HIV/AIDS: the crisis, the care, the community

A special issue of Caring Headlines designed to coincide with the Boston Black Church Week of Prayer for the Healing of AIDS
HIV/AIDS: our resources and our resolve

This is a special and very important issue of Caring Headlines. MGH is once again participating in the Week of Prayer for the Healing of AIDS, and this issue was specially designed to coincide with our service in the MGH Chapel to support this effort to raise awareness about the effects of HIV/AIDS on the black community. MGH is an internationally recognized leader in HIV/AIDS care and research, and we are honored to be part of this important event.

I hope you’ll take advantage of this opportunity and read the many stories and articles in this issue of Caring Headlines. They tell a compelling story about the HIV/AIDS crisis and the communities most affected by this international pandemic. They remind us of the courage and commitment of patients and caregivers alike as they battle this terrible disease. And they call upon us as individuals and as a society to get involved.

Part of being involved is knowing what resources we have in place to help educate and support our patients with HIV/AIDS. Toward that end, I offer the following list of HIV/AIDS-related resources available here at MGH and in our community.

Let us all defy that voice inside us that says we can’t make a difference.

Resources

- Infectious Disease Associates offer comprehensive HIV care; anonymous HIV testing; primary care; specialty clinics with neurologist, dermatologist, and nutritionist; access to HIV clinical trials; a Hepatitis-C co-infection clinic; an acupuncture clinic (for side-effect management, symptom- and stress-reduction); a multidisciplinary team of nurses, social workers, case managers, doctors, and mental health services (including: individual, couples, family, and group); psycho-educational forums; and collaboration with West End House for addiction services.

- The Andrews Unit is an outpatient psychiatric service that specializes in HIV care.

- Our department of Social Services has a specialized team of HIV social workers that assists with case management, crisis intervention, mental health services, staff training, educational forums, and consultation. Social workers are available to assist clients with special programs (including: PEP (a post-exposure prophylaxis program for healthcare workers, individuals who have been sexually abused, and others); insurance programs (HDAP/CHII, which covers HIV medications, COBRA payments, premium payments for individual non-group programs; home care through the Social Services Department; and The Family Care program (Social Services: (617-724-5600)

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A special thanks

Our hospital community was besieged by tragedy last week when a devastating storm claimed the life of MGH employee, Ricardo Diaz, and a deadly fire destroyed a night club in Rhode Island. I cannot begin to express how proud I was of our MGH family as, in the face of great sadness and grief, you rallied to come to the aid of those who so desperately needed our help. I can’t recall a time when I’ve seen greater effort put forth, or greater challenges overcome with such grace. Thank-you for the incredible strength and compassion you showed. You did yourselves and MGH proud, one more time.

Distribution of people estimated to be living with AIDS by race/ethnicity at the end of 1999

<table>
<thead>
<tr>
<th>United States</th>
<th>Massachusetts</th>
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<tbody>
<tr>
<td>38.3% White</td>
<td>48.5% White</td>
</tr>
<tr>
<td>40.6% Black</td>
<td>26.4% Black</td>
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<tr>
<td>19.7% Hispanic</td>
<td>24.0% Hispanic</td>
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<tr>
<td>0.8% Asian/Pacific Islander</td>
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<td>0.3% Am Indian/Alaska Native</td>
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Week of prayer for the healing of AIDS

—by Deborah Washington, RN

The Boston Black Church Week of Prayer for the Healing of AIDS is 14 years old this year. The event is part of a national initiative to raise awareness about the effects of HIV/AIDS on the black community. In addition, the week highlights the work of black churches in addressing this health crisis for black people around the world. The Week of Prayer is the largest AIDS awareness program in the country to focus on the black community. It is modeled after a program created in Harlem in 1989 by the founder of The Balm in Gilead. Many will recognize the name of this Harlem-based organization as the title of what was once a ‘Negro’ spiritual.

Sometimes I get discouraged, and think my work’s in vain.

But then the Holy Spirit revives my soul again.

There is a balm in Gilead to make the wounded whole...

According to the Hebrew Bible, Gilead was an ancient city renowned for its physicians and a special healing ointment believed to have miraculous powers.

This year the Week of Prayer for the Healing of AIDS is a collaborative effort between the AIDS Action Committee’s Who Touched Me Ministry, Healing Our Land, and the Multicultural AIDS Coalition.

Robin M. Fuller-McGill, faith-based initiative manager of the Who Touched Me Ministry, says, “Services of worship, prayer, and educational workshops will be held at various congregations throughout greater Boston and beyond focusing on the theme: ‘Black people are dying; it’s time for a change.’"

