25) Pulmonary Complications
*Nine lectures prepared and presented by Dr. Hutton

Documentation of learner outcomes: Learners consisted of health care providers from India: 32 physicians, 12 residents, 4 medical students, 1 fellow. Of the 49 registered participants, 29 completed all testing and 26 earned a Certificate (18 physicians, 5 residents, 2 medical students, 1 fellow)

Dissemination and impact: Dr. Hutton’s lecture ‘Anatomy of a Pediatric Clinical Visit’ was made available for viewing on the Open-Access section of the CCGHE website: http://www.ccghe.jhmi.edu/CCG/distance/HIV_Courses/pediatric_HIV.asp. No registration is required for this section of the site. Dr. Hutton’s lectures have been viewed a total of 341 times as of 10/15/2010.

2. HIV Clinical Care Discussions in Ethiopia (2006 to current)

JHU TSEHAI – Technical Support for the Ethiopian HIV ART Initiative
Johns Hopkins Center for Clinical Global Health Education (CCGHE)

Background/need: Clinicians working in resource-limited settings need accessible ways to continue their professional learning. This improves patient care and professional satisfaction, reduces burnout and loss of trained professionals to higher-resource settings, and builds international collaboration. The Johns Hopkins University Bloomberg School of Public Health leads an initiative, under the direction of Dr. Andrea Ruff, to “roll out” antiretroviral therapy for HIV infected persons of all ages in four regions of Ethiopia. Health professional education is a core strategy for implementing this goal. In Ethiopia, pediatric care is provided by health officers and general practitioners in urban and rural health centers. Pediatricians are limited to the central and referral hospitals. Therefore it is important that pediatric content be included in all clinical educational initiatives.

Learning objectives:
Participants will increase their knowledge about the management of HIV and its complications
Participants will increase the appropriate prescribing of available medications for antiretroviral therapy, opportunistic infection prevention and treatment, and treatment of pain.

Educational strategies: Clinical cases are prepared and presented by Ethiopian physicians; Johns Hopkins faculty members prepare and present teaching discussion followed by group questions and comment. These live broadcast video case conferences are held twice monthly; every 3rd conference focuses on pediatrics. Participants at Johns Hopkins Baltimore and other US sites (NIH, East Carolina University, Mayo Clinic) are linked with Addis Ababa University Medical Faculty and other Ethiopian sites (Hawassa, Jimma). Conferences are scheduled on Friday afternoons from 3-5 pm Ethiopian time (7-9am EST) and held at Black Lion Hospital in central Addis Ababa to maximize opportunities for busy Ethiopian clinicians to attend. Instructive clinical cases and diagnostic or treatment challenges are prepared as power point presentations by Ethiopian physicians with support from JHU TSEHAI. Cases are sent via email to selected Johns Hopkins HIV experts prior to the live video conference so that discussion can be prepared. These broadcasts can be viewed by learners at other sites live via a link in the CCGHE website or viewed later via the CCGHE archive.

Instructional materials:
106 video case conferences have taken place with 225 cases reviewed.
8-9 discussions each year are devoted to pediatric cases (see list of pediatric case conferences in Appendix O).

The case conferences (power point slides and video of case presentation/discussion) are archived for on-demand viewing (URL: http://www.ccghe.jhmi.edu/CCG/distance/HIV_Courses/Ethiopiaart.asp).

Documentation of learner outcomes:
Registration is not required. 25-40 Ethiopian providers participate in each session.

Dissemination and impact:
Since 2006, Dr. Hutton has led case discussions for 24 HIV video conferences covering the following topics: pediatric antiretroviral treatment, pediatric adherence, psychosocial issues such as diagnosis disclosure to children, and pain and palliative care.
As of 10/15/2010, this case series (adult and pediatric) has been accessed for viewing 3252 times.


Palliative Care for People with HIV/AIDS: a curriculum and teaching resource for medical educators
The Center for Palliative Care Education, Northwest AIDS Education and Training Center (AETC)
URL: http://depts.washington.edu/pallcare/training/overview.shtml

Background/need: Anti-retroviral therapies have transformed AIDS from a progressively fatal disease to a chronic illness. Clinicians providing care to patients with AIDS need palliative care education designed specifically for this clinical context. In addition, improved palliative care is important in AIDS because, despite advances in highly active anti-retroviral therapy (HAART) and sharp declines in mortality rates, AIDS remains a leading cause of death among Americans aged 25 to 44 years.

The goal of this curriculum is to improve the quality of care that patients with HIV/AIDS receive throughout the illness and at the end of life. This is accomplished through increasing the capacity of the AIDS Education and Training Centers to train clinicians in palliative care, and through increasing the HIV/AIDS care skills of palliative care clinicians. This curriculum is designed to provide the materials which medical educators need to deliver effective training sessions on a number of palliative care topics.

