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# **The Story of AIDS**

## **Experiencing AIDS Through Story Telling**

A Clendening Proposal by Lase Ajayi



## Introduction

Telling a story, particularly telling one's own story, is empowering. By telling one's story, one is able to control characters, their actions, and ultimately, their fate, because the storyteller is expressing outwardly what he or she knows intimately and has experienced personally. The story is not told from the perspective of another person, who is either guessing or approximating what another person is feeling or has experienced. In addition, telling one's own story has a cathartic effect. It allows one to dispose of a burden that might be weighing one down. It provides an outlet to vent and release the different emotions generated while the experience was unfolding, but which were suppressed in order to deal with that moment. Thus, choosing to tell one's story has a beneficial and healing effect.

The story has a different effect on the listener. By listening, the audience is transported into the story of the orator. They experience whatever the orator creates, causing a series of different reactions in the process. Perhaps it strikes a chord with their own experience and causes them to review their own initial response, or perhaps it makes them reflect more deeply on the event. It may even leave them changed permanently. One only hopes the change is a positive one.

Africa is home to 80% of the children living with HIV in the world. The estimated number of newly infected adults and children in Africa reached 3.5 million at the end of 2001<sup>1</sup>. In 2004 it was estimated there were 300,000 deaths from AIDS and 2 million AIDS orphans in Nigeria<sup>2</sup>.

Each of these children has a story to tell. Each story, as each individual life, is unique, and deserves to be told and heard. In particular, children who are critically and perhaps terminally ill deserve to tell their stories, so that they can have a chance to gain control over their illness and their situation. They deserve a chance to release the tumultuous emotions that might be locked away in their hurt and confusion. The project I am proposing for the Clendening Fellowship will allow children infected with HIV/AIDS or orphaned by the disease to share their stories. These stories will be in whatever forms the children express themselves in. With the children's permission, I hope to publish their stories and their pictures as a book.

My ultimate goal in doing this is three fold. First I would like the proceeds from the sale of the books to help support the two Non-Governmental Organizations in Nigeria that I will be working with: ITUUNU and Jierch. Second, I hope that by publishing and distributing these childrens' stories, I will reach a wide audience. It is my hope that the more people read this book, the more people will be encouraged and even excited to join the fight against AIDS. Most of all, I hope that by talking to these children about their stories, I help start their healing process. The proceeds from the book, and the support of those who read the book, can help complete that process.

The remainder of this proposal contains a background section, which discusses the benefits of story telling and healing summarized from two literature reviews, and describes the Non-Government Organizations in Nigeria with which I plan to work. A complete description of my proposal follows, then a proposed budget, and finally a concluding statement about the relevance and importance of this project.



## Background Section

### Benefits of Storytelling:

A study was done in which a team of doctors went to multiethnic schools in Montreal in order to assess the benefits of storytelling among migrant children. There, they employed certain activities among the children of these schools. These activities included: children illustrating and commenting on myths, tales, or legends belonging to non-dominant cultures, children drawing and telling the story of a character of their choice who has been through a migration process, and children bringing in myths and tales from their families and communities. The results were published in *The Journal of the American Academy of Child and Adolescent Psychiatry*. In summary, Dr. Rousseau and her team stated that over the past decades, creative expression-activities such as storytelling have been increasingly recognized as a useful way to work with migrant and refugee children, especially those coming from war-torn countries. These activities have been used to help them to construct meaning, to structure identity, and to work through their losses and reestablish social ties. They also aid in promoting children's emotional well-being while simultaneously strengthening the link of the child to the group<sup>4</sup>.

Storytelling also enjoys popular recognition as a means of coping with difficult subjects. The *Cancer Monologue Project*, based on the success of the acclaimed *The Vagina Monologues*, is a collection of 30 stories told by survivors of cancer, and sometimes by their close friends. This book has inspired people living with cancer and HIV to perform their stories for family and friends with profound impact for many novice storytellers. The honesty with which the stories were told created a foundation for self-healing as well as providing strength for audience members<sup>5</sup>.

### Non-Government Organizations in Nigeria:

Because of the stigma attached to being infected with HIV/AIDS in Nigeria, many people living with HIV/AIDS have little support from family, friends or the community. In fact, HIV/AIDS patients are often ostracized from their communities. To alleviate gaps in the social safety net, the United States Government (USG) supports Nongovernmental Organizations (NGOs) that provide home-based care and support groups for people living with HIV/AIDS.<sup>3</sup> ITUUNU and Jirech are two examples of NGOs supported by the USG.

The ITUUNU organization is a non-governmental organization based in the city of Ibadan and is located within Ibadan North local government. The organization aids in the prevention of mother-to-child transmission of HIV and provides home-based follow-up care for HIV positive mothers and their children who are receiving antiretroviral therapy (ARV) at the University College Hospital in Ibadan, Nigeria. The organization also provides nutritional support, health education on infant feeding, and psychosocial support to mothers.

The Jierch Foundation is a home-based NGO located in Benue State, Nigeria. The volunteers of this organization keep and care for children who have been orphaned by the disease. With some funding from the USG, but mostly out of their own pockets, they clothe, feed and pay for the children to attend school. This foundation also helps the orphaned children who are infected with the virus to access treatment.



## **The Description of Proposed Project**

In designing this project, I consulted with Dr. Femi Soyinka, a dermatologist in Nigeria who chaired the committee that organized the Worlds AIDS Conference in Nigeria this year, about the appropriate amount of time required for this project along with the specific details of the proposal.

I will travel to Nigeria on the first of June and stay there until the first of July. I will work primarily out of Ibadan and southwest Nigeria, working with the ITUUNU organization in Ibadan and Jierch in Markurdi, Benue State. Although there are no specific hospitals dedicated to pediatric HIV/AIDS, there are many hospitals and clinics that treat large numbers of affected children due to the prevalence of the disease in Nigeria. I will use the University College hospital in Ibadan and the University Hospital in Ile-Ife, both of which have sizeable pediatric AIDS divisions. In addition to the hospitals, the aforementioned NGOs will give me access to homes, where I can conduct my interviews.

With the help of Dr. Femi Soyinka, I have made arrangements with the consultants in charge of the children's hospitals and clinics in Ibadan and Ife to observe their wards and visit the children. I plan to work first with the ITUUNU organization in Ibadan and will visit the children there for my first week and a half. It is my goal to have at least 15 "stories" from these visits. For the second week I will travel to Benue State and work with the Jierch foundation, where I will continue my interviews. The remainder of my time in Nigeria will be split between Ibadan and Ile-Ife, working with the hospitals in these areas.

I have patterned my procedure for conducting the interviews with the children after some of the exercises that Dr. Rousseau and her team used, as well as the procedure I used for my senior honors thesis, which involved interviewing over 100 girls ranging in age from six to twelve. I first introduce myself to the children, and let them feel comfortable around me by allowing them to ask me questions, or playing with any equipment I have with me (recorder, microphone, etc). Once we have established a rapport with one another, I will ease into a prepared series of questions that will help me obtain their story. What I want from these stories is how the children visualize their disease and or situation, and how they deal with it. I want the children to tell me, in their own way, how this disease affects them, and how they cope, if they do in fact cope. I have worked with children long enough to know that this will not be as easy as it sounds for many reasons. Each child is unique, the topic I want them to talk about is an extremely sensitive one, and there is no telling how each child will react, not to mention how I will guide them to stay on topic. I have attached a list of questions that I plan on asking the children in order to increase the chances of getting the stories I am looking for. The list also includes other techniques I plan on using should I experience other difficulties. These questions and techniques will hopefully allow me to deal with the different abilities and willingness of the children to tell their story.

Though English is the official language in Nigeria, there are over 250 other languages spoken. This will not be a problem while I am in Ibadan and Ife as these are Yoruba regions and I am fluent in Yoruba. English is primarily spoken in Benue State, but I will have a translator with me for assurance.

In order to publish the book, I am currently in contact with different children books publishing houses such as Knowledge, Ideas & Trends, Library Services for Education, Modern Curriculum Press and Multicultural Connections. Should none of these companies pull through, I am fully prepared to publish the book on my own. Increasingly, new writers utilize self-publishing as an alternative for promoting their books for others to see. Books like "Bartlett's Familiar Quotations," a standard reference book, and "The Elements of Style" are examples of successful self-published books. These



books sold well, and publishers bought the rights to publish them in greater quantity. Programs such as Microsoft Publisher, Adobe InDesign, and QuarkXPress are excellent for self-publishing and I have ready access to them.

I am also fully aware of how much hard goes into publishing a book, let alone being a self-publisher. That is why I have allotted myself four weeks to compile these stories. I plan to return to the states and spend the remainder of my summer working with as many others as needed to get this book published. I have plenty of support from many talented friends, and I am dedicated to this project and will see it through to completion.

## **Conclusion**

Storytelling is such an integral part of Nigerian culture that I swear my first words were in the form of some tale. Telling stories is not just how we express or entertain ourselves, it is also how we teach and learn. I want the stories these children tell to teach the world what it is like for a child to suffer HIV/AIDS. I want the world to hear from the child's own mouth what they go through, their experiences and how they rise above their situation, or even what happens if they don't. I want these children to teach the world, because as the world listens to (or reads) these stories, they will enter world of the child and be transformed. Hopefully this transformation will stay long enough for readers to take action and join the battle against this debilitating disease.

What about the children who are telling these stories and teaching the world? What do they gain from it? They gain an ear and a voice. They get the chance to actually tell someone what they are going through. To restate my introduction, releasing one's story is cathartic. It lightens one's burden, plus it just feels good to have someone listen to you. Not many, if any, of these children have had a chance to talk about what they are feeling, what they felt and how it affects them. This project will not only give them the chance to tell their story, but to also let them know that someone is listening and that someone cares. My hope is that they will also gain better services via the financial support that their stories gain.

These stories are not only to promote cross-cultural understanding between different groups of children who are living with AIDS; it is also to allow children to educate and energize people into action. Children are the best storytellers of the world. When they speak, and if we listen, we can learn a lot from them, we just need to give them a voice.

## Budget

|                                                        |         |
|--------------------------------------------------------|---------|
| Round trip Kansas City to Nigeria.....                 | \$2,000 |
| Travel From Ibadan Nigeria to Benue State Nigeria..... | \$500   |
| Food/Accommodations in Benue State.....                | \$300   |
| Support for Children.....                              | \$100   |
| Total.....                                             | \$2,900 |

I understand that my estimated total exceeds that of the Clendening Grant, but I am confident that I can raise the rest of the money I need for this project.

## Sample Questions and Exercises

Where were you born?

Can you tell me something about your family? Parents? Siblings?

Do you remember how you got here? (here referring to either the NGO or the hospital)

What is the happiest you have ever been?

What is the saddest you have ever been?

What worries you the most now?

What things bring you the most joy now?

What upsets you the most now?

What is the worst part, the hardest part for you now?

What helps you feel a little better?

What helps you feel a little safer?

If HIV/ AIDS was an animal, what kind of animal would it be?

If HIV/ AIDS was a person, would it be a girl or a boy? Why?

What would you say to him/her? What would he/her say to you?

What would you want it to say to you?

Can you draw me a picture and tell me a story about someone either you know or made up who has had to leave their home?

Read them a Nigerian Folk tale in which a child lost his or her parents or sibling and then ask the child to tell me what they thought of the story.



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# A Study and Evaluation of the Universal Health Care System of Brazil: Urban and Rural Disparities

## Clendening Summer Fellowship Proposal



Patients wait to see the doctor outside the PSF in Jacunda, Para, Brazil

Amber Bledsoe  
February 20, 2006

## **Introduction –**

During the summer of 2005, I and four other students from my university's Community Service Program traveled to Northern Brazil. There, in the small town of Jacunda, Para, we spent two months living and volunteering at a shelter for abused, disadvantaged, or orphaned children. This shelter was started by two women living in eastern Kansas, one Brazilian and one American. The shelter derives its support from certain Northeast Kansas church communities, as well as the town and residents of Jacunda. While there, I spent most of my time working with the children on their school work, doing tasks to help with the maintenance of the grounds, or just playing games. At the same time, there exists a great opportunity for any volunteers interested in the medical field. The grounds of the shelter also house a PSF clinic (Posto de Saude da Familia – Family Health Post), one of the sites of free health care administration through the Brazilian government. This clinic receives most of its support from the government, but does receive some equipment and medication donations from American shelter volunteers. Unfortunately, my time in the clinic was very limited due to my language skills and the needs of the shelter. But over the summer, as my Portuguese improved, I became more and more interested in working at the clinic. Every morning, patients would begin lining up as early as 6:30am to have a chance to see the doctor. Some days, these patients would be turned away and forced to return tomorrow, even earlier in the day. Before my group arrived, the clinic did not have a working blood pressure cuff. I began to wonder, "Why does the care at this clinic seem so poor, when we are in a country with government supported health care?" Last summer, I became very close to the children living at the shelter and many of the townspeople. I would like to return to Jacunda this summer to understand how the Brazilian healthcare system works and to do anything I can to ensure that the people of Jacunda are getting the care they need.

## **Background-**

Brazil is a country vast in size, covering almost 50% of the South American continent. It is also a country with vast differences in the wealth distribution among its population. The richest 1% of the population control 10% of the country's wealth; this is the same percent of wealth controlled by the poorest 50% of the population (Development Challenge,1).

The Brazilian government is taking steps to correct this inequality. In 1991, 20.2% of the population was living below the absolute poverty line. By 2000, this number had been reduced to 14.5% (Development Challenge, 2). Among Brazil's efforts to assist its impoverished population was a universal health care plan.

In 1990, Brazil created the Sistema Unico de Saude (Single Health System), granting all of its citizens free access to medical care. The management of this care is mostly the responsibility of the states but the federal government continues to provide the majority of the funding. Providers come from both public and private sectors with the private sector being reimbursed by the government. The private sector actually delivers the majority of the government funded care. Many people also have access to private health insurance plans; these tend to cover lost cost procedures and leave the most costly treatments to be covered by the public health system ([www.photius.com](http://www.photius.com)).

Despite this valiant effort, there are still large gaps in the access to care. There are many more doctors and clinics in the South than there are in the North. The majority



of the funds follow the same distribution. Even in the South, the money is not evenly distributed. Costly procedures benefit mostly the wealthy, while the poor rely on pharmaceuticals for their cure ([www.photius.com](http://www.photius.com)).

### **Description of summer experience-**

As stated in the introduction, I hope to return to Brazil this summer to obtain an understanding of how a universal healthcare system works. In particular, how effective is the Brazilian healthcare system? Is it able to adequately support the needs of all its citizens, both urban and rural? If not, why not? Where is there room for improvement?

From the observations I made last summer, I would propose that the health care in Jacunda is less than ideal. Some patients seen in this clinic do not have access to the proper medications. From my previous observations, I also hypothesize that there is very little preventative education occurring. I believe this lapse in quality care is not due to problems with the staff, but most likely due to a lack of time and funding.

This summer I would like to spend more time in the PSF clinic, working with the doctor to find out what is limiting the quality of care. To determine the extent of the limitations affecting the Jacunda clinic, I also plan to spend time in an urban PSF clinic in Sao Paulo. Hopefully, this will give me a sense of the level of care that is available at government supported free clinics. From this, I will be able to determine if there may be neglect of clinics in rural areas or if clinics nationwide experience the same kinds of limitations to quality care.

I plan to spend four weeks at the PSF clinic in Jacunda, where I will have meals and a place to sleep provided by the children's shelter. The hours of the clinic vary from day to day, but are most often from around 8:00am to 3:00 or 4:00 in the afternoon. I plan to spend this time with the doctor, observing the number and types of cases he is seeing and discussing these cases with him to find out if he feels like he was able to provide the patient with an adequate level of care. I believe that these observations will then lead me to a conclusion on what is limiting the quality of care in this small town clinic. In addition to seeing patients at the clinic, the doctor and one of his nurses spend some afternoons outside the clinic making house calls. I do not plan to join the doctor on these calls, but do plan to discuss the idea with him. House calls are most likely the only way of providing treatment to very ill persons in the town that do not have access to transportation. While this may be an effective strategy for treatment in Jacunda, house calls are something that I am quite unfamiliar with, as they are no longer widely practiced in our country. I would also be interested to see if this is something that is also practiced in the larger cities. I would also like to be able to discuss with some of the patients any difficulties they may have had in obtaining care. While they most likely will not be able to judge the completeness and adequacy of the care they are obtaining, they will be the best source for determining the obstacles to obtaining care the townspeople face.

For my observation of the urban PSF, I plan to spend a week in the city of Sao Paulo. My observations here will take the same format as in Jacunda: observing and discussing the cases and limitations of treatment.

## **Methods-**

I plan to begin my time in Brazil by spending a week in Sao Paulo at the PSF there. I will spend the days shadowing the clinic doctor, making note of the cases seen during the day. I will follow up on each case by discussing with the doctor whether he feels he was able to provide the appropriate treatment and counseling to the patient. I will also be observing how the patient will obtain any medications they might need. I am also interested in finding out if the doctor has access to all the examination equipment and support staff he might need. I also plan to question him about when he feels the need to send patients to other clinics or hospitals. Another factor that I am very eager to look at is the prevention and management of chronic illnesses. I will be interested to find out the prevalence of issues such as hypertension and Type II diabetes and how the doctor addresses them. I plan to ask how often he is able to conduct follow up visits with patients with chronic illnesses. I am also very interested to find out if there are any illness prevention strategies in place. This does not only apply to the chronic illnesses mentioned above, but also to things like smoking cessation, cancer screenings, and safe sexual practices.

