

Reflections

Voices of Hope in Our Community



Indiana University School of Medicine
2008 - 2009

*Hope is the thing with feathers
That perches in the soul,
And sings the tune without the words,
And never stops at all.
~Emily Dickinson*

Cover Art
Butterflies and Houses
Joani Rothenberg

This piece was created after the artist was diagnosed with BRCA2- a genetic mutation that causes an increased susceptibility to certain types of cancers, most notably breast and ovarian.

This painting embodies hope in our community by depicting floating butterflies as symbols of rebirth and freedom.

Note from the Editorial Board 2008-2009

Reflections: Voices of Hope in Our Community is a collection of literary and artistic works by members of the healthcare community at Indiana University School of Medicine and Clarian Health Partners. This volume is the fifth in a series that began in 2004 out of a partnership between the IU School of Medicine Relationship Centered Care Initiative (RCCI) and the Dean's Office of Medical Education and Curricular Affairs (MECA). It is a gift to incoming students from the rising second year class and provides an introduction to the community they are joining.

The poems, essays, photos, journal entries, and other creative pieces represent the work of health professionals, students and faculty as well as, patients, patient families, and friends. It is our hope that this art will provide opportunities to witness and understand each others' ordeals and victories, improve our capacity for empathy and professionalism, and foster dialogue about the quality of relationships and medical care to which our community aspires. Our thanks to those who shared their experiences in this collection.



INDIANA UNIVERSITY
SCHOOL OF MEDICINE

Foreword

“Garlands”

Years ago, when my wife Nancy and I traveled to Bali, Indonesia, we were looking forward eagerly to participating in the International Clinical Epidemiology Network program, seeing friends and colleagues from many other universities, and having our first glimpse of that storied island. We knew Bali to be a world destination for tourism, one of the larger islands in the Indonesian archipelago, and a land made famous in the West by the work of Dutch artists who documented the beauty of its nature, people, and folkways.

The meeting lived up to our expectations, but the few days we remained on Bali after the meeting are more vividly anchored in my memory. On those days we traveled inland, away from the coast, to a bungalow in the small town of Ubud. Unlike the five-star hotel used for the INCLEN meeting, Mrs. Oka Kartini’s compound was unostentatious and close to village life. It accommodated a workshop where many young women came to sell their hair while others crafted the wigs, an arts display and sales area, and rooms for tourists that encircled an inner garden and small pool. Its location assured easy access to the traditional dances performed nightly throughout Ubud that recreated the history and myths of the Balinese people to the exotic music of the gamelan - a percussion, flute, gong, bamboo chime, and stringed instrument orchestra unique to Indonesia.

During the day we visited the marketplaces. Tightly clustered fruit stands with exotic offerings (snake fruit, dragon fruit, mangosteens), cotton sarong stalls, poultry sellers, and wood carvers dominated these markets, and flowers were for sale in wild profusion. Among the flowers,

we grew especially curious about the small tightly woven garlands of tiny blossoms sold on strings that people carried away from the market for purposes we couldn't at first discern. Later, we were told that these garlands would be placed in sacred locations by the Balinese as they returned to their homes by night after the torch-light dances.

We slept late our first morning in Ubud, lulled into napping by the soft air and quiet of Oka Kartini's bungalow. When we opened our door, a basket of fruit was there for breakfast, together with a now-cool pot of tea. There was also one garland on the step - a decoration, we thought, for the foreign guest to enjoy. After fruit and tea we ventured out of the compound onto the street in mid-morning and began to notice other locations marked by the flower garlands. Various street corner curbs, a public telephone, many household entryways, certain street signs, a policeman's station, a taxi cab stop, and still more - Were such ordinary, everyday, undistinguished places all sacred!? As we spent our too-few days in Ubud, leaned into the life of the place, and watched people more closely, we began to understand. Even in the bustle of the village, life does sanctify the ordinary. The sacred emerges in the midst of our living, in our interactions with one another, and in the blessings we experience in the daily round of work. This kind of emergence occurs, of course, not only in Bali but also in Indy.

The volume you have in your hands is a string of garlands laid in special places by members of the community of IUSM. They are brought to us by the efforts of those who created, juried, edited, and now disseminate them for your reflection and enjoyment. Think of these contributions as markers of what is sacred in our community. See what blossoms have landed on your front step.

Tom Inui, MD

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Before You
Christie Taylor

Christie Taylor is a parent involved in the Indiana Down Syndrome Foundation, a group that serves as a conduit for information, support, and advocacy for individuals with Down Syndrome and their families. She has submitted this poem in dedication to her son Joseph.

Before I knew you
I never knew what I was missing
I never knew love could be so pure
I never knew rolling over would make me cry

Before I saw your face
I never realized the beauty I was missing
I never realized how precious motherhood truly is
I never realized how my heart would swell in my
throat when you cry

I was a mother once before you
But I was missing something
I think back now and wonder what your brother did
And what I shorted myself on during his infant years

Before you, a doctor never said, "I'm sorry"
Before you, a stranger never said, "I'm sorry"
Before you, those I thought were friends never said,
"I'm sorry"
Before you, I never felt sorry for all of them

Before you I never knew what I was missing
Before you I was not a bad person or bad mommy
but...
I am a better person for the time that has come since
you came to me.

For my sweet Joseph, you have taught your mommy
so very much and I love you all the more for it.

Christie Taylor
March 7, 2008



Anything

Nirav H. Shah, Student - Class of 2011
Indiana University School of Medicine

I was walking down the very same street as the Arc de Triomphe in Paris when I saw her praying steadfastly among waves of pedestrians. Silent and motionless she begged, prayed, and hoped for any charity. I refused to stop, gawk, and point a camera at her, so I composed from the hip. I had one chance as I walked by, and half a second later I receded into the crowd.

When I take a photo like this I find myself caught in a binary of selfishness and sympathy, because I am not an objective observer simply looking for Aesthetics as much as I would wish to be.



Leaves– IU Cancer Mosaic Collaborative

This mosaic depicts the falling leaves of autumn, changing colors with the turning of the seasons. The seasonal changes can serve as a beacon of hope, since every spring the trees bud and leaves regrow. An old Zen proverb tells that “sitting quietly, doing nothing, spring comes, the grass grows by its self.”

About the Mosaics:

The mosaics reproduced throughout this publication are the result of the Cancer Mosaic Collaborative, an initiative of the Indiana University Cancer Center. The Collaborative provides facilitated workshops during which people affected by cancer gather, share their stories, and transform their collective stories into a piece of art. The Cancer Mosaic Collaborative was established by Dr. Larry D. Cripe of the IU Simon Cancer Center as well as the Founding Director of the CompleteLife Program, Liza Hyatt, a local mosaic artist, and John and Tina Gianfagna of Creating Hope.

Not With Skill Alone

Gordon W. Burton, Staff Chaplain
Methodist Hospital, Clarian Health Partners

Brick and mortar
steel and glass
buildings rise to become
houses of healing,
filled with all manner of device,
scans
and probes,
unheard of not long ago,
obsolete only too soon.
The digital frontier pushed
far past the limit.

Yet,
for all this,
these are worthless,
less than so,
save when touched
by hands
of those skilled,
and more
by lives
Caring,
Concerned,
Open,
Giving.

Herein is the true gift of medicine,
human kindness
honed to a scalpel's edge,
touching Body
 Mind
 Spirit
not with skill alone
but with the depth of
heart
 and soul.