Learning objectives:
For Overall Curriculum:
- AETCs will increase their capacity to train clinicians in HIV palliative care
- HIV clinicians will increase their palliative care skills
- Palliative care clinicians will increase their HIV/AIDS care skills

For Pediatric Module:
- Consider how HIV/AIDS palliative care for children differs from that for adults
- Discuss issues related to communication with pediatric HIV/AIDS patients and their families
- Learn assessment skills related to palliative care needs for pediatric patients
- Become familiar with management options for symptoms in pediatric patients, including pain, anorexia, fatigue, sleep disturbance, dyspnea, and psychiatric symptoms

Educational strategies: small group presentation and discussion is recommended.

Modules include:
- Learning objectives
- PowerPoint slide presentations with accompanying slide notes
- Skills building and interactive exercises
- Sample agendas
- Evaluation forms
- Suggested handouts
- Resource lists
The materials can be adapted to the needs of the training session participants, to the time frame, and to the training format. The materials can be used intact, or individual elements can be selected, modified, and used as needed.

**Instructional materials:**

Module 1: Overview of HIV/AIDS Palliative Care
Module 2: Advance Care Planning
Module 3: Communicating with Patients and Family
Module 4: Cross-Cultural Issues in HIV/AIDS Palliative Care
Module 5: Pain & Symptom Management
Module 6: Psychosocial & Psychiatric Issues

*Module 7: Pediatric HIV/AIDS Palliative Care*

Module 8: Care of the HIV Positive Patient in the Correctional Setting
Module 9: HIV and Hepatic Failure

*Dr. Hutton developed this module. See Appendix P.*

**Documentation of learner outcomes:** The modules were piloted, evaluated, reviewed, and revised before being made publicly available.

**Dissemination and impact:** Dr. Hutton used this module in several training settings nationally and internationally, including OSI sponsored seminars in Kiev, Ukraine; Salzburg, Austria; Tbilisi, Georgia; PACTG sponsored training in Cape Town, South Africa and Harare, Zimbabwe; CRS PEPFAR sponsored training outside Nairobi, Kenya for 9 focus countries; and JHU PEPFAR sponsored education in Addis Ababa and Hawassa in Ethiopia.

The Ethiopian Ministry of Health approved a national curriculum for HIV Palliative Care that was based on the University of Washington Northwest AETC, including Dr. Hutton’s Pediatrics module. This training has already reached 575 nurses, health officers, and physicians through on-site training; 93 nurses through pre-service training; 26 nurses, health officers, and physicians through off-site training. 54 physicians and health officers were trained to be trainers to further disseminate this curriculum.

4. **U8: The Hospice and Palliative Care Approach to Caring for Pediatric Patients (2008)**

*Hospice and Palliative Care Training for Physicians: A Self Study Program, UNIPAC Series, Third Edition*

American Academy of Hospice and Palliative Medicine

**Background/need:** Hospice and Palliative Medicine is a medical subspecialty newly recognized by the American Board of Medical Specialties (ABMS). The certifying exam is co-sponsored by ten primary specialty boards and covers the care of patients from birth through the elder years. This self-study curriculum was extensively revised and updated to reflect the best evidence base so that it could be used by physicians preparing for the certifying exam via the “practice pathway”.

**Learning objectives:**

Specific learning objectives were prepared for each of nine volumes. The objectives for the volume on pediatrics revised by Dr. Hutton are:

- Learn the differences that exist between palliative care of adults versus pediatric patients.
- Confront the unique clinical, ethical, psychological, developmental, and spiritual issues of caring for pediatric patients with life-limiting illnesses.
- Gain critical guidance on managing pain and non-pain symptoms.
- Get comprehensive medication tables specific to pediatric patients.
- Learn about non-pharmacologic interventions, sedation at the end of life, and communication issues specific to pediatric patients.
• Gain strategies for managing grief and bereavement.

Educational strategies: Independent self-study program; CME credit available. The following materials are available for each volume in print or on CD-ROM:

- Learning objectives
- Pretest
- Reading material
- Clinical situations to demonstrate knowledge application
- References
- Posttest

Instructional materials:
U1: The Hospice and Palliative Medicine Approach to Life-Limiting Illness
U2: Alleviating Psychological and Spiritual Pain in Patients with Life-Limiting Illness
U3: Assessment and Treatment of Physical Pain Associated with Life-Limiting Illness
U4: Management of Selected Non-Pain Symptoms of Life-Limiting Illness
U5: Communication and the Hospice and Palliative Medicine Physician’s Role on the Interdisciplinary Team
U6: Ethical and Legal Dimensions of Treating Life-Limiting Illness
U7: The Hospice and Palliative Medicine Approach to Caring for Patients with HIV/AIDS
U8: The Hospice and Palliative Medicine Approach to Caring for Pediatric Patients*
U9: The Hospice and Palliative Medicine Approach to Selected Chronic Illnesses: Dementia, COPD, and CHF

*Dr. Hutton updated and revised this volume. A copy of this book is submitted with the portfolio. See appendix Q for electronic copy.