After my time in Sao Paulo, I will be flying to the state of Para, where I will begin my observations in the rural PSF. I plan to stay here for four weeks. Observations and questions will be mostly the same as in Sao Paulo, but with a few additions. I will be interested to find out how far patients travel to receive health care in Jacunda, as it may be the closest location with a doctor for many people living in extremely rural areas. I also plan to include some patient questioning to my observations in Jacunda, as I will have more time here. I plan to keep patient questioning as objective as possible with questions such as how many times the patient had to come to the clinic before being seen by the doctor, why they chose to come to this particular clinic, and how long they waited after becoming ill before they decided to come in. All of these questions will be directed toward discovering any obstacles the patient may have had to receiving care. I plan on asking these questions to approximately one patient per day which would give me a sample of 20 patients by the end of 4 weeks.

## **Problems and Boundaries-**

One of the greatest difficulties of my study will be the fact that quality of care is a very subjective thing. What one American feels is important may not be important at all to someone on the other side of the world. It is very unlikely that a person living in impoverished, rural Brazil suffering from tendonitis will even visit the doctor, let alone insist on an orthopedic consult as I have witnessed in American clinics. To deal with this problem, I have tried to gear my observations toward more objective measures such as how many times a patient had to come to the clinic before being seen by the doctor. In addition, I plan to base my observations on the local physician's ideal treatment, not necessarily how we would treat the ailment in the United States.

The other major barrier to my summer project is the language. In rural Jacunda, very few people speak English, and it is likely that the doctor staffing the clinic will be no exception. While my Portuguese was very limited during my first visit to Jacunda, it has since improved and I am now able to carry out basic conversations. When I first arrive in Jacunda, I will be able to take advantage of the help of other American volunteers with stronger language skills than mine to help with the translations as I get readjusted to the

language and accustomed to medical terminology. In Sao Paulo, I will have access to English speaking doctors to help in my basic understanding of how the national health service works.

#### **Objectives-**

- 1- To evaluate whether the government funded healthcare system is delivering an adequate level of care to its citizens.
- 2- To determine if disparities exist between the levels of care available in urban free clinics and rural free clinics.
- 3- To assess whether there are any strategies for the prevention of illness in the free clinic setting.
- 4- To observe the material needs of the PSF in Jacunda to provide a list of these needs to future American volunteers for potential donations.
- 5- To improve my Portuguese language skills.
- 6- To further develop my own opinion on whether or not a universal health care plan would be effective in the United States.

#### **Time Frame-**

June 18-Departure from United States  
June 19-Arrive in Sao Paulo  
June 20-Meet with contacts, visit Sao Paulo PSF  
June 21-Commence week of observation in Sao Paulo clinic  
June 28-Depart Sao Paulo by plane, arrive in Belem, Para  
June 29-Depart Belem by bus, arrive in Jacunda, Para  
July 3-Commence four weeks of observation in Jacunda clinic  
July 29-Depart Jacunda for tourist travel around Brazil  
August 14-Departure from Brazil (based on Aug 17 as first day of classes)

#### **Budget-**

|                                                      |       |
|------------------------------------------------------|-------|
| Plane tickets from Kansas City to Belem.....         | \$900 |
| (round trip-based on ticket price in summer of 2005) |       |
| Housing and meals in Sao Paulo (hostel).....         | \$250 |
| Transportation in Sao Paulo (bus, taxi).....         | \$75  |
| Bus tickets from Belem to Jacunda (round trip).....  | \$40  |
| Housing and meal donation in Jacunda.....            | \$300 |
| Total: \$1565                                        |       |

I assume full responsibility for all travel costs not associated with the research project and for any unexpected costs beyond the amount of the Clendening stipend.



**Contacts-**

Helena Kilian -- Volunteer Coordinator PRAY mission (children's shelter)  
Sally Savery – General Coordinator for PRAY mission, living in Sao Paulo  
Dr. Josh Freeman – KUMC Family Medicine, connection to Sao Paulo contacts  
Dr. Marcelo Levites – Sao Paulo physician  
Werley Rodriguez – English speaking Jacunda resident, helps organize American volunteers to PRAY mission once in Brazil

**PRAY Mission address and phone:**

Rua Santa Terezinha  
n 100  
Cx Postal 21 – Bairro Boa Esperanca  
CEP 68590-000  
Jacunda, Para  
Brazil  
Phone: 55-94-3345-1241

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UNICEF [http://www.unicef.org/statistics/index\\_countrystats.html](http://www.unicef.org/statistics/index_countrystats.html)

American Indian Reservation Healthcare

Tyler Buser

Clendening Fellowship Proposal

History and Philosophy of Medicine Department

University of Kansas Medical Center

20 February 2006

## INTRODUCTION

Doctor Buffaloe is a physician who works in the Navajo Reservation in New Mexico. Diabetes is a common problem on the reservation, so it is not surprising that a patient with a diabetic foot ulcer has come into the clinic. As Dr. Buffaloe walks into the exam room, there is a "clean, healthy smell;" a natural healer has packed the lesion with *pinon pine tar* (pronounced *pin-yon*). The strange thing about this remedy is if he scrubs it off and cleans the wound, it generally worsens; however if he leaves the pinon to do its work, it always heals.

Archaeologists believe that many centuries ago there was a temporary land bridge made of ice that connected present day Alaska and Russia through the Bering Strait. A group of people migrated across this bridge; some settled in North Western Canada, some followed the Rocky Mountains into the American Southwest. There they met the Anasazi, which are the indigenous people of the area from over 2,000 years ago. Over time, these cultures became collectively known as the Pueblo Indians.

As European nations encroached on the area, the Pueblo were split into many groups. Two of the commonly known groups are the Navajo and the Apache. The Navajo are popular today because they practice some of the native traditions widely recognized by mainstream society such as rain dances and strong beliefs in the dream world. During World War II, the American military employed Navajo in order to use their language as an encoded communication. These famous enlistees are known as the "Codetalkers." In present day, the Navajo have a sovereign land bigger than many of the world's countries. Plus they have their own government, police force and court system separate from the American government. Clearly, this culture has a rich history and the prospects for a rich future are very likely (*Dutton*).



American Indians have always been an interest of mine. My interest was fueled by a course I took in college: History of Native Americans. This class dealt with the political problems they have faced with reservations, removals and assimilation. Today most Native Americans are a struggling minority. Many tribes, having lost the majority of their reservation many years ago, have been forced to integrate with the dominant society. A great problem for many tribes is maintenance of cultural identity.

I am fascinated by the fact that the Navajo of Arizona and New Mexico have not lost their original land. This is due to a series of political battles and the fact that the desert was not a land sought by settlers early on. Because of this they have managed to keep their traditional way of life. They represent the biggest population of on-reservation Indians -- one-third of all reservation Indians living in Arizona -- and their reservation is by far the largest. Most reservations cover an area less than 50 square miles, while only 7% of reservations cover 100 square miles or greater. The Navajo Indian reservation covers 24,334 square miles (*please refer to the attached "Arizona" map*). To put this into perspective, it is approximately the size of West Virginia. Some of the inhabitants of this vast reservation are fluent in both Navajo dialect and English, but still many only speak Navajo (*Frantz*). Some live in modern housing, while others live miles from any paved road with no running water or electricity.

What do the Navajo think of healthcare? The strongly traditional ones are distrustful. Historically, the Navajo culture fears hospitals, and avoided them completely when they first appeared on the reservation. Many have come to accept the modern healthcare over the years, and now the on-site medical care operates as a typical rural health clinic; yet there are still some who choose to practice the natural shamanistic methods (*Griffin-Pierce*).

## PROPOSAL and METHOD

My proposal is to live on a Navajo Reservation during the month of July. My ultimate goal will consist of two parts, the first of which will involve me shadowing Dr. Robert Buffalo. My American Indian teacher from Kansas State University referred me to her former student who now teaches on the Navajo reservation, and the former student is the one who directed me to Dr. Buffalo. He lives in Gallup, New Mexico which is a short distance southeast of the Reservation and works at the Tohatchi Medical Center, a state funded clinic on the reservation (*please refer to the attached "New Mexico" map for Gallup and Tohatchi*). With my shadowing, I hope to gain medical experience working in a rural health clinic.

The second part of my goal in living on the reservation will be integrating, learning, and experiencing Navajo culture. My hope is to achieve this by living with a traditional Navajo family. Dr. Buffalo tells me this family has no running water or electricity; they climb up to the mountains during the hot months to let their sheep graze. I will organize my time in that during the evenings, I will be with my host family. In addition, I will schedule talks with willing traditional and non-traditional families to expand my understanding about Navajo family life and culture as a whole. On weekends I will travel throughout the reservation to popular sites such as Shiprock and Chaco Canyon to further my knowledge of the original inhabitants of the Southwest desert. By the time I leave the reservation, I will have gained a valuable clinical experience as well as a greater understanding of an ancient culture still thriving. From what I will learn, I will organize a presentation for the KUMC students and faculty on the Navajo culture and relate it to their healthcare. I want to raise awareness of this aspect of our society.

In preparation, I plan to read about the Navajo history as well as review the events of reservations and removals. Books on this subject can be found at any public library.

Furthermore, I will make a trip to the library at Haskell University in Lawrence, KS to spend a day referencing more directed materials. Also, there is a weekly publication called the *Navajo Times* available online that I plan to read regularly. This will keep me up to date on current Navajo events.

## BUDGET

I will leave Kansas City on Saturday July 2 and depart the Navajo reservation on Wednesday July 19<sup>th</sup>. Total mileage is 1026.36 miles from Kansas City to Gallup, NM. The current mileage reimbursement at KUMC is 40 cents per mile.

- \$100 for motel one night there and one night back in Amarillo, Texas.
- \$300 for rent/food (payment to host family)
- \$821 per mile cost

TOTAL = \$1221.00

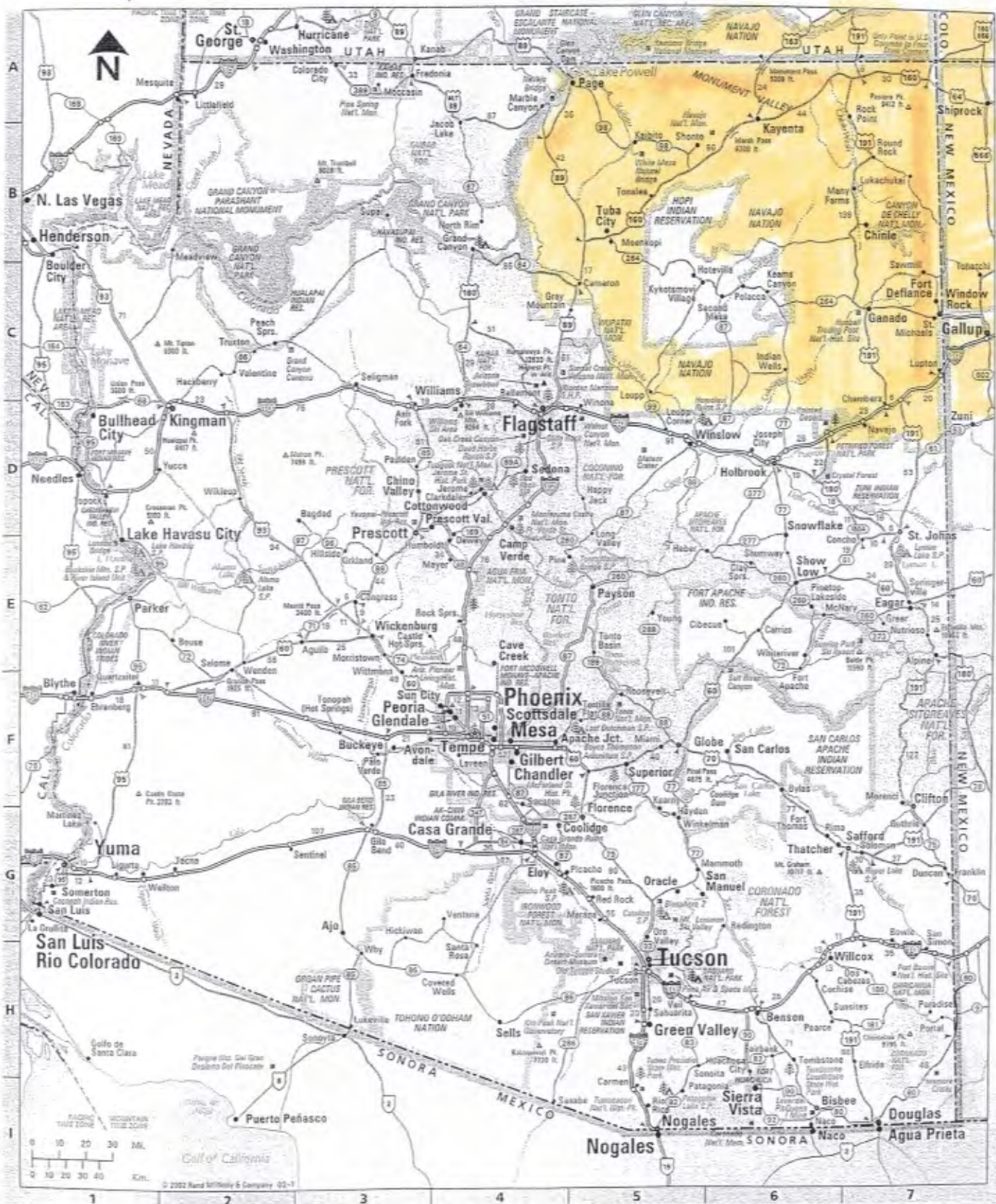
Contact Information  
Dr. Robert Buffaloe



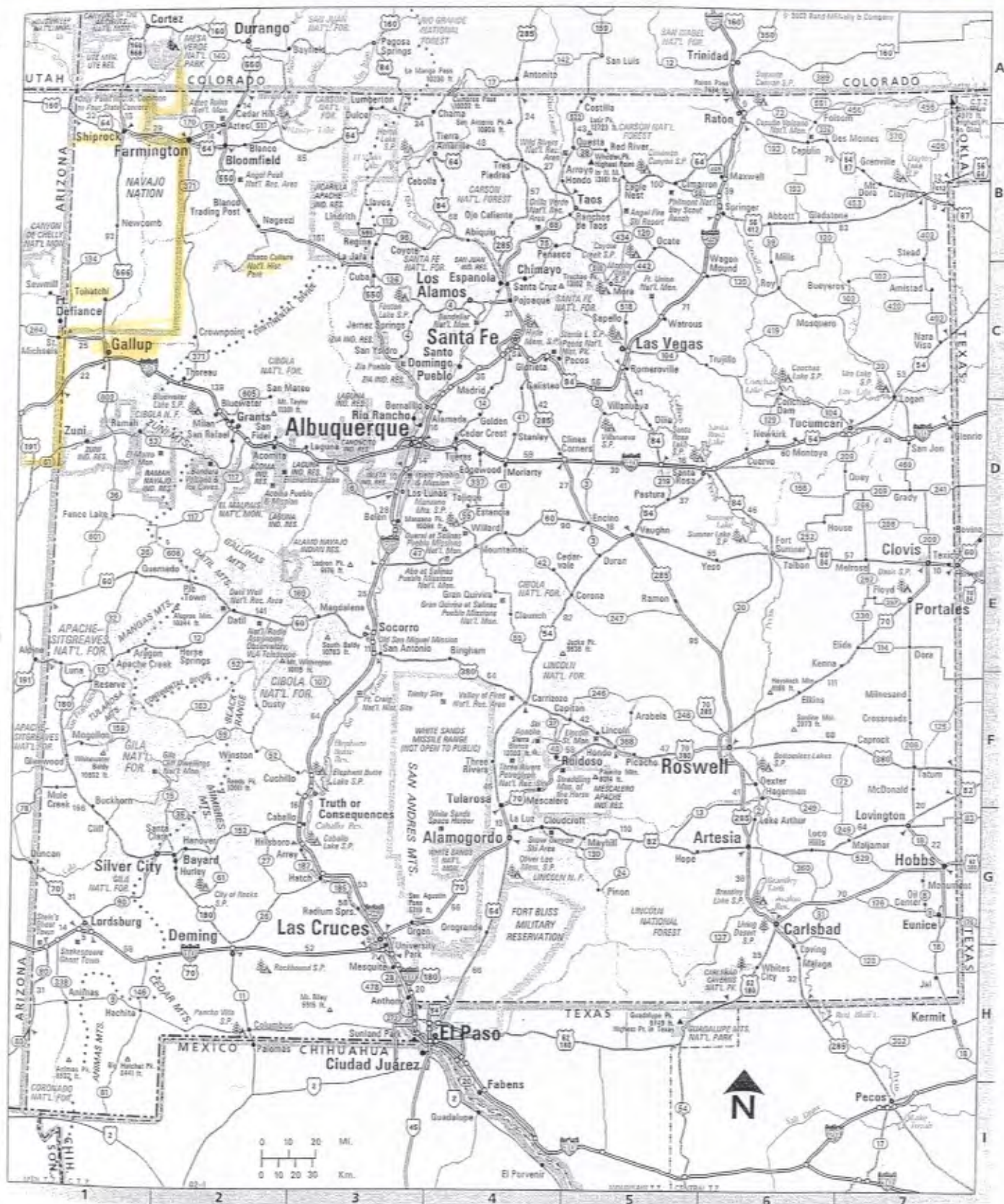
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Clendening Fellowship Proposal:

A Glimpse into Universal Healthcare

Greg Isaac

February 20, 2006

## **Introduction:**

Entire families will come into the JayDoc Free Health Clinic. Everyone, including the children less than 7 years old, is uninsured and cannot pay for the healthcare that they need. Working as a lab technician, I've drawn and seen many people in the same situation: no health insurance, cannot afford care, and need to be treated. The JayDoc program encourages me a little—that there is some hope for those who cannot afford medical care. Yet the clinic is opened only 2 days a week and can only see a few of the many people that come in.

