

# HEALTH ADVOCACY BULLETIN

The Journal of the Health Advocacy Program at Sarah Lawrence College

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## Illness Narratives and Health Advocacy

By Sayantani DasGupta  
Faculty, Health Advocacy Program

What is it to experience suffering? Almost six years ago, the course "Illness Narratives: Understanding the Experience of Illness," was introduced to the graduate program in Health Advocacy by Dr. Marsha Hurst and myself with this question in mind. We initially posited that by reading narrative accounts of illness and disability, health advocates could be trained in a deeper understanding of the individuals with illness and disability with whom they would work in the future. Part of the inspiration for such a course was the then burgeoning field of narrative medicine, a term coined by Columbia University physician and literary scholar Dr. Rita Charon. Therefore, our initial inclinations were to privilege the written text, as well as the individual experience. However, these notions were quickly challenged when we considered the needs of the students in the Health Advocacy program, who have historically brought a wealth of professional and personal experience in health care, illness, and caregiving. We would have to construct a course that not only drew from narrative texts, but personal reflection, a course in which students could read, write, discuss, and share, a course in which they would have a chance to enter the well crafted narratives of gifted writers as well as the raw and in-the-moment narratives of ordinary individuals. The course would additionally address the social, cultural, and political contexts of illness, the relationships

of the ill to their caregivers, and the experience of illness in families, communities, and societies.

What is it to represent the experience of suffering? This second question, which points to the difference between the *experience* of illness and the *story* that one constructs about that illness, is one whose importance has become more central to the course. Over the years, it has become clear that it is not enough to privilege the authority of the first person narrative without providing students an understanding of the process of narrative construction – including the complicated is-

ues around memory and the various narratives that individuals construct in partnership with their various listeners. Alongside the rich autobiographical and other texts on this course's syllabus are readings from the cannon of scholarly narrative medicine theory. Class discussions are centered as much around the content of illness narratives as around the issues of representation and craft in narrative. In addition, one of the major class requirements is that students write an ongoing series of narratives about a per-

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### Poet-Physician David Watts Returns to Sarah Lawrence

On October 11, David Watts, celebrated director of "Writing the Medical Experience," the week-long SLC summer seminar for clinicians, patients and writers, returned to the campus as guest speaker. Dr. Watts spent the morning attending the illness narratives course taught by Sayantani DasGupta and subsequently shared his prose and poetry at a lunchtime reading to HA and MFA students.

Dr. Watts is a regular commentator on NPR's *All Things Considered*. His book of poems, *Making*, won the 1999 Talent House Press Award. *Taking the History* was published in 1999 and a CD, *Powerful Seeds*, a poetry and jazz collaboration, was released in 2000. His latest book of poems,

*Blessing*, was published in 2003 and his television documentary, *Powerful Words: Poetry and the Art of Healing*, is in production.



David Watts

*Bedside Manners*, a collection of stories from the practice of medicine, was published in 2005 by Harmony Books. He is currently working on a memoir.

Dr. Watts graciously agreed to be interviewed by Pat Stanley for this publication:

P.S. When was it that you started writing?

D.W. In college I wrote a few love poems which were imitations of Shakespeare's sonnets. They were pretty dreadful. Then I wrote when my children were born in my first family. I wrote some heavily rhymed and metered verse, which I collected for them and then it stopped. That would have been when I was in my twenties. I didn't really start writing again until around the time I was about to turn 40. A personal stressful situation in my life, a breakup of the family, was taking place and I needed to know a little more about what was going on inside of me. I instinctively felt writing poetry would get me to answers in that regard or at least show me the things that needed working on, better perhaps for my psyche than psychotherapy. So I started writing poetry and went back and took some classes

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# Letter from the Editor

By Pat Stanley

When Marsha Hurst, Director of the Health Advocacy Program, asked me to edit this issue of the *Health Advocacy Bulletin* with Sayantani DasGupta, I immediately accepted. The issue would be on illness narratives, a passion of mine since I first enrolled in Sayantani's illness narratives course in the summer of 2003. Actually I have become obsessed with illness narratives and have participated four times in Sayantani's course (twice after graduation).

Syantani and I both share a love of oral history, narrative medicine, and the HA co-sponsored writing week at SLC, "Writing the Medical Experience." This issue leads with her article on the development of her course, "Illness Narratives: Understanding the Experience of Illness" which explores the experience of illness through story, narrative medicine theory, personal reflection and an exploration of witnessing. We have also included an excerpt from her book which she edited with Marsha Hurst, *Stories of Illness and Healing: Women Write Their Bodies*.

Sarah Lawrence has hosted the writing conference and workshop directed by David Watts for the past two years. I was fortunate to interview him after he gave a reading and led a discussion on the intersection of illness and creative expression at the Faculty House this fall. We can all look forward to his return this summer as chair of the third writing conference in which Sayantani will again participate as an instructor.

Another celebrated teacher from SLC and the writing conference is Penny Wolfson whose memoir, *Moonrise: One Family, Genetic Identity and Muscular Dystrophy*, tells the story of her son Ansel's experience with Duchenne muscular dystrophy. Penny has given us a picture of Ansel's life now that he has graduated

from Columbia University. Penny has both a BA and MFA from Sarah Lawrence.

We are fortunate to have two former students at SLC and past participants of "Writing the Medical Experience" who have submitted narratives and poems inspired by their experiences with illness. Rose Bromberg writes about the fragmented world of both patients and healthcare providers and her personal experience with fibromyalgia. Marisa Bois has written several poems excerpted from her opus, "Beneath This Skin", a narrative she continues to write about living with chronic illness.

Juli Buyon, a 2005 graduate of HAP, narrates from the perspective of a "self advocate" after a recurrence of cancer.

Several current SLC students are represented in this issue. Julie Christman, who is currently attending the MFA program, writes of two cyborg artists who relate their struggle with Crohn's disease through robots. Heidi Weiss, currently enrolled in HAP, creates a narrative intervention for the developmentally disabled. Jean Anne Cipolla, also an HAP student, relates her application of

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## Letter from the Editor

By Sayantani DasGupta

Stories are as old as time. We humans have used stories since time immemorial to make sense of our lives, and to communicate our lives to one another. Stories form the foundations of our families and communities. Stories are the means by which we construct our societies.

In the face of illness, stories allow us to make sense of not only the experience, but the shift from the person who was *before* to the person who is *after*. They enable us to form relationships with those who listen to our stories – our families, caregivers, clinicians – who help construct our stories in the questions they ask, the responses they give, in their very presence as receivers of our narratives.

This issue of *The Health Advocacy Bulletin* honors the stories of illness, explores the role of such narratives in our scholarship, and provides examples of stories being enacted – translated into advocacy, policy and action. In the same way that the graduate program itself integrates a diversity of voices and experiences, this issue of *The Bulletin* includes creative

prose and poetry, essays, and an interview. This heterogeneity of voices and genres reflects the varied conceptions of story in the work of health advocacy, as well as the varied ways that stories can enable and empower the work of health advocacy.

In honoring stories in this way, this issue of *The Bulletin* intends to highlight some of the activities taking place within and without the Health Advocacy Program and provides fertile ground for future activities at the interces of narrative, advocacy, and health care. With the forthcoming inauguration of Sarah Lawrence's new president, Karen Lawrence – who has, among her other many accomplishments, been the president of the Society for the Study of Narrative Literature, and been involved in promoting collaborations between the humanities, arts and sciences at UC Irvine – we at the Health Advocacy Program look forward to continuing our role as a clearing house for work in health, narrative and advocacy, and engaging in even more collaborative scholarship, service, and social change both on and beyond the Sarah Lawrence campus.

*Syantani DasGupta, MD MPH is Assistant Clinical Professor of Pediatrics as well as Advisory Board Member and Faculty in the Program in Narrative Medicine at Columbia University. She is a guest faculty member in Health Advocacy at Sarah Lawrence College, where she teaches a required course on illness narratives and is working on curriculum and program development in the new field of narrative genetics. She also teaches prose during the summer Writing the Medical Experience conference. She is co-editing a forthcoming book with Marsha Hurst on women's illness narratives.*

[www.slc.edu/health\\_advocacy](http://www.slc.edu/health_advocacy)

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# Powers That Be

By Penny Wolfson

Ansel and I are in the emergency room at Westchester Medical Center eating salty potato chips from the vending machine down the hall. He's sitting up on a stretcher waiting for X-rays; the chips may be our only meal for hours to come.

The circumstances that brought us here are nearly too absurd to relate: On a dark wet evening when all the parkways in Westchester have flooded and Paratransit cannot be roused, Ansel falls on top of a tow truck driver who has attempted to carry him from his wheelchair in my stuck car into the cab of his high-bed truck.