Silent Struggle

Sharon Emeghebo, Student - Class of 2010
Indiana University School of Medicine

The following piece is a third-year medical student's reflection on what she learned from a domestic violence intersession conducted prior to starting her family medicine clerkship.

People can be such great actors in this life- act as if life is perfect- when in fact turmoil and hurt is hidden behind closed doors. Others must be very sensitive to the internal messages and unconscious emotions that are subtly reflected from people who have been physically, emotionally, or mentally hurt. Not only must we be sensitive, but we must offer comfort, reassurance and safety in addition to medical care. In time you will learn ways to approach a patient who may possibly have been abused or is in an abusive relationship.

Patients must feel trust and comfort in their physician, as if they were talking to their best friend, to reveal such a deep, personal matter. Communication and empathy is an art of medicine and is crucial to the health of abused patients. My eyes have been opened to the various ways in which people can be abused and how I can possibly bring hope to them out of a harmful, potentially deadly situation. Family violence can be so subtle yet the effects on the victim can be deep and cutting.



Shattered Lives

The Julian Center

This mosaic was created by two residents as part of a service learning project at the Julian Center. The Center is a nonprofit agency providing counseling, safe shelter, and education for survivors of domestic violence, sexual assault, and other life crises.

Through their activities, The Julian Center hopes to provide these survivors with a better life to return to once they leave the Center's care.

This mosaic, like the art therapy projects that women at the Julian Center undertake, represents the reforming of lives shattered by domestic violence. In the mosaic, one can see a woman holding a child with a stethoscope intertwined, much like the interrelated natures of the IU School of Medicine and the Julian Center.

Introduction to “Mindfulness in Medicine”:

*A column
from the Relationship-Centered Care Initiative*

The following five selections have been taken from the Mindfulness in Medicine (M&M) column, which runs bi-weekly in the SCOPE newsletter. M&M was created as part of an effort to stimulate conversations about our campus environment. The purpose of this column is to engage our medical school community in discussion and reflection about our learning and working culture, which can be considered an informal curriculum operating in tandem with the formal curriculum.

Each column features real stories, letters, poetry or art from members of our campus community, similar to other pieces found in this publication. Some content speaks for itself; in some instances commentary from one of our professional colleagues will be included. M&M stories and material acknowledge our challenges and also highlight laudable ethical and professional behaviors in the face of these challenges. It is hoped the M&M stories will alternately entertain, inspire, stimulate reflection and conversation, and call attention to compassionate and humanistic achievements. In the words of Ronald Epstein, MD, Director of the Rochester Center to Improve Communication in Health Care, “Critical self-reflection enables professionals to listen attentively to others’ distress, recognize their errors, refine their technical skills, make evidence-based decisions, and clarify their values so that they can act with compassion, technical competence, presence and insight.” (JAMA. 1999; 282: 833-839).

M&M: Mindfulness in Medicine is an editorial collaboration among the Teacher-Learner Advocacy Committee (TLAC), the Relationship-Centered Care Initiative (RCCI), and the Office for Medical Education and Curricular Affairs (MECA). M&M welcomes submissions via email to meca@iupui.edu – please include “Mindfulness in Medicine” in the headline. To view more M&M columns, visit <http://meca.iusm.iu.edu/Resources/M&M.htm>

-The Editorial Staff

M&M Submission: A New Normal

published 12/15/06

(Excerpt from a letter to a Riley physician.)

Doctor,

Thanks again for all the wonderful care you gave to (our child) the past 5 years. You not only took care of her but also took care of us. We feel that we received exceptional care from you and the rest of the GI team.

I was deeply saddened to hear of the death of (another child). I'm sure the family feels the same way that we do about the exceptional care they received. I don't know how losing two of your transplant kids in the past 3 weeks affects you, but I just wanted to let you know that we know, and I'm sure the (other) family knows, that you gave 110 percent to each of the children and we are very grateful.

We will miss our trips to Riley. We did enjoy them and seeing all of you. It was like seeing a good friend you hadn't seen in quite some time, and even though it didn't seem like it, (our child) enjoyed seeing you also. We are doing O.K. We are learning a new "normal." Each day something slams you in the gut and reminds you "I can't do that anymore because my little girl isn't here anymore." I'm sure that as time goes by we will heal, but for right now we cry quite frequently. I've been told this is good for the healing process.

Thanks again for all you did for us. You are an extraordinary doctor with a very compassionate heart and please don't ever let that change.

Sincerely,

(A Riley Mother)

**Response to A New Normal:
“A Professional’s Goodbye and Thanks”**

I thank the children
For showing me how to best help them,
For leading the way,
For teaching me how to listen to their real needs,
For helping me gain the courage and the strength of
heart
That alone can see clearly from here to there.
For helping me live more and more
by the love and light of life
So that we would not turn away from what was difficult
to face or bear,
But continue on together,
Sharing the treasures of heart
Which allow burdens to be carried more lightly,
Fears to fade in the dawn of inner knowing,
The heart itself to be uplifted from outer
sorrow to inner peace.
I thank the parents
For sharing their children with me,
For sharing their own hearts with me
As we walked through the fire together,
For teaching me how to survive and to gain
inner strength from personal crisis,
For mounting the courage to take the children home
whenever that was appropriate –
Even if the move was a step into the unknown.
For loving their children selflessly enough
to set them free when that was needed

[A poem by Lee Horsman from *Wounded Healers*]

M&M Submission: Learning Early

published 5/26/06

The following story was shared by a first-year medical student at IUSM-Northwest. The response was written by Pat Bankston, PhD, assistant dean and director, IUSM-Northwest, and professor of anatomy and cell biology and pathology.

Student's experience: This program concentrates on patient-centered learning, so I had begun my history-taking training already, while also studying the intricacies of gross anatomy, embryology and histology in the classroom. My preceptor told me this was a chance to try out my new skills and asked if I would go see the patient in room 3. Trying to look calm, I was actually in a state of panic at the prospect of interviewing a real patient this early in medical school.

The patient complained about the remnants of a recent cold and some esophageal reflux. Because I was studying the heart for my upcoming exam, I had learned that heart problems in women often presented with different symptoms than men, and heart pain could feel like the pain of esophageal reflux. As I interviewed her, I noticed that, even though she said the pain was localized, her hand movements described a more radiating pain. She said the pain was intermittent at first, but had become constant in the past several weeks. When the doctor came into the room, I told her about the patient's cold and esophageal reflux pain and mentioned my concerns about her heart.

The doctor ordered an immediate EKG. After comparing the new EKG to an older one in the chart, with a clearly surprised glance in my direction, she and I returned to the patient's room. My preceptor informed

the patient that despite the probability that her cold and esophageal reflux were the cause of her symptoms, some new findings about her heart required her to get it checked out right away. As we left the room, the preceptor told me that she would not have expected a first-year student to pick up on a possible underlying heart issue with this patient and that I had done a great job. It was then that I was reminded that the books and exams are preparations for these kinds of interactions with patients. So I took a deep breath and was thankful for this first moment that helped me refocus on why I'm here in medical school.

Response to Learning Early:

I heard this story in the histology lab the next morning, while we were reviewing slides of the myocardium for the upcoming exam. I was very gratified. We spend a lot of time, money and effort to provide students with history and physical examination training, with standardized patients and preceptor visits, starting on day one of our curriculum. We believe that when students begin their professional training in all aspects of being a physician early, it helps them understand the need for hard work in the classroom for the sake of being the best doctor they can be for their patients. Our problem-based learning curriculum, which uses case studies in basic science classes every other day for two years, makes it clear to students that what they are learning has relevance to their future care of patients. This student's experience, which reminded her of her ultimate goal in patient care, is our reward for designing and implementing this innovative approach to our student's training. Even more importantly, it might have saved a patient's life.