Documentation of learner outcomes: pre and post test for self evaluation; CME credit available

Dissemination and impact: Between May 2008 and December 2010, AAHPM sold 2628 sets of the 3rd edition of the UNIPAC series and an additional 78 individual copies of U8: Pediatrics. Dr. Hutton has just accepted the invitation to be primary author for the revision and update of this volume for the 4th edition, anticipated 2012 release.

5. Patient, Physician, and Society Course - Palliative Care Selective (2006-2009)
Johns Hopkins University School of Medicine

Background/need: Traditional medical school curricula have neglected the clinically and professionally important arena of caring for patients with life-threatening illness and those who are dying. This selective was created as one of several interventions to remediate this educational gap. It focuses on students in Year 2 who are well into their medical school experience but have not yet begun their clinical rotations. It was discontinued after 2009 in lieu of the new palliative care intersession designed as part of the Genes to Society curriculum (see below).

Learning objectives:
- Introduce and explore the practice of palliative care
- Explore psychosocial and spiritual aspects of palliative care
- Identify basic concepts of pain and symptom management
- Discuss the experience of loss and accommodation of grief
- Explore the integration of palliative care with disease-directed therapy
**Educational strategies**: small group discussion, short didactic presentations, video clips of clinical scenarios, role playing, written reflections. Selective met for 2 hours per week for 4-5 weeks per year; 18-30 Year 2 Medical Students per year.

**Instructional materials**: syllabus, readings, video clips, role descriptions for interdisciplinary team meeting role play (Appendix R)

**Documentation of learner outcomes**: Students were assessed based on their participation in small group discussions, their weekly reflective essays, and a final essay intended to demonstrate the application of palliative care principles.

**Dissemination and impact**: This selective has been selected by 92 students over 4 years. Elements of this curriculum have been used in the new palliative care intersession (below).

### 6. Palliative Care Intersession – Genes to Society Curriculum (2010 to current)

**Course Directors**: Michael Carducci, MD, Grace Cordts, MD. Nancy Hutton MD

Johns Hopkins University School of Medicine

**Background/need**: In the newly designed Genes to Society curriculum for Johns Hopkins medical students, intensive one-week topic-focused intersessions are offered between longer blocks of pre-clinical and clinical training throughout the four years. Palliative and end of life care is a cross-cutting area with specific knowledge and skills that all physicians in training need.

**Learning objectives**:
- Differentiate between palliative care and hospice
- Recognize that specific skills can be acquired in order to deliver good palliative care
- Outline an approach to symptom management
- Establish a framework for communicating bad news to individuals and their families
- Give examples of the multidimensional aspects of palliative care
- Appreciate the role of the physician in the interdisciplinary team in delivering palliative care
- Examine personal response to caring for the dying patient
- Distinguish the expected course of normal grieving from complicated bereavement

**Educational strategies**: lectures, small group discussion and exercises, team-based learning, standardized patients, home/hospice visits, readings, pre- and post-testing, reflective essay

**Instructional materials**: syllabus and class schedule (Appendix S), Primer of Palliative Care, clinical case scenarios, standardized patient scenarios, power point presentations, readings

**Documentation of learner outcomes**: Students were assessed based on their attendance and participation, team presentations, multiple choice exam, final essay.

**Dissemination and impact**: 63 students participated in the first intersession in May 2010. The Student Assessment and Program Evaluation (SAPE) Committee will review this course following its second offering in 2011.

### D.4. EDUCATIONAL ADMINISTRATION & LEADERSHIP

**Medical Students**
- Coordinator, Medical Student Outpatient Pediatric Clerkship, Harriet Lane Clinic (1 student per month, 3 years)
- Course Leader, Introduction to Palliative Care; Physician & Society Course (Year 2 medical student class, 4 years)
- Course Leader, Selective in Palliative Care; Patient, Physician, and Society Course (Year 2 medical students, 92 students over 4 years)
- Course co-leader, Intersession in Palliative Care; Genes to Society Curriculum (63 students following first clinical rotation, initial offering 2010)
- Leader, Summer Sub-Internship in pediatric HIV/AIDS care (1-3 students/summer, 15 years)

Pediatric Residents
- Leader, Resident Elective in pediatric HIV/AIDS care (5 residents, by request)
- Course Leader, Pediatric Palliative Care Lecture Series; Pediatric Residency Noon Conference (10-30 residents, medical students per lecture, 4-6 lectures per year, 9 years)
- Leader, Resident elective in pediatric hospice & palliative medicine (10 residents over 2 years)

Clinical Fellows
- In preparation: Program Director, Pediatric Hospice & Palliative Medicine Fellowship (submit for ACGME approval; anticipate 1 fellow per year)