Ansel had been working at his job as a docent at the Union Church in Pocantico Hills, where he shows the Chagall stained-glass windows; they'd let out early because without good light it's hard

to appreciate the windows. So he asked me to come.

It takes me half an hour to get there. At 4:30 pm, as I pull into the soaked parking lot I spot him out front in his new natty professional attire—pleated cords and a button down blue striped shirt topped by a navy blue sports coat. But as I make the final maneuver into the handicapped spot, the power steering belt in the wheelchair van suddenly snaps.

It doesn't seem like a disaster at first, just a car breakdown, even a pretty-easy-to-fix car breakdown, but it quickly devolves into dark comedy: For even if it's just a belt that needs replacing, the van will no doubt need to be towed, and where, exactly, can a person in a wheelchair go when his specialized transportation evaporates? The rest of us could summon a cab, hitch a ride from a friend, climb into a repair truck, if need be. There is no bus route here, high up in these

Rockefeller hills, and the closest train station, at Sleepy Hollow, is several miles away, down a long and treacherous hill without sidewalks or lights.

I can't think of one friend to call who might be able to help with this koan, this puzzle. I do call my husband Joe in Manhattan, but he's oversubscribed with patients and couldn't get here for two hours anyway. So I call triple A, imagining they can help me fashion a solution out of thin air, whole cloth, whatever resources and supermen they might have in their never-seen control headquarters. Call the triple A! It's like calling the Marines, right? They're supposed to get you out of a fix.

They don't send me any superman. Instead they send me a not particularly robust looking fellow in a baseball cap who brings a giant flatbed and a heavy flashlight. He can't repair the belt; he will

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## Illness Narratives and Health Advocacy

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sonal or familial experience of illness or disability. Weekly suggestions are made for students to experiment with point of view, genre, theme and plot, to construct their narratives in a way that highlights the construction of the narratives they read in class. These personal narratives help students articulate, narrate and therefore differently understand the personal experiences that they bring to their careers as advocates.

In being audience to one another's narratives, students begin a communal process of advocacy, a process that leads to yet another question: What is it to witness the experience of suffering? Through

this class, students gain an understanding of themselves as witnesses – to the texts they read, to themselves as sufferers, and to one another. In addition, both the course texts and many of the personal narratives that students write explore the experience of professional and familial caregivers – those who witness the suffering of others. The second major requirement of the class, which is conducting, transcribing and writing a paper based on an oral history interview of an individual with chronic illness, is a scholarly enactment of witnessing. This exercise helps students to investigate their own role as witnesses, and to ask – what is it to represent the witnessing of suffering?

"Illness Narratives" is a course whose

strength lies in its students, and in its concern not with hard and fast answers, but with helping students to ask the right questions. The use of narratives enables us to take the experience of illness from the personal and individual, and to examine its wider ramifications. Each member of this class engages in numerous acts of witnessing over the semester. And so, as a community, we continue to explore at least one last question, which is – what is it to witness the witnessing of suffering? In being witness to one another's witnessing, we bring a collectivity to what was once experienced in isolation, creating habits of communal support that can last students throughout their advocacy careers.

### Writing the Medical Experience

#### A Conference and Workshop at Sarah Lawrence College: July 8-14, 2007

This intensive weeklong program in the literature of illness and recovery is open to doctors, nurses, other health care professionals, patients and their families. Writers with a special interest in medical subjects are also welcome. Applications will be considered in two categories: poetry and prose. Acceptance into the program is based on the quality of the application sample. Previous participants need not submit their work.

The medical experience can lead to some of life's deepest moments and is thus a rich source of subject matter for literature; but it is often difficult to write about. Bringing together individuals with a shared interest in a literature of the body, and with our diverse ways of handling the body's challenges, will better equip us for writing the medical experience. The conference will consist of lectures, workshops, panels, readings and informal gatherings. It takes place on a wooded campus just 15 miles north of New York City.

**Full information on Writing the Medical Experience can be found at [www.sarahlawrence.edu/summer](http://www.sarahlawrence.edu/summer). Applications are due Monday, April 30, 2007.**

# Sick Robots

By Julie Christman

James Powderly had a fistula in his sigmoid colon that cauterized to his abdomen, a PICC line, Crohn's arthritis he referred to as Fat Leg, an abdominal abscess due to a recurrence of the fistula, surgery to remove 18 inches of colon, and a colostomy all before he turned 30.

James was diagnosed with Crohn's disease, or chronic bowel inflammation, in 1995. His Crohn's took a turn toward severe in 2000, the year he moved to New York City, started NYU's Interactive Telecommunications Program (ITP - a professional master's program in interactive media), and met his wife-to-be, Michelle Kempner. Over the next five years James's Crohn's would enter an aggressive phase. His life would be partitioned into two radically different worlds. James and Michelle learned, through trial and error, to negotiate the world of the sick. It was their sense of humor and their dedication to each other that got them through the darkest, most absurd episodes of James's chronic illness. Until they were blindsided.

On New Year's Day, 2005, shortly after James's colostomy reversal surgery, James woke up at 3 a.m. sticky and cold. A dark stain had spread around his legs and crept toward his sleeping wife. James woke up Michelle and she called 911. She asked if they should take a car service to the emergency room. The dispatcher reassured her an ambulance would come to pick them up. Michelle waited for the ambulance outside on the corner, worried the driver would miss their apartment, with a Manhattan Avenue street address and a door on Jackson Street, as James sat in his boxer shorts on the white Flokati throw rug in the living room. When the paramedics arrived, Michelle took them into the dark bedroom, the only room in their apartment without a light, to assess the blood loss. As the paramedics prepared James for the trip from Brooklyn to Manhattan, their landlord appeared to offer his assistance. Michelle and James remained calm throughout the ordeal and joked with each other about the strangest moments of their New Year's morning.

The cause of the bleeding remains a mystery. It was the scariest episode James and Michelle experienced together. Try-

ing to explain the episode to co-workers and friends confounded Michelle. How does one explain waking up covered in blood from her husband's rectum? It inspired a dialogue between Michelle and James about the juxtaposition of their dual worlds. As a result of this episode, they found a team of competent doctors to manage James' illness, joined the *Get Your Guts In Gear* bike ride to raise money for Crohn's and colitis research and decided to tell the story of 2004 - the year they got married and survived the abscess, surgery and colostomy.

James and Michelle decided to tell their story using robots. They would recreate 12 scenes from 2004 using robotic representations - mechanical actors in animated scenes in the hospital, at home - scenes that illustrated the private places in their sick life. They called the project *Inside Out Life Story (IOLS)* and secured an Artist in Residency from Eyebeam Art and Technology Center ([www.eyebeam.org](http://www.eyebeam.org)) to do preliminary research and development.

Michelle and James chose technology to narrate their illness for two reasons. First, technology is their primary art form. Both are graduates of ITP; Michelle is a programmer and James, an engineer by profession. Technology is their most accessible medium. The second reason is a sociological theory in robotics called Mori's Uncanny Valley, developed by Japanese roboticist Masahiro Mori in the 1970s.

Mori tracked the emotional response humans have to robots. When this emotional response is graphed, the response is increasingly positive as the robot approaches human likeness. That positive response peaks and quickly descends into a valley, called Mori's Uncanny Valley, when the robot becomes creepy - not exactly human, not exactly artificial. Zombies and prosthetic hands belong in this Uncanny Valley.

Sick people also belong in the Uncanny Valley. Mori examined emotional response to sick people after he considered emotional response to robots. He found that the emotional response toward paraplegics was more negative than toward humanoid robots. James and Michelle want to create sick humanoid robots that people could relate to and

sympathize with, a dual affront to Mori's Uncanny Valley.

In the eight months of their residency, James and Michelle discovered creating sick robots is time consuming, emotionally draining, and expensive. They have made several unsuccessful attempts to secure additional funding to continue their work; consequently, the project is on a backburner.

I have been audience to *IOLS* from the beginning - Michelle and I have been close friends since high school, and I have dutifully supported all her creative endeavors. I became invested in the concept of *IOLS* through my study of illness narratives at Sarah Lawrence College, within the graduate health advocacy program. I elected to take Illness Narratives to supplement my graduate nonfiction writing program.

With the enthusiastic encouragement and guidance from Dr. Sayantani Das Gupta, I recorded James's and Michelle's life stories and composed several theoretical-based essays about James's and Michelle's experience with illness and their particular form of illness narration. Through my writing about *IOLS*, I explored at length the concept of cyborg artists and the seedy, absurd world of the sick from James's and Michelle's perspective. I have dedicated my thesis to telling their story of illness and their alternative method of illness narration. Their sick robots need to be brought to life.

James has recently received press for his work at Eyebeam, where he is a fellow, with the Graffiti Research Lab ([www.graffitiresearchlab.com](http://www.graffitiresearchlab.com)). James and his partner at Graffiti Research Lab have appeared in *The New York Times* (6/25/06) and *TIME* magazine (9/4/06). James and Michelle hope that *Inside Out Life Story* will someday receive the same caliber of attention.