M&M Submission: The Littlest Patient

published 11/28/05

The letter below was written by parents to their child's physician at Riley Hospital.

First, we want to tell you a story. We first met when you wanted to do an assessment of our son during rounds. He was about four weeks old at the time and still only about 1 ½ pounds. When you began your examination, you did something no other doctor, nurse or respiratory therapist had done - you *spoke* to our son as if he were a healthy, normal-delivery newborn. You called him by his name and sympathized with him like people do when trying to calm a child.

Later that night, we went home and cried. Not out of sadness, but out of gratitude, appreciation, and hope. For the first time, someone who fully comprehended the severity of our son's situation had treated him like he was a real person and not just a small fetus in an incubator.

We also want to tell you something about our past. Both of us started undergraduate courses as pre-meds. One of us actually took the MCAT, was accepted to medical school and completed the second year. We both tell people we couldn't stand the sight of blood, but that isn't the real reason. The truth is that we both became disillusioned with the people in medicine. We both wanted to help and care for people.

The medical profession seemed to be reduced to people who made decisions about peoples' lives based on risk-assessment and statistical probability, something like a computer. The medical emphasis seemed to treat the patient's body, rather than the patient as a whole. The profession seemed to work too much like a business, maximizing profits at the expense of care. Whether or not these impressions were accurate or fair, they barred our entrance to the field.

The last place we would have expected to learn that truly great doctors still do treat the patient as a whole – and the place we needed it the most – was in the Riley NICU. You treated our son like a person, not just a case. You treated our family like an important piece of his health, not as annoying individuals who had to be updated. Your care was influenced by our son's individual situation and not just by some blind risk assessment.

You might think this is simply what you do as a routine part of your job, but your love for our son and compassion for our family is why we think you are the most exceptional doctor we have ever met.

M&M Submission: Who saves a life?

Published 8/25/06

The following story was shared by a nurse at Indiana University Hospital.

A nurse reported: Once there was a patient in my care who rather suddenly had a major GI bleed. This problem called for the immediate collaboration of everyone and to my relief, that is exactly what happened. Nurses, physicians, bed control staff, ICU staff, administrative assistants, and others all worked together like clockwork. I approached a resident on the unit and said “I need you!” The urgency in my voice resulted in an immediate response from the resident – and more. It was a systems approach. The patient stabilized, recovered and was discharged. Months later, he came back to the unit and asked “to see the nurse who saved his life.” I was so touched to be recognized in this way, but I couldn’t take the credit. If *anyone* had not done his or her job, this patient would not have lived. We are all ordinary people doing the extraordinary – together.

Partnerships are at the core of excellent health-care delivery. The depth of our resourcefulness is properly gauged by assessing the strength and diversity of the community of others who are ready to act in concert for a common purpose.

M&M Submission: *Post-Tribune of Northwest Indiana Letter*

On January 25, 2008, a remarkable commemoration event happened on the campus of Indiana University School of Medicine-Northwest, in Gary . First-year students, their second-year peers, and several professors had gathered in the gross anatomy lab to pay their respects to those who had “given their bodies to science” and become the cadavers these students had systematically dissected as a part of their training.

In most schools, cadavers remain anonymous. Students learn no more about them than what they discover through dissection. At IUN, however, students know names and a few details of personal history. Even more unusually, when they come to the end of their time with cadavers, the students invite family and friends of their deceased subjects to a “Service of Thanksgiving and Remembrance.”

One of my colleagues helps plan and conduct this annual commemoration, and I've sometimes thought of tagging along. This year, however, more than curiosity beckoned. An old friend was among the cadavers. I had performed his wedding ceremony some years back, and more recently assisted with his funeral. To my surprise, this latest rite of passage proved as profound as those that preceded. I'm still pondering why.

Within moments of arriving, I noted clues pointing to meaningful relationships between the medical students and the individuals we'd gathered to commemorate. I asked the two students assigned to welcome guests whether they had “worked on” my friend David. “No,” they answered. “We took care of Florence.”

continued on next page...

Of course, I thought. That's what doctors do. They don't merely work on people. They take care of them. Whatever other roles they play, cadavers remain people, and worthy of care.

The longer we remained in the laboratory, the more I understood how complex these caring relationships can become. They could never know David's wit or Florence's voice, but these students had a remarkably intimate relationship with the individuals for whom they cared. They came to know their bodies better than those of the children they may have some day, the ones they will bathe, diaper, hold, and nurse; better in some ways than the lovers with whom they will lie skin to skin; better even than their own, living bodies, the internal mysteries of which they will never see.

Something of this deep knowing permeated the grammar and syntax by which the students attempted to express deep gratitude for what they had learned from these "first patients," and for all this would mean in their eventual practice of healing. Over and over, they said, "Thank you," trying to make those simple words convey all that filled their hearts. Several supplemented words with music. Many gently salted their words with tears.

We stood that day on holy ground, lingering at the border between life and death and pondering the mystery of dead folks still gifting the living with extraordinary generosity. In the end, the simplest but greatest gift any of us can ever give is our flesh and blood. That's all a frightened child needs. It's the most anyone can truthfully promise a spouse. Even the grief-stricken benefit from our presence much more than our words.

Those soon-to-be doctors who let us eavesdrop on their sacred moment clearly understood this. David, Florence, and the others had helped to teach them anatomy, but they'd given them so much more. It seemed clear that those young men and women in lab coats would never forget the silent teachers they'd gathered to honor, and regardless of how difficult and complex the study and practice of medicine might become for any of them, deep down, it will always remain care-giving. And their way of gifting others with themselves.

Fred Niedner
Chair, Department of Theology
Valparaiso University

Indexes

Sanjay Mohanty, Student - Class of 2011
Indiana University School of Medicine

I.

On our first day with patients,
We stood around dissection tables
Presenting black body bags
Smelling faintly of olives in brine.
Our lab manual detailed
Preparation, washing, & observation of cadavers,
But neglected talk of human beings,
Their final warm baths, clenched limbs,
And birthmarks clustered on a buttock.

II.

Jeremiah found the tubs & began the inventory
Of instruments that would, for two hours,
Wash & trace the temperature & shape of absence:
A razor, paper towels, sponges,
And plastic trays of warm soap & water.
They forestalled for us the use of
Less intimate, more decisive instruments
Which would give sound & sensation to the anat-
omy of human layers:
Scalpels, blunt probes, & Stryker bone saws.

III.

For some time after the body bags
Had been discarded,
I do not remember how long,

We did our best to seem unfazed by a black toenail
And the earnestness accompanying a nude.

IV.

In the white, plastic donor bucket on the floor,
Body hair & flecks of skin gathered.

V.

Before leaving, we preserved the limbs & head.
Recreating haltingly, two of us on either side
lifting a frigid torso,
Our eyes momentarily meeting,
We wrapped with wet gauze & garbage bags,
And without discussing the order of things,
Finished with the face.

In April, Dr. Morgan told us, the contents of the
donor bucket
Would be turned to ashes & given to the family.

VI.

I think of a human pieces index:
A tooth, intermediate filaments, ossicles, eye
lashes--
Scattered onto Southern Indiana treetops from an
aeroplane.