D.5. NATIONAL & INTERNATIONAL SCHOLARSHIP IN EDUCATION

Invited talks and consultations:
I am sought after to teach health care professionals in two main areas of specialty: pediatric HIV/AIDS care & treatment and pediatric palliative care. I have taught about the integration of palliative care with disease directed therapy, especially for HIV/AIDS, in the United States, Mexico, Canada, Brazil, South Africa, Zimbabwe, Kenya, Ethiopia, Austria, Ukraine, and Georgia. International organizations that seek my expertise include the Open Society Foundations, the Pediatric AIDS Clinical Trials Group, Catholic Relief Services, the US Government Office of the Global AIDS Coordinator and its PEPFAR (President’s Emergency Plan for AIDS Relief) Program, the Worldwide Palliative Care Alliance, and the WHO Stop TB Programme. A complete list of my presentations is found in my CV.

I want to highlight the teaching and technical assistance I provide as part of the JHU TSEHAI project in Ethiopia. I have visited Ethiopia about twice each year for the past five years. During each trip, I visit clinics and inpatient hospital units and provide individual clinical teaching and group lectures for health care professionals on topics ranging from basic medical management of pediatric HIV infection, to developmental issues such as diagnosis disclosure and adherence, to systems of care such as medical record keeping and chronic care follow-up. I have hosted Ethiopian pediatricians here in my pediatric HIV clinic (Intensive Primary Care or IPC). More recently I have focused on professional education about pain management, a critical need in Ethiopia. I lectured as part of the pilot of the national pain training for physicians and then organized full day trainings with Johns Hopkins invited faculty in nursing and pain medicine to extend this education to key professionals working in Black Lion Hospital, the premier referral and teaching hospital in Ethiopia. Throughout this time, I have contributed to the pediatric clinical case discussions broadcast live between Ethiopia and the US (see Curriculum #2 above on pages 24-25 and Appendix O).

Professional Meetings
My educational leadership at professional meetings began in 1990 when I co-founded and led a new Special Interest Group at the annual meeting of the Ambulatory Pediatric Association for Generalists Caring for Children with HIV/AIDS. This forum provided education and open discussion among academic pediatricians working on the front lines of the AIDS epidemic for seventeen years. From 1999-2004, I chaired and organized the pediatric pre-conference for the Brazil/Johns Hopkins HIV/AIDS Conference for five years. I chaired and organized a palliative care mini-course at the Pediatric Academic Societies annual meeting in 2004.
Educational Materials with National & International Impact

Early in my general pediatric career, I authored book chapters in two pediatric textbooks, the second through three editions. “Special Needs of Children with Chronic Illness” in Oski’s *Principles and Practice of Pediatrics* was a product of my fledgling interest in the primary care of children with chronic, complex conditions in the context of their families and communities. I also authored three chapters in the Starfield’s ground-breaking book *Effectiveness of Medical Care: Validating Clinical Wisdom* that helped initiate the movement toward evidence-based medicine.

My scholarly focus shifted quickly with the advent of pediatric HIV/AIDS in Baltimore and my pivotal role developing and leading the Pediatric & Adolescent HIV/AIDS Program at Johns Hopkins. I contributed to ethical and policy discussions organized by the Johns Hopkins Bioethics Institute and I authored or coauthored chapters in two resulting books. This work took place at a time in the history of the domestic AIDS epidemic when the rush to “protect” children tempted well-meaning professionals and government agencies to trample the rights of women to make health care decisions autonomously for themselves and their unborn children.

In the second decade of the AIDS epidemic, as children increasingly suffered and died with this disease, my scholarly focus expanded to include the emerging field of pediatric palliative care. My educational publications integrated the principles of primary care for chronic illness, medical care for HIV/AIDS, and palliative care for patients and families living with incurable conditions. The chief of the HIV/AIDS Bureau at the Health Resources and Services Administration (HRSA) invited me to an expert planning meeting that resulted in the publication of *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS* in hard copy and downloadable from the HRSA website. I wrote the chapter on the care of children and adolescents for this book based on my unique perspective and experience. (Appendix T)

In the third decade of the AIDS epidemic, significant US government funding and international advocacy efforts began to extend access to life-saving antiretroviral therapy to HIV-infected people in parts of the world with minimal financial resources and often minimal health care infrastructure. Dr. Joseph O’Neill, the lead editor for the HRSA Guide and now the White House “AIDS Czar,” invited me to Cape Town, South Africa to meet with African authors for a planned adaptation of the HRSA Guide to the Sub-Saharan African context. I became the Pediatric Collaborating Editor of *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS in Sub-Saharan Africa*. I worked with pediatric authors from South Africa and Uganda to craft a seven chapter section on the care of children and adolescents that was a significant adaptation and extension of my own chapter in the original Guide. (Appendix U) This book was originally published on line by the Foundation for Hospices in Sub-Saharan Africa (FHSSA) and has since been taken over by the African Palliative Care Association (APCA). Although only limited data are available, APCA reports that 122 printed copies of the book and 229 CD-ROMs have been distributed by them (the cost of the book and the shipping is prohibitive for most professionals in Africa). There is no information available on downloads. The African Guide serves as the HIV textbook for the Diploma in Palliative Medicine at the University of Cape Town, the premier university in Africa.