Visit [www.robotclothes.com](http://www.robotclothes.com) for more information on *Inside Out Life Story*.

*Julie Christman is a Master of Fine Arts candidate in creative nonfiction writing at Sarah Lawrence College. She lives at the top of Manhattan, in a charming neighborhood called Inwood, where she shares her office with her medically-involved dog. She earns her keep writing for the Executive Vice Chancellor for Academic Affairs at The City University of New York.*

# The Patient Advocate as Patient:

They say doctors make the worst patients. Do patient advocates make the best?

By Juli Buyon

A month after receiving my master's in health advocacy (HAP), I was diagnosed with a recurrence of cancer. Despite my panic, I knew I was coming to this disease with a level of experience, education, and training enjoyed by few other people diagnosed with serious illness. Unlike so many, I knew what was possible, and I had a far better understanding of when to ask for help and of whom to ask it. This knowledge, central to the role of the health advocate, can profoundly change the experience of illness and its treatment.

So competent was my self-health advocacy that the high-risk case manager assigned by my insurance company told me, "Gee, you sound like you have everything under control," and then didn't check up on me for three months. Nonetheless, I needed professional health advocates to help see me through my recurrence; to prevent the postponement of my surgery, to control post-operative pain, to help me understand and decide on courses of treatment, to hold my hand.

Because of my HAP experience, I was certainly a better patient, if not the "best." I was more demanding of interaction and engagement by my physicians (and I have many) than I would have been otherwise. I insisted that that they hear my story – that they have *some* understanding of what this illness means to *me* and where this chapter fits into the larger narrative of my life. I insisted on being more than "the 47 year old recurrence in Exam 2."

But it is not only my *Illness Narratives* class that resonates. I consider the *Ethics* of my special treatment at the hospital because I have great connections, not the least of which put me first on the list for a private room. I recall *Communicating with Patients* and contemplate how many of the health care providers I came in contact with should take that class. I am empowered because I understand my rights under the *Law*. I contemplate the *Economics* of health care and waste when certain drugs are rejected by insurance company yet nobody questions duplicative imaging tests.

My class work in health advocacy gave

me a keen awareness of the degree of patient privacy required by the HIPAA regulations. When, during my illness odyssey, this privacy was blatantly, if unintentionally, disregarded in the halls of the hospital, my shock was considerable. Like many surgical patients, I was required to bank some of my own blood pre-surgery. People at the blood bank who were donating for *others*, however, were publicly identified and sent home with gift umbrellas. The rest of us just got surgery. This was an internationally renowned *cancer* center; they might just as well have handed me a shirt emblazoned, "I have **CANCER** and all I got was this lousy tee-shirt."

Even the elevator seemed an invasion of privacy and taste. On visiting my surgeon, I watched the floors flash by, each helpfully labeled not only by number, but by specialty; "thoracic oncology," "gynecologic oncology," etc. While I realize that the objective is to provide helpful information to patients, it strikes my morbid sensibility that all that's missing from this "elevator of death" is an attendant announcing: "Sixth floor, colon cancer! Ninth floor, ovarian cancer! All off, please!" Riding all the way up to the tenth and last floor, I know what most people on my elevator will likely die from. This is *way* too much information.

When health care workers ask me to explain my degree in health advocacy I jokingly say that I have "a master's in being a pain in the ass." This past year, I have been described – not to my face – as "verbal," "anxious," and – yes – "a pain in the ass." I ask what every pill is for, what is in every infusion, challenge the necessity of every test. I refuse all duplicative blood tests and x-rays. I have not valiantly battled cancer in this last year; I have survived cancer treatment and institutional health care.

Recently, I returned to work as a patient advocate at a tertiary care hospital in a low-income, urban community. I bring with me a new empathy and hard won understanding of pain, loss, despair, and what it feels like to have life implode. Now, I am more determined than ever to advocate on behalf of my patients and to teach them to demand a whole lot more of their health care providers.

Last week, I met Mr. Riveros, who was admitted to the hospital with esophageal cancer that has spread to other parts of his body, including his pancreas. These tumors are very painful and make it almost impossible for him to eat. He has lost twenty-three pounds in just the last few months. Because the tumor is so widespread, surgical removal is not a viable option. This cancer will take Mr. Riveros' life. That he is also an alcoholic, whose liver and whose ability to cope with the world even when sober are both extremely limited, does not help his grave situation.

Despite these hurdles, I enjoined Mr. Riveros to be a partner in his health care; to report to his physician *everything* that is bothering him, no matter how minor, because the odds are they can be managed. I assured him that he need not suffer unnecessarily from the sleeplessness, anxiety, pain, nausea, and other difficult symptoms that accompany cancer and its treatment. I told him that physicians frequently forget to ask about these lesser but important complaints while focusing on the larger issue of cancer, and that it is incumbent on each patient to bring these issues up rather than assume side effects must be borne in silence.

Dr. Pak, the resident overseeing Mr. Riveros' care, joined me at his bedside. I could sense her rising panic as I coached him in the art of being a patient, and I imagine that she envisions seemingly endless burdens from this patient and that he will take up a lot of her time.

I hope that Mr. Riveros will do just that. I hope that he will demand that his doctor become involved with his life and understand the dimensions of this illness. I hope that Dr. Pak will hear him, because if she does she will learn a great deal about being a good doctor and perhaps conclude that Mr. Riveros is her "best" patient. I hope Dr. Pak will become a major character in this final chapter of Mr. Riveros' story.

*Juli Buyon is a recent graduate of the Health Advocacy program, which she completed between cancer episodes. She works as a hospital based patient advocate specializing in palliative care.*

# Poet-Physician David Watts Returns to Sarah Lawrence

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when I discovered I couldn't write poetry very well and got some craft under my belt. I went from writing narrative poetry about the standard subjects of love, loss and longing to poems about medicine, health, illness and recovery to NPR commentaries on the practice of medicine, and from there to memoir, short stories if you will, true short stories about the practice of medicine published in *Bedside Manners*. Now it has taken another evolution and I am writing a memoir about my early years.

P.S. Tell me about becoming a doctor. Did you always know you wanted to be a doctor?

D.W. No, I had no idea I wanted to be a doctor. When I was in high school I went back and forth from medical missionary to chemical engineer to astronomer. My interest in careers as a teenager seemed to revolve around something having to do with the church or having to do with science, but I had been playing music, the French horn, all along. My mother was a pianist and taught music. My father was a theology professor at a small liberal arts college in Texas and I sort of synthesized all those things into my life and ideas. I started out as a music major in college, but I decided I didn't want to practice three, four or five hours every day for the rest of my life. So I thought, well, I can play music on the side. Then I thought about something that would put together my interest in doing something beneficial for people in general and my love of science and it just came out that it would be medicine. Nobody in my family had ever done that field before.

P.S. How did your experience in medical school and in medicine affect your feeling about the need for writing and for medical students to write, doctors to write, healthcare providers to write?

D.W. When I was in medical school I didn't have any inclinations toward writing aside from the few little verses I was writing for my children, and I didn't really have any notions about physicians being writers. Only after I discovered for myself that writing opened up all

these new vistas, that it got at hard truths that were otherwise difficult to ascertain and also deepened you as a person did I begin to feel that it was important to apply that to the medical profession. Then I began to look at this whole problem that we have in medicine of the dispassionate or cold and distant physician and it's a perfect match: Writing is a perfect cure for that problem because it doesn't allow you to get around the issues of emotional engagement with your patients.

P.S. And are these primarily stories that have a medical connotation?

D.W. Yes, they served the nucleus of the material and the pieces that went into the production of the book, *Bedside Manners*.

P.S. Can you tell us what writers you have learned from the most during really tough times when you felt distressed or needed some advice or a place to go? Whom did you read?

D.W. Well Rumi is number one, that mystical wonderful poet and the Coleman Barks translations are just luminous. So I read him, Hafez and Lala are also fun. Those are from the old times. But modern poets: Bill Matthews had a wonderful rye humorous way of looking at very stiff tough problems and Galway Kinnel has a grand style. So I took a lot from those writers.

P.S. Any prose writers?

D.W. During the time when I was starting to write, it was all about poetry and I sort of backed into prose. And now since I am doing memoir, I have bought eight

or ten memoirs and I have read them so I have become much more acquainted with the memoir field than I used to be. But for inspiration, poetry is what gets me going.

P.S. Tell us about "Writing the Medical Experience," the week long workshop that you have organized. How did it begin? What is your vision for it and where do you see it going?