How many more people are not receiving care in Kansas City? How many in the U.S.? The statistics do not reflect much improvement with “more than 15 percent of the total [U.S.] population was uninsured in 1994” (Altman 2) which is not only “growing, but those without insurance are remaining so for longer periods of time” (3). More current figures have the uninsured set at “roughly 44 million” (Loewy 144) in 2001. A developed, modern society should have a high standard of living. Can the United States have a high standard of living when such a high number of Americans cannot access health care?

Universal healthcare has become a popular concept for people looking to answer the growing number of uninsured. Indeed, many people within the U.S. and most around the world would agree that “[universal] coverage is consistent with prevailing notions of social justice” (Altman 387) and therefore a human right. Then why has the United States not adopted a universal healthcare policy? That scope is too broad for this paper alone, but Chinitz and Israeli, researches of U.S. health policy, describes the U.S. barrier to universal healthcare as “a lack of trust and confidence” (Loewy 87) in the government.

Despite the barriers, the United States needs modification. Experts comment how “[the] American health care system has been called a ‘paradox of excess and deprivation’” (Lassey 27) because of its large costs and poor access. Those who can afford the costs “probably secure the ‘best’ health care in the world...[where physicians] and other health professionals receive the finest and most specialized training available anywhere” (Lassey 27). How can a system be so great at helping and be so inept at caring for its population?

France has adopted “near universal insurance coverage but with diverse alternatives for consumers” (Lassey 152). Although, France does have a history of bureaucracy and that has not excluded medicine, unfortunately making its “delivery system for health care...the most complicated in the world” (Lassey 152). In France, “[physicians] remain relatively free to operate private medical practices if they so choose. They see an average of 10 to 12 patients per day, compared to much higher numbers in other countries, and earn an average on only \$45,000 per year” (Lassey 157). Some experts have characterized France as having the top healthcare system in the world and most agree that it far surpasses the American system mostly due to the number of people who can access its services.

In the changing face of American medicine and society today, new systems of health care will be debated and explored to cope with the poor access to care. These days “nearly every developed nation is committed to providing healthcare to its population regardless of ability to pay” (Altman 402) which is why the United States “has much to learn from these societies that have found it worth their while to provide universal health insurance coverage” (Altman 402). I do not know how many people have experienced a



different healthcare system firsthand, but if the U.S. is going to change, people need to know about different healthcare systems available and experience them. Assuming that the U.S. will move towards a more equitable and universal healthcare system, a physician will need to know how to operate in it. With huge amounts of pressure to change the healthcare system of the United States, physicians must have a chance to examine other systems. For this reason, I would like to scrutinize not only the merits of a system such as universal healthcare, but also its caveats. Physicians and patients of France have different perspectives and insights into their own system and how healthcare should be provided. The Clendening Fellowship would allow me to gain a firsthand experience with universal healthcare.

#### **My French Background:**

Ever since I was little, I wanted to explore the world. Maybe the thought of the rush that the unknown would bring fueled this fire to see the world. In high school, language was first offered, and I chose French. The French language seemed the most beautiful-sounding, the most mysterious language of our foreign language options.

After four years of high school French, I went to college not knowing what subject I wanted to major in but with the sole purpose of spending a year abroad. Majoring in French was the most conducive to going there so that is what I did. People would always question me, "What are you going to do with that, teach?" I didn't know. I didn't care. I knew where I wanted to go. The language did not come naturally to me at all; I barely received a C in my French conversation class. Although frustrated, I kept dreaming of going to France.

Finally I was able to go to Besancon, France my junior year. My excitement and wonder quickly mixed with frustration and embarrassment. After 6 years of French, I could not communicate. When the French spoke to me, it sounded like a beautiful jumble of sounds without meaning. The next 6 months were tough. My ears were slow to decipher the sounds, my mouth was unaccustomed to forming the words, and my support group all spoke in English—not much support for learning French. I stuck it out, made some friends, and met some distant family. I learned to kayak and enjoy just being with people. Before, I felt that I always had to be doing something. In France, I learned to slow down and appreciate people and life. I loved the culture and found a different perspective of the world that I could only find by being there. The last 3 months, I began to understand and communicate freely. Through friends I met some medical students who took me to their classes. There, it dawned on me. I wanted to become a physician.

Coordinating these two parts of me, French and physician, was not easy. Most people did not understand it. “So you want to be a doctor in France,” they would say. I geared up to enter medical school—taking mostly sciences, courses for which I first had a natural affinity and ability. Throughout all this process, I would dream of the country, the people, the tastes and smells, and the sounds that I missed. I would go back twice. Once I had pushed my week there too hard and caught the flu. My friend that I was staying with called a French physician who came to the house and evaluated me. I effectively communicated with him. By the end, when it was time to pay him my French friend Jean-Philippe paid. When I said that I would send him money for the doctor visit, he told me not to worry and that the Sécurité Sociale would reimburse him. You can imagine that a student would think that universal healthcare is the greatest thing on Earth

at that point. I later went back for a month before medical school to see friends and family and to kayak. I fell in love all over again. Even now I continue to smile when remembering my experiences there, and from time to time I still think of how I would express myself in French. I will always dream of France.

**Goals:**

1. To establish a contact in order to spend a month rotation in France during the fourth year of medical school. Currently, KUMC has no French connections for an international rotation.
2. To improve my French and especially my medical vocabulary.
3. To assess how French physicians perceive their system and universal healthcare.
4. To learn about cardiology and how the French practice it.
5. To develop my own opinion of universal healthcare and the French system firsthand.
6. To determine if I would like to practice medicine in France.

This research is not to suggest that the United States adopt the French healthcare system for "it is impossible to impose a system designed for one country on another country with a different set of social values" (Long 158). The general cultures and attitudes of the United States and France have vast differences despite the fact that both countries are considered part of Western society and systems which work there would not work or at least in the same way here. However, certain aspects of the French system may be beneficial and effective for the United States. Furthermore, the main target of the research will be to examine the benefits versus disadvantages to the physicians and patients on a personal level.



The fellowship will also allow me to be exposed to a different healthcare system and see how physicians, patients, and healthcare professionals operate in it. I will also be able to examine the advantages and disadvantages of the system. I could hear firsthand how the French feel about their system and what should be changed. The experience will contribute to my understanding of universal healthcare and healthcare systems in general which will allow me to better contribute to our own changing system.

### **The Proposal:**

I will spend the summer in Besançon, France at the University Hospital Jean-Minjoz in the cardiology department. I will research the current healthcare system of France at the level of the physician. I plan to provide a quick survey and observe their critiques of their system. In this way, I will be able to obtain the physicians' impressions of their universal healthcare system. A list of possible survey questions is provided. The format of the survey may include various estimated averages for the physician's practice, satisfaction using a numeric system (1 to 10), and a series of statements in which they will be asked to circle strongly disagree, moderately disagree, neutral, moderately agree, strongly agree. The surveys will be introduced at a convenient time to the physicians.

The daily experience will include spending 2 weeks in each unit (intensive care, long term stay, and short term stay). The structure will consist of a course in the morning from 8:00 am to 9:00 am, making rounds with the physician, attending staff meetings from 11:00 am to 12:00 pm, and then continuing rounds with the physicians. The staff meetings are when the physicians and residents review the previous night's cases.

### **Possible Survey Questions for Physicians:**

What is the liability of practice?

How much autonomy do you have in your practice?

Does compensation seem adequate or fair?  
How much time do you spend with each patient on average?  
How many patients on average do you see in a day?  
How many times does cost of care appear in encounters with patients?  
Is cost of care a barrier to treatment/diagnosis of your patient? How frequent?  
How efficient, effective do you feel your system is?  
Would you change your system?  
Rate how well the system is for patient care?  
Rate how well the system is for physicians?

**Budget:**

|                 |             |
|-----------------|-------------|
| Plane ticket:   | \$820       |
| Room:           | \$150/month |
| Food:           | \$300/month |
| Transportation: | \$120       |
| Total:          | \$1840      |

**Timeline:**

May 23 to July 5

**Contacts:**

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Assistant to Prof. Bassand  
Chief of Cardiology  
University Hospital Jean Minjoz  
Boulevard Fleming  
25000 Besancon

Professeur François SCHIELE  
Service de Cardiologie  
Pole Cœur Pouxmons  
Centre Hospitalier Universitaire Jean-Minjoz  
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Natacha Maury van Goch  
Infirmière aux soins intensifs de cardiologie

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# **Traditional Medicine and the Dynamic of Healthcare Provision in Malawi**

Nick Krehbiel  
Clendening Summer fellowship proposal  
2/20/2006

**Introduction:**

My name is Nick Krehbiel and I am an aspiring medical student from rural Kansas. I grew up around the medical profession so I gathered much of what I know about the profession from those experiences. Allopathic medicine is what I grew up with and the system that I know. It is a familiar experience to visit my family physician for a check-up or visit a specialist for a more specific ailment. I had a vague notion that the medicine I know is not the same throughout the world, especially in developing nations. During my collegiate career at the University of Kansas in Lawrence, I had the opportunity to see that this is in fact the case. Developing nations tend to depend much more on the medicine that they know and not necessarily the up to date allopathic medicine that you and I know. I had the opportunity to participate on a medical mission team in Haiti and discovered that allopathic medicine is not the only means to receive care and most often is not even the primary method of care. The country of Haiti is a nation of African slaves that won their independence from France so they carry with them many traditional medical and religious practices to this day. Their African homeland is still a place where traditional medicine is a viable way of providing care. This trip sparked a curiosity about other developing nations and their dependence on traditional medicine. It is also extremely interesting to gauge the balance between traditional medical practices and the westernized form of medicine that we know.

**Background:**

It has been well publicized that sub-Saharan Africa is a public health nightmare. Infectious diseases are certainly taking their toll on the people of these nations. Unfortunately, it seems that these countries with so much physical need are lacking physicians to provide services. Medical education does exist in several of these places. It seems that the problem is that the opportunities in developed nations are drawing qualified people away from their own. With this so called "brain-drain" effect depleting countries of their most qualified citizens this leaves few places for people to turn. One place that is left to look for assistance is traditional medicine. Many of these practices have withstood the test of time and are thought to be very effective. The success of traditional medicine seems to have a lot of grounding in a specific culture's health

beliefs. Traditional medicine relies on natural resources. Unfortunately, these resources are becoming more difficult to obtain. Even in developing countries there are efforts to expand which leads to the destruction of forests and plants that are home to some of the most effective natural remedies. As one can imagine, getting these resources in an urban area is becoming more and more difficult because most traditional healers reside in small villages. With serious public health issues, qualified physicians leaving, and natural resources being depleted, this then begs the question, what is the future of medicine in sub-Saharan Africa?

The country of interest is Malawi, the so-called, "warm heart of Africa". It is a small nation in sub-Saharan Africa inhabited by about 12 million people. There are two national languages, English, and Chichewa. Estimates indicate about 10-15% of these people are infected with HIV. The current life expectancy is about 37 years. All of the circumstances mentioned above have been documented in Malawi. Unfortunately, the answer to the question I present is so complicated that a summer in Africa will not be able to provide a fully encompassing solution to the issues surrounding medicine in sub-Saharan Africa. However, the project that I am proposing will provide insight into the next steps that need to be taken to improve healthcare in Malawi.

### **Objectives/Goals:**

The primary objective of this project is to explore the current situation surrounding the provision of health care in Malawi. Given the time frame, I have chosen what I feel is one of the more significant areas of the dynamic that exists between the methods of health care delivery in Malawi. I want to learn more about the people and culture of Malawi and gather their perspective on the situation.

Another goal is to determine to what degree traditional medicine is used in urban Malawi. If there really is a problem with resources as the literature suggests, the availability of natural remedies may not be as prevalent as they once were. I do want to find out how common the use of traditional medicine is in urban areas, as well as attitudes toward the current state of health in Malawi. This will provide information about the attitudes that surround the facts of traditional medicine use in urban Malawi.



I also want to broaden my own spectrum of how I view medicine and healing and gain a better appreciation for another culture. Currently, I have some interest in spending some time practicing in a developing nation in the future and this experience would certainly be beneficial in developing that interest.

### **Methods:**

I will travel to Blantyre, Malawi on June 4 and plan to return July 6. This should allow for enough time for me to collect data and immerse myself in the culture. Blantyre is the largest city in Malawi and is home to about 450,000 people. There are a couple of post-secondary education institutions in Blantyre that would serve well to gather information. I realize that this somewhat limits the sample to well educated people in an age range of about 18-25. However, considering that 42% of the population is illiterate, communication with the average person becomes a roadblock without a translator. I would like to work without a translator if possible. Using a university setting for the sample represents the group of people that is easiest to work with in the time that I have and also would have the most influence on public policy and the future of their nation. These people are able to speak and write in English making communication easier. The easiest access to this group of people may be dependent on instructors allowing me to distribute and collect a short survey. To gain the most information from a large sample, a short survey seems to be the most feasible means of conducting this project. The survey would provide for indications of age and gender and the following questions:

- 1) Have you ever used natural cures for illness?
- 2) Have you ever visited a natural healer for a cure to an illness?
- 3) If you answered yes to 2 or 3, did you feel better after your treatment?
- 4) Do you believe plants and trees used for medicine are accessible in Blantyre?
- 5) If you felt sick, would you rather visit a natural healer or a doctor trained at a university?
- 6) Do you believe there is a problem with healthcare in Malawi?
- 7) How can health be improved in Malawi?

Upon collection of surveys from students, I will compile their answers to the questions and formulate conclusions based upon their responses.

**Logistics:**

The country of Malawi is of interest to me, but it is no coincidence that there are several people that I know that would be able to aid in the logistics of this project. In fact, there is a group of six undergraduate students from the University of Kansas who are going to Malawi for the summer. They are going under the direction of a campus ministry organization called the Navigators that I was a part of during my undergraduate career. There has been a partnership established between the two places for several years now. Karen Pankratz is on staff with the Navigators and is coordinating this trip. I have been in discussion with her and have worked out travel and lodging with them. We plan to stay at a guesthouse in Blantyre for the duration of our time there. There is public bus transportation in Malawi which is the most likely form of in country transportation that I will be using to get from the guesthouse to the university. The guesthouse provides food for us as well.

The coordinators of the ministry organization in Malawi are Sam and Eunice Banda. I have met them only twice, as they have only been in the United States twice. These two people will be of help in my gaining access to students at the university. Because of the nature of the project that I am proposing and the work that the team that I will be there with is doing, accessing people to complete this study will not be an issue. The team will be talking with students at the university as well, so I would be able to have contact with them throughout the duration of the project. We would be going to the university most every day that we are there to talk with students. Overall, the logistics of this project are as set as they possibly can be considering the international travel involved.

**Budget:**

|                        |               |
|------------------------|---------------|
| Airfare:               | \$2800        |
| Lodging:               | \$ 450        |
| Transportation:        | \$ 50         |
| Food:                  | \$ 300        |
| Other travel expenses: | <u>\$ 100</u> |

|           |                 |
|-----------|-----------------|
| Subtotal: | \$3700          |
|           | <u>- \$2000</u> |

Total out of pocket: \$1700  
All other expenses will be paid for out of pocket.

**Completion:**

By completing this project, it is my hope that we can gain a better understanding about the current medical situation in Malawi and discover how healthcare providers in developed nations can best support this nation in their severe healthcare shortcomings. It is becoming common knowledge to most people, regardless of their involvement in healthcare provision, that sub-Saharan Africa is a haven for infectious diseases. By learning about what is actually going on there in terms of the dynamic between methods of providing care, and the attitudes that surround the situation, perhaps we can help them develop a plan of action to improve the health and quality of life of their citizens in the future.



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Karen Pankratz can be reached by email: [kpank@ku.edu](mailto:kpank@ku.edu)

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**HIV/AIDS, the Impact on Family Roles and Structure**

**Clendening Summer Fellowship Proposal  
February 2006**

**Abigail Maze**

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## Introduction

In December of 2005 the Global Health Reporting estimated that 40.3 million people worldwide were living with HIV/AIDS, 4.9 million people were newly infected, and 3.1 million individuals had died due to HIV/AIDS. The fight against global AIDS is nothing new. It has been a struggle for over two decades, primarily in Africa which is home to 70% of the world's HIV positive individuals but only 13% of the world's population. There are countless resources to find HIV/AIDS statistics. Most articles addressing AIDS start with the same statistics, such as those given above, and progress with the latest news on treatments, distribution of infection, information about prevention, or impact of HIV on an individual. The perspective that I am interested in is the impact on the family. The family is the oldest institution; it provides economic, social, and emotional support. But the institution of the family is threatened by HIV/AIDS. Clearly the disproportionate infection of Africans has led to an abundance of death due to HIV and AIDS in Africa. It is also leading to significant loss of generations. Each person lost fulfilled a role in the family: Caretakers, dishwashers, worker, the intellectuals, and the comedians-gone. Loved ones left behind, parents, siblings, and children may need to adapt. Some roles are vital and must be taken over. Death certainly has a dramatic impact on the family and roles of the members within the family.