As discussed in the curriculum section above, I co-directed and lectured for a web-based training course on the management of pediatric HIV infection for health care providers in resource-limited settings sponsored by the Johns Hopkins Center for Clinical Global Health Education (CCGHE). (see Curriculum #1 on pages 23-24)

In the US, the dramatic clinical responses to highly active antiretroviral “cocktails” led to the unintended and unhelpful loss of recognition that AIDS continued to kill thousands each year in our well-resourced
country. Although some of these deaths could be attributed to patient behavior (ie. poor adherence to therapy) and be considered “preventable,” many were due to incurable complications. As described on page 17 above, I contributed pediatric expertise to the Robert Wood Johnson sponsored Workgroup on Palliative and End-of-Life Care in HIV/AIDS. The published monograph “Integrating Palliative Care into the Continuum of HIV Care: An Agenda for Change” identified gaps in care, education, research, policy, and funding and made recommendations to the field. (Appendix L) I contributed the pediatric module to the University of Washington Northwest AIDS Education and Training Center (NW AETC) web-based curriculum on HIV Palliative Care which has been adapted for use internationally (see curriculum #3 on pages 25-26 above and Appendix P). In response to a more recent editorial invitation, I mentored a junior colleague in writing a comprehensive review article that integrates the principles of primary care, HIV care, and palliative care for practicing pediatricians. The outline, overall content, tone, and final revision are my work. This article exemplifies my approach and philosophy of HIV care for the general pediatrics audience (Appendix V).

Within the larger palliative care community, I am an expert in pediatric hospice and palliative medicine. I have co-authored chapters in three key textbooks on pediatric palliative care (CV page 14, Book Chapters #15, 16, 17). I revised and updated the pediatric volume of the self-study curriculum for the American Academy of Hospice and Palliative Medicine (AAHPM) (see Curriculum #4 on pages 26-27 above and Appendix Q). I piloted curriculum modules for the Initiative for Pediatric Palliative Care (IPPC) and appear in one of their teaching videos. I have written invited editorials for two key journals in the field.

Currently, I am a member of the National Collaborative Project on Defining the Pediatric Palliative Care Competencies and Developing a Shared Curriculum for fellowship training programs. This working group will present draft recommendations for peer review and discussion at the Annual Assembly of the AAHPM in February, 2011.

D.6. HONORS AND AWARDS IN EDUCATION

Teaching Award, Division of General Pediatrics and Adolescent Medicine (GPAM), 2009

Excerpts from peers and colleagues in support of the GPAM Teaching Award:

“Dr. Hutton is a remarkable teacher... Her willingness to share examples from her own experience allows people to be honest about their development. On a personal level, she taught me a great deal about the power of physician presence, the importance of good pain and symptom management and the reality of practicing effective teamwork and collaboration.” Elizabeth Keene Reder, 12/17/2008

“You can only learn by watching how she practices...I could not ask for a better role model to me as a nurse and as a person...You could not have a better teacher. Johns Hopkins has had a long, long list of physicians...outstanding in their fields. Many...have been recognized nationally and internationally thru their discoveries and teaching. I honestly believe that Nancy Hutton should rank with the best of them. She is a hero to me.” Carolyn Kiefner, 1/28/2009

“I have watched her teach her patients with expertise, patience, and kindness...She has patiently answered my questions...providing constructive, encouraging information and feedback. She always makes time for you, and doesn’t make you feel that you are imposing, even when you know that she is very busy.” Nancy Sybert, 1/2009
“she has a gift for mentoring both by modeling and by how she leads/facilitates discussions one-to-one, in small groups (like family meetings and interdisciplinary meetings) and with patients and their families... It is remarkable how one person has been able to contribute so much to who I am as a doctor...” George Siberry, 12/16/2008

D.7. ADVISOR & MENTOR

The majority of my mentoring activities are “informal” rather than formal. I am sought out by trainees and junior faculty for my content expertise in pediatric & adolescent HIV/AIDS and in hospice & palliative medicine, my skill as a clinician in the care of patients with complex and life-threatening illness, my experience as a translational and transdisciplinary program builder, and my genuine concern for the professional development of young people. The following table lists those with whom I have had the most focused and longitudinal mentoring relationship.