D.W. I had been a participant in Squaw Valley community writers for about 13 years and it is such a wonderful experience because the tone is set in such a way that widely famous Pulitzer writers sit down as equals to their participant students and have a dialogue. And so I got to know these people intimately as writers and of course I learned a great deal from them in terms of sharpening my craft and skills as a writer. So I thought why shouldn't this happen to the medical profession in the sense of getting all the people involved with the healing arts especially the patient. It is very easy for doctors to get their own ideas about what is going on and exclude from consideration the notion of the patient, a totally ridiculous concept but all together too often true. And magically what I anticipated happening did happen at these conferences when we first got started. The physicians came in all blustery and went away transformed. The patients came in with messages to speak and got their opportunity. All the other members of the community had their input and there was a wonderful rich sharing of ideas and approaches and emotions that turned out to be very rewarding for all concerned. We ran it one year at Squaw Valley and they were very good to let me try it but it was too large a program for them. It was too complicated for them to manage. They have a very small staff. So I took a year off to think about where to put it. One of the graduates of Squaw Valley was a graduate of Sarah Lawrence, and she said, "You know there is a health advocacy program at Sarah Lawrence College that would be a perfect fit." And I said, "Woe, sure!" And so Marsha Hurst came into the picture and she was very gracious and we had some conversations

## Fragment at the Beginning of Something

My son brings me a stone and asks  
which star it fell from,  
he is serious  
and so I must be careful, even though  
I know he will place it  
among those things that will leave him  
someday, and he  
will go on gathering. For this  
is one of those moments  
that turns suddenly towards you, opening  
as it turns, as if for a moment  
we paused on the edge  
of a heart beat, conscious  
of the fear that runs beside us  
and how lovely it is to be with each other  
in the long resilient mornings.

—David Watts

*The poem appears as part of the story "Annie's Antidote"  
in Bedside Manners from Harmony Books, 2003.*

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# Poet-Physician David Watts Returns to Sarah Lawrence

*Continued from page 6*

and first thing you know we had a conference. I modeled it in many ways after the Squaw Valley experience but it is different because it involves both poetry and prose in the same conference, at the same time. And also it is organized around a thematic style of writing, the medical experience. But it has worked out very successfully.

P.S. Do you feel that your writing and your poetry have informed your medical practice and made you a better doctor, and have you also seen that happen to other colleagues?

D.W. Absolutely. In fact, in the talk I give to medical schools I give specific examples of approaches and ideas I have learned from writing that I would not have learned anywhere else, and that apply directly to the patient I am thinking about or considering at the moment. Writing is a way of exploring the options in a deeper way, perhaps more than intellectual ones, because it encompasses not just the linear rational thinking part of the brain but all aspects, emotional, spiritual and social. So when you come across a truth it has influence in all these spheres simultaneously.

P.S. You have a new style of writing, which is memoir. Do you think one has to be of a certain age to write memoir? What are the new skills you have had to learn to do this?

D.W. I blame Random House for this because I had no intention of writing memoir. But they seemed to have seen something in my style that they thought would fit with memoir so they suggested I try one. My first thought was, what's interesting about my life? I have not been abused, I do not have a bank robber as a father, my mother was not a crazy lunatic out on the church steeple somewhere as a lot of the memoir stuff is all about. So I didn't know there would be the kind of substance in the events that happened around my life that would attract. But at the same time I also knew that it wasn't necessarily the drama of the events. It is how they are thought about and handled, and what impact they make, and whether they evoke some change in behavior or life direction because everybody experiences at some level different kinds of events similar to the ones that are expressed. I decided that it wasn't so much whether or not I had had dramatic moments occur in my life, it was whether or not I could make them into something as a way of creating a story that would be

important to people. Well I tried it out and it is different. It is a very different style of writing from either poetry or these short stories that I have been writing. It is different because you really have to find the right voice to get it to hold together as a fabric. When that happens all these other details fall into place naturally. They are not forced. It's genetic. It's in the genome of the piece rather than being applied from without.

P.S. Writing teachers are always talking about voice and the importance of finding your own voice. How does one know?

D.W. The subconscious mind knows. The point is to free it up because it is down there somewhere. And what we have done is we've layered it over with all our rational thinking and shut it off. So part of it is just permission: one part giving the other part the freedom to experiment. You have to trust what you are attracted to. If a phrase pops into your head and you say, I really like that phrase, you better darn well write it down because it is not going to pop into your head the same way again ever. And something about the way it hits you at that moment resonates all those different chambers you are trying to get to and ties them all together. That is what happened to me with the memoir. I had been messing around with all these different pieces and couldn't tie them together and I threw them away for a brief moment and, bingo, this little two sentence beginning popped into my head and it started falling into place.

P.S. You certainly have a very busy life with a number of careers going on simultaneously. What would your recommen-

dation be to would-be writers on how to find time to write? How do you find time to write and how would you advise others?

D.W. At the risk of appearing to give a snap answer, you don't find time, time finds you. Because if you are passionate about something, you will find the time. That is what happened to me. People don't understand how I can have a full practice of medicine, a full family life, play in a symphony orchestra, and write in three different genres. You know they are all of a piece, they are all of the same thing. It's just different ways of expressing the same kinds of human characteristics, human existence. And yes, you do occasionally have to make time, and I do that. I take a day off occasionally. I just started doing that because of writing the memoir. I didn't when I was writing poetry because you can write poetry in between times. But the memoir requires a little concentrated effort.

P.S. David, you consider writing a priority?

D.W. Writing is necessary. It is most necessary where it is not. Because you will find that governments who have no passion or compassion are probably the same ones that don't celebrate the arts. And you will find that professions that are not too good at inter-human relationships may not be spending enough time living in that quadrant of our existence that has to do with writing and literature, poetry, music, art. It is there for a reason. It is not just decoration. It has survived over the centuries because it has purpose for us and that is to keep us tuned to what is human.

## Letter from the Editor

*Continued from page 2*

personal testimony to political advocacy in the mental health arena. Rosie Hoffman is the daughter of Maggie Hoffman who has attended SLC and is currently enrolled in the new Applied Research Ethics Certificate program. Rosie writes about her illness experience as a high school student.

This issue is filled with writings that have been spawned either in the illness narratives course from the Health Advocacy program, SLC writing classes and/or the "Writing the Medical Experience" workshop. We have tried to give you a sampling of different genres, perspectives and applications of narrative. We hope

that your experience as readers of these stories will be rewarding and that you too will agree with David that writing these stories is necessary "to keep us tuned to what is human" and with Sayantani, that witnessing the witness of suffering creates "habits of communal support", an antidote to what the ill experience in isolation.

*Pat Stanley graduated from the Health Advocacy program in December, 2005. She is working on projects with Rita Charon in the Narrative Medicine Program at Columbia University and is currently conducting a patient/caregiver narrative writing workshop with oncology outpatients at New York Presbyterian Hospital.*

# Giving Voice to the Developmentally Disabled: the Challenge of Creating a Narrative of Loss

By Heidi Weiss

In my work as a social worker in the field of life threatening and terminal illness, I meet many individuals and hear stories surrounding their illness and life history. Some of these individuals are elderly and have an abundance of diverse stories to tell about the lives they have led. Others are diagnosed in their twenties to fifties, and have just begun, or are in the middle of reflecting and creating their stories. What remains the focal point for all of these clients is the story they have to tell.

But what about those individuals who are compromised cognitively, physically or emotionally in their ability to tell their story? Do they have a voice, too?

I work at Westchester Jewish Community Services (WJCS), the largest not-for-profit community agency in Westchester County, in the Pathways to Care (PTC) program. This program provides a range of services and resources for families facing life threatening and terminal illness. The progressive interest in collaboration among divisions has allowed me the opportunity to work interdepartmentally with the professional staff of the Community Residential Care (CRC) division. The CRC department provides services for people with developmental and related disabilities that include community and residential based services. It was a staff request for services for several residents that prompted us to address directly the issue of grief at the end of life with the developmentally disabled (DD). Improving a resident's well being during the grief process can pave the way to a more successful recovery and ease the distress and disruptive functioning that unprocessed grief may cause.

This interdepartmental work began with a phone call from a CRC professional to the PTC director asking if anyone on our staff would consider talking with some of the group home residents who had recently experienced a loss. There had been some behavioral issues but the genesis of these behaviors was not clear. We decided to form a bereavement group which I would facilitate together with a psychology intern who had been working in the group homes. The initial six members of this group came from several different homes and had varying cognitive and verbal capacities. The common thread was the experience of loss.

We began with a simple conversation about feelings, a discussion about things that make them happy, such as holiday times with their families or sad, such as missing a deceased relative or friend or angry, such as trouble with another resident. Some participants with very limited expressive speech still had some capacity for receptive language. In these cases, we would offer choices of responses, and they would either choose one of the options offered and say it aloud or acknowledge with a shake of their heads. In spite of their limitations, we engaged them in discussion and were able to elicit who or what had made them sad. We also offered opportunities to use a simple art project and a written or dictated expression of their feelings to share with the group.