Historically African families are of the extended family system type (Nhongo, 2004). A child's Uncle holds the role of the father. Cousins are like brothers. The extended family acts as one unit. There are norms that govern family life Africa, for example as parents become elders they expect their children become the heads of the households and take on the care of the elders. Recently African families have undergone urbanization. Family members leave to find jobs in the city, sending back remittances to the family they left behind. In Uganda the majority of rural families receive remittances from urban family members. But what happens when that family structure is gone? What happens when the remittances go away, and sick children need to come home? In Uganda parents are the primary caregivers of AIDS patients (Ntozi, 2001), and 40% of orphaned children live with grandparents, of whom 64% are below poverty (Nhongo, 2004). What happens when the Grandmothers, being called "Africa's Newest Mothers," have to take care of the children? Widows in Africa lose access to land, labor and credit (UNDP). What are the adjustments a widower must make after the loss of his wife? The changes that the HIV/AIDS epidemic has placed on African families cannot be measured by numbers alone.



## **Background and motivation**

I grew up on a small farm in outside of Hiawatha, Kansas with my 4 siblings. During high school I had a fantastic biology teacher who did a wonderful job educating us about biology and global health. I began to understand what was really happening in the rest of the world, outside of Kansas. It was there that I was introduced to the HIV epidemic in Africa. At that time I was also finding my interest in medicine and public health. As we discussed the events surrounding HIV, I Africa I began to feel a calling to go there, do something to help, something to understand. During the rest of my high school years I was increasingly drawn to medicine and Africa and of course I saw the two coming together in future trips I could take as a physician. But that was nearly 8 years ago, and as you might guess, I've been getting anxious to go on my first "medical mission" to Africa. During that time I went to college at K-State where I was involved a STDs/HIV peer education group called SHAPE-Sexual Health Awareness Peer Educators. I was very involved in SHAPE for 3.5 years including one year as president and a semester as the Health Promotion and disease prevention intern for the department that ran SHAPE. Through that group I presented to organizations, schools, and many types of groups how HIV/AIDS/STDS are transmitted, what behaviors are risky, how to prevent infection. We addressed myths and stigmas as well. Through SHAPE I went to a conference, and was in touch with what was happening in the global fight against AIDS. I was also an HIV/AIDS educator for the Red Cross. As you can see I have a long time interest in HIV and AIDS, but one aspect I have not seen are the people. I have yet to understand, first hand, the impact the disease has on people, families and communities. This fall when I was told about the Clendening fellowship, I immediately saw an opportunity to go to Africa and see the side of HIV and AIDS that I had so many questions about, but so few answers.

## **Proposal**

One of the questions I've had over the years is 'How does the loss of family members impact the traditional roles of the family and it's structure.' This summer I would like to spend June 28<sup>th</sup> to July 25<sup>th</sup> working with the Uganda Village Project developing, and disseminating throughout the Iganga district, a resource guide to local testing facilities, clinics, and other resources. During that time I will also conduct interviews with family members who have lost loved ones to AIDS to discover the changes that have taken place in their family structure and micro culture as a result. My ultimate goal is to compile my interviews into a journal style piece of literature that I can share with others who are interested in the impact HIV has had on family structure.

## Methods

My stay in Uganda will be with a non-government organization started by the International Federation of Medical Student Associations called the Uganda Village Project. While working with the Uganda Village Project-HIV/AIDS: Solutions and Resources Project, I will be traveling through the Iganga district of Uganda with a group of 4-6 other volunteers and Nichole McCalvin our project coordinator. We will be assessing what residents know and do not know about local testing facilities, clinics and other HIV resources (such as distributors of anti-retroviral which arrived in Uganda only a year ago) who have registered with the Health Ministry of Uganda in order to ascertain how we can best spread the information. Ugandan media is primarily tabloid and there aren't great methods available to spread useful information. Our goal will be to overcome those obstacles and develop a way to educate the people of the Iganga district and surrounding rural villages about their resources. The Uganda Village Project encourages outside projects that students bring, such as mine, and work with us to promote our projects. The language there is Lusoga, and my contacts at the Uganda Village Project confirmed that I would have no problem finding an interpreter, most likely for free. The Uganda Village Project will also help me to identify interviewees with their families registered with their NGO. While in Iganga I will be staying with other volunteers in my project group at rental houses or with host families (to be decided by UVP) that have been inspected and Okayed by the Ugandan government.

I will be conducting semi-structured interview sessions, allowing the interviewee the freedom to talk and discuss any stories or information they feel is pertinent or important. I have a list of topics to discuss in each interview but will not limit the interview to that list. I hope to conduct one interview per day except on Sundays. I believe each interview will last approximately 45 minutes.

Each night I hope to work on the organization and rough draft of my journal, as I will begin school shortly after I return from Africa. My journal will be written as a first person account of my experiences. I hope to capture more than the words of my interviewees, I want to convey their emotion, their settings, and their character.

## Goals

The goals I have for my experience are:

- Discover the impact death due to HIV had had on family structure and family micro culture in Uganda.
- Develop an African perspective on HIV/AIDS
- Develop skills for future medical missions to Africa
- Develop a piece of literature to document my experience and share it with others
- Have fantastic time learning about a new culture a half a world away!



## **Contacts**

My primary Ugandan Contact is Alison Schroth, a UVP employee who had been to Uganda Several times with UVP. My other contact is 'The HIV/AIDS: Solutions and Resources Project' project/volunteer co ordinator Nichole McCalvin. I have been in contact with both women about the requirements and details of the project, as well as my interest in participating.

## **Budget**

The budget used is the Uganda Village Project's budget. I have added to the flight estimate due to finding higher fares in my own research.

**Airfare \$1500-\$1800 (variable depending on dates)**

**Lodging/Food \$2.50/day**

**Transportation with project \$100**

**Required fundraising \$300-\$500**

**(The required fundraising money goes towards logistics in Uganda like helping our partners to host us, administrative and project logistics, and an emergency fund for unexpected project costs)**

**-As a personal side note I would estimate that you would want to bring \$500 to \$1000 of personal money to spend on things like souvenirs, internet time, rafting on the Nile, safaris, and other fun stuff**

## **Back-up Plan**

I applications to UVP are due on March 1<sup>st</sup>. I have talked to Allison about the competitiveness of the application and what they are looking for. I believe I will be accepted into the project. In the event that I am not, I have been invited by Bishop Maseraka of Uganda (Retired) to come to the Bishop Masereka Christian Foundation, where I may conduct my interviews, spend time with the staff physician and HIV/AIDS counselor. I have had had contacts with Maggie Geller and Dr. Daniel Fort who both highly recommend this option.



# Berlin:

## The Doctor-Patient Relationship and the Public Perception of Healthcare since November 9<sup>th</sup>, 1989



Clendening Summer Fellowship Proposal  
Sean Pauzauskie  
February 15<sup>th</sup>, 2006

## 1) Introduction:

In essence, the city of Berlin has served as the crossroads for European history for the past 100 years. In the first half of the twentieth century the German capital served as the focal point of great cultural, artistic, and philosophical movements, ranging from its accommodations of the Brücke (or “bridge”) movement in painting in 1910 and Russian émigré author Vladimir Nabokov in the 1930s to the great national and political struggles embodied by the twentieth century’s two World Wars. In the wake of the latter, the Cold War dawned, and the city and its Wall became the bifurcated symbol of opposed Western and Soviet political influence.

A focal point of these relatively recent historical events, Berlin has also, in its long history dating to the 13<sup>th</sup> century, served as an important center of medicine and its development in Europe and throughout the world. After an outbreak of plague in 1709, convinced that the study of anatomy could contribute to medical knowledge and therefore the demise of such diseases, King Frederick Wilhelm I of Prussia promoted an anatomy dissection effort (the “Theatrum Anatomicum”) that would ultimately lay the precursors for what became the Charité network of hospitals in what is now modern-day Berlin.<sup>1</sup> The medical historical achievements of the Charité include those of the great Dr. Rudolph Virchow, who published ground-breaking findings in histopathology and neuropathology, such as the discovery and detailed characterization of neuroglia and thromboses, and who famously coined the term “leukemia.” For 300 years researchers and physicians at the Charité network of hospitals have contributed to the foundations of nearly every medical field, including major discoveries in surgery, neurology, mental illness, ophthalmology, anesthesiology, obstetrics and gynecology, and infectious diseases (many via the work of the famous pathologist, Dr. Robert Koch). As in its great cosmopolitan, artistic, and political past, Berlin also achieved great historical status in medicine, with the Charité hospitals and its faculty providing the place and inspiration for those achievements.

The past 100 years of political and social bifurcation, and then reunification of Berlin forced medicine to operate within its turbulence. By June 1948 the Soviets blocked all ways into the western part of the city, forcing President Truman to order military planes to fly rescuing flights of coal, food, and medicine over the blockade in the historical nine month Berlin Airlift. A combined 280,000 of these flights with the help of France and Britain helped sustain a western economic and social ideology, and the clinical practices of the physicians stressed by physical and ideological schisms engendered in the wake of World War II. A physical barrier stood for the next fifty years, a maligned and graffiti-ed Wall symbolizing what Winston Churchill deemed the “iron curtain”, standing until Soviet reform policies had failed and social unrest came to an historic climax on November 9<sup>th</sup>, 1989. Berlin became one city again.

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<sup>1</sup> See: Oommen-Halbach



In the fifty years in between the rise and fall of the Wall, the two halves of Berlin experienced drastic polarization in terms of medical care. The Soviet Union demanded complete control of the eastern half's resources, stripping private practices of fiscal autonomy and mandating theoretical, socialized standards of care. The medical practices in the western half endured in this period, however tensely as they rested in an island of capitalism surrounded by communist East Germany. The opposed social and political ideologies in East and West Berlin inevitably affected the most fundamental relationships in the practice of medicine, including those between doctors and patients, and patients' relationships with and perception of their respective polarized healthcare systems. This historical backdrop lives on today as Germany strives to better its medical standards after the reunification of the borders of its most important city nearly two decades ago.

## 2) Background:

My passion to study my chosen topics of medical history in Berlin stems from the combination of many personal experiences. As an undergraduate interested in medicine I was fortunate to participate in work on many levels in the dynamic of our healthcare system. In my early undergraduate years I learned the fundamental practices of molecular biology in a research lab at the University of Kansas, where I contributed to a research project funded by the NIH, seeking a fundamental understanding muscle-related disorders. Curious and encouraged by faculty mentors, I applied for and was accepted to a summer research internship at the National Institute of Mental Health after my junior year, where my understanding of the medicine-research dynamic grew through conversations with researchers who not only ran their labs but also participated in the process of developing their discoveries further into socially applicable pharmaceuticals and therapeutics. These experiences broadened my knowledge and perception of our healthcare system as a citizen and taught me how much complexity – both academic and personal – contributes to every decision a physician makes in administering care to patients. I discovered firsthand how thousands of hours go into a single prescription rendered in an office in approximately fifteen minutes.

Eager to learn more about the processes entailed in what I had seen at the NIH, I applied for and was accepted to an internship in the Energy and Commerce Committee in the United States House of Representatives. Working with the Oversight and Health Subcommittees my perception of our healthcare system again changed dramatically, as I learned of the sometimes broad and sometimes minutely detailed factors governing healthcare law. In one project<sup>2</sup> I researched the Bayh-Dole Act of 1980 (Sen. Bob Dole the co-author), which among finer details defines a system in which Universities, the Government, and Industry work together to bring innovations in the life sciences from laboratories to the public good in FDA-tested and -approved pharmaceuticals. Increasingly aware of the complexity of these processes, which I learned involves the collaboration between quite disparate professional thinking (and then what seems incredible efficiency therefore), and I

<sup>2</sup> See: Campbell, Koski, Blumenthal.



have developed a substantial interest in how members of a particular nation perceive the healthcare system which serves them. Specifically, I am interested in the Berlin public's understanding of their post-1989, reunified system and what sources of information and key factors (e.g. insurance coverage, choice of caretaker, prescription costs) or lack thereof influence their ultimate bias for or against the system they use.

As a complement to this and in concurrence with my future intentions to practice clinical medicine, throughout my experiences as a first year medical student, I have also developed a substantial interest in the doctor-patient relationship and how it is defined. Preceding and underscoring my first-year, brief experiences with standardized patients, I worked for a year prior to entering medical school as a residential assistant at Cottonwood, Inc., in Lawrence, KS, assisting developmentally disabled people in their daily lives. Over full weekends I was responsible for administering their medications and sundry other tasks involving their domestic care. While not participating in the decision-making of their medical therapies, I learned how important the relationship between medical care-takers and the cared-for is on even the most basic levels, not the least of which being the degrees of patient freedom and the constant need for feedback to the party administering care. Concurrent with the aforementioned experiences in medical science and government, I would like to achieve a higher degree of academic understanding in an historical context the various models for and determining factors of the doctor-patient relationship.

I have seen how Berlin will provide an ideal location, as a microcosm of recent socio-economic and cultural change, to assess the defining factors of these two primary research interests. Long before I entered medical school Berlin cast its historical spell on me. I have traveled to the city twice, once as a nineteen-year-old after a summer study abroad trip, and then again this past summer of 2005 at the end of a month-long trip across Europe. My aunt, a former practicing physician who now works on the insurance side of medicine, and my cousin, Alexandra, a soon-to-be law school graduate, have lived in a West Berlin apartment for nearly thirty years and I have been fortunate to stay with them during both visits. Some of my earliest memories of historical significance are evenings as a nine-year-old spent watching the major networks' coverage of the Berlin Wall and throngs of people celebrating its dismantling. As I experienced the city this past summer, saw the widespread and sprawling industrial development projects, manifestations of the capitalist West and communist East in everything from disparate architecture to the state of existing commerce, and discussed the city's changes since November 1989 with my aunt and cousin in the morning over breakfasts, I have become determined to apply my experiences at home in a Berlin medical history research project.

I would like to incorporate my understanding of pre-existing scholarship in the fields of public perception of medicine and the doctor-patient relationship, from my experiences in Washington, D.C., undergraduate history of science and medicine readings<sup>3</sup> and the articles<sup>4</sup> recommended to me by Dr. Crenner in the Department

<sup>3</sup> For one title see: Greenberg, D.

<sup>4</sup> See: Szaz and Hollender.



of History and Philosophy of Medicine concerning the doctor-patient relationship. The latter will provide the primary structural models for the latter topic of my intended research.

As I have not ruled out further graduate study in an area related to medical history, public health, or policy<sup>5</sup>, my desire carries this in addition to all opportunities provided by a Clendening Summer Fellowship. Thus far I have been fortunate to experience a multifactorial personal journey in fields involving the complex history of medicine, and I feel the next step of my professional development could lie ahead in Berlin.

### 3) Description of Project:

I plan to conduct the bulk of my Clendening Research Fellowship during the month of June in Berlin, with the last week in May devoted to research in the medical history library at KUMC. While in Berlin I will investigate through interviews with doctors and patients effects on the doctor-patient relationship and public perception of healthcare rendered over the past 18 years since the city's reunification. I am primarily interested in collecting firsthand testimonials from three sources: 1) clinicians in private practice, 2) clinicians and patients within the Charite hospital network, and 3) professors and scholars working currently in medical history at the Charite. Secondarily, I have submitted an application to the Charite hospital (known as an "Antrag"), that, if approved by the ethics committee – a process that can take up to two months – would allow me to administer, for educational reasons only, surveys to patients and physicians within a few clinics. If this privilege is for some reason not granted, I will use my base of interviewees as the core source for data collection. If granted, my source for data will greatly increase.

I plan to arrive in Berlin with substantial background research already conducted. Thus far I have the oral agreement of time from several private practitioners (including friends and former colleagues of my aunt) to provide personal answers to the interview questions I have already composed. I have been in touch with several professors and researchers in the department of the History and Philosophy of Medicine at the Charite network, and have scheduled meetings with them during my stay. One professor in particular specializing in the history of the Charite over the past 50-100 years, Dr. Udo Schagen, has agreed to offer his direction and advice both pre- and post-arrival in Berlin.

My investigations will continue for the final two weeks within the Charite network of hospitals, with interviews of clinicians in the various institutes, searches of available medical libraries, and a visit to the brand new Charite medical history museum, which will provide a physical embodiment of my understanding of the Charite's history. I have requested the opportunity to shadow an internal medicine physician in the Campus Mitte division and await confirmation on this opportunity. As the largest University Hospital in Europe, comprising over 10,000 employees in

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<sup>5</sup> I had seriously considered a non-traditional M.D./Ph.D. program at the University of Chicago before enrolling at KUMC.



50 institutes and with a capacity of over 2,300 beds, I am confident that with the help of my established contacts at the Charite that I will be able to obtain a substantial number of arranged interviews in addition to the ones already arranged during this portion of my research. Though I know it will take a great deal of energy and hard work, I am confident that I will have the necessary resources to overcome professional and cultural barriers in the city, as well. I will have the lodging resources of my aunt and cousin's apartment, as well as their assistance in traversing the city and dealing with the language barrier. Public transportation is available within the city (both buses and an underground train) when needed.