This year, the week begins on Sunday, March 2, and continues through Saturday, March 8. During the week, spiritual leaders throughout the city will share information on the devastating effects of this disease on the black community. Seeking to educate, promote prevention, eliminate the stigma, and provide spiritual comfort, black churches and others who support this agenda, will offer services during those seven days. Services at MGH will take place on March 6, at 12:00pm, in the MGH Chapel.

This is the second year the MGH Chaplaincy, with the support of the Week of Prayer Planning Committee, has been involved in this annual event. MGH continues to be the first and only hospital in the city to participate.

We are becoming increasingly aware of healthcare disparities in the United States. Former US Surgeon General, David Satcher, MD, spoke about racial disparities in a recent presentation at MGH. In short, multicultural communities do not enjoy the same level of health, or health care, as white communities. Healthcare providers, researchers, and policy-makers are only just beginning to synthesize this data into a meaningful format, which will give us some understanding of how we can work together to change this current state of affairs.

AIDS is a pandemic disease in the national and global black community. The involvement of MGH in events like the Week of Prayer and other collaborations with community organizations, is an important link in the dissemination of information and in promoting access to quality health care for all. We are proud to participate in this week of prayer for the healing of AIDS, but let us not forget how much remains to be done in meeting the healthcare needs of a truly diverse and multicultural society.

Facts about HIV/AIDS and the global black community

- African American children represent 62% of all reported pediatric AIDS cases.
- One in 50 African American men is HIV-positive.
- One in 160 African American women is HIV-positive.
- African American senior citizens represent more than 50% of HIV cases among persons over 55.
- In 1999, black teens accounted for 15% of the adolescent population in the United States. More than 60% of AIDS cases reported that year were among 13–19-year-old blacks.
- 48% of the world’s HIV/AIDS cases are in eastern and southern Africa.
- Of the estimated 40,000 new HIV infections each year, more than 50% occur among African Americans.
- AIDS is the number one cause of death for African American adults aged 25–44.
- AIDS is the number one cause of death in Africa. Not war. Not famine. AIDS.
- As of December, 1999, there are 360,000 adults and children living with HIV/AIDS in the Caribbean.

Oh, the things we learn... when we listen

Life and all its journeys. Do I dare define these last few years as a journey? Or rather a quest of self-discovery. An expedition that has allowed me to travel continuously through time.

So many thoughts, experiences, emotions, and images run through my mind as I finally start to put words on paper. My first thought is where on earth do I begin? I guess the logical place is the beginning.

In all the books I’ve read in my 35 years on earth, I’ve always enjoyed learning about the authors and their personal histories, for it’s their experiences in life that made them who they are. So let me start by telling you a little about myself. I’m one of three children. I was born in Boston. My parents still enjoy a loving marriage and have always stressed the importance of education. Growing up, I participated in high-school sports and always planned on attending college. I have childhood memories of sleepovers, school dances, track meets, ski trips, and playing with neighborhood kids.

After high school, like many others, I went to college to continue my education. I lived away from home to expand my journey and broaden my life experiences. The only difference is, while I was in college, I was infected with HIV. It went undiagnosed for many years until one cold day in October, 1994, the diagnosis finally came. My T-cells were 34. As you can imagine, with the diagnosis came many issues and complexities. And, as I have discovered over the years, being a white, heterosexual, professional woman with HIV comes with its own set of challenges. One of the biggest questions is where do I fit in?

I’ve been to support groups where I’ve been asked if I’m the facilitator? I’ve gone to AIDS Action and been handed a job application. I attended another support group where I was asked, “Are you a reporter?”

I work as a sales representative. One day, while making sales calls, I was asked to volunteer for a crisis hotline for people with HIV and AIDS. I yearned to tell the woman that I could be one of those callers looking for guidance. And that brings me to my next question: How am I supposed to look?

The diagnosis shocked me and my Irish Catholic family. My new life consists of taking medications daily and coping with the side-effects that accompany each drug. Think of those television commercials we’ve all seen and laughed at because the side-effects are worse than the illness. Well, that’s my life. The only difference is that I don’t have the luxury of not taking these drugs. These medications keep me alive. Some of the side-effects include: nausea, vomiting, diarrhea, headaches, fatigue, dizziness, and dry mouth. My body is a portable pharmacy.