Hope

Jeff Rothenberg, MD

Indiana University School of Medicine

Hope is an instinct, an insistent human reflex in the face of negativism and despair. Hope floats. Hope is the opposite of fear. Hope heals. Hope is universal. Hope is truth. Hope is healthy. Hope is vital. Hope is a girl's name. I hope to get some sleep tonight. I hope my son is happy. Hope is humanity. Hope springs eternal. I hope to deliver a baby. Hope for the best. Hopefully or hope fully. Hope is a four letter word. Hope never dies. Hope is hop with an e Hope is essential for health. Hope for world peace. Hope never dies. Create life. Create hope. Hope is wonderful. Hope is infectious Hope is healthy. Hope defies reason. Hope for a better tomorrow. The opposite of hope is fear. Hope breeds enlightenment. Hope without limits is fool hearty. Hope must not be taken for granted. Hope for change. Hope for stability. Never hope blindly. Hope is a personal prayer. Hope creates more hope. Hope for a miracle. Never hope for something bad. Hope creates optimism. Hope burns bright in the darkness. Always give hope; sometimes it is the only thing that we can give to another. Hope without boundaries is meaningless. I hope that I pass the third year. Cape of Good Hope. Hope is the name of the Israeli national anthem. Hope is in each and every one of us. Hope defines who I am. Faith and hope are siblings. Hope for equality. The audacity of hope. The cost of hope. Doctors' have a delicate balance in keeping hope alive. Finding hope in knowing the universal capacity for evil is sometimes difficult. A world without god is a world without hope. Hope lost is a recipe for disaster. Bob Hope. Screening for abnormal embryos offer couples hope after heartbreak. A future full of hope is bright. Hope and glory. Gas keeps going up and up with little hope of relief. Cross my heart and hope to die... Doctors operate where risk, choice and

hope converge. Be a beacon of hope. Optimists hope while pessimists perishes. Faith, hope and love say it all. I hope to god that... I hope this is finished soon. I hope that I don't hurt any patients. Never hope before trying to understand. Hope implies a certain amount of despair. Hope college. H.O.P.E.-hackers on planet earth. Even when lying in the gutter, hope to see the stars. Learn from yesterday, live for today, hope for tomorrow. Hope is the most exciting emotion in life. Hope never abandons us, we abandon hope. Hope is the dream of a soul awake. Dum spiro, spero. Hope is to the soul what water and oxygen are to life. Live inside the hope you create and you will be happy. Hope is essential to being a caring physician. Never hope for evil to befall someone, it has a way of collapsing around you. Hope is passion. Hope is like a flashlight—it helps when things are dark. I hope to live up to my full potential. I hope I don't disappoint my parents. I hope for winning lottery numbers. I hope that people will treat me with respect. I hope that I don't make a mistake. Never, ever hope that harm will befall another—you may not be able to afford the interest. Hope is a wish to get something to happen. Hope is a confident desire. Hope is trust. Hope is the expectation that life will get better. I hope to be the best doctor that I can be and make the world a better place. I hope this is the end.

Distress to Soaring

Rev. Karen Estle

Wishard Health Services

A sudden bad diagnosis
Thought it was pneumonia
But lung cancer already spread
Anxiety overwhelming.

Radiation therapy started for her brain mets
She hopes to return to work soon
But her prognosis is very poor
Respirations continue to be a problem.

A strong connection made with the chaplain.
Doesn't know God well but hopes to learn
Guided imagery calms her as she clutches my hand
She chooses to think of being in an airplane

As she soars among the big fluffy clouds
Listening carefully to her navigator
Her breathing becomes easy, steady.
She was able to return to her comfortable place

Many times in the next few weeks
Once in the shock room
The sound of her navigator's voice
Helped her calm down immediately

She asked her son, "Am I dying?"
Her physician asked why she had asked.
She replied, "I can feel it."
What does death feel like?
How does one relax feeling death?

Feeling death brings anxiety.
Radiation was not helping, cancer progressing
Home with hospice to her son's
In preparation for her death.

The guided imagery helped her manage
The doctors were surprised to discover
Tattoos of an airplane and clouds on her abdomen
She had all she needed for this journey after all.

In memory of Ms. Deborah Jenson
July 18, 2007
Rev. Karen Estle

Why I Love Being a Palliative Care Nurse

Jo Groves, RN MS

Clarian Health Partners

I believe there are two great privileges in nursing. The first is seeing babies born because in my value set, that is God's assurance that He wants us to go on. The second is being able to assist terminally ill patients in their transition from life here to the better place that lies beyond. For the last nine years I have been working with Palliative Care patients and they have taught me these valuable life lessons:

- ◆ There are worse things than dying- Physical, mental and spiritual suffering to mention a few.
- ◆ Patients give me more than I give them.
- ◆ It's all about relationships, not possessions or what you are able to do or have.
- ◆ You die like you live.
- ◆ The importance of being connected, utilizing every opportunity for relationship.
- ◆ Dying patients have taught me how to live.
- ◆ God has increased my capacity and ability to love, even in the face of my sadness due to my patients dying.
- ◆ I have been blessed to be able to do my ministry right where I work.
- ◆ There is something great, wonderful and fragile about every person.
- ◆ You make a difference in this world one person at a time.

Kenyan Heroes

John Sidle, MD

Introduction by Matt Gentry

Introduction

Late in 2007, a controversial election in the African country of Kenya threatened to disrupt the actions of The Academic Model for the Prevention and Treatment of HIV (AMPATH), Kenya's most comprehensive initiative to combat HIV and one of the cornerstones of the IU-Kenya partnership. Fallout from the elections led to violence between native ethnic groups. In the western province of Rift Valley, violence was particularly intense between Kikuyu and Kalenjin peoples and resulted in thousands of displaced citizens forced to reside in Internally Displaced Persons (IDP) camps.



Children outside a patient shelter at the Burnt Forest IDP Camp

(Introduction cont.)

Many forced to flee were patients of the AMPATH clinic in Rift Valley's city of Burnt Forest. Clinic workers were faced with the daunting task of locating patients requiring medical care in widely scattered camps that housed potentially hostile residents.

John Sidle returned to the area in January 2008 amidst continued unrest to help the Burnt Forest clinic with operations. He was able to relay back to us the stories of the true heroes working at the Burnt Forest AMPATH clinic. It has been said before that heroes are ordinary people that have accomplished extraordinary things. These pieces are placed throughout this year's Reflections to profile the members of our medical community who have, through their selfless acts of courage and dedication, provided hope to the patients they so dutifully serve.

KENYAN HERO – HOSEA SOME

Hosea Some is the clinical officer in charge of the Burnt Forest clinic. He is a strong community leader who directs our AMPATH clinic and also heads a program to provide food to orphans and vulnerable children in the area. Despite his strong community connections, people tried to burn down his house (thankfully averted by the police) and he was accosted by one patient in the IDP camps who accused him of being responsible for her own home being burned. Hosea is personally responsible for the success of all the Burnt Forest activities over the last month. He has worked with other health centers to create a network of satellite clinics. He has fearlessly entered camps where other Kalenjins fear to go. He has worked with

community health workers to notify patients where to go for drugs, and he has gone miles out of his way to deliver drugs to patients who could not access care. He has provided non-partisan leadership to the other staff to try to heal divisions that might exist. He has gone out of his way to arrange armed protection for other staff who were going to sites, even when he himself was taking greater risks. His dedication to his community and to our patients is inspiring. I asked him once if he feared moving around to all the IDP sites, and he told me “I will be OK. Our patients are more important. This place needs healing.” When I asked him to go on leave for a much-needed rest, he refused to take more than 2 days off, saying, “I’ll rest when this is over. Right now we are all needed.”