#### 4) Methods:

So that I may develop a better understanding of the doctor-patient relationship and public perception of healthcare in Berlin, I will first spend time investigating the academic components entailed in these two fields of interest. As these two subjects remain closely linked to each other – in other words, often a person's perception of healthcare *is* their doctor – I have and will almost certainly continue to encounter an amount of confluence in my preparatory bookwork.

Thus far under the direction of the aforementioned readings I have developed a list of ten questions (attached), comprising distinctive sets for doctors and patients, that probe elements of the changes in healthcare since 1989 within the context of my two research areas. They have been translated by a close friend, Matt Davis, an undergraduate English and German major who has spent the past two years in Nurnberg, Germany, studying for his graduate degree, and have been proofread by two native speakers including one physician (Dr. Georg Birli who practices in Nurnberg). I will, by utilizing pertinent resources at the Clendening Medical history library, continue to develop my interview questions so as to achieve maximum efficiency of eliciting academic goals when conducting research.

Though intentionally broadly stated, my interview questions each center around one specific factor governing the public perception of healthcare and the doctor-patient relationship. Specifically, as mentioned from the pre-existing scholarship recommended by Dr. Crenner, interview question number eight utilizes the theoretical framework of Thomas Szasz and Mark Hollender, who in their classic essay demarcate three potential models for the doctor-patient relationship: as "1) Active-passive, 2) Guidance-cooperation, and 3) Mutual participation." I will collect data that attempts to fit the system in Berlin from the perspective of those interviewed. The remaining questions for patients focus on issues of medical choices, rights, expectations, monetary constraints, East vs. West differences/disparities, and their opinions of "polyclinics," the most common form of private practice in Berlin, which mirrors multi-physician clinics in the United States. Each of these issues will funnel into the broader "perception of healthcare" umbrella intended in this study, broken down individually. Pre-existing questions for physicians focus intentionally on some of the same issues so as to design potential convergences or divergences of opinion between doctors and patients, while expanding into areas like doctors' options for care and criteria for satisfaction with quality in the medical profession.



I will continue academic studies in Berlin under the direction of Dr. Udo Schagen, who has arranged time to meet with me during the first week of June. Dr. Schagen has published many scholarly articles in medical history of the Charite over the past 100 years and will provide an excellent resource for direction of content concerning the hospital and the broader historical context of the Charite.

The bulk of my project research will come through the arranged interviews and meetings with physicians in Berlin, both in private practice (week 1) and working in the Charite (weeks 2-3). The scheduled interviews are, of course, voluntary, and I will record content and observations per the wishes of the interviewed in written journal format daily.

I expect to find many interesting things through this study, including disparities between standards of care in private clinics opposed to those operated by my interviewees at the Charite solely based on funding, have requested specifically interviews with private practitioners in the East and West portions of the city in order that special attention may be given to residual differences in the wake of 1989, and anticipate an myriad opinions as to "what has gone right" and "what has gone wrong" with in terms of healthcare in Berlin since 1989. My research data will reflect those findings, with the key role-player constituting the historical changes rendered by reunification.

Recently in correspondences my aunt has lamented the "drying up of money for science" and the "standards years behind the United States" that have primed my attention to certain potential target areas of influence. However, with an open mind what excites me more than anything about the opportunity to further develop and conduct this project is what I do not know I will find. For this reason, while the project's research focuses remain narrow, like Berlin itself, they are flexible and open to future ideas.

#### 5) Goals:

- 1) To investigate the status of the doctor-patient relationship in Berlin since 1989, in a practical and academic context.
- 2) To learn about the public perception of healthcare in Berlin after reunification of the city in 1989, with a focus on differences between the former Eastern and Western portions.
- 3) To determine to what extent observed changes in the doctor-patient relationship fit the Szaz-Hollender model structure.
- 4) To understand some of the key factors determining a doctor/patient's ultimately positive or negative perception of the Berlin healthcare system
- 5) To obtain a better understanding of the history of the Charite hospital through its museum and library archives.

## 6) Detailed Timeframe:

Four weeks: one for research, three for interviews and data collection in Berlin

Tuesday, May 23<sup>rd</sup> – Tuesday, May 30<sup>th</sup>, research at the Clendening medical history library

Tuesday, May 30<sup>th</sup>, Depart for Berlin

Wednesday, May 31<sup>st</sup> - Wednesday June 7<sup>th</sup>, interviews under the direction of Dr. Alexandra Hornung, M.D.

Wednesday, June 7<sup>th</sup> – 10 a.m. meeting with Dr. Udo Schagen, Campus Mitte, Charite Hospital, Department of History and Philosophy of Medicine

Thursday, June 8<sup>th</sup> – Thursday, June 22<sup>nd</sup>, interviews with practicing clinicians within the Charite Hospitals under the direction of Drs. Udo Schagen and Dr. Volker Hess

Friday, June 23<sup>rd</sup>, return to MCI

## 8) Detailed Budget:

|                                        |           |
|----------------------------------------|-----------|
| Flight from MCI to Berlin-Schoenefeld: | \$1066    |
| Passport: (valid, already obtained)    |           |
| Lodging:                               | \$0       |
| Food:                                  |           |
| \$250                                  |           |
| Travel while in Berlin:                | \$300     |
| Research materials:                    | \$150     |
|                                        | <hr/>     |
|                                        | \$1766.00 |

(I accept full responsibility for any unforeseen expenses and will compensate for them on my own if necessary)

## 9) Contacts:

1) Dr. Udo Schagen

+

2) Dr. Volker Hess

+

3) Dr. Alexandra Hornung

#### 10) Bibliography:

1. Campbell, E., Koski, G., Blumenthal, D.. "The Triple Helix: University, Government and Industry Relationships in the Life Sciences." Brookings Institute Panel Working Paper. Privately funded by the Ewing Marion Kauffman Foundation (remains unpublished). June, 2004. (For information concerning distribution contact Eric G. Campbell, Assistant Professor, Institute for Policy. 50 Staniford Street (9<sup>th</sup> floor). Boston, MA. 02114. Email: [ecampbell@partners.org](mailto:ecampbell@partners.org))
2. Greenberg, D. *The Politics of Pure Science*. The University of Chicago Press, Ltd. London. 1967, 1999.
3. Oommem-Halbach, K.D. *In the Shadow of Sudhoff: German Medical History in the Weimar years*. University College London Press. London. 2004.
4. Szaz, T., Hollender, M. "The Basic Models of the Doctor-Patient Relationship." *The Social Medicine Reader*. Duke University Press. Durham. 1997.

#### Pertinent Links:

- 1) Charite Hospital Main Page:  
[http://www.charite.de/kompakt/english/p0.00\\_frame.html](http://www.charite.de/kompakt/english/p0.00_frame.html)
- 2) Charite Medical History Library:  
[http://www.charite.de/kompakt/english/p8.00\\_frame.html](http://www.charite.de/kompakt/english/p8.00_frame.html)



### Interview Questions for Physicians (translated):

1) Hat der Fall der Berliner Mauer und die Wiedervereinigung der Stadt Berlin das Verhaeltnis zu Ihren Patienten beeinflusst? Wenn/Falls ja, wie? Weitere Fragen: Wie lange hat es gedauert bis Veraenderungen bemerkbar wurden? Waren die Veraenderungen staerker als Sie erwartet hatten?

2) Bevorzugen Sie das Gesundheitssystem vor, oder eher das nach der Wiedervereinigung? Und warum? Denken Sie, dass das System nach 1989 Ihnen mehr Spielraum/Handlungsfreiheit fuer eine optimale Patientenbetreuung gegeben hat? Falls ja, wie?

3) Denken Sie, dass das System nach 1989 Ihnen mehr Freiheit gegeben hat um ihren Patienten die notwendige Versorgung zu gewaehleisten?

4) Denken Sie, dass Ihre Sie als Dienstleister nach der Wiedervereinigung anders wahrgenommen haben? Wenn ja, wie?

5) Denken Sie, dass sich die Qualitaet des Gesundheitswesens nach der Wiedervereinigung veraendert hat? Wenn ja, wie?

6) Wuerden Sie das heutige Gesundheitssystem aendern wollen? Wenn ja, wie? Weitere Fragen: Was ist Ihrer Meinung nach die groesste Herausforderung des berliner Gesundheitssystems?

7) In Deutschland wird von einer 2/3 (Sozialhilfe, gesetzliche, private)-Klassengesellschaft bezueglich des Gesundheitswesens gesprochen, das sich in den kommenden Jahren noch staerker auspraegen soll. Denken Sie, dass Ihre Patienten ....Denken Sie, dass in diesem System Patienten der 2. oder 3. Klasse erhebliche Nachteile bezueglich der Qualitaet und des Leistungsangebots haben?

8) Welche der folgenden Aussagen trifft am besten auf das Verhaeltnis zu Ihren Patienten sowohl vor, als auch nach der Wiedervereinigung zu? 1) ein vaeterliches Verhaeltnis 2) beratende Funktion 3) gegenseitiges Vertrauen und Interesse? 4) Keine von den dreien. Warum genau haben Sie diese Antwort gewaehlt?

9) Was Patienten mit chronischen Krankheiten (wie zum Beispiel Diabetes mellitus, Hypertonie) angeht, hat sich was an deren Versorgung seit 1989 geaendert?



10) Denken Sie, dass sich das Verhaeltnis zu Ihren Patienten in der letzten Zeit geaendert hat? Falls ja, wie? Kommen wir auf Frage 8 zurueck, denken Sie dass es sich vom einen (1,2,3) zum anderen veraendert hat? Wenn ja, von welchem zu welchem?

#### **Fragen zu den muendlichen Interviews mit Patienten:**

1) Hat der Fall der Berliner Mauer und die Wiedervereinigung der Stadt Berlin das Verhaeltnis zu Ihren Aerzten beeinflusst? Wenn/Falls ja, wie? Weitere Fragen: Wie lange hat es gedauert bis Veraenderungen bemerkbar waren? Waren die Veraenderungen staerker als Sie erwartet hatten?

2) Haben Sie nach der Wiedervereinigung eine Veraenderung im Berliner Gesundheitssystem wahrgenommen? Wenn ja, wie? 1) Denken Sie, dass es eine positive oder negative Veraenderung gegeben hat?

3) Wuerden Sie das heutige Verhaeltnis zu Ihren Aerzte aendern wollen? Wenn ja, wie?

4) Denken Sie, dass sich die Qualitaet des Gesundheitswesens in West Berlin nach der Wiedervereinigung veraendert hat? Wenn ja, wie?

5) Lassen Sie sich lieber in Ost- oder Westberlin aerztlich behandeln? Warum bevorzugen Sie den Osten, beziehungsweise den Westen?

6) Denken Sie, dass die Moeglichkeiten im Gesundheitswesen fuer Sie als Verbraucher nach der Wiedervereinigung erweitert oder eher reduziert worden sind? Wenn ja, wie? Denken Sie, dass sich dies wirklich positive beziehungsweise negative auf das System ausgewirkt hat? Was sind Ihrer Meinung nach in Berlin die wichtigsten Gesundheitsbereiche, die von den Veraenderungen profitieren konnten?

7) Denken Sie, dass sich Ihre Rechte als Patient nach der Wiedervereinigung geaendert haben? Wenn ja, welche? Beispiele: Datenschutz, die freie Wahl des Dienstleisters, das Recht bei langfristigen Krankheiten mitzuentscheiden?

8) Welche der folgenden Aussagen trifft am besten auf das Verhaeltnis zu Ihren Aertzte sowohl vor, als auch nach der Wiedervereinigung zu? 1) ein vaeterliches Verhaeltnis 2) beratende Funktion 3) gegenseitiges Vertrauen und Interesse? 4) Keine von den dreien. Warum genau haben Sie diese Antwort gewaehlt?

9) Behindern finanzielle Beschraenkungen Ihre Moeglichkeiten als Benutzer des Berliner Gesundheitssystems? Wenn ja, in wekchem Ausmass? Was spielt die Versicherung in ihrer Gesundheitsversorgung fuer eine Rolle, und traegt diese finanziell positiv bei?

10) Denken Sie, dass sich Ihre Erwartungen bezueglich des Berliner Gesundheitssystems nach 1989 geandert haben? Wenn ja, wie? Was denken Sie hat sie zu diesen Erwartungen veranlasst?

11) Haben Sie jemals eine Polyklinik in Berlin besucht? Wenn ja, wie wuerden Sie die Versorgung auf einer Skala von 1-10 beurteilen? Warum?

#### Questions for interviews with physicians:

- 1) Did the fall of the Berlin Wall and the reunification of the city of Berlin **affect** your relationship with your patients? If yes, how? Follow-up: How long did it take for the changes to seem apparent? Were the changes more extreme than you expected?
- 2) Did you **prefer** the healthcare system you were working in more before or after the reunification of Berlin? Why?
- 3) Do you feel the pre- or post-1989 system changed your **freedom** to administer the care you believe patients need? If yes, how?
- 4) Do you feel your patient's **perception** of you as a healthcare professional changed after reunification? If yes, how?
- 5) Do you feel the **quality** of healthcare changed on the whole after reunification? If yes, how?
- 6) Would you change the healthcare system today? If yes, how? Follow-up: What is the largest issue in your opinion that faces the Berlin healthcare system?
- 7) Do you feel your patients have **monetary constraints** in terms of facilitating their health (care) today? If yes, why do you think this is the case? Follow-up: Do you think this inhibits the patient's ability to maintain good health?
- 8) Of these three choices, which best fits your **description** of your relationship with your patients both pre- and post-reunification: 1) as a parent, 2) as a consultant, 3) as a mutual partner, or none of these three? Follow-up: Why does this description best fit your relationship?

- 9) In patients with **chronic health needs** (e.g. diabetes mellitus, hypertension) has your care for them been affected since reunification in 1989? If yes, how? Follow-up: Do you feel more involved or less involved in the care for the chronically ill today than you did before reunification?
- 10) Do you feel that your relationship with your patients is **changing now**? If yes, how? Follow-up: Returning to question #8, do you feel it is shifting from one of the three aforementioned descriptions to another? If yes, from which to which?

#### Questions for interviews with patients:

1. Did the fall of the Berlin Wall and the reunification of the city of Berlin **affect** your relationship with healthcare providers? If yes, how? Follow-up: How long did it take for the changes to seem apparent? Were the changes more extreme than you expected?
2. Has your **perception** of the Berlin healthcare system changed since reunification? If yes, how? Follow-ups: 1) Do you think the changes were managed in a way that improved or worsened your care?
3. Would you do to **change** the relationship with your Berlin healthcare providers today? If yes, how?
4. Does healthcare seem better or worse in **West Berlin** since reunification? **East Berlin**? If yes, how? Follow-ups: 1) What makes you draw your conclusion about the care in the East versus the Western half?
5. If given the choice, would you **choose care** in the Western half of the city or the Eastern half? If yes, what is the basis for this judgment?
6. Do you feel your **choices** have been restricted as a customer (consumer) of the Berlin healthcare system or expanded since reunification? If yes, how? Follow-ups: 1) Do you think this is ultimately beneficial or detrimental to the system? 2) What are the most important health issues in Berlin in your opinion that could benefit from changes?
7. Do you feel your **rights** as a patient in Berlin have changed since reunification? If yes, which ones? Examples: the right to privacy in medical records, right to choose your healthcare provider, the right to manage your own treatment if illness is long term (e.g. diabetes mellitus, hypertension)
8. Of these three choices, which best fits your **description** of your relationship with your physicians both pre- and post-reunification: 1) physicians are



more like a parent, 2) a consultant, 3) as a mutual partner? Follow-up: Why does this description best fit your relationship?

9. Do **monetary constraints** limit your choices as a customer (consumer) in the Berlin healthcare system? If yes, to what degree? Follow-up: What is the role of insurance in your care and has this contributed to the constraints in any meaningful way?
10. Do you feel your **expectations** of the Berlin healthcare system have changed since reunification in 1989? If yes, how? Follow-up: What do you feel leads you to these new expectations?
11. Have you ever visited a **“polyclinic”** in Berlin? If yes, how would you rate the care you received on a scale of 1 – 10? Why?

## **Clendening Fellowship Proposal**

The Effect of Disasters on Health Care in El Salvador



Neal Peterson  
University of Kansas School of Medicine  
Class of 2009

# Clendening Fellowship Proposal

## The Effect of Disasters on Health Care in El Salvador

### Introduction:

On January 13, 2001 I was in the city of Juayua, El Salvador talking to a woman by her two story, makeshift house. While we were talking, the ground began to shake. Then I couldn't stand still. The woman cried for her baby who was inside and when the ground stopped shaking, we rushed inside to make sure the baby was alright. The baby was fine. Then I stepped outside and saw a cloud of dust rising above a dormant volcano in the distance.

The rest of the day, I went around looking at the city. While most of the cement buildings were fine, there were many adobe houses that were destroyed. When trying to sleep later that night, I would jump out of bed and run outside with every aftershock.

For the next week, foreign aid came into El Salvador. I helped French doctors who spoke English translate. Later that month I translated again, this time for United States Air Force doctors.

The medical care that was given by both the French doctors and the Air Force doctors was not really specific to the earthquake. Most of the people seeking medical attention were looking to be treated by a medical professional for problems not related to the disaster. At the same time, though, there were many people trying to get medical care for problems associated with the earthquake, when medically there was nothing wrong with them.