<table>
<thead>
<tr>
<th>Mentee</th>
<th>Position at JHU</th>
<th>Work Focus</th>
<th>Current Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Siberry, George, MD, MPH</td>
<td>1991-2008</td>
<td>Medical student, MPH student, Pediatric resident, Pediatric Infectious Diseases fellow, Assistant Professor Pediatrics</td>
<td>Pediatric HIV infection, Medical Officer, Pediatric Adolescent Maternal AIDS (PAMA) Branch, NICHD, NIH; Assistant Professor of Pediatrics, JHUSOM</td>
</tr>
<tr>
<td>Parsons, Genevieve, MD</td>
<td>2001-2005</td>
<td>Instructor Pediatrics, Pediatric HIV infection</td>
<td>Pediatric Practice, San Diego, CA</td>
</tr>
<tr>
<td>Sanders, Renata, MD, MPH</td>
<td>2003-pres</td>
<td>Adolescent Medicine fellow, Assistant Professor Pediatrics</td>
<td>Adolescent HIV infection, Assistant Professor of Pediatrics, JHUSOM</td>
</tr>
<tr>
<td>Boss, Renee, MD, MHS</td>
<td>2004-pres</td>
<td>Neonatology fellow, Assistant Professor Pediatrics</td>
<td>Pediatric Palliative Medicine, Assistant Professor of Pediatrics, JHUSOM</td>
</tr>
<tr>
<td>Agwu, Allison, MD</td>
<td>2004-pres</td>
<td>Pediatric &amp; Adult Infectious Diseases fellow, Assistant Professor Pediatrics</td>
<td>Pediatric &amp; adolescent HIV infection, Assistant Professor of Pediatrics &amp; Medicine, JHUSOM</td>
</tr>
<tr>
<td>Stewart, Miriam</td>
<td>2005-pres</td>
<td>Premedical student, Medical student, Student leader, IPC Big Buddy Program</td>
<td>Pediatric &amp; adolescent HIV, Pediatric Palliative Medicine, MD anticipated 2011 JHUSOM</td>
</tr>
<tr>
<td>Name</td>
<td>Years</td>
<td>Roles &amp; Contributions</td>
<td>Mentee Role</td>
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<tr>
<td>---------------------------</td>
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<td>----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Symons, Heather, MD</td>
<td>2005-pres</td>
<td>- Pediatric Oncology fellow &lt;br&gt;- Assistant Professor Pediatrics</td>
<td>Pediatric Palliative Medicine &lt;br&gt;Assistant Professor of Pediatrics &amp; Oncology, JHUSOM</td>
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<tr>
<td>Michaelis, Annie, PhD</td>
<td>2006-2009</td>
<td>- Doctoral candidate in Health Policy &amp; Management, SPH &lt;br&gt;- Student leader, IPC Big Buddy Program</td>
<td>Thesis – Transition to adult health care for ped HIV survivors &lt;br&gt;Research Associate, Monitoring &amp; Evaluation, Clinton Foundation</td>
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<td>Simpkins, Evelyn, MD</td>
<td>2007-2008</td>
<td>- Adolescent Medicine fellow &lt;br&gt;Adolescent HIV infection</td>
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<td>Marolen, Khensani</td>
<td>2008-2009</td>
<td>- RISE scholar, KKI &amp; SPH</td>
<td>Pediatric HIV infection &lt;br&gt;MPH</td>
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<td>Crewe, Stephanie, MD</td>
<td>2009-2010</td>
<td>- Adolescent Medicine fellow &lt;br&gt;Adolescent HIV infection</td>
<td></td>
</tr>
<tr>
<td>Levine, Deena, MD</td>
<td>2009-pres</td>
<td>- Pediatric Oncology fellow &lt;br&gt;Pediatric Palliative Medicine &lt;br&gt;Fellow, Pediatric Oncology, JHU-NIH</td>
<td></td>
</tr>
<tr>
<td>Fanone, Kathleen, MSW</td>
<td>2009-pres</td>
<td>- LEAH fellow &lt;br&gt;- Social work clinical intern &lt;br&gt;- Study coordinator &lt;br&gt;Pediatric &amp; Adolescent Palliative Care</td>
<td>Study Coordinator, JHU site/multicenter trial adolescent advance directives</td>
</tr>
</tbody>
</table>

Feedback from four key mentees was elicited in October 2010 and is reproduced below.

**George K. Siberry, MD, MPH**  
**Assistant Professor of Pediatrics, Johns Hopkins University School of Medicine**  
**Medical Officer, Pediatric Adolescent Maternal AIDS (PAMA) Branch**  
**Eunice Kennedy Shriver National Institute of Child Health and Human Development**  
**National Institutes of Health**

“Dr. Hutton has been a clinical and career mentor to me since I first began working with her as a Johns Hopkins medical student in 1991. She has been a consistent, important source of guidance and support in my career development throughout this time.