Hosea Some delivers medications to patients in IDP camps

Lesson #1

Selyne Samuel, Student Class of 2011
Indiana University School of Medicine

The baby sits quietly on the sofa until he sees a mysterious red object under the table. Giggling with excitement he turns onto his stomach and slides down the sofa, landing on his diaper-cushioned derriere. He starts to walk, a walk that closely resembles a waddle. Moving from side to side, he tentatively places each foot on the floor, pausing slightly to check his balance- all the while never taking his eyes off the object.

Big Sis sees him and knowing he is going to try to eat the object; she moves it and places it on the table. He furrows his brow in disapproval, but nonetheless he is not deterred. He turns around and notices grandpa's cane in the corner. With the cane in hand he returns to the table. Using the cane he begins to move the object, and just when it was within his reach, big sister yells "No, no, no" as she grabs it.

This time around she intends to make sure he can't get it, so she places it on the dining table. Big Sis then turns around, picks up the baby and returns him to his former position on the sofa. Moving to the edge of the sofa, he is filled with fascination and continues to study the object. Big Sis feeling that she has succeeded in keeping the object away from baby brother skips merrily to the backyard to help grandpa with the gardening.

Several minutes later, with lightening speed that can only be displayed by a 15 month old, he slides off the sofa and waddles to the dining table. He stares at the object then turns around and waddles. He walks towards grandpa's cane, grabs it, and walks back to the table. He leans the cane against the table and begins to climb onto the dining chair. Once on the chair he grabs the cane, and uses it to move the object from the center of the table to the edge.

Many minutes later, Big Sis runs back in to get grandpa a glass of cold water from the kitchen. She notices grandpa's cane on the floor and the object is no longer on the dining table. Exasperated, she calls out to her baby brother but doesn't get an answer. Walking towards the sofa she sees her baby brother sleeping soundly. Lodged firmly in his little arms is the big red ball that had captured his attention for the past 20 minutes.

Lesson #1: No matter the obstacles, if you have your eyes set on something, as long as the resources are available, seek to attain your desire, never give up.

KENYAN HERO – VERONICA WAWERU



Veronica Waweru is our head nurse for the clinic. She lives in Burnt Forest. While she remained physically safe, her home was insecure and the homes of some of her family members were destroyed. Many nights she could not sleep because of new unrest within the town, the sound of gunshots, or reports of gangs nearby.

Despite this, Veronica refused to leave the clinic. She came every day to the clinic from the day after elections until the second week of February (when we literally forced her to take a week off) and waited for patients to come for care. She was determined that no patient would arrive at the clinic without receiving drugs or care. Even when roads were unsafe and other staff could not come, Veronica doggedly manned the clinic, often working alone to assess patients and provide renewal medication. Because of her efforts, the clinic did not close for even one weekday throughout the entire crisis.

On My Way to Yoga Practice

Frances Brahma, MLS PhD
Indiana University School of Medicine

Sobbing
And shaking her head No
She sat in front of University Hospital
Her face contorted
Head bowed, her long stringy hair
Hung wet with tears.

When I came up to her
And asked her what was wrong
What I could do
She said:
I can't lose her
I can't lose another one.

I offered her a drink of water
She kept weeping

I reached out and put my arms around her
And as she leaned into me
The dam broke and like a flash flood
Her pain came pouring out.
I lost my mother, my brother and my aunt
And now my daughter
I can't lose her
She's my only one.

I later went to the surgical waiting room
And found her sitting with her sister.
Rosemary pointed to me and said to her sister,
She's the one, she's the angel I told you about.

KENYAN HEROES – HENRY MUITERERI &
SUSAN MUCHIRI



Henry Mutereri and Susan Muchiri are both Kikuyu staff who were displaced during the fighting. Henry is a support group worker, while Susan is a nurse. Henry knows most of our patients, and so he willingly travelled to IDP camps all around the area, often braving dangerous roads to reach the sites, despite significant personal risk. When we decided to track our patients in the Nakuru camps, Henry volunteered to go and survey the camp to see if many of our patients were there. The day he was going, I received word that Total Junction and Makutano (two towns he would have to pass through) had been burned the night before and that Kikuyus were being attacked in the area. I called him to tell him to cancel the trip. “Don’t worry Daktari,” he said, “ I’m already halfway there and I think I can reach there safely”.

He called me later from Nakuru to tell me he had reached the camps and that he had already found some of our patients. That day, fighting also broke out in Nakuru, leaving Henry stranded there for several days. Since he was there, he continued to work in the camp and establish contacts with patients and the clinic staff at the camp. Susan had already been displaced to her family's home near Nakuru, where 40 family members had taken refuge from the violence.

They volunteered to work in the camps to track our patients and provide drugs to those who could not access other programs. In fact, we learned that they were the first (and only) HIV clinic staff to arrive to assist HIV patients at the site. Susan reports that when they arrived, our patients greeted them with hugs and tears of joy. "We thought we would never see you again," they said. "But you have come to find us and help us!" The relief clinic staff stationed at the camp have been amazed by the AMPATH patients and also by Henry and Susan's relationship to them. "We've never seen patients like these ones", they say. "They aren't ashamed to be seen coming for treatment, and when they come you all sit and talk like friends and family."

In addition, the camp director personally tells me that Henry and Susan are educating all the other health staff on HIV care while providing great assistance to AMPATH patients and patients from other treatment programs as well. In addition to supplying drugs and other care, Henry and Susan have been able to help patients get tents, food and milk, and other supplies. They are currently caring for 65 AMPATH patients in the camp along with 22 patients from other treatment programs. Other AMPATH patients in the Nakuru area have also begun visiting them for assistance now that they know AMPATH is there.

Rocking

Tracy Davis, RN
Clarian Health Partners

This reflection comes from a transcribed response to the question "Please think of a time, a specific event, situation or circumstance that stands out for you... A time that brought out the best in you and in which you felt connected to your values and your calling. Tell me the story of that event." These inquiries were carried out with Clarian staff in order to understand their values as expressed in the staff members' work.

There was a time last summer when we had a 2 ½ year old patient on our floor. We usually have kids much older, but he'd been here pretty much his whole life minus a couple of days. It was one of those things where he was spiraling downhill very quickly. We always called him the mascot of our unit because everybody knew him - he was so well liked. It became evident to everyone that he was going to pass away, so it was a very, very difficult transition. During this time he started talking and he had more of a personality than a baby. Which was cool, because we usually don't see this transition, so it was a lot different for us.

He had to be in isolation because he had an infection. It was very hard, you know, for a 2 ½ year old to be in isolation all the time. Usually before I'd go home every night I would go in and rock him to sleep, because his mom was a single mom and couldn't be here a lot. I couldn't stand the thought of him always going to sleep by himself.

There was one Sunday night in particular - I received a call from work at home, they said "You know he's not doing very well and we're really, really busy. We think he needs to be rocked to sleep, and were wondering

if you would come in.” I said, “Absolutely.” When I got there he was just sitting there awake. He was starting to get very swollen and puffy, but he could still look out of one eye. I could tell he kind of knew what was going on because when I picked him up he started to shake back and forth. We called this shimmying and I said, “Are you going to shimmy?” And I thought, “He still knows. He still feels okay.” So I rocked him to sleep that night. I’m really glad I came in and did this because he passed away Tuesday morning, and that was one of the last times I got to spend with him.

I liked that the staff recognized it was a very busy night and that he needed someone there. Since there was really no one else to call and they knew that I was rocking him every night, they took it upon themselves to call me. It was very meaningful to me because I got to spend that last little bit of time with him, when he still knew what was going on, because Monday - just the next day - he was so sick he couldn’t even open his eyes.