### Problem:

Natural disasters are no respecters of persons. In the last few years, the news has been flooded with reports of hurricanes, tsunamis, earthquakes, and the list could go on. In most developed countries, the response to a natural disaster is usually prompt and efficient (though recent evidence even in the United States may disagree). Regardless of the initial response, however, the healthcare infrastructure and other resources available make it possible for developed countries to quickly rebound from natural disasters and continue life as usual.

Developing countries usually do not have the same infrastructure and resources that developed countries have. Even before disaster strikes, there may not be adequate health care. Thus, when a natural disaster does strike, the health care situation becomes even more strained.

According to Newsweek, after Hurricane Katrina, the majority of the people who needed health care were people who needed regular medical attention, such as those who were receiving chemotherapy or other drugs (Kalb, 67). In developing countries, the people who suffer in a disaster are not those who can't get continued medical relief, but those who can't get any relief at all.



## Methods:

El Salvador is no stranger to disaster. Though it is only roughly the size of Rhode Island, it has had a Texas portion of natural disasters. Before I arrived in 1999, El Salvador was recovering from Hurricane Mitch. When I was there from 1999 to 2001, there were two earthquakes with an accompanying mudslide. From then until now, El Salvador has had hurricanes, a volcanic eruption, and more flooding and mud slides (EM-DAT 2006). With that background, I have decided that El Salvador would be the perfect place for me to research the effect of natural disasters on health care.

In addition, as a future physician, I want to be prepared to help when a disaster strikes. According to a web page on Disaster Medicine from the American Academy of Family Physicians, "Disasters come in many shapes and forms...Family physicians stand as the front line to help detect, support, direct and participate in all disasters that might strike a community" (Disaster Medicine 2006). By going to El Salvador and learning some of the methods employed during a disaster, I will be better prepared for disaster as a physician in the United States.

## Goals:

1. Understand how less developed countries respond when there is a natural disaster
2. Learn how medical care is different during crises versus the norm in El Salvador
3. Improve my medical Spanish by speaking the language around citizens
4. Understand the workings of Central American clinics by shadowing and interviewing medical doctors in various parts of El Salvador
5. Prepare for future natural disasters as a physician in the United States

## Sites of Study:

Santa Tecla- site of two devastating mud slides

Sonsonate-near the ocean, a place affected by hurricanes and flooding.

Juayua- in the mountains; home to the indigenous people

Ahuachapan- near the Guatemala border, furthest from the big city of San Salvador in the west of the country

## Potential Interview Questions:

What are the major medical issues that people come to be treated for?

What are the biggest disasters you've seen?

What are the protocols that are in place for a disaster?

What types of services do you perform in an emergency that you do not normally perform?

Where do people go for treatment when they have no money after a disaster?

How heavily does El Salvador rely on outside help for disasters?

What would the people do if there was no medical assistance given?

What are the supplies and other equipment needed for medical and disaster care in a developing country, and how does that differ following a natural disaster?

### Qualifications:

As an undergraduate statistics major at Brigham Young University, I proposed and carried out a project researching the increased mortality associated with poor breastfeeding practices in Bolivia in 2005. While in Bolivia, in addition to my research project, I helped administer cognitive surveys to children in local schools. By completing that project, I not only learned how to deal with non-profit organizations and improved my research skills, but also gained experience and skills specific to researching in a foreign country.

From 1999 to 2001 I was in El Salvador as an LDS missionary. Part of that time was spent helping reconstruct after a large earthquake. That experience taught me how to communicate well in Spanish. It also gave me a better understanding of natural disasters and glimpse into the medical profession in El Salvador. With contacts that I established in my two years there, I will be able to navigate through El Salvador with relative ease and find people to interview about their experiences with disasters and medical care in El Salvador.

Finally, in the summer of 2004, I worked at Philmont Scout Ranch in the medical lodge. From training in the Boy Scouts and while in the medical lodge, I learned about the different types of natural and medical disasters that can occur and some of the protocols and response that is implemented during a natural disaster.

### Contacts:

- Jay Porter- former director of HELP international, spent several years in El Salvador doing humanitarian aid. Has many friends who are doctors in El Salvador.
- Dra. Velasquez, Pediatrician, owner of a pediatric clinic in El Salvador.
- Dr. Duarte, teaches at the National Medical School of El Salvador.
- Citizens of various cities in El Salvador I met during my two years there

Budget:

\$800 flight to El Salvador on American Airlines  
\$10 tourism card  
\$250 lodging for two weeks  
\$250 transportation (taxis)  
\$150 food  
\$150 miscellaneous thank you gifts and expenses related to El Salvador  
\$100 for communication and miscellaneous photocopying and printing related to research  
(\$200 gift for my wife for missing our anniversary)  
\$27.15 exit tax

Total\*

\$1937.15

\*This is an estimate based upon the best of my knowledge. I am aware that any amount over \$2000 will be my responsibility.

Timetable:

May and June 2006: make preparations and finalize arrangements  
July 12-20, 2006:  
July 12: fly to El Salvador.  
July 13-14: stay in San Salvador, speak to Dr. Duarte and Dr. Velasquez about disaster medicine.  
July 15-16: visit the city of Ahuachapan and interview doctors and visit clinics.  
July 17-18: visit the city of Juyaua and interview doctors and visit clinics.  
July 19-20: visit the city of Sonsonate and interview doctors and visit clinics.  
July 21-22: interview doctors in the city of Santa Tecla.  
July 23 return to Kansas City  
July and August 2006: prepare and finalize presentation and report

Sources Cited:

Kalb, Claudia and Murr, Andrew. "The Cost of the Katrina Effect." Newsweek  
12 December 2005: 67.

EM-DAT : the International Disaster Database. Center for Research on the Epidemiology of Disasters. Belgium. 2006.  
<<http://www.emdat.net/disasters/Visualisation/profiles/natural-table-emdat.php?country=El%20Salvador>>

"Disaster Medicine: Recommended Curriculum Guidelines for Family Practice Residents." The American Academy of Family Physicians. Leawood, KS. 2006.  
<<http://www.aafp.org/x16647.xml>>



## **Proposal**

My proposal for the Clendening Fellowship is to visit the Ann Sullivan Center in Lima, Peru for three weeks in order to observe first hand how this school is able to meet the needs of students with developmental delays. The information that I obtain in Peru will then be compared to schools that I will be visiting in the state of Kansas. It is my intent that from this fellowship I will gain a better understanding of the education of children with developmental delays.

## **Personal Background**

The topic of special education is an issue that has tugged at my heart since childhood. Two of my siblings have mental retardation and while I was growing up I was often responsible for assisting each of them with learning activities. As they have progressed through school I have questioned on numerous occasions how best to educate children with developmental delays. I feel this fellowship would allow me the opportunity to gather a more knowledgeable view of what special education programs are in place in the state of Kansas and abroad and to determine if they are successful in promoting a positive learning experience and high achievement as an adult.

Prior to choosing to pursue a career in medicine I considered the option of being a special education teacher. Although I have strayed from that career choice I have never lost interest in assisting and caring for children with developmental delays and my true passion lies there. My interest in special education and assistance programs for children with developmental delays has only been heightened as I have continued in my medical education. I have had the opportunity to shadow a physician at the Developmental Disabilities Center and have learned to appreciate that the successfulness of the education programs we have in place are vitally important to the type of accomplishment a child will have as an adult.

The goals I have currently set for my education are toward a career as a developmental pediatrician. The discussion of caring for patients with developmental delays is a topic that is glazed over during medical school. I feel that on a professional level it would be a tremendous asset to have an understanding of what educational opportunities are present for patients with developmental delays. Acquiring knowledge of these programs would be extremely beneficial when it comes time to educate families on choices for education.

## **History of Special Education in the United States**

The format of special education has taken on many appearances over its lifetime but its goal has remained essentially unchanged. To teach and educate underdeveloped and disabled children is a task so intense that our society has yet to perfect it. Mainstreaming, the idea of placing children in the least restrictive environment available did not emerge until about 35 years ago. Before and during the 1960's special education was entirely segregated from the regular classroom. In 1975, The Education of All Handicapped Children Act deemed that handicapped children should be educated with non-handicapped peers.<sup>1</sup>

This movement, however, was slow to take off. It was not until the late 1980's that disabled children regardless of severity were placed in regular classrooms. In 1997, the Individuals with Disabilities Education Act Amendment recited that education of the disabled child in a regular

classroom setting would be favored unless the teacher and parents felt it would not be beneficial. This type of education would be available to all children with disabilities from birth to age 21.<sup>2</sup>

The main approach of mainstreaming currently revolves around inclusion. Children with learning disabilities are placed in the regular classroom setting but a trained teacher or paraprofessional is often present to assist the child throughout the day. This is a sharp contrast to the previous system of resource rooms, which were often used for special-needs children to spend part of the day with a teacher who is trained to deal with their disability. These pull out programs were thought to be disadvantageous because children were missing vital instructions from lessons when they were absent from their regular room. Today we are currently focused on placing a child in the least restrictive environment but there continues to be concern about the quality of instruction that special-needs students receive.<sup>3</sup>

### **Ann Sullivan Center**

In the country of Peru there are over three million people with disabilities, but only 28,000 receive service. Government assistance in this country is nearly nonexistent and the opportunities for educating people with disabilities are severely limited. Dr. Liliana Mayo recognized this need for educating children with developmental disabilities when she started The Ann Sullivan Center in Lima, Peru, in 1979. The Center initially served 8 children with different disabilities. Today the Center serves over 400 families and it is recognized internationally for providing quality educational programming to individuals with significant disabilities.<sup>4</sup>

The educational programs available for students span from birth through adulthood and include classes ranging from early childhood preschool to vocational education. The Center focuses on a functional and natural curriculum. This emphasizes a focus on the development of skills, which would increase participation in the community, school, family life, and work environments. The overall goal of the curriculum is to prepare each child for a productive and fulfilling life as an adult.<sup>5</sup>

In addition to educating students, on-going educational programs for both the staff and families has also been incorporated. In-services for teachers take place three afternoons each week. In addition to continual teacher education, families are also taught how to be successful teachers to their child. Each parent is given the opportunity of 120 hours annually in educational classes. Programs have been established for educating the siblings of children with developmental delays and teachers also visit the family at their home. It is the school's intent that this team approach helps in further advancing each child's skills. The success of the program is evident as there are currently nearly 90 students working in jobs with wages, some of which are the sole financial supporter of their family.<sup>4</sup>

### **Goals**

- To observe in a number of schools and witness a variety of curriculums.
- To determine what makes a special education program successful.
- To recognize weaknesses that are still present in special education.
- To assess how schools work to meet the needs of each child.

To identify how schools prepare developmentally delayed children for adulthood.  
To gain a better understanding of how to further educate my siblings as well as patients with developmental delays that I may encounter.

### **Method**

In order to learn about special education, information will be gathered by prolonged engagement in each setting. Observations will be made at three schools. The majority of my time will be spent at the Ann Sullivan Center on the days of June 5, 2006 through June 24, 2006. Classes at the Center begin at 8 a.m. and go through 3:30 p.m. I will be observing in a range of classrooms including: early intervention, early childhood preschool, classes in self-help, prevocational, daily survival and academic skills, vocational education, supported employment, and open school. In addition to regular school classes, the Center has several other programs in place.

*Staff education classes* - Every Tuesday, Thursday and Friday from 4 p.m. to 6 p.m.  
These classes are designed not only for the permanent teachers but for the volunteer staff as well.

*Parent education* - Every Wednesday night from 6 p.m. to 8 p.m.

*Education of siblings* - Saturday June 17 and 24 from 8 a.m. to noon  
In these sessions siblings of the children that attend the school will learn what their role is in education.

*Training in the home* - June 21 through June 23  
On these days I will be accompanying teachers to the homes of students and will be observing the family in their everyday environments. Teachers will be educating parents on ways to continue education outside of school.

In addition to observing I will also be conducting interviews of parents and teachers. It is my goal to speak with five parents and five teachers. The Center will be helping me in setting up these interviews. The Center requires parents to volunteer their time at the school if they are unable to afford tuition. This will allow for easy access when interviewing.

### **Questions for teachers:**

Explain the benefits of a functional and natural curriculum based around inclusion.  
What assistance programs does the school provide parents in educating their child?  
Explain the barriers, financial or other, that deny you from acquiring an ideal curriculum.  
What programs are in place in order to meet individual needs of students?  
How does the curriculum offered at your school adequately prepare students for adulthood?  
What programs are in place that allow teachers to receive continual training for their position?  
Are there any issues your school is currently working on for improvement?

### **Questions for parents:**

Describe the working relationship between parents and teachers.



Are you satisfied with the amount of communication you have with your child's teacher?  
What additional education programs or resources outside of school, if any do you use?  
What are some areas that you feel the school needs to improve on?  
Overall are you satisfied with the education your child receives?  
Do you believe that the curriculum is individualized toward your child's needs?  
In what ways do you feel the school helps to prepare your child for adulthood?

I will also be spending time at two schools in the Wichita area. The first school is Chisholm Life Skills Center in the Wichita school district. This is a vocational and life skills training school specifically geared toward students aged 16-21 with special education problems. The second school is Amelia Earhart Elementary in Goodard, KS. This school is primarily focused on mainstreaming although resource rooms are available depending on the child's needs. I will be spending four days observing at each of these schools. I will conduct interviews with teachers at each school. The interview questions will follow a similar format as the ones asked in Peru. At this early date, I am working with instructors at the schools to determine the possibility of interviewing parents.

### **Possible Barriers**

I am not fluent in Spanish, however many of the parents and teachers at the school speak both Spanish and English. As you will see under my budget I have included a fee for a translator if one is needed during interviews. I have spoken with Dr. Mayo and she has assured me that this will be possible.

### **Contacts**

Liliana Mayo-director at the Ann Sullivan Center

Doug Anderson-coordinator for the special education program in the Wichita area

Merlene Switzer-teacher at Chisholm Life Skills

**Budget** - based on 3 weeks in Peru

|                                                         |        |
|---------------------------------------------------------|--------|
| Lodging (includes breakfast & supper)                   | \$300  |
| Transportation                                          | \$45   |
| Lunch at the Center                                     | \$45   |
| Lunch outside the Center                                | \$45   |
| Center expenses (transportation, materials, translator) | \$150  |
| Miscellaneous expenses                                  | \$120  |
| Flight                                                  | \$1000 |
| Passport (already paid for)                             | \$97   |
| Gas and expenses in Wichita*                            | \$150  |

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**Total of all expenses** **\$1952**

\*Please note that no lodging expenses have been calculated for time spent in the Wichita area as I have family there and will be staying with them.

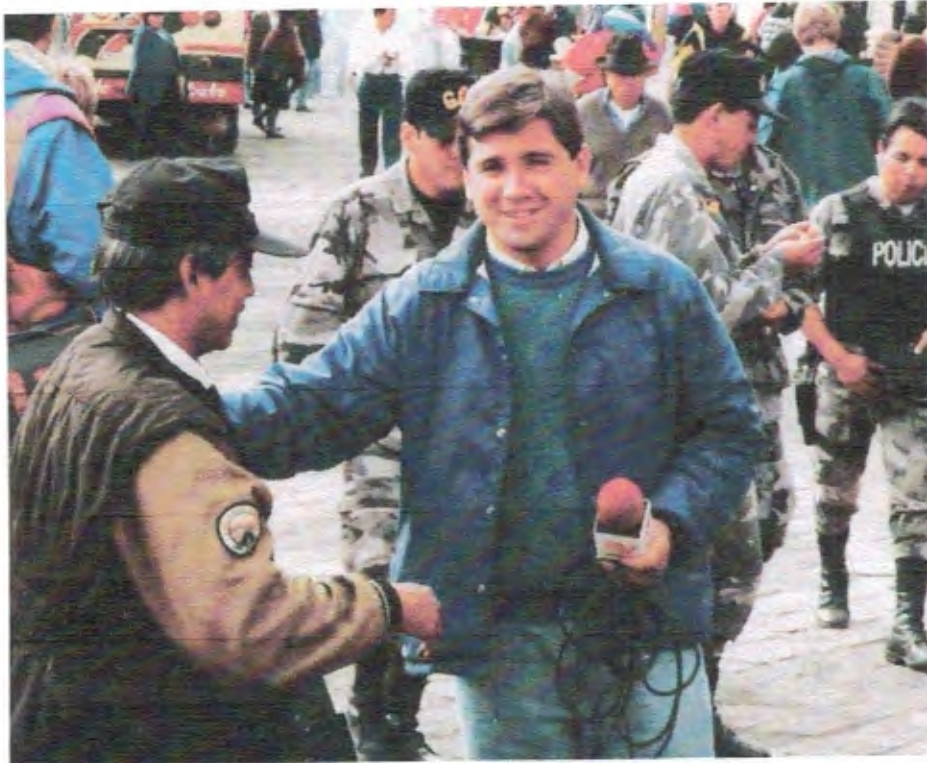
**Timeline**

May 22-25 - observations at Chisholm Life Skills 8am-3pm  
 June 5 - begin observations at Ann Sullivan Center  
 June 17 and 24 - training with siblings  
 June 21-23 - training at the students' homes  
 Every Tuesday, Thursday and Friday 4-6pm - training of teachers and volunteers  
 Every Wednesday 6-8pm - training of parents  
 June 25 - return to USA  
 July 10-13 - observations at Amelia Earhart Elementary School 8am-noon

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3. Berger, K. S. The Developing Person Through Childhood. New York: Worth Publishers, 2003.
4. Mayo, L. and J LeBlanc. Making the impossible, possible with CASP: A first class program, in a third world country, with fourth world resources, 2005.
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## **Education and the Power of Television News**



**Jen Spiegel**  
**University of Kansas School of Medicine**  
**Clendening Summer Fellowship Proposal**  
**February 20, 2006**



Jen Spiegel, University of Kansas School of Medicine  
Clendening Summer Fellowship Proposal  
February 20, 2006

## **Education and the Power of Television News**

### **Proposal:**

I propose to travel to Quito, Ecuador, for one month to explore the role of television news in educating viewers about cancer, specifically the benefit of cancer screening. To enhance my ability to communicate on topics related to cancer, and to improve my understanding of their societal relevance, I will enroll in a four-week medical Spanish program that includes clinical immersion experience. This program is called SALUD, offered through AmeriSpan.