I approached Dr. Hutton about working in the pediatric HIV field when I was still a medical student, drawn to the area by my development work in Haiti, my interest in pediatrics, and my work as a translator at Hopkins for a 4-year-old Haitian boy who was ultimately diagnosed with HIV infection. It was through my experience with this boy and his family that I was introduced to Dr. Hutton and her IPC program for pediatric HIV infection. Despite her own junior status at the time and her overburdened commitment and my complete lack of clinical training at that point, she agreed to have me work with her and her team. She modeled the compassionate, skilled clinician that helped me create a vision for the type of physician I would aspire to be. She included me as a member of an interdisciplinary team of
physicians, social workers, nurses, nutritionists, child life workers, pharmacists and research staff, a training experience that helped me enormously when I would (much later) take on the task of directing the Harriet Lane Clinic and plan for the creation of its new model of care in a new building. Recognizing my knack for organizing processes, Dr. Hutton challenged me to create an HIV-tailored clinical encounter form that would streamline clinical care and documentation and work with the team to test and improve it. Dr. Hutton enabled me to take on a primary care role for that Haitian boy, under her supervision, but in a way that helped me develop my interpersonal and clinical skills, serve a family in need and build a deeply meaningful and formative experience that lasted through my medical and public school years and residency, until his death in the late 1990s. She helped me not only provide his comprehensive medical care but also facilitated my direct role with participation in Pediatric AIDS Clinical Trials Group (PACTG) studies. Under Dr Hutton’s mentoring and the experience she helped me create early in my medical training, my goals to pursue a career in pediatric HIV care and research, to serve disadvantaged communities, and to insist on the value of interdisciplinary participation were both informed and firm.

As I continued through the other stages of my training, Dr. Hutton found a way to have me continue my clinical work in IPC. After I finished my pediatric and infectious diseases training, I joined the faculty. We had often discussed the value of the clinical data accumulated from IPC patients since Dr. Hutton founded the program at the onset of the epidemic. She encouraged me to pursue the “IPC Cohort Study” project as a source of data for program improvement evaluations and for answering research questions about pediatric HIV clinical epidemiology. Armed with my MPH training, I reached out to colleagues who had developed the highly productive adult HIV Moore Clinic cohort study. In her mentor role, Dr Hutton gave me complete access to this rich database, held regular planning meetings with me about goals and procedures for the project, and helped me learn the IRB application process. We were able to develop the project successfully, allow other faculty members and trainees to collaborate, and it resulted in many valuable scientific abstracts and publications for me and others.

Dr. Hutton continued to play a pivotal role during my junior faculty years in giving me guidance and opportunities – opportunities that she was often giving up for herself in order to benefit me – that allowed me to develop my research portfolio and begin to create a national reputation. The CDC approached Dr Hutton about participating as a site PI in their nation-wide, multi-site epidemiologic “LEGACY” study of HIV-infected children and youth; Dr. Hutton offered me the lead. She invited me to take over the pediatric HIV lecture in the Hopkins HIV for the Practitioner course and to participate in the biennial JHU-Brazil HIV course in Rio de Janeiro, activities that I have now continued to do for years. She advocated for me to join the DHHS Pediatric Antiretroviral Treatment Guidelines Working Group. When Hopkins would no longer be funded as a DAIDS IMPAACT research site, Dr. Hutton encouraged me to take the lead in a successful application to be an NICHD IMPAACT site. These opportunities strengthened my research advances and made me sought after for additional research and educational opportunities nationally and internationally.

Finally, when I had an opportunity to join Dr. Lynne Mofenson Pediatric AIDS Branch at NICHD, Dr. Hutton was one of the first people from whom I sought counsel. Even though my departure would mean upheaval for IPC and for Dr. Hutton, I knew that she would help me critically evaluate if that decision would be in my best interest.

In short, Dr. Hutton has been my career “parent”. She has consistently led by her example, facilitated my research and clinical opportunities, and ensured that I have progressed along a successful and rewarding career path. I shall be forever grateful.”
“At the beginning of my fellowship in Neonatal-Perinatal Medicine at Johns Hopkins in 2004, Dr. Hutton became one of my two primary research mentors. Because my research interests spanned the areas of neonatology and palliative care, Dr. Hutton has been an invaluable resource for both the content of pediatric palliative care as well as the process of combining disciplines. Throughout my fellowship Dr. Hutton met with me regularly to assess my progress and make plans for future directions. She helped me to make connections with other palliative care researchers from within the institution and around the country. She assisted me with grant writing, IRB protocol development, manuscript preparation, and presentations of my work at national research meetings. Her support and guidance helped me to become a 2008 Clinical Research Scholar of the National Center for Palliative Care Research, and the pediatric member of the American Academy of Hospice and Palliative Medicine’s Research Subcommittee. This work became the foundation for my NIH-funded K23 in the area of neonatal palliative care. In addition to her support of my research, Dr. Hutton has continued to support my development as a clinician. In 2010 she sponsored my application for Certificate of Qualification in Hospice and Palliative Medicine from the American Board of Pediatrics. She has also collaborated with me to expand clinical programs of palliative care into the perinatal and neonatal services provided at this institution. Dr. Hutton has been a superb mentor and role model for me as a fellow and now as junior faculty. She has helped to open multiple doors for me along this path.”