I am an extremely aggressive patient of Doctor Nesli Basgoz, the director of HIV Clinical Services here at MGH. Over the years, together, we have forged ahead trying many new drugs yet to be approved by the FDA. I have had to qualify for clinical trials just to get access to these new and precious drugs. I strongly support clinical trials, for how else are we to learn how to combat this terrible disease?

One of the trials I participated in involves women and lipodystrophy. I laugh to myself as I write this for two reasons: one, you’re asking yourself what lipodystrophy is; and two, my ‘spell check’ doesn’t even recognize the word. (I’ve always felt that a sense of humor is critical to anyone’s survival. Even the word, survival, echoes in my ear.)

I don’t know why I expect everyone to know what lipodystrophy is. Lipodystrophy causes people to have increased fat at the back of their neck or belly, enlarged breasts, or loss of fat in their face, arms and legs.

Nonchalant this verbiage has become. Labs, blood work, T-cells, viral load. I guess they breeze in and out of our lives. Do they enter our lives by coincidence, or do they magically appear at the precise moment when their memories will be forever embedded in our hearts?

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A Patient’s Perspective
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Prayers for the healing of AIDS

The following verses represent some of the readings offered as part of the Week of Prayer for the Healing of AIDS service sponsored by the Boston Black Church Week of Prayer for the Healing of AIDS Steering Committee, the PCS Diversity Program, the MGH Chaplaincy, and the MGH HIV Clinic.

A prayer from the Buddhist tradition
(Thich Nhat Hanh)
Let us be at peace with our bodies and our minds.
Let us return to ourselves and become wholly ourselves.
Let us be aware of the source of being, common to us all and to all living things.
Evoking the presence of the Great Compassion,
Let us fill our hearts with our own compassion—Towards ourselves and towards all living beings.
Let us pray that we ourselves cease to be the cause of suffering to each other.
With humility, with awareness of the existence of life,
And of the sufferings that are going on around us,
Let us practice the establishment of peace in our hearts and on earth.
Amen.

A reading from the Muslim tradition
(ascribed to Mohammed)
O God, give me, I pray Thee,
Light on my right hand
And light on my left hand
And light above me
And light beneath me.
O Lord, increase light within me
And give me light
And illuminate me.

A reading from the Jewish tradition
(Hannah Shenesh)
There are stars whose radiance is visible on earth,
Only when they have ceased to exist.
There are people, the brilliance of whose memory continues to light the world,
Though they are no longer with us.
These lights which shine in the dark of night—
They light the way for humanity.

I’m currently in a support group here at MGH, which allows me to share my experiences with other HIV-positive women. This disease is so powerful on an emotional level that some people in group actually change their names to protect their true identity. There are little things, too, everyday things that constantly remind me of the power of this disease. Like when I see a Red Cross sign, or just the word, ‘Ad,’ and I think it says ‘AIDS.’ The store, HMV, reminds me of HIV. When the pharmacist calls out the names of my drugs, I panic hoping people around me don’t know what they’re for.

I try not to let HIV control my life. But there are days when, on a physical and emotional level, I can’t deny its impact. I’ve had friends die too young, and it amazes me the number of people who breeze in and out of our lives. Do they enter our lives by coincidence, or do they magically appear at the precise moment when their memories will be forever embedded in our hearts?

My life is cluttered with things like T-cells, viral load, side-effects, clinical trials, support groups, co-pays, doctor visits, and a topic I never believed would be part of my world... AIDS.
The air is steamy in Kwa-Zulu Natal, and sweat is part of the uniform you wear each day. It’s amazing how quickly the body can adjust to weather, particularly when the warmth and fellowship of the people are present, too. I spent 14 months in South Africa with the Zulu people. Among them, everything is shared. The circle of life and the sharing of food and fellowship are profoundly simple concepts. They live simply and close to the earth, sharing life’s joys in their smiles, laughter, and most moving of all, in their song. And these are just some of the reasons I love Zulu-land.

Returning to Boston from South Africa is not an easy transition. The Zulu people are kind-hearted and welcoming, so it was easy to feel at home with them. Their hearts are filled with love and joy. Their greatest challenge is the struggle they face with HIV/AIDS. This disease has caused devastating loss of life, but has not managed to kill their hope.

Working so closely with the people, I saw their fear, doubt, and confusion. After gaining their trust, I saw and heard the depth of their pain, enveloped in the crisis of HIV/AIDS. Nurses, teachers, community activists, support group members, youth leaders, new mothers, infants and children are dying, and so are vast numbers of government officials, doctors, and lawyers. The economic backbone of their society is breaking, but there is hope in the unbroken spirit of the people. The people of Zulu-land took me into their townships, homes, and most of all, into their hearts; and what a blessed place it was to spend 14 months.