### **Personal background:**

The power of television news intrigued me at an early age. Before graduating from the University of Kansas with degrees in Broadcast News and Spanish, I was fortunate to have the opportunity to travel to Quito, Ecuador, to work in the news department of a television network. After graduation, I first worked as a producer with KTKA-TV in Topeka, Kansas. One year later, I began working at KMBC-TV in Kansas City, Missouri. During this time, I developed a keen interest in health-related news and was impressed by the feedback to these news reports that I received from viewers.

Cancer became a particular interest for me. After leaving television news, I worked for a program of the National Cancer Institute, the Cancer Information Service (CIS). Each day, the service is contacted by people all over the world seeking information about cancer. Some want general information, some want to learn about specific treatments or clinical trials, and some are looking for help in covering the cost of their treatment. I was continually distressed by the number of Latin Americans searching for all levels of information and assistance. Many explained to me that the educational resources available through the CIS are not available in their country. Many of these contacts were made through our online service; I could only imagine the scarcity of information for those without Internet access or the ability to use a computer. The level of fear I observed related to the mystery of cancer was continually troubling.

I strongly believe in the power of education to alleviate fear and provide empowerment. Presenting information at a level understandable to an individual can open his or her eyes to basic concepts that had not been understood before. I have witnessed this reaction in working for the CIS, and have also experienced a similar reaction while working in television news. I believe that television news, when produced responsibly, can play a powerful role in educating and promoting understanding related to cancer.

### **Television and education:**

The Kansas Association of Broadcasters and Missouri Broadcasters Association indicate that broadcasters have a mandate to serve the public interest of the communities in which they operate. In each organization's summary of public affairs it is stated that "Through public affairs activities, stations help increase the awareness of issues that affect their audiences."<sup>3,4</sup> KMBC-TV Healthwatch reporter and anchor Kelly Eckerman explains: "I think we can fill a public service, and be a source of general information." For example, in 2003, 86% of Missouri television stations and 50% of Kansas stations reported airing a news segment on breast cancer or other women's health issues. In the realm of cancer-prevention topics, 71% of Missouri television stations and 38% of Kansas stations reported airing a news segment on anti-smoking. The percentages were similar for the use of public service announcements related to these topics.<sup>3,4</sup>

### **Background on Ecuador and cancer:**

Cancer affects all populations and the Ecuadorian people are no exception. In men ages 20-59, malignant neoplasms are the third leading cause of death. In women ages 20-44, cancer is the second leading cause of death, and it is the number one cause of death in women ages 45-59.<sup>2</sup>

The specific types of cancer, however, are somewhat different from those reported in the United States. The most frequent cancer killer in women is cancer of the uterine cervix, a highly detectable and treatable form of cancer. The second most frequent cancer killer among women is stomach cancer, a cancer with a relatively low incidence in the United States. For men, this is the leading cancer killer. For Ecuadorian men, lung cancer is the third leading cancer killer.<sup>2</sup>

Life expectancy has increased from 68.8 years for the general population in 1990-1995 to 69.9 years in 1995-2000. According to public health officials, this improvement reflects the work that has been done in health education and public health promotion, accomplished in part through national media campaigns.<sup>1</sup>

### **How Teleamazonas can help:**

During my television news internship in Quito, I spent most days shadowing and learning from reporter Bernardo Abad. Mr. Abad allowed me to accompany him around the city and throughout Ecuador for news-gathering. I was surprised at the differences in news coverage from what I had experienced at home. We had many lively discussions on this topic during that summer, and Mr. Abad has followed my career since that summer. We are both looking forward to the possibility of further discussions, specifically related to public health issues and cancer screening.

With 22 years of experience in television news, Mr. Abad is now the Executive News Producer at Teleamazonas, in charge of much of the programming related to public affairs.

Teleamazonas began transmitting on February 22, 1974, becoming a national network serving all of Ecuador. The network produces much of its own local programming, including at least four hours of news programming per day. Teleamazonas is unique among Ecuador's television networks in its

level of dedication to issues that serve the public good. The morning programming includes segments focusing on viewer phone calls and issues of the day. The network specifically describes its coverage during the morning hours as focusing on social issues, including public health. Bernardo Abad tells me that the majority of his station's health coverage is related to cancer and cardiovascular health.

In keeping with our tradition of mentor and mentee, Mr. Abad has offered to allow me to participate in the daily news production activities at Teleamazonas. In this capacity, I will have the opportunity to gain perspective from television news professionals about their role in public health education. I also hope to meet and interview Ecuadorian public health officials. Through this contact, I will be able to learn the health officials' assessment of the adequacy of health coverage by television news teams. I will have contact with patients and physicians who may take part in health-related coverage and hope to gain an understanding of their motivation for participating in this coverage. During my clinical immersion experience through the SALUD medical Spanish program, I will have additional contact with patients and physicians. This contact will provide an opportunity to assess the impact of television news coverage of health-related issues, specifically cancer screening. I will focus on the frequency with which patients receive health-related information from television news. I will investigate the degree to which the patient is able to apply this information to his or her own life, as well as the lives of family members. I will learn whether information presented through television news influences patients to act to improve their health, including seeking cancer screening. I will also be interested to learn the physicians' assessment of the accuracy of the medical information in this coverage.

### **AmeriSpan's SALUD program**

SALUD is a language-learning program developed by AmeriSpan for people studying or practicing in health-related fields, including medical students. The programs are designed for groups of 10-20 participants with varying levels of Spanish proficiency. SALUD includes education related to the specific country's medical system and its public health challenges. Participants attend daily medical Spanish classes and are immersed in the health care environment through clinical experiences. AmeriSpan has existed since 1993, and its SALUD program was first offered in 2000. Since its inception, more than 500 health care students and professionals from 44 U.S. states and other countries have participated in SALUD.<sup>5</sup> By participating in this program, I hope to enhance my ability to communicate on topics related to cancer, and to improve my understanding of their societal relevance.

### **Goals:**

- To learn how physicians may work with television news staff to promote understanding related to cancer and cancer screening
- To understand strategies for communicating with patients about information they gather from television news
- To assess the level of trust the public places in cancer-related information presented in television news
- To gain an awareness of the cancer-related issues most frequently covered on television news



## **Methods:**

I will begin this project during the week of June 18, 2006, by participating in the morning news-gathering activities at Teleamazonas. Mr. Abad begins his day at the station at 6 a.m.; I will also arrive at Teleamazonas at this hour. I will participate in the morning staff meeting, during which decisions on daily news coverage are made. Story assignments are made at this time, and my presence at the meeting will allow me to accompany any reporters and photographers who may be assigned to medical stories for the morning. Considering my past experience in television news, I may also offer ideas on potential news stories. By accompanying the news-gathering team, I will be able to witness first-hand the plight of the people whose stories will be told on the air. Also through the interaction with the Teleamazonas staff, I will have the opportunity to gather opinions about the role of the media in educating the public on cancer screening.

Questions to ask Teleamazonas staff:

- What do you see as your role/the station's role in providing coverage of health issues, especially cancer screening?
- What are the cancer topics you find important to cover?
- How do you choose the stories you cover?
- What sort of feedback do you receive from viewers or doctors about your coverage?

By participating in the news-gathering and interviewing process, I may also have the opportunity to interact with public health officials. In this case, I will take the opportunity to discuss the role of television news in public health education related to cancer.

Questions to ask public health officials:

- How often do you work with the television news media to promote cancer awareness?
- How do you approach the television stations with this information?
- What is the usual response from the television stations, and how often do stations use your information on-air?
- What is your opinion of the television news media as an information source for the public on cancer and cancer screening?

Since television news is unpredictable and I cannot anticipate with certainty my chances of interviewing public health officials, I plan to make contact independently. Before leaving for Quito, I will plan to establish contact with members of the public health organization, Sociedad de Lucha Contra el Cáncer del Ecuador. I plan to ask the aforementioned questions.

My site visits to Teleamazonas will continue through my first two weeks in Quito, as my schedule permits. In the afternoon, I will attend medical Spanish courses through the SALUD program.

In the third week, I will begin my clinical immersion experience through SALUD in local clinics in Quito. This experience will allow me to practice my Spanish, my clinical skills, and continue gathering information about the perceived role of television news in educating the public about cancer screening. At this early date, I am not able to obtain information about the specific clinics or

physicians I will encounter. However, I have requested to be paired with those providing cancer screening or cancer treatment whenever possible. Since virtually any physician bears the responsibility of discussing some form of screening with his or her patients, I am certain that this element of care will be incorporated into my experience. Considering that the focus of this clinical experience is actual medical care, I realize that my time with patients will be limited, yet full of educational experience. If I am given the opportunity, I will discuss the following issues with patients:

- How often do you watch television news?
- How often do you see reports related to cancer on television news?
- Do you trust the television news as a source of information about cancer?
- Have you ever discussed with your doctor something you saw on the news?

In an ideal situation, I would wish to focus on cervical cancer, a cancer with a high rate of incidence in Ecuador and high potential for screening. Though its incidence is not as high, colorectal cancer would be another logical focus. However, due to the nature of the "news" and the inability to predetermine its contents, I will not limit myself to these specific cancer types.

#### **Timeline and significant events:**

|                    |                                                                                                                     |
|--------------------|---------------------------------------------------------------------------------------------------------------------|
| Sunday, June 18    | Arrive Quito, Ecuador via Mariscal Sucre Airport                                                                    |
| Monday, June 19    | Begin medical Spanish classes through SALUD program                                                                 |
| Wednesday, June 21 | Morning: First site visit to Teleamazonas<br>Afternoon: Continue ongoing medical Spanish classes                    |
| Monday, July 3     | Morning: Begin clinical immersion experience at local clinic<br>Afternoon: Continue ongoing medical Spanish classes |
| Friday, July 14    | Morning: Final clinical immersion experience<br>Afternoon: Final medical Spanish class                              |
| Saturday, July 15  | Return to USA                                                                                                       |

#### **Budget:**

|                                                                                                                             |        |
|-----------------------------------------------------------------------------------------------------------------------------|--------|
| Estimated plane ticket and taxes:                                                                                           | \$1000 |
| Medical Spanish/clinical immersion program<br>(including homestay costs, 3 daily meals, transportation to and from airport) | \$1745 |
| Estimated daily transportation costs                                                                                        | \$80   |
| Incidental costs                                                                                                            | \$150  |
| Total estimated cost                                                                                                        | \$2975 |

**Information sources:**

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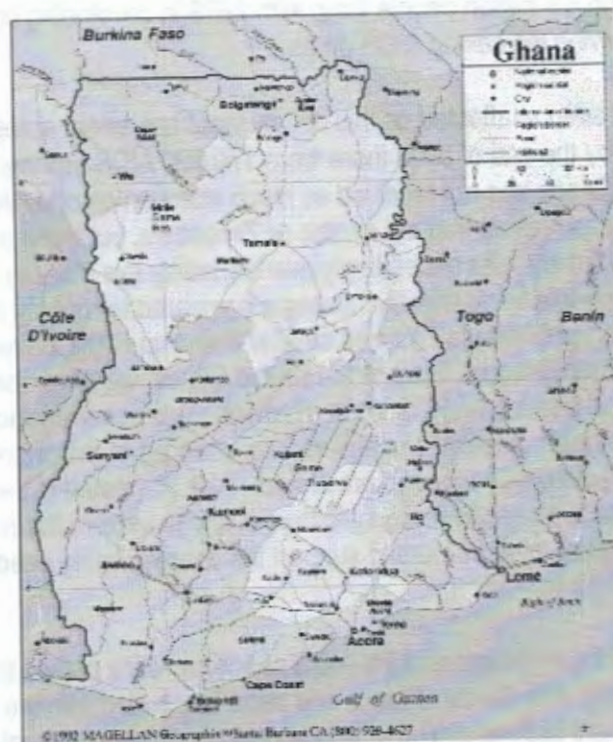
**Contacts:**

Bernardo Abad, Teleamazonas  
Elizabeth Gregory, SALUD Medical Spanish Program  
AmeriSpan

Kelly Eckerman, KMBC-TV



# **“A Comparative Study of HIV Treatment Protocols in Ghana and the United States”**



**Accra, Ghana—West Africa  
Summer 2006 Clendening Proposal**

**Amanda Valliant  
February 10<sup>th</sup>, 2006**

Donna Sweet and her staff. While in Ghana, I will be staying with the daughter of one of the doctors with whom I will be working during my stay. An organization called Volunteering In Africa has arranged for me to work with several doctors in the Accra area, observing and learning about the practice of medicine in Ghana and, specifically, the treatment of HIV in this country. I've tailored my visit to primarily spend time with HIV positive and AIDS patients, but I will also have the opportunity to see other aspects of Ghanaian medicine, and I will be spending some time on call with OB, Internal Medicine, and various other departments. I hope to spend some time in more rural areas as well, and I will be pursuing any occasions to travel with the physicians that arise during my stay. I have been corresponding with two medical students who worked with these physicians last summer and I am confident that opportunity abounds in Ghana for both medical learning and personal growth.

My time spent in Wichita will focus on the aspects of Dr. Sweet's practice that relate specifically to the treatment of HIV, including new treatment protocols currently being explored, opportunity for research trials in the United States, and the inherent difficulty of juggling many immunocompromised patients. I am excited to learn from Dr. Sweet on the subject of HIV, and I have arranged to spend time with both her clinical and research staff to further develop the picture of HIV treatment in this region of the world. I have family and friends in Wichita, so I will not have to pay for meals and accommodations while I am there.

I will be putting together a physician survey, between now and May, to use as a tool for my research in both Accra and Wichita. I plan to consult with Sheryl Kelley, a project specialist with the Kansas AIDS Education and Training Center who works closely with Dr. Sweet, and use her feedback to construct an effective survey that will help me to quantify my studies.

I intend to depart on this adventure and complete the study even if I am not awarded one of the Clendening scholarships; however, the scholarship money would certainly help to alleviate the financial burden. I also take full responsibility for any expenses incurred that are above and beyond the Clendening award amount, should I be awarded the scholarship.

### **III. Goals/Questions to Answer**

- Do patients treated in the United States have an advantage when it comes to new treatment possibilities, better medications, and trial research opportunities? If this is the case, and it likely is, how large is the disparity between the pharmaceutical options in Ghana and the United States?
- What are the major cultural differences that come into play where treatment of this type of disease is concerned? What effect does this have on treatment protocols and options?
- What is the current climate of HIV/AIDS education in Ghana? How does that differ from the education level found here in the United States? How does this inequality translate to patient care? How does the difference in education levels affect the responsibility patients

July 6, 2006

July 8, 2006

July 10-July 21, 2006

Flight 2423—American Airlines—3:20 pm ORD to MCI

Arrive in Kansas City, unpack and repack, etc.

Drive to Wichita, KS—meet with a contact from an HIV counseling resource regarding the infrastructure of care in Wichita

Spend days in the KU Internal Medicine clinic with Dr. Donna Sweet and Dr. Ha Ta, as well as the nurse practitioners that work with them, focusing on the fraction of their patient load that is HIV positive. I will be spending at least one day with the research coordinator that works with Dr. Sweet (Sheryl Kelley) to explore issues regarding access to clinical trials and special care.

## **V. Contacts**

Ebenezer Mensah  
Program Coordinator  
Volunteer In Africa

Donna E. Sweet, M.D.  
Professor of Medicine  
KU School of Medicine—Wichita

Sheryl Kelly  
Project Specialist  
The Kansas AIDS Education and Training Center  
KU School of Medicine—Wichita

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## **VI. Bibliography**



***Laryngeal Dysfunction: A barrier to communication***

Clendening Summer Fellowship Proposal

February 20, 2005



*Laryngeal Pacing*

Beverly Wilson

University of Kansas School of Medicine

## Introduction:

In the few years that I've been on earth, I've realized that mankind has an unbelievable ability to overcome adversity. Everyday people are forced to deal with tragedy, tragedy that may range from losing a toe to losing a leg. No matter how large or small the problem, patients and physicians have come together to find ways of coping. Unbelievably, many people who were once considered blind can now see, once considered deaf can now hear, and the once immobile are now mobile. Assistive devices such as the wheel chair, glasses, and hearing aides have helped thousands of people around the world to function with some sense of normalcy where they otherwise may not have.