We then formed a new group that included two residents with the greatest capacity for expressive language from the initial group and four additional residents who had recently experienced a loss. These participants were of more compatible verbal and cognitive abilities and much better equipped to talk to each other. Within a couple of sessions, one of the former participants began to journal some of his thoughts and feelings and shared them with this new group. He wrote about how sorry he was not to have the chance to say goodbye to his mom. He wrote about how he watched his father grow ill and "end up dying of cancer. That's what happened when you smoke too much." It was some of his material that encouraged group discussion in the subsequent weeks with each participant sharing particular concerns and issues.

After six weeks this group was suspended because of logistical constraints and lack of investment in the project by the direct care staff. Behavioral and emotional issues continued in the daily life of the group homes. It became clear that the staff needed training and support to help those with cognitive impairments communicate their grief.

The CRC director of nursing and myself attended a training course for end of life issues and the developmentally disabled given by the New York State Association for Retarded Citizens (NYSARC). With this training we developed our own course to train staff to:

- 1) improve their understanding of what the group home residents had to endure during periods of loss.

- 2) increase their understanding of the unique ways loss and anticipatory loss are processed by the disabled;

- 3) enable residents to express what it means to lose one of their own and

- 4) access a range of support services when terminal illness strikes for themselves as well as for the residents.

The trainings have been well received and the staff has acquired numerous skills that empower them to be more confident and capable while attending to the end of life needs of their constituents. A working and living environment has been created that provides support, respect, knowledge and recognition that is invested in each resident. When the staff is faced with the terminal illness of a resident, that resident's daily life is now improved by proper medical treatment and supportive emotional care tailored to that resident's feelings and needs. In addition, the staff is empowered to address the needs of all the surviving residents of that home, the extended family, by recognizing the impact of a housemate's loss and addressing their grief either on their own or by requesting the help of professionals to aid them.

Historically, the DD have not had many opportunities for personal reflection or attention from involved listeners. For so long it was believed they had no story to tell. Their losses and their grief are no less significant than anyone else's. The ultimate goal of treating the DD individual with person centered planning, with choices and preferences, with presence, with dignity while following the principles of 'do no harm,' 'do what is good' and 'do what is just' will assure that we have respected the rights of the DD who may be dying, or suffering the loss of a loved one. It will validate that we can treat and respect them as we would want to be treated and respected. It will invite us to bear witness to their suffering and to ensure that their voices are heard.

*Heidi Weiss, LMSW, is a licensed social worker at Westchester Jewish Community Services. She received her BA from SUNY Buffalo and her MSW at the University of Connecticut School of Social Work. Presently she is working as a care manager in the Pathways to Care program, a program that provides an array of services for individuals and families facing life threatening, chronic and terminal illness. In addition, she is presently pursuing a second Master's degree from the Health Advocacy Program.*



# From Economics Paper to Op-Ed and Speechmaking: One Student's Journey into the Political Arena

By Jean Anne Cipolla

I began the Health Advocacy Program in September 2005, initiating a two year process of professional change, leaving 18 years of technical writing behind. Personally, I struggled with depression and anxiety, finding good treatment for my mental illness in my late 30s. In my application essay, I wrote,

"I come from a middle class family who are now well-educated about mental illness. I have had excellent insurance. And even so, I have had serious issues getting good mental health care ... been treated badly in the workplace because of my illness or had my illness dismissed or ignored as 'all in your head' by friends and co-workers ... I want to turn my experiences into a positive growth change for the larger community and contribute in a meaningful way. More people deserve to get better mental health care."

Because other loved ones who suffered from serious mental illness and addictions also had trouble getting access to good mental health care and appropriate insurance coverage, I felt drawn to study mental health policy and insurance parity issues. Each class allowed me to examine these subjects differently. But one changed my experience from the personal, that of a student heading towards a new career, to the political, where the internal me needed to quiet fears and move quickly into unfamiliar territory – the worlds of Op-Ed writing, public speaking, and legislative politics – all in less than two months.

How did it happen? Enter Peter Arno, Ph.D., who teaches the Economics of Health class. For his class, we were assigned two ten-page papers on health economics. But Peter offered us a challenge. We could substitute an Op-Ed piece on any area of health economics for one of those papers and try to get it published. None of his previous students had taken him up on this challenge. It seemed intriguing and yet too difficult.

None of us wrote an Op-Ed for the midterm assignment. I wrote my paper on the economic effects of the mental health parity law in Vermont and had written a previous paper in Health Care Policy class on the legislative process used to bring Timothy's Law (the NY State Assembly's version of a Mental Health Insurance Parity Law) through the New York State Assembly. When we were

ready to start our final economics papers, Timothy's Law was coming to the floor again in the New York State Senate for a vote. The mental health and recovery communities, supportive legislators, and advocates around the state were gearing up for rallies and speeches. I decided to take the chance, write what I knew about the economics of mental health parity in New York State and how passing Timothy's Law could help more of the mentally ill and chemically dependent gain access to the treatment they needed without increasing insurance costs.

I submitted my first draft. Peter showed the piece to a friend, a writer named Thom Forbes. They edited the piece with me. Thom pushed me hard on the facts, which I proved out with my source materials. I rewrote the piece many times in one week until both Peter and Thom thought it was ready for submission. There was an upcoming Timothy's Law Rally being held the following week in White Plains, so we agreed that *The Journal News* was a natural fit. I sent it off via email and hard copy. I held my breath. On April 30, 2006, my Op-Ed appeared in the *Sunday Community View* section. It was published.

The snowball effect was overwhelming. Thom and his wife Deidre are active in the Timothy's Law Campaign and Faces and Voices of Recovery (FAVOR), a national advocacy campaign for addiction recovery. Their contacts in the Timothy's Law Campaign wanted to include my Op-Ed in the press pieces being handed out at the statewide rallies. How and why would I refuse? Thom had been so helpful to me; I was writing to advocate for passage of a mental health parity law in New York State based on the economics and people wanted to use my work. I was stunned; I wasn't an economist. I was just a graduate student, still learning.

The national FAVOR organization asked to post the piece on their website. Several other mental health and news websites posted it without contacting me first (ah - the power of the internet – but if they don't credit you correctly, you have to correct them.) Sarah Lawrence added a link to *The Journal News* piece and a description of my work on the "Voices of Health Advocacy" webpage. Now I am "Google-able."

The shock came when the Timothy's Law Campaign invited me to speak about

the economics of mental health parity at the rally in White Plains. Thom Forbes was the master of ceremonies on a sunny May day. Tom O'Clair, Timothy's father, was the first speaker and powerfully relayed to the gathered crowd the suicide of his 12-year old son, an unnecessary death if Timothy had been able to get the treatment he needed. The rally was held on what would have been Timothy's 18<sup>th</sup> birthday. I spoke after Tom O'Clair; he'd been speaking on this issue for 5 years. I'd never spoken in public before. My hands, with my notes in them, shook. People, including my 82-year old father and 75-year old mother who'd never been to a political rally before, held placards aloft which read "Pass Timothy's Law NOW!" and "End the Discrimination!" Two of my classmates, Barbara Robb and Joyce Jacobson, were there to support Timothy's Law and me. I looked out to the crowd and told them what I knew, the economics from the research I had done. I spoke and became part of the circle of advocacy. I never used my notes. When I left the stage, Tom O'Clair thanked me and hugged me. I shook hands with politicians and supporters. I had become a public speaker and public advocate.

Several individuals told their stories of mental illness and addiction and families who have loved ones in the struggle spoke beautifully. After the rally was over, my parents, Joyce and I went to lunch. My father said he never understood what parity would mean to people until he heard them telling their stories. It made him cry. Now he knows why it's so important. I'll keep studying, writing, publishing, advocating and speaking publicly when given the chance.

Author's note: Gov. Pataki signed Timothy's Law on Dec 22nd and it went into effect on Jan 1, 2007.

*Jean Anne Cipolla is a graduate student in the Health Advocacy program at Sarah Lawrence College with academic interests in mental health law and policy, insurance parity and the use of illness narratives and oral history therapies as mental health treatment modalities. She has completed fieldwork with the Riverdale Mental Health Association and Westchester Children's Association and is currently working on a report for WCA on available mental health resources in Westchester County for children between the ages of 0 and 6 and their families.*

# Beneath the Skin

By Marisa Bois

The following poems are excerpted from a lengthier piece entitled, "Beneath this Skin." This illness narrative began as a conference project during my first year as an SLC undergraduate in 2001 and is continuing today, as I mature into a woman

learning to live with a chronic illness. My involvement in the Health Advocacy Program as an undergraduate student included participating in workshops and readings; and as a graduate I have been lucky enough to attend the conference entitled "Writing the Medical Experience." After two summers I hope to revisit WME in 2007!