So this was a really good experience for me. It was sad, but it was good.

KENYAN HERO – PATRICK BUNDOTICH

Patrick Bundotich is a clinical officer for the clinic. He reported to us that he mistakenly assumed that he would not be attacked because he was a health care worker. However, one day a large crowd of youths brandishing weapons came to his home and threatened him and his family. Fortunately one of the youths recognized him as a health worker and told the others not to harm him; however, they proceeded to vandalize and loot his house. He saw one of the youths carrying away his radio--a prized possession that he had saved for and really treasured. Later, while working to treat patients injured in the ongoing skirmishes, Patrick recognized one of the injured patients as the person who had threatened him and stolen his radio. Despite his feelings of anger, he decided that he could rise above the occasion, and he treated the young man's wounds as if he were any other patient, even ignoring the chance to accuse or charge the young man with his crime.

AUTHOR'S REFLECTION ON KENYAN HEROES

Many of us may never understand the depth of the divisions that caused this crisis, but over the past six weeks I have observed many Kenyans who were willing to rise above those divisions and put themselves on the line for our patients and for their community. I have learned an immeasurable amount about courage, forgiveness, and compassion from all the staff at Burnt Forest clinic and from our brave patients who continue to smile in the face of adversity. I am humbled and honored to have the opportunity to work with them.

--John Sidle



**A Group of children show appreciation
at an AMPATH clinic site**

Selected Blog Excerpts

Fredrick Chite Asirwa, MD, Medical Resident
Indiana University School of Medicine

The following are a series of excerpts from a web log (blog) kept by Fredrick Chite Asirwa that he uses to reflect on his patient interactions and his experiences in medical training. He hails from Africa, and he hopes to use his skills and knowledge from his US training to improve the lives of all Africans living in poverty.

I Want to Be a Patient!

I was working at one of the HIV/AIDS clinics that Indiana University has helped establish in Kenya and there was one patient left, before we closed the clinic.

The day had been long and we had seen close to 100 patients in this 2-roomed clinic.

The last patient came into the room. I will call him: J.

J. was 28 years old, 5' 10" tall, slender and had completed 12 years of schooling. He quickly sat down and as usual I offered a handshake. J had a good grip, notably shaky and with sweaty palms.

I started my usual questions. I asked him to give me a piece of paper that showed his HIV status.

He had none.

He had an explanation.

"I know I am HIV positive but I have tested three times now and my results are always negative. I have travelled for 2 days to get to this clinic and there is no way that you are going to turn me away now. I want to be part of this program-AMPATH"

I quickly went and got the rapid HIV kit. I told him that I was going to test him for HIV again and explained the whole concept to him. I also informed him that if negative he would have to come back in three months for a re-test. He agreed albeit grudgingly.

My pre-test probability was very low. He denied any high risk sexual encounters. He had not been sick before. No recent weight loss. No history of alcohol use or illicit drug use. Monogamous. Had 3 children.

The test result was Negative. Again. I was happy for him.

He went ballistic! He could not believe it!

This was an unusual reaction. I had never encountered anyone who would be livid on discovering that they were HIV negative.

J. tried to "sweet-talk" me into enrolling him in the program but I informed him that we only enrolled HIV positive patients. Unfortunately, he promised me that he would be back!

I later found out that he wanted to be part of a family that cares. He had heard a lot of positive things about AMPATH and wanted to be a member. Part of it was because of poverty. He wanted to get the services provided by AMPATH.

With this organization patients are seen by doctors, are cared for and seen in reasonable time, and are given free HIV treatment and treatment of opportunistic infections. Patients are taught survival skills, are supplied with food the first few months after diagnosis and offered training on business and farming initiatives etc. He wanted to be part of all these...

continued on next page...

On the other hand... If HIV negative there is nothing for free and one pays for what one gets. With most of the population below the poverty line, it's no wonder someone would rather be HIV positive.

This experience was an eye opener for me.

I want to dedicate my life to the care of these poor people and work with them in establishing systems that can absorb the non-HIV positive poor patients.

It is my hope and prayer that J. does not show up to the AMPATH clinic at all, because I am very sure he will be positive this time round!

Chite.

Lets Pray

I was on call and cross-covering a patient on another team. I had received a change over that the patient was likely to die that night. I will call him Mr. X

Mr. X had been diagnosed 5 years earlier, with Idiopathic Pulmonary Fibrosis. He had been given less than 2 years to live as his disease was so extensive.

His family had all along known what was coming and It was no wonder that he was a DNR.

I was called to his bedside by the nurse as Mr. X had gotten more short of breath and was now on supplemental oxygen by face mask. I briefly introduced myself and talked to him. I do not think he understood. I knew he was about to die. I then called his wife and informed her to come to her husband's bedside as this was it.

20 minutes later she was there with her daughter. The time was 1:00am. He finally breathed his last at 5:12am.

His wife was devastated. His daughter, uncontrollable emotionally.

I led them to a conference room nearby.

I was overwhelmed with their emotions. I had thought that it was going to be relatively easy to talk to them because they had spent quite some time with him from the time of diagnosis and they knew what would happen.

It's never easy even when death is expected.

I asked them if they were believers.

Yes they were.

I asked for permission to pray with them.

Gladly they accepted.

We held hands and I offered a short prayer. It may have been just a minute or two but it was effective.

They quickly calmed down and started reliving some wonderful moments they had with him. They even talked about some of his favorite jokes. He was truly a great man as gathered from their recollection. He was a war veteran too!

I listened. Sometimes, added a comment. I did not know the man before this night. I was simply caring for him as one of my colleague's patients but I was left richer by my interaction with this family.

I excused myself to attend to other patient duties.

It was not until 2 months later that I received a card in the mail from the two women: mother and daughter.

They had appreciated all the efforts we had done in taking care of their loved one. The phrase that touched me immensely is when they said:

"He (their loved one), could not have died at a better time and under your care (me). You eased the transition for us and we will be forever grateful, for it is doctors like you that make us have immense confidence in the health care system. You care. God bless you"

There were tears welling in my eyes and I relived the whole experience again.

There is never a good time to die but when you do, the little things that us health care professionals do become memorable by the deceased relatives' years to come and may impact them forever.

Chite.

The Mirror Image

I was on call and had just admitted an unfortunate young man:

30 years old with Chronic kidney failure, Hypertension, Diabetes Mellitus type 1, history of Stroke with neurological deficits and left eye blindness. He also gave a history of having a "small" heart attack in the past. He had been admitted countless number of times for diabetes. He had been diagnosed as being diabetic at the age of 7 and been on insulin since then but had been very non-compliant to meds and follow-up appointments. His primary care had been emergency rooms and he spent more time in the hospitals than he was in school, hence did not graduate from high school.

2 hrs later, I admitted a 17 year old boy in a diabetic crisis (diabetic ketoacidosis), he also had issues of non-compliance and had not been taking his medication. He did not even want to have a primary care doctor to follow him up. He thought since he was young, he

could get by most days without his insulin. It did not help matters that he was already emancipated.

The following morning I was struck by an idea that I discussed with the Medical social worker on my service. After confirming that I was in the clear I went for it.

I went to the 17 y/o who I will call Eric. I did the usual counseling about compliance to medication and bla bla bla... about complications of uncontrolled diabetes. One could tell that he had heard this several times over and over and he was not paying much attention anymore.

I still went on and on.