Although there are still many medical conditions left to defeat, the medical community is quickly gaining. Each disability or injury can be difficult to bear but no patient's journey is without hope. While we gratefully acknowledge the medical miracles of the past, we all hope for an even more amazing future.

Some of the most debilitating conditions involve the ability or lack thereof to communicate, a technique almost essential to human survival. According to an article from the *National Dissemination Center for Children with Disabilities*, approximately one in ten people in the United States suffer from some type of communication disorder. They state that, "Because all communication disorders carry the potential to isolate individuals from their social and educational surroundings, it is essential to find appropriate timely intervention."<sup>iii</sup> In an effort to gain an understanding of the wide range of effects a very specific communication disorder, namely laryngeal dysfunction,

can have on a patient and the types of treatments available, I'd like to spend much of my summer completing research here in Kansas and in a couple of locations across the U.S.

### **Background/Motivations:**

About five years ago I was in an accident that left my own larynx, lungs, and trachea badly damaged. Over time my lungs and trachea have mostly healed but my larynx remains nonfunctional. This is the result of laryngeal nerve paralysis. Although I've managed to gain a quiet speaking voice, this came at the cost of using a stoma for breathing. Now, I am faced with a difficult time creating speech.

As a person with a communication disorder, I've found it incredibly hard to complete normal daily activities efficiently and effectively. Because of my nonfunctional larynx, my own voice is weak and breathy sounding. Speaking to someone in a noisy room, something I once took for granted, is now almost impossible. This is also in part because many times a laryngeal problem will require that a patient have an alternate route for breathing. This alternate route is known as a tracheotomy or stoma. A stoma requires that you close the hole for speech and then open the hole for breathing, creating just one extra step in the already awkward process of communication.

In a strange twist of irony, I learned of my own great grandfather's inability to speak, once I had already lost mine. Although I never met him, I'm told that his experience was relatively similar. His injuries were the result of throat cancer after a long history of tobacco use and the subsequent removal of his larynx. As a laryngectomee, he was left without the tools for creating speech. Thankfully, even in his generation, he had the opportunity to use a mechanical voice box to significantly improve his ability to communicate. I wonder though, was this a widely available tool? What



would've become of him without such a tool and how did this affect his life, his job, his marriage? What were his strategies for coping and were they essentially the same that someone would use today?

American physicians have had the capacity to treat terminally ill patients with the removal of their larynx since 1884.<sup>iv</sup> As a result; voice rehabilitation has been a significant issue in America for quite some time. More recently it's been estimated by physicians at Vanderbilt's Voice Center that, "about 6,000 patients are stricken with bilateral laryngeal paralysis each year in the United States." This number, although taken from an article in 1999, is much larger than I ever would have imagined. Adding that on top of the many who suffer from laryngeal removal, means that thousands of people are being challenged to find alternative techniques for creating speech and effective communication. I think it's obvious now that myself, as well as many other Americans, would benefit from speech enabling strategies and new techniques aimed at treating this condition. If I am able to gain a better understanding of this disability, I will surely be able to help others who are in this exact situation, someday soon.

### **Proposal/Methods:**

I believe that in order to truly understand a problem, you must start from its roots. In an attempt to do this I will focus much of my research on learning more about the topic of historical treatments for this sort of disorder. I plan to start my journey here in Kansas City. I would like to spend three weeks doing a primary search for data. This would include spending the first two weeks investigating the history of the disorder in the Clendening History of Medicine Library. There I have found a great wealth of historical records on otolaryngology. Also during this time, I will interview my grandparents about

my great grandfather's disorder. The third week of my project will be spent discovering the latest techniques in the field through Dykes Library and through online medical journal searches using collections such as Pub Med.

Although many of my methods are aimed at discovering the hard facts for treatment of laryngeal dysfunction, I will also be spending time learning about the more personal aspects of the disorder. This will be accomplished through personal interviews with patients having speech disorders. I also intend to use literary works describing the psychological aspects that are involved.

All of this will prepare me for the second stage of my research. This will involve traveling to Nashville, TN and Alexandria, VA. In Nashville, some of the latest and most innovative techniques are being discovered and attempted.<sup>ii</sup> I plan to spend one week in Nashville at Vanderbilt's Voice Center where they have created a revolutionary pacing technique for individuals with bilateral vocal fold paralysis. There I will immerse myself into one of the nation's leading otolaryngology departments with interviews and shadowing of their physicians and speech pathologists.

Once I have completed a week of research in Nashville, I plan to travel to Alexandria, VA. This is the country's headquarters for the American Academy of Otolaryngology- Head and Neck Surgery Foundation. This location provides a multitude of information including oral collections of major contributors to the field, a historical museum, a library, and archival collections dating back to the 1600's. This will be a fun and interesting way to gain a better understanding of the progress otolaryngology has made. It will also allow me the opportunity to interview the department's director about her knowledge on the subject.

## **Goals:**

My goals can be divided into two categories, the first of which concerns people of vocal inability of the past, particularly in the 20<sup>th</sup> century.

### **Past:**

1. Discover laryngeal patients' ability to complete activities of daily living, work, maintain independence, and communicate effectively.
2. Discover the effect communication disorders have on patients' quality of life.
3. Discover patients' surgical/procedural/assistive options for improving condition/ability to complete ADL's/ quality of life.

The second set of my goals deal mainly with laryngeal dysfunction in present time and otherwise are identical to the first set.

### **Present:**

1. Discover patient's ability to complete activities of daily living, work, maintain independence, and communicate effectively.
2. Discover the effect communication disorders have on patients' quality of life.
3. Discover patients' surgical/procedural/assistive options for improving condition/ability to complete ADL's/ quality of life.

### **Integrated:**

1. Compare and contrast past and present, taking note of major medical advances in otolaryngology's treatment of laryngeal disorders.
2. Discover if the quality of life for these patients has improved within the last century and what still needs to be done in helping to improve it.



## Timeline:

Week 1-3: Complete research at KU's Clendenen Medical History Library

Complete interviews with family members and current patients

Complete a literary review of current treatments/ongoing research

Week 4: Nashville, TN - shadow/interview physicians at the Vanderbilt Voice Center

Week 5-6: Alexandria, VA - review oral collections, library, and historical museum

Week 7: KCK - Integrate research materials/complete project

## Contacts:

### ❖ Kansas City

Dawn McInnis  
Rare Book Librarian  
Clendenen History of Medicine Library  
University of Kansas Medical Center  
MS 1024 3901 Rainbow Blvd  
Kansas City, KS 66160-7311  
(913) 588-7244 PH  
(913) 588-7080 FX

George and Mary Lou  
Young

### ❖ Nashville

Vanderbilt Voice Center  
7302 Medical Center East, South Tower  
1215 21st Avenue South  
Nashville, TN 37232-8783  
Phone: (615) 343-7464 FAX: (615) 343-0872

Barbara and Roger Steveson

### ❖ Alexandria

The John Q. Adams Center for the History of Otolaryngology-Head and Neck Surgery  
AAO-HNS Foundation  
Traci Sullivan: Director of History of Otolaryngology  
One Prince Street  
Alexandria, VA 22314-3357  
Phone: (703) 686-4444 TTY: (703) 519-1585  
Fax: (703) 683-5100

**Budget:**

| <u>Travel<sup>1</sup>:</u> (\$2.35/gal, 25 mpg) | <u>Miles</u> | <u>Cost</u> |
|-------------------------------------------------|--------------|-------------|
| KCK > Olpe, KS > KCK                            | 224          | \$21.06     |
| KCK > Nashville                                 | 567.9        | \$53.38     |
| Nashville > Alexandria > KCK                    | 1772         | \$166.57    |
| <u>Hotel/Accomadations:</u>                     |              |             |
| KCK:                                            |              | \$0.0       |
| Nashville, TN: lodging provided                 |              | \$0.0       |
| Alexandria, VA:                                 | \$75.78/n    | \$1,024.08  |
| (+taxes/fees)                                   |              |             |
| <u>Meals:</u>                                   |              |             |
| Approx. 21 days of travel (\$20/d)              |              | \$420       |
| <u>Research Materials:</u>                      |              |             |
| Article purchasing etc.:                        |              | \$150       |
| <u>Remaining Balance:</u>                       |              | \$164.91    |
| Personal Expenses/ Travel W/in City             |              |             |
| <u>Total Costs:</u>                             |              | \$2000      |

**\*I will assume all costs exceeding the Clendening allowance.**

### **Bibliography:**

- i. <http://travel.travelocity.com/hotel/CheckoutSwitchModule.do>
- ii. <http://www.mc.vanderbilt.edu/reporter/index.html?ID=883>
- iii. <http://www.nichcy.org/pubs/factshe/fs11txt.htm>
- iv. Weir, Neir. *Otolaryngology: An Illustrated History*. 1990. Great Britain: Butterworth and Co. Ltd.
- v. <http://www.mc.vanderbilt.edu/reporter/index.html?ID=2021>



When Death Approaches:  
*Attitudes and Beliefs About End-of-Life Decisions  
from the Perspectives of Major American Religions*

Clendening Fellowship Proposal

Erin Zahradnik

February 20, 2006

## Introduction

In 2005, the case of Terri Schiavo hit the front pages of the newspapers. It was the culmination of years of court battles between Terri's parents and her husband, all over whether or not to remove the vegetative woman's feeding tube, which would inevitably cause her death. This case became, not simply a bitter contention among one family, but a debate that gripped the nation; one in which religious groups, state officials, members of Congress, the President, and even the Vatican were involved. It moved beyond the simple question of what Terri would want, into the realms of morality and religious ethics. Because Terri had no advance directives in place, no one could definitively *know* whether she would wish to live or die in her unfortunate state, and this left her family no option but to make their best guesses.

Unfortunately, similar situations, albeit without the media and government involvement, happen every day around the country. Family members are confronted with having to make end-of-life medical decisions for loved ones who are in medically precarious situations and no longer able to communicate their own desires. Even advance directives such as DNRs (Do Not Resuscitate orders) and living wills cannot cover every single conceivable circumstance. Thus the family members are left in limbo, holding the final say, but often reluctant to make such life-or-death decisions.

Although hospitals do have some resources to help families deal with such decisions (doctors, nurses, social workers), many people choose to turn to trusted advisors, often of a religious nature, for additional advice. Religion is undeniably a major part of the American society, and times of crisis often make it even more important. Death and religion have been bedfellows for most of mankind's history, and in a very spiritual America (81% of American adults identify with a religion<sup>1</sup>), it should be no surprise that end-of-life decisions often heavily involve input from the patient's (or their family's) religion.

Though the medical community in general is hesitant to involve themselves in the religious lives of their patients, it is important for physicians to be aware of the variations in religious traditions when it comes to the matter of end-of-life decisions. In a country of such diversity, it is crucial to understand not only cultural and religious differences among potential patients, but also the reasons for those practices and beliefs. The better that medical practitioners can understand the roots of their patient's beliefs and attitudes towards the most

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<sup>1</sup> Kosmin, Barry and Egon Mayer. "American Religious Identification Survey." The Graduate Center at the City University of New York. 2001. <[http://www.gc.cuny.edu/faculty/research\\_briefs/aris/aris\\_index.htm](http://www.gc.cuny.edu/faculty/research_briefs/aris/aris_index.htm)>.

sensitive of healthcare issues, death and dying, the better they will be able to assist their patients in such situations.

I am very interested in medical ethics and in the intersection of religion with modern healthcare. Because almost all religions deal so intimately with suffering and death, it is no surprise that the act of dying can bring even mildly religious people to seek out spiritual advice. It is therefore absolutely necessary to make sure patients have full access to their spiritual advisors, and to take the guidelines laid out by that particular religion very seriously. My project will create a concise and comprehensive resource for healthcare providers in such situations, so that they will be familiar with many religious end-of-life guidelines they might encounter, the reasons behind them, and what sort of accommodations might be needed for the patient.

### **Proposal**

To start off my project, I will attend Georgetown's Kennedy Institute of Ethics summer Intensive Bioethics Course from June 6-11 in Washington, DC. This course is a thorough introduction to the field of bioethics, and includes lectures, panel discussions, and small group discussions centered around current issues in medical ethics, with opportunities for discussion in more specific topics, including end-of-life decisions. It is taught by national experts in bioethics. This course will give me a solid foundation in the methodology of bioethical principles, exposure to different ideas and approaches in the field of medical ethics, and access to a wealth of resources through the Kennedy Institute's National Reference Center for Bioethics Literature, which harbors the world's largest collection of bioethics resources.

The rest of my project will focus more specifically on the interaction of major American religions and end-of-life ethics. I will concentrate on several current issues in end-of-life decisions, not only for their importance to medical practitioners, but also because they elicit a multitude of widely-varying stances among the major American religions. The issues will include DNRs, the withdrawal of life support (including removing ventilators and feeding tubes), and human tissue donation/transplantation (mainly organ donation and blood transfusion).

I would love to research this subject amongst all of the religions practiced in America, but such a venture far exceeds the timeframe of a summer project. Therefore, my



research will focus on major American religions, by which I mean those that are practiced by the majority of Americans (as determined by poll data<sup>2</sup>). These will include:

- Christianity
  - o Catholicism
  - o Mainline Protestantism (Presbyterian, Methodist, Lutheran, Baptist)
  - o Church of Jesus Christ of Latter-day Saints (Mormon)
  - o Pentecostal/Evangelical/Fundamentalist (this group includes many technically separate branches, but all have similar social views, and are evolving along a theologically similar path)
  - o Jehovah's Witnesses<sup>3</sup>
- Judaism<sup>4</sup>
  - o Orthodox
  - o Conservative
- Islam

My project will focus on understanding:

- 1) each of the religions' views on the aforementioned end-of-life medical decisions, and
- 2) the theological basis of those views.

As a side note, although euthanasia is undoubtedly a hot button issue in medical ethics, I am not including it in my project because virtually every religion is against it for the same reason (variations on 'thou shalt not kill,' which includes suicide). Physician-assisted suicide will also not be included for similar reasons (again, suicide is universally decried in the religions I am focusing on).

I have a strong background in the study of religion due to extensive classwork and a religion independent study project while I was an undergraduate at the University of Rochester. Therefore, I already have a good working knowledge of the major religions I am

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<sup>2</sup> Kosmin, Barry and Egon Mayer. "American Religious Identification Survey." The Graduate Center at the City University of New York. 2001. <[http://www.gc.cuny.edu/faculty/research\\_briefs/aris/aris\\_index.htm](http://www.gc.cuny.edu/faculty/research_briefs/aris/aris_index.htm)>.

<sup>3</sup> The one exception to the majority rule will be Jehovah's Witnesses, because of their unique and important view on blood transfusion even in lieu of life-threatening circumstances.

<sup>4</sup> I am not including Reform Judaism, due to its emphasis on individual choice (not necessarily based on religious doctrine) in regards to ethics.

planning to focus on, although more in-depth study on their particular medical ethics views will certainly be necessary.

## **Methods**

I will use written or transcribed official sources for garnering information on end-of-life directives from the various religions, because I am seeking to gather standardized information from each religion, thereby eliminating the factor of individual biases. Even in variations between practitioners, there is a core set of beliefs and guidelines, off of which each practitioner will base his or her opinion, and it is this core that I wish to understand.

Although I do believe I need to use reproducible sources for the end-of-life directive information, I will consult with clergy, theology scholars, and/or church members on the theological aspect of my research. I feel that it is very important for me, as an objective researcher, to avoid potential misinterpretations or misconstruals of various theologies. I currently have contacts, either in the Kansas City area, or elsewhere through email, with knowledgeable persons from all of the religions I will research.

## **Goals**

- To focus on the following American religions: Christianity (mainline Protestant, Catholic, Pentecostal/Evangelical/Fundamentalist, Mormon, Jehovah's Witness), Judaism (Orthodox, Conservative), and Islam.
- To research the above religions and find out their guidelines on end-of-life directives, as stated in official sources.
  - o The end-of-life directives will include DNRs, withdrawal of life support, and life-saving human tissue donation/reception.
  - o This will also include specific definitions of what constitutes death according to the religion.
- To discover the reasons behind those guidelines, be they scriptural interpretations, statements by religious leaders, or evolving theological doctrine.

- To gain an overall understanding of bioethics methodology and implementation, with special focus on end-of-life medical ethics.

### Budget

|                                                                            |                 |
|----------------------------------------------------------------------------|-----------------|
| Kennedy Institute Bioethics course (student rate)                          | \$ 850          |
| Roundtrip flight from Kansas City to Washington, DC (Reagan Int'l Airport) | \$ 204          |
| Lodging in DC (with family)                                                | Free            |
| Food/misc expenses in DC                                                   | \$ 150          |
| Rent in Kansas City (two months)                                           | \$1200          |
| Food/gas/misc expenses in KC                                               | \$ 400          |
|                                                                            |                 |
| <b>Total:</b>                                                              | <b>\$2804</b>   |
| <b>Clendenning Fellowship</b>                                              | <b>- \$2000</b> |
| <b>Out-of-pocket expenses</b>                                              | <b>\$ 804</b>   |



### Sample of Projected Bibliography

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  - o Catechism of the Catholic Church: Revised in Accordance With the Official Latin Text Promulgated by Pope John II. U.S. Catholic Church. 2<sup>nd</sup> ed. Our Sunday Visitor, 2000.
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  - o "Right to Live and Right to Die." Interfaith Symposium of Islamic Medical Association. Houston, TX. Nov. 1987.