When I say it *hurts*, that I can't get out of bed, can't even get to my feet, what do you think?  
do you see me in black and white, a photo faded, parts of me peeled away, aged with too many years?  
do you see me through glass, a shield *you* have grown, luminescent green leaves crushed between, so you can't reach through to touch this new skin?  
do you trust me? That you don't have to see the way lack of sleep lies in shadows beneath my eyes, to believe?  
How will you know, I mean really *know*, if I'm telling the truth, that I'm not overreacting, dramatizing, or worse, lying? Maybe I just don't want to wake up and face this day.  
How will *I* know if you believe me, that you won't think I'm a wuss, that I'm overreacting, that I'm just *weak*?  
Should I grow my own wall, one of bone and blood; an even thicker skin than I already have, so that no matter what I may see pass through your eyes, my heart won't curl inwards, away from you, away from us.

Illness creates  
space  
room  
for things  
to take root  
soil rich and  
dark  
home of  
insects with  
delicate legs  
a thousand eyes  
to see both you  
and  
I

let's grow  
beneath  
silvers  
rain  
metal moons  
the sick heat  
of suns  
let's bury  
our toes in  
earth deep  
twining green  
vines  
ache for light  
we are  
we  
will be  
animals that  
live beneath

Stitch me with  
memory's  
thread  
sewn into bone  
below muscle  
through veins  
bring blood onto this  
skin

pink beauty beneath  
steel  
scalpel slows  
silvers tip  
slips below  
skin  
close to bone

soft  
it snakes and  
sticks  
skin rose  
rubbed smooth a  
stone worn  
by  
a river's run

tethered to its  
coiled tail  
marred  
more beautiful

in a brilliant white  
room  
beneath fingers  
sewing  
moving inside  
help me  
remember

silk threads they  
stitch memories  
into this  
skin

Since graduation Marisa has been living in Portland, Maine and teaching art to both middle and upper school students. She writes on her own, takes art class on the side and recently attended a creative writing/visual art retreat where the facilitators believe in the connection between the arts and healing. She hopes to use the creative arts to work with youth living with illness while they are staying in the hospital.

# Powers That Be

*Continued from page 3*

have to tow the van. I mention the problem with the wheelchair, and he peers into the car, sizing up Ansel with a glance. "What do you weigh, buddy?" he asks, and Ansel answers, "A hundred and ten," but what the guy doesn't realize is that lifting a 110-lb. person with muscular dystrophy is not like lifting someone else of equal weight; it's like lifting a 110-lb. sack of wobbly, yielding potatoes. Can you do it? I ask and he says he can, but he doesn't seem to take this as seriously as I know he should.

But what am I to do? I maneuver the wheelchair sideways; he lifts Ansel out of the van and I sit and wait in the driver's seat with my fingers crossed. Within a minute, from the other side of the truck I hear a faint but sharp sound and then a low moan; and I rush over to see what's happened. They are sprawled there on the wet asphalt, the skinny driver clutching an injured Ansel on his chest, in the pose of a distorted Pieta, and neither shows any sign that they might get up. "Are you OK?" I ask frantically, first of Ansel and then of the driver. "Is my jacket

ruined?" Ansel whispers back desperately. His back hurts, he says, and I think he might cry. I can't get a straight answer from the driver; He just seems amazed that he's fallen.

We somehow lift Ansel back into his chair and I reopen the carved wooden door of the church. The driver follows us in, which doesn't seem wise: I think Ansel and I now really need our own tête-a-tête, a private reorganizing, a family huddle.

Once inside the tiny chapel, Ansel finally breaks down; he curses the triple A, Paratransit, and just to be fair, God, which disturbs the driver no end. "I know you're hurt," the guy says, "but not in a church, not in a church. It just ain't right". This just makes Ansel more furious; his face becomes an angry, shamed blur, and he starts to weep.

I realize we no longer need Good Samaritans; I dial 911.

It seems as though every emergency vehicle in creation instantly arrives. Members of the church, as well as the minister, roused by the lights and sirens, also crowd in. The EMTs, solid and reliable and godlike, check Ansel's vital signs and lift him onto a narrow stretcher and into



*Penny Wolfson*

an ambulance. I wheel the power chair into the car; within a few minutes, the triple A man has whisked them to some anonymous garage.

And so here we are in the ER, sneaking in some dinner while we wait for results. Joe and Toby join us, bringing the other car and the manual chair into which Joe will schlep Ansel when we are able to leave. Exhausted, I fall asleep on the leather sofa in the waiting room.

Ansel's OK, just bruised; after some tests they give him some Percoset and send him home. Next day the sun is out. I call the garage, they have fixed the belt, and I take a \$28 cab ride up to Hawthorne to retrieve the van.

*Most of the time Ansel rolls quirkily, merrily along. In September he and his 19-year-old sister took a trip to England and Holland, and aside from a one-day transatlantic wheelchair emergency, they did fine. Ansel is busily studying for the GREs so he can apply to graduate school in museum studies, and in February 2007, he starts his internship at the Museum of Sex in Manhattan. There I have a feeling he'll be able to recite obscenities against pretty much anyone and no one will care.*

*Penny Wolfson has been writing about her son Ansel and Duchenne muscular dystrophy for nearly twenty years. She won a National Magazine Award in 2001 for her essay "Moonrise" and is the author of a memoir of the same name, published in 2003 by St. Martin's Press. Her work has appeared in The New York Times, The Atlantic Monthly, and The Washington Post, and will appear in Vogue and Print this year. She teaches non-fiction writing at the college.*

## Applied Research Ethics Certificate Program

Sarah Lawrence College is offering a new Applied Research Ethics (ARE) Certificate Program aimed at healthcare professionals who will work on research-related issues in clinical settings, with disease-specific groups, with research organizations and in oversight agencies and local communities. The focus is on learning strategies to formulate research questions, design studies, insure informed consent and human subject protection, increase accountability and educate patients and the general public. The program kicked off in January 2007 and current students are very enthusiastic. The ARE program is organized as a series of theme-based modules, each of which will include a professional development component, featuring experts who will discuss career opportunities within the field. In addition, students will be required to complete a capstone project, which will connect students directly with a faculty advisor and with workplace settings.

The program is designed on a "low-residency" model with the working professional in mind. Courses are offered on weekends and in short, intensive sessions that require minimal time off from work. Participants may enter the program in June or January. To earn the certificate, participants must complete all modules associated with the program. Alternatively, modules may also be taken for Continuing Education Units.

For more information on the Applied Research Ethics Certificate Program, please visit [www.sarahlawrence.edu/ARE](http://www.sarahlawrence.edu/ARE) or contact Dr. Rachel Grob, Associate Dean of Graduate Studies, at [rgrob@slc.edu](mailto:rgrob@slc.edu) or (914) 395-2371.

# WORD: The Illness Narrative

By Rose Bromberg

It began with a bout of mononucleosis. The mono ran its course, yet I continued to feel ill.

I had debilitating fatigue and weakness, muscle and joint aches and pains, fever, headaches, sore throats. It felt like a 'chronic mono' or crushing flu. Yet my exam and tests were negative except for immunological abnormalities. No one knew what to make of them.

Many doctors didn't take me seriously and many didn't want me as a patient. I began to investigate what this illness was and how to treat it. But there was one problem: If I didn't know what it was, how could I look it up to read and understand?

I read all I could on viral syndromes and chronic mononucleosis and came up with a series of articles on chronic fatigue syndrome (CFS). The symptoms of this syndrome sounded exactly like me, and eventually a couple of doctors confirmed the diagnosis. Yet there was no specific treatment. At about the same time, the CDC and NIH were collecting data and conducting research on CFS. There was much controversy over the information. This posed other problems.

So I was given a name for my symptoms: chronic fatigue syndrome. I then was able to further research and try to make sense of what had happened to me, only to find out that there was a stigma attached to this name and illness, and I was no better off than before.

In fact, my then-insurance company wouldn't cover me for some medical tests because chronic fatigue syndrome was not yet listed as an illness, so there was no specific diagnostic code. According to many insurance companies, I had an illness which categorized me as ineligible to obtain certain types of insurance policies. And our government and court systems didn't want to give credibility to my disability claim because there was no impairment code listing. To some I had an illness, but to others I did not.

No one appeared to understand why a normal, healthy individual who was working full time, enrolled in a Master's program, hiked, swam, socialized, and

was independent, had mononucleosis and one year later was often bedridden with debilitating symptoms. Nor did I.

When I'd mention my health situation, I'd be asked: chronic fatigue *what?* And I'd have to explain that this is a syndrome, a constellation of symptoms (and I'd

to volunteer in various capacities but, in each case, my symptoms waxed and waned. Sometimes a new problem would appear. This led me to be inconsistent, unreliable, and unable to meet deadlines, so unlike my old self.