The AIDS virus is killing the youngest and brightest in the lush green Natal territory. That anything and everything grows there is a strange irony. The sadness of what was happening around me sometimes overwhelmed me.

A young teacher named, Grace, whom I befriended and visited often, asked me time and again as she grew weaker, “When will I be able to get the medicines I hear about?” I had no answer for her. And she will never know; she died this past autumn. A good friend named, Thabo, a committed young activist and community health motivator, asked me a year ago to watch out for his fiancée, Lindewe, while he was away in another township. She had been sick for a while. Lindewe died while Thabo was away motivating others to take up the struggle for AIDS education, treatment and prevention. When young people like Grace and Lindewe died, I felt powerless to make a difference.

In times when I was weary, I would drive along the Indian Ocean to renew my spirit. I could hear my father telling me to, “Follow your heart.” My father’s presence was an enduring reminder of a profound and greater grace. There was no denying that my heart and soul were with the Zulu people. In my time with them, I was not only welcomed as a guest into my Zulu brothers and sisters’ lives, I was connected to them on a deeper level than I could, or needed to, define.

In suffering my own personal loss when my father died, I returned to South Africa where my Zulu family grieved with me and supported me. Their loving presence in the midst of my crisis somehow made my grief tolerable. Their joy, laughter, and song in the midst of their own crises gave me courage and hope. They sang many songs, but one that continued on next page...
Recalling the Zulu Spirit  
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forted me most said simply, “I know the Lord will make a way for me, yes for me.” In the harmony of their voices, raised together as one, every song was powerful, but particularly that one that simply affirmed faith. In a land rich in tradition and culture, the heart of South Africa is as rich and green as the fields of Kwa-Zulu Natal, and South Africa’s soul reverberates in the harmony of the Zulu people’s voices.

I am ever aware that the struggle continues. My colleague and friend, Krista, is still there. She is a doctor from MGH who continues to listen and respond to the needs of the people. Krista works to ensure that quality treatment and care get to the people. Her energy and love for the Zulu people are enormous. Just last week she sent me a note about a mutual friend, Antoine, a young, HIV-positive community health worker. He revealed his status in an effort to help teach others about the disease. He worked to educate the public in the busiest metro transport station in downtown Durban. He was bright and funny and seemingly healthy just a few months back. As he grew weaker in my last days in South Africa, Krista scrambled to get him medications. But they came too late. I cried when I got Krista’s message that Antoine had died at the age of 25 with so much life left to live. I think about the message he would want to leave behind. I’m sure part of it would be to tell the world to listen to the people of South Africa, who are blessed but in dire need of help from the global community.

I once heard it said that, “To be heard is to be loved.” As a people, we need to listen, hear, and respond so the beautiful voices of South Africa are not silenced. For so many to die of a treatable disease is unconscionable.

I had the honor of working closely and traveling with the Sinikithemba Gospel Choir. In Zulu, Sinikithemba means, “We give hope.” Recently, the MGH community had an opportunity to hear this amazing group of South African men and women when they performed here on Valentine’s Day.

Gospel music is an interactive exchange of call and response. The Sinikithemba Choir reminds us that there’s hope in the face of unprecedented strife. They call upon us to listen… they call upon us to respond.

For information about the Sinikithemba Gospel Choir, send e-mail to: kmcmognagle@partners.org.

Members of the Sinikithemba Gospel Choir perform at MGH.
Espíritu y la cabra: un relato de fe, esperanza, y comprensión

We are Sandra McLaughlin, LICSW, clinical social worker, and Mary Martha Thiel, director of the MGH Chaplaincy. We wanted to share this narrative because it highlights the importance of clinical collaboration and spiritual caregiving in the delivery of culturally competent care to this patient living with HIV. Please note that Esperanza contributed to, and gave permission for, this narrative to be published.

Sandy Esperanza is a 27-year-old, South American woman who came to the United States to further her education in hopes of becoming a nutritionist in the rural parts of her native country. A few years after coming to the US, she contracted a series of infections. Eventually, she was diagnosed with HIV in December, 1998.

Espíritu was overwhelmed, isolated and extremely depressed. Based on her limited knowledge of HIV, she felt she would die a quick and painful death. Her MGH doctor encouraged her to meet with an HIV social worker for support, but for months she wasn’t able