“\n
Allison Agwu, MD
Assistant Professor of Pediatrics, Johns Hopkins University School of Medicine
Division of Pediatric Infectious Diseases

“I first met Nancy Hutton when I was a first year fellow in infectious diseases. I met with her to discuss my interest in HIV and specifically its impact on adolescents and youth. She shared my excitement and immediately began brainstorming with me about how she could help facilitate my development in the management of this population. From that moment, she became and remains one of my most valued mentors.

Dr. Hutton has been involved in treating children with HIV since the beginning of the epidemic and has been an innovator in creating and sustaining a desperately needed, invaluable program (Intensive Primary Care Program) to address the medical and non-medical needs of the affected children and their families. Although the patients she sees often present with complicated social circumstances, Dr. Hutton possesses the sensitivity to put them at ease, establish rapport, while appropriately addressing the relevant issues. She has an amazing way of synthesizing the need to control the virus, with the often chaotic reality of life for many of the children. She has had an immeasurable impact on the lives of the children, many of whom consider her to be their second and in some cases, their only mother. She commits to them and tirelessly fights for them. More recently, she has been certified in Palliative Care medicine, undoubtedly in response to what she has experienced as she has helped to guide many of the children she has cared for from cradle to grave, literally.

Through her hard work, her teaching, and most importantly through her example, she has left her mark on numerous trainees from all levels (domestically and internationally), of which I am proud to include myself. As I have transitioned from a fellow to a junior attending and colleague, I continue to work..."
alongside Dr. Hutton to care for our cohort of infected children and families. Every day I am impressed and affected by the soft-spoken, yet dynamic, and energetic silver-haired Dr. Hutton, who continues her tireless fight for her kids.”

Khaliah A. Johnson, MD
Clinical Associate, General Pediatrics and Adolescent Medicine, 2010-2011
Pediatrics Residency, Johns Hopkins Hospital, 2007-2010
Accepted for Palliative Medicine Fellowship, Children’s Hospital of Philadelphia, 2011-2012

“My personal definition of a mentor is someone who not only possesses character traits that you seek to emulate, but who is also genuinely invested in seeing you develop traits that will lead to your own success and happiness. A mentor supports your dreams and simultaneously helps you to maintain perspective; she guides, nurtures, and teaches by example. For me, Nancy Hutton has been that mentor.

I was first introduced to Dr. Hutton by a former supervisor, who has also been actively present in my life over the years as a mentor. When I called him up asking for advice on choosing a residency program in pediatrics, he said, “Well, I know the perfect person to help you … you have to talk to Nancy Hutton.” I remember speaking on the phone with Dr. Hutton one evening, just two days before my rank order list for pediatric residency was due. I was so touched by how much she seemed to care about my decision and the path I was preparing to embark on. In retrospect, I have seen Dr. Hutton interact with other pediatricians-in-training with a similar degree of care and investment. This truly speaks to the manner in which she prioritizes opportunities to support rising clinicians.

Once I began pediatrics residency at Johns Hopkins Hospital, my mentor-mentee relationship with Dr. Hutton continued to grow. In my intern year, she offered me a listening ear and invaluable encouragement as I struggled with the sudden illness of a patient I cared for. She made it clear to me that despite her numerous clinical and teaching responsibilities, she was always available to assist in any way that she could. At a time in my training when nearly everything felt stressful and overwhelming, it brought me so much peace of mind to know that there was someone senior to me, who had once walked the same path I was now on, looking out for me.

During my second and third years of residency, due to my interests in working with medically complex patients, I engaged in clinical electives with Dr. Hutton in the Intensive Primary Care/Pediatric HIV clinic, and on the Harriet Lane Compassionate Care Team. Ultimately, her role-modeling and encouragement lead me to decide to pursue a career in pediatric palliative care. She has supported me in palliative care project work in Ethiopia, assisted me to attend the American Academy of Hospice and Palliative Medicine national assembly in 2010, and endorsed my application to pediatric palliative care fellowship (which assisted me in attaining one of three spots in an accredited [pediatric] fellowship program offered in the entire country annually). In my new role as a pediatric attending, I now have the privilege of working with Dr. Hutton once a week on the pediatric palliative care consult service as the Johns Hopkins Children Center. Each time that Dr. Hutton and I staff a consult together, attend a family meeting, or talk with our pediatric colleagues about the importance of palliative care, I learn something new from her. She continually gives me something to strive for.

Many people spend their entire careers searching for mentorship similar to that which I have received from Dr. Hutton. Both knowing her and being able to call her a mentor, colleague, and friend, is an incredible honor.”
## APPENDICES – TABLE OF CONTENTS

Appendix materials referenced in the portfolio text are listed below in the order in which they appear. Each is in pdf format with the file name indicating its letter designation. All 22 files are found in the submitted zip file entitled: Nancy Hutton Portfolio Appendices.zip

In addition, hard copy of key materials (*) are submitted for ease of review.

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