I experimented with traditional treatments as well as complementary measures including acupuncture and nutritional and herbal remedies. I tried to live within my limitations. I went out and experienced life in short intervals when possible.

For some time, I was feeling better but symptoms were still unpredictable. I developed new interests and hobbies and tried to live without defining myself by my illness or allowing the illness to define me. But there were times the illness took over and I had no control. And I missed my old life. When speaking to people, I often found myself making reference to my former life and activities, mourning and marking the time passed, by saying "When I used to swim 40 laps," or "When I used to hike 10 miles with the Sierra Club."

From time to time I wondered if I had fibromyalgia, a condition similar to CFS. Because they were so similar, some doctors used the words fibromyalgia and chronic fatigue syndrome interchangeably. It was difficult to find doctors who were knowledgeable or who cared about my situation. I was more internet savvy at this point, and often perused Medscape and Medline to keep up with the latest research and treatments, and /or to help me formulate questions to ask my healthcare professionals. I thought this would allow me to be a participant in my health and recovery and make informed choices. Yet there was still so much I didn't know.

I then tried calling the offices of some rheumatologists. After being questioned on the phone about my medical history and symptoms, I answered them by first explaining I had chronic fatigue syndrome, then listing my symptoms, but none of them would see me. Some practically hung up on me.

Then it occurred to me take another tack. Through my research and direct contact with the medical community, it

## WORD

*Crazy*, he mumbles,  
the end of his white coat  
clipping the exit  
as he turns and swings  
into the corridor.

His hand briefly holds  
the edge of the doorjamb  
as if it couldn't support  
itself without him.

Crowned in hauteur,  
he leaves through  
the Arc de Triomphe, a curvature  
made only for emperors.

Cold sitting here  
in this paper robe,  
my skin, goose bumps  
bristling like sandpaper,  
absorbs the chill  
left in the air  
from a word.

—Rose Bromberg

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SUNY Upstate Medical University,  
October 2006

name them), with no specific etiology or treatment, at least for now. I'd get some very strange looks or responses. One person asked me why I wanted to be sick. Another said dubiously, "You look well." And yet another, on those days when I looked as awful as I felt, said "Would you like some make-up?" Some in the medical community questioned my credibility altogether.

I made efforts to go back to work and

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# WORD: The Illness Narrative

*Continued from page 10*

was becoming apparent that choice of language might be critical. One piece of terminology might be remote and another more accessible. Cracking this code and overcoming the language barrier turned out to be my big breakthrough.

When I called another office to try to make an appointment and was asked about my history, I first mentioned the possibility that I had fibromyalgia. I then described my symptoms. It was like magic, I was able to get an appointment for a consultation.

When making future appointments, I continued to make sure I first used the magic word. I was able to get more polite responses. Although some of these doctors still wouldn't see me, I was able to get appointments more easily than others. Fibromyalgia did continue to open doors.

So, who actually gets the formal diagnosis of fibromyalgia? This poses an interesting dilemma. According to the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) and the American College of Rheumatology (ACR), to be diagnosed with fibromyalgia, a person has to have "widespread pain in all four quadrants of the body; both right and left sides as well as above and below the waist lasting more than three months and the presence of tender points." The ACR has also designated 18 sites on the body as possible tender points. For a diagnosis a person must have 11 or more tender points, and the person must feel pain when pressure of four kilograms is applied.

If patients with fewer than 11 tender points are given a diagnosis, studies or data may be skewed. Yet there may be patients whose medical history is consistent with the fibromyalgia diagnosis, but who happen to have fewer than 11 tender points upon exam. In addition, tender points can often vary in location and severity on different days. This is due to a variety of factors including symptom triggers and treatment strategies.

I finally saw a rheumatologist who told me my history was consistent with the diagnosis and I have tender points, but not the classic 11 to 18. As he sat there, he was thinking out loud and briefly considered whether or not he'd write the word fibromyalgia in his report. By the way he spoke and acted, it appeared arbitrary to him. I then asked him a question. He dismissively waved his arm into the air like a wand, essentially told me I

had to do things his way, and left the room with an attitude, his white coat bouncing off the door frame.

It happened so fast, yet that flick of his wrist and pen to paper changed my life. My diagnosis became fibromyalgia. That one word has such a different connotation in the medical world. Although still met with much skepticism, fibromyalgia is a more acceptable diagnosis than chronic fatigue syndrome because of the clinical finding of tender points.

Yet I'm the same person, the same patient. I basically have the same symptoms as I did when I first became ill. So what really changed?

Simply put, the name of the diagnosis. That changed perceptions. Changing perceptions changed thoughts, feelings and behaviors. This changed my experience of illness. I now had more credibility, more access to doctors who took me seriously and access to better healthcare.

What are chronic fatigue syndrome and fibromyalgia? Are they the same illnesses? Related illnesses? Two different illnesses? Did I have chronic fatigue syndrome and develop fibromyalgia? Or did I always have fibromyalgia but originally wasn't diagnosed with the pain syndrome? I don't know.

In various ways, some of which I explain in this narrative, I live in a fragmented world. It's fragmented in the way our culture and society perceive illness, particularly certain types of illness. It's fragmented by the nature of our healthcare system, by insurance, government, and social providers who are often not in sync and often at odds.

This is the world in which I seek help and live. Living through these difficulties teaches me how to become an educated healthcare consumer, how to navigate these problems, and how to advocate for myself.

I now manage my illness in a variety of ways and have integrated illness into my life. I found people who understand me and my illness, but who also see beyond my illness and who don't define me by it. I am lucky. I have a wonderful husband and friends. I'm now a published poet. I have established new interests and am able to volunteer/work with people who are willing to accept my situation. I also have a few healthcare providers who have been very professional and helpful, and to whom I am grateful.

My poem, WORD, using one particular doctor as a caricature, speaks to many of my medical experiences, emphasizing doctor-patient relationships which include issues of power and control, gender, labels, and general communication. My poem and the accompanying illness narrative are a commentary on how both healthcare providers and patients work and live in a fragmented world, and how all of us need to function together to create a whole system to more effectively relieve suffering and create a community of healing.

*Rose Bromberg, in addition to being happily married to her husband Sam, has five nephews and one niece, devotes much time to developing and advancing her poetry, and is involved in narrative medicine.*

## Robert Wood Johnson Health Investigator Award

Rachel Grob, HAP Faculty Member and alumna ('92), has begun work – along with Barbara Katz Rothman of the City University of New York – on her foundation-funded research about newborn genetic screening. Current projects include an expanded qualitative research study examining parents' experiences with newborn screening; an analysis of parental involvement in the policy-making process; and content analysis of newborn screening media coverage. Rachel's first publication in this area, "Parenting in the Genomic Age: the 'Cursed Blessing' of Newborn Screening," was published in the journal *New Genetics and Society* in August of 2006.

# To Pee or Not to Pee

By Rosie Hoffman

I am sick. I have a couple of health problems that have clear diagnoses, and a few issues that are still without a label. Sometimes I have to urinate twenty times a day. At other times I have “retention” when I can’t pee even though I’m dying to. For a time it was thought that my bladder problems were caused by the stress of my other illnesses. During this stage, my urologist out-sourced me to alternative medicine practitioners.

I was sent to a bio-feedback therapist who told me that I should “have eyes closed, listen to the meditation tape, let go of any assumptions.” Then to a physical therapist, who specialized in pelvic floor dysfunction, who massaged my lower abdomen to release my tense muscles. Next I saw a social worker who also practiced sex therapy (the pink-painted walls had pictures of genitalia-shaped flowers adorning them), looking to uncover deep seated emotions. After that failed to help, I visited a massage therapist who employed Native American dream catchers and New Age music to set a spiritual ‘house of wellness.’

Within four months I was back in the urologist’s office, with two complaints – I still had my physical pain, and now my sensibilities were inflamed too. He prescribed uro-dynamic testing.

It took two doctors, a Fellow, and a nurse, using various machines (including a specially-rigged toilet), watching me pee, to figure out that I have a real dysfunction of involuntary bladder muscles. My urologist had me try many medications; none proved effective.

My doctor recommended Clean Intermittent Catheterization (CIC). CIC is the process of sticking a long piece of plastic up one’s urethra in order to release urine, every three to five hours. It sounded pretty awful, but if it would relieve my urinary symptoms, it seemed worth it.

I called the doctor’s office to schedule a nurse’s visit to learn CIC, but the receptionist informed me that the nurse was on vacation and would call me back. So I waited a week and called again, when I was told that the nurse (Nancy) was very busy and would call me to schedule an appointment. It took me five weeks to chase her down, and when I finally got on the phone with her, she barked at me explaining that she didn’t have time to schedule me in and she would call me back. I had to call the Doctor, who actually *was* busy, to tell him that I couldn’t

learn CIC because his nurse wouldn’t schedule it. Finally she called and the appointment was scheduled. If it took that much effort to book the lesson I could only imagine how arduous it would be to learn under this nurse.