Then I went to the 30 y/o who I will call James. He had learnt his lessons by now and was very compliant to meds and all. He was admitted this time around for hemodialysis. I asked him if he could be willing to tell his story to someone who unfortunately was already going his path but luckily was still intact-organ systems-wise. I did not have to ask twice or even convince him at all. He was more than willing to talk to anybody that was willing to listen and who would hopefully be changed by his experiences.

I now had to convince Eric to listen to one last person before he was discharged. I found his father in his ward room and it helped. Once I explained to them what I wanted to happen, he agreed. We organized for the two to meet. It also helped that they had similar backgrounds.

I did not have to wait for long.

His father came and told me that Eric wanted to speak to me.

continued on next page...

Eric wanted me to arrange his follow-up care. Get him an outpatient doctor close to his home. He would have wished to come to my clinic but it's downtown and he could not keep appointments.

He wanted to take control of his life now. He wanted to know all the resources at his disposal.

He sounded more like a man that had been newly diagnosed!

I was ecstatic!

It worked.

I checked the records one month later and he had been to his doctor. That was a good start. I can only hope that he is doing well.

My mum always says "seeing is believing"

Chite.

Lessons

Matt Gentry, Student - Class of 2011
Indiana University School of Medicine

Though business has resumed its self
in past I've been a medic

Through balmy nights at summer camp
for children-diabetic.

Their condition's won no cure as yet
though science makes its bids,

sans glucose tabs and needle jabs
they're just like other kids.

Wanting to talk turtles
or visit the earth's ends

They laugh and play and sing and pray
Get homesick and make friends.

By walking hidden nature trails,
obtaining some skinned knees,

they are humanized as patients-
they are more than their disease.

While treatment's "as good as it gets"
for their malady most chronic-

Life need not be a bitter pill.
Compassion is their tonic.

Do they know what they've taught
this young doctor to be?

"Your patients are still people"
the patient has cured me!



Family– IU Cancer Mosaic Collaborative

This mosaic depicts the type of joy that can come through spending time with family. Many times hope manifests its self through the night vigil kept by a caring parent or through the unquestioning love of a child.

Forty Things I Needed Most

Jill Bolte Taylor PhD

Indiana University School of Medicine

At thirty seven the neuroanatomist Dr. Jill Bolte Taylor experienced a massive stroke which left her unable to talk, walk, write, read, care for herself, or recall any of her previous life. Through the help of rehabilitative therapy and immense support from her mother, she has made a full recovery and has published a book about her experience. She has served as an instructor in Neuroscience at the Bloomington center. Dr. Taylor hopes that what she learned from her experience can be used to positively influence others. This appendix from her book, My Stroke of Insight, entitled “Forty Things I Needed the Most” describes her feelings during her recovery process and has been reprinted with her permission.

1. I am not stupid, I am wounded. Please respect me.
2. Come close, speak slowly, and enunciate clearly.
3. Repeat yourself- assume I know nothing and start from the beginning
4. Be as patient with me the 20th time you teach me something as you were the first
5. Approach me with an open heart and slow your energy down. Take your time.
6. Be aware of what your body language and facial expressions are communicating to me.
7. Make eye contact with me. I am in here – come find me. Encourage me.
8. Please don't raise your voice – I'm not deaf, I'm wounded.
9. Touch me appropriately and connect with me.
10. Honor the healing power of sleep.
11. Protect my energy. No talk radio, TV, or nervous visitors! Keep visitation brief (five minutes).

12. Stimulate my brain when I have any energy to learn something new, but know that a small amount may wear me out quickly.
13. Use age-appropriate (toddler) educational toys and books to teach me.
14. Introduce me to the world kinesthetically. Let me feel everything (I am an infant again).
15. Teach me with monkey-see, monkey-do behavior.
16. Trust me that I am trying – just not with your skill level or on your schedule.
17. Ask me Multiple-choice questions. Avoid yes/no questions.
18. Ask me questions with specific answers. Allow me time to hunt for an answer.
19. Do not assess my cognitive ability by how fast I can think.
20. Handle me gently, as you would handle a newborn.
21. Speak to me directly, not about me to others.
22. Cheer me on. Expect me to recover completely, even if it takes twenty years!
23. Trust that my brain can always continue to learn.
24. Break all actions down to smaller steps of action.
25. Look for what obstacles prevent me from succeeding in a task.
26. Clarify for me what the next level or step is so I know what I am working toward.
27. Remember that I have to be proficient at one level of function before I can move on to the next level.
28. Celebrate all of my little successes. They Inspire me.
29. Please don't finish my sentences for me or fill in words I can't find. I need to work my brain.
30. If I can't find an old file, make it a point to create a new one.
31. I may want you to think I understand more than I really do.

32. Focus on what I can do rather than bemoan what I cannot do.
33. Introduce me to my old life. Don't assume that because I cannot play like I used to play that I won't enjoy music or an instrument, etc.
34. Remember that in the absence of some functions, I have gained other abilities.
35. Keep me familiar with my family, friends, and loving support. Build a collage wall of cards and photos that I can see. Label them so that I can review them.
36. Call in the troops! Create a healing team for me. Send word out to everyone so they can send me love. Keep them abreast of my condition and ask them to do specific things to support me – like visualize me being able to swallow with ease or rocking my body up to a sitting position.
37. Love me for who I am today. Don't hold me to being the person I was before. I have a different brain now.
38. Be protective of me but don't stand in the way of my progress.
39. Show me old video footage of me doing things to remind me about how I spoke, walked, and gestured.
40. Remember that my medications probably make me feel tired, as well as mask my ability to know what it feels like to be me.

Reflection

Val Simianu, Student - Class of 2010
Indiana University School of Medicine

When I applied to the palliative care ICM group, I had a mixed agenda. I sort of wanted to understand more about patients who were approaching their death and how to speak with them. This was a fairly personal motive, as my grandfather had been paralyzed by a stroke and bedridden for a few years at that time. I also wanted to challenge myself, I suppose, to see how I would handle seeing and trying to understand another person's death.

At the beginning of the year I was assigned to a patient on hospice care. I will refer to my patient as D, for the sake of confidentiality. She had a complicated medical history including epilepsy, mental retardation, HIV and renal failure. And while I tried, as an eager first year, to wrap my mind around her medical problems, I soon realized that my role in my relationship with her was to take a different path.

I met D for the first time about a week into the semester, when we went to her hospice facility. We sat down at the dining room table to talk. She stuttered very badly and it was extremely difficult for me to understand what she was saying at first. I found myself waiting, often what I felt was awkwardly long, after she would finish. But she would always start talking again.

As I continued to visit her every 2-3 weeks, our communication had a lot of ups and downs. Sometimes she said more, sometimes she said less. At times, I saw her in the hospital. Other times, I saw her when she had absence seizures and didn't speak for an entire visit.

Even though I tried to have an agenda for what I wanted to ask her, I became an expert at waiting for her to speak and guide the conversation.

I don't think she ever knew my name, even though I introduced myself regularly. But I knew she recognized me, because she would light up and stop whatever she did to talk to me. She would describe her seizures to me in her own words. She told me about her parents and her childhood. She explained what she understood about death – that when a person died, they would get to see their parents again. Our conversations cycled with the complications of her disease and the side effects of her many medications.

D died at the end of the year, during our finals week.

The significance of this experience was realizing that the role I may set out to play is not always the one in which I will end up. Medical school is pretty daunting in the first year. And at least for me, I think I intimidated myself with the expectations I placed on myself as I tried to imagine myself in the role of doctor, or healer, or I guess some sort of miracle worker. Making “the difference,” as people always say, doesn't have to come from some sort of wonder. For me, it came from braving the awkward silence and listening to someone who no one else would listen to. And I'm ever grateful for that lesson.