We got to the office and, as usual, sat in the waiting room for an hour, only Montel Williams blasting on the ceiling-mounted TV to keep us occupied. We were then escorted to an exam room to wait another hour. The distraction offered in our room was a colorful array of charts illustrating erect penises, dysfunctional penises, a wide variety of bladder problems, and enlarged prostate glands, all advertising various medications. Finally Nurse Nancy decided to grace us with her presence.

The nurse was all of 4’9” with dyed brown hair, large plastic glasses, and a scowl. She apologized half-heartedly about her rudeness on the phone. She spent the next hour explaining the workings of the bladder, the history of catheterization, and insisted that the doctor was a moron about types of catheters. Then Nancy told me that there are so many more painful things that patients must do and I shouldn’t complain, it wasn’t a big deal. By the end of her lecture I was sobbing and threatening to leave.

A catheter is a large plastic tube, and there are lots of things that accompany it. I’d have to carry around a catheter, liquid soap, paper towels, zip lock bags, and lubricating gel with me. I am a teenage girl. Other girls constantly look through my purse without asking, for lip gloss, mints, etc. There was no way that I could successfully hide all of this equipment in my bag. The idea of having to explain what was in my purse was awful. I imagined having to say “Yeah that’s the thing I stick up my urethra to pee.” Lovely.

The nurse menacingly told us that with my attitude she simply couldn’t teach me. I explained that my attitude wasn’t going to change simply because she told me to. After bickering with her, my Mom, the day’s designated referee, decided it was time.

We went into the bathroom. Nurse Nancy explained that I’d have to lubricate the catheter, find my urethra, and

stick it up there. Some background: the entrance to the female urethra is not apparent to the owner’s eye, unless a second party holds the magnified side of a mirror in front of the barely visible anatomical part. Nurse said I wasn’t allowed

to look, “just use your finger,” so I blindly searched for the supposed bone that my urethra was in front of. She got very frustrated and, using her latex-gloved finger, showed me where it was. After I failed to get the catheter in, she positioned it and shoved it in for me. I was instructed to rinse, and repeat. By the end of our practice session, I was bleeding, in horrible pain, and so traumatized that I didn’t really learn how to do it.

We left the bathroom, and she explained to me that I shouldn’t use numbing jelly until I got used to the correct placement, but that in a week it should stop being so painful. As a treatment, Nurse Nancy showed me how to fill a condom with hot water, tie a slippery knot, and then stick it in my underwear to relieve my pain – a modern day hot water bottle. I wondered what my friends would think seeing condoms in my bathroom. What if one flew out between my legs? I’d have a lot of explaining to do.

Cursing under my breath, “Mom, let’s just get the f... out of here,” we gathered our goodies (catheters, tubes of lube, condoms) into a bag, and promised that I’d begin the every 3 – 5 hour schedule later that evening.

Nurse Nancy was right. After a week I stopped bleeding. After two weeks I was used to the schedule. I was able to find an inconspicuous makeup case to hold my paraphernalia. While I am successful with CIC, it hasn’t fully resolved my urinary problems. It appears that I’ll need a number of new medications in order for this to work, and I’m currently busy experimenting.

And that is what I did over my summer vacation.

*Rosie is a student at Village School, and also at North High School, and the Student Director of the musical at South High School. She travels to three schools every day! Rosie is the daughter of Maggie Hoffman, founder of Project DOCC, who is enrolled in the Applied Research Ethics Certificate program at SLC.*



Rosie Hoffman

# Women's Illness Narratives: The Importance of Voice and the Privilege of Witnessing

By Sayantani DasGupta and  
Marsha Hurst<sup>†</sup>

Illness narratives are particularly important for women, who have historically had their bodily experiences defined, categorized, and encapsulated through narratives structured by the patriarchal medical system. The medicalization of women's health has sought to narrowly define experiences such as puberty, childbirth, or menopause, attributing them to biological "truths" and ignoring the impact of culture, ethnicity, nationality, class, or sexuality. To listen to women's individual voices is to acknowledge the variety of women's experiences and move beyond narrow, medically defined categories. Prior to the professionalization of medicine, illness was a private experience located within families and traditionally under the dominion of women. With the rise of the medical profession, the illness experience became primarily removed from private suffering to a public experience mediated by physicians. Therefore, listening to the stories of women allows for a new understanding of the relationship of those individuals to themselves, but also to their medical caregivers, their families, and their communities. The story of women's illness narratives is the story of the personal made public, or, if you will, made political.

The invitation into this text is not without risk. In the words of physician-writer Richard Selzer, "I feel some hesitation to invite you to come with me into the body. It seems a reckless, defiant act." By inviting you into these stories of suffering, this book risks participating in and facilitating a kind of voyeurism, whereby suffering is "construed at a safe distance, without the social responsibility of real engagement." At the very least, these narratives run the risk shared by both medicine and literature, a risk emerging from their nature as representational, a risk of becoming totalizing enterprises.

Recent published illness narratives of

otherwise public figures, including, among others, athlete Lance Armstrong, writer Joan Didion, and television film critic Joel Siegal, reflect a very literal desire to "identify the face" of illness. This is totalizing to an extreme, whereby there exists a story that is the cancer narrative, the Alzheimer's narrative, the woman's narrative, and so on. It is important to remind ourselves that illness narratives, and particularly published illness narratives, represent a distinct minority of those who suffer from disability and illness. For each individual who has the skill, facility, and time to translate her story into writing, let alone the ability to publish that writing, there are countless others whose stories remain unheard. These stories are often those that are difficult to hear—angry stories of medical mistreatment, stories of socially marginalized individuals such as prisoners, and stories that are unresolved and still in the midst of chaos. The practice of eliciting, witnessing, and recording oral stories is one methodology by which to bring to public attention these stories that might otherwise have remained private suffering.

Whether written or oral, illness narratives are not only important to those who do the telling but those to whom they are told. Indeed, illness stories are inherently social and usually presuppose an audience. This audience can be the physician or the friends and family who listen to the ill person's verbal tale, the support

group who reacts to the shared journal entry, the community of sufferers who reads a personal story in a newsletter, health-care scholars and students who study a published poem about sickness, or the wider public who reads a variety of published work about illness and health. How, then, is the reader of this volume to position him or herself? It can perhaps be posited that not only listeners, but readers of illness narratives can engage in what Arthur Kleinman calls "empathetic witnessing." And so, in answering this call of the suffering body—these narratives of women's illness experiences—the reader becomes engaged in a very critical and special position: the reader becomes witness.

Whether man or woman, student or teacher, health-care provider or patient, policy maker or family caregiver, the reader of *Stories of Illness and Healing*, will be invited to engage with these narratives and allow them to engage the reader. They are intended to impact not just our personal understanding of illness but the public ways in which we apply that understanding. Be it activism, education, policy making, advocacy, family caregiving, or personal transformation, this book is ultimately an invitation to translate the witnessing of suffering into empathy, care, and action.

[Note: References available on request from mhurst@sarahlawrence.edu or in forthcoming book.]

## Health Advocacy Represented at the Narrative Matters Conference in Nova Scotia

In May 2006, Marsha Hurst chaired a symposium at the Narrative Matters conference held at Acadia University in Wolfville, Nova Scotia. Sayantani DasGupta and Pat Stanley joined Dr. Hurst in presenting papers with oral historian, Jessica Wiederhorn and Rose Newnham of the Oral History Department at Columbia University. The title of the symposium was "Listening to the Patient's Voice: An Interdisciplinary Approach Integrating Oral History, Illness Narratives and Advocacy." The panel demonstrated that oral history, typically constructed with an historical gaze, focuses first on an external frame as a place to gather interviews of a particular population. It is the external framework that gives impetus to the collection of interviews for how people saw an event or lived through an era. Oral historians, as such, build a box which serves as a place to gather interviews of a particular population. In contrast, the roots of illness narratives are literary. They stem from the individual story told by the patient, caregiver or witness which gives voice to the ill body and is told through that ill body. The literary gaze looks at what is inside the box and the framework is constructed around the internal content. Looking inside the box, narrative study decodes, recognizes and recontextualizes this content to create a new interpretation. Although the roots of both disciplines are very different, the panel concluded that both oral history and narrative study can inform each other and mutually expand the visions of each with additional layers of interpretation and application.

<sup>†</sup> Excerpted from "The Gendered Nature of Illness," the introductory essay in *Stories of Illness and Healing: Women Write their Bodies*, a collection of women's illness narratives edited by Sayantani DasGupta and Marsha Hurst, forthcoming in October 2007 from the Kent State University Press.

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