Hope in the Everydayness

Robin Bandy, JD/MA Bioethics Student
Indiana University School of Law - Indianapolis

For the past two years I have been a student in the joint JD/MA – Bioethics program at Indiana University. During my studies I have had the opportunity to hear clinician experiences regarding communication between doctor and patient, especially the communication of a bad prognosis, such as cancer. One concern is how to better serve terminally ill patients in our current medical culture, where the focus is on cure and recovery. For example, a patient who is told that “nothing more can be done” may fear abandonment by a physician who, up until this point, has been supportive in the attempt to treat the illness. At this point, it is important to help patients reframe their goals from cure and recovery to pain relief, comfort care, and spending as much time as possible with loved ones.

An author who illustrates how important it is for terminally ill patients to remain hopeful and to have support while adapting to their new goals is Marjorie Williams, a political writer, who was 47-years-old when she died from liver cancer. She left behind a husband and two small children. In her book *The Woman at the Washington Zoo* she includes a cancer memoir entitled *Hit by Lightning* in which she describes her journey through “cancerland.”

In this memoir, Williams frequently mentions how important it was for her to maintain hope, despite all of the doctors who indicated she did not have much to hope for. When she was first diagnosed the cancer was

already staged at IV(b) (as she mentions “there is no ‘V’ and there is no ‘c’). Therefore it is clear why many of the doctors who she consulted for treatment were not very optimistic about her outcome. She mentions that there was only one physician who allowed her to hope that chemotherapy would slow her cancer; that was Dr. Jerome Groopman who is well-known for his books and articles concerning how patients and doctors communicate. After several chemo cycles she was told the impossible – that her tumors responded to the chemo and were shrinking – which at least bought her some time. She writes about celebrating with family, friends, pizza and champagne on her front porch on a lovely September evening.

Although I did not know Marjorie Williams personally her story has become very important and personal to me because as a woman, wife, and mother who had the opportunity to raise her children to adulthood I am painfully aware of what she missed. What Williams shows us in her memoir is that remaining hopeful when one is terminally ill does not necessarily mean hopeful that there will be a cure or recovery. Remaining hopeful can mean that you get to spend a little more time with your husband, have coffee with friends, have more pancakes with your children or help them get ready for Halloween; have one more day to become etched in their memory so that they won’t forget who you were and how much you loved them; have one more day merely to exist and do all of the everyday, ordinary things that we so enjoy and take for granted as human beings.

How a Dental Student Came to Be

Rachel Dunlop, Class of 2010

Indiana University School of Dentistry

When I was little girl, my life was perfect along with my teeth. My teeth were straight and white with no spaces; I got compliments all the time on how perfect my teeth were. Slowly but surely, I lost one baby tooth at a time and started to get my permanent teeth. My new teeth were awful and the two front teeth were completely overlapping and it looked like I only had one tooth instead of two. The teeth on the bottom were also very crowded and I thought I looked hideous. To confirm my suspicions, everyone at school called me “one tooth” and asked if I could cut open canned food with my one big tooth. I sat in my room and cried for days until my mom told me I was beautiful the way I was but that I could get my teeth fixed by a special dentist called an orthodontist. I was so thrilled and nervous at the same time.

When I arrived at the orthodontist’s office, everyone was very friendly which eased my nerves. He looked at my teeth and told me that although I had a beautiful smile, he could change it to any way that I wanted with braces. I was dumbfounded. I expected the orthodontist to laugh and tell me that there was no way a smile that awful could be fixed.

However, braces at my school were considered dorky. When I voiced this concern to the orthodontist he told me even though some people did make fun of him in school when he had braces, he ended up with such nice

teeth that it was worth the ridicule. I wore those braces for one short year until I had the perfect, straight teeth I had always dreamed of. I thanked the orthodontist and he told me that I was one of his best patients.

As the years passed, I loved my teeth more and more and I never forgot how one person changed my life. Once I entered college, I realized that my passion was staring me in the face and I knew what I had to do. I worked very hard in college and my dream finally came true when I was accepted into the IU School of Dentistry. Dental school challenges me every day but I know that this is what I'm meant to do.

My very first patient in clinic had so many cavities and needed restorations. I helped her gain her self-confidence back and put a smile on her face. That is why I want to help people one smile at a time.

Where I'm From
Rich Frankel, PhD
Indiana University School of Medicine

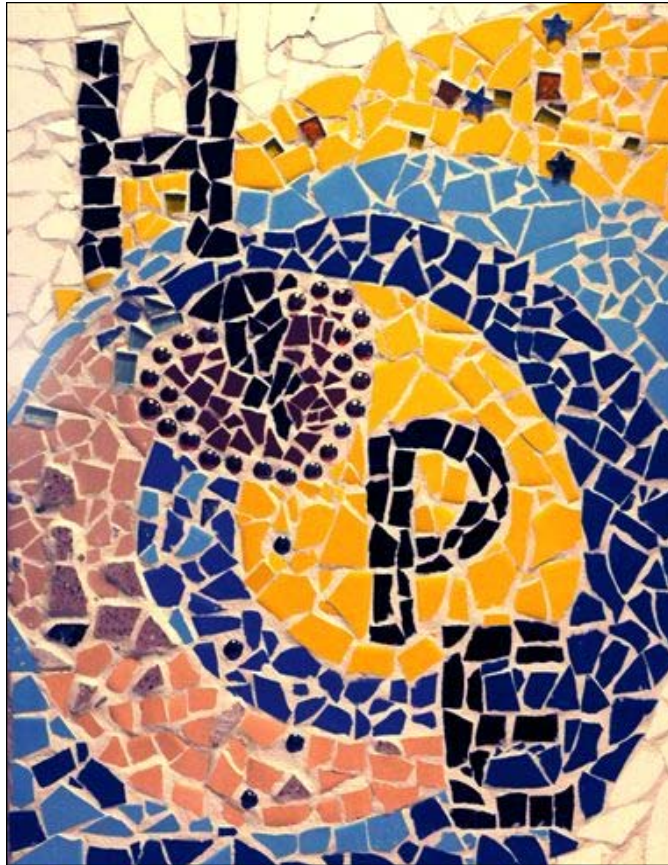
I am from traffic noise
and city sounds.
Horseradish
and unleavened bread.

I am from Red diapers
and potato latkes.
Needle scratched
phonographed voices
Seeger, Robeson, Guthrie
(Peter, Paul, and Woodie)
spinning at seventy eight
revolutions per minute.
Singin' truth to power.
Who does this land really
belong to?

Through the bedroom window
I can hear
The Bronx Bombers
playing baseball
in the House that Ruth built.

The sounds of
peanuts, popcorn and
cracker jacks.
Kaching. Kaching.
Damn Yankees!
my father would say.
After the revolution
things will be different.
And the Dodgers will
move back to Brooklyn.

I am from Big Science.
A biologist and chemist
to be exact.
Their hopes and dreams
for changing the world
more safely rooted now in
Darwin's revolution.
Their credo.
Respect all who pass your way.
And believe in the capacity
of science to unlock
the mysteries of
of the human condition.



Hope

IU Cancer Mosaic Collaborative

This mosaic shows that a heart broken open by the experience of cancer can find a spiritual transformation, seen in colors of yellow and blue that swirl out from the heart. Through this process of healing, an unexpected hope emerges.

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2008 *Reflections* Editorial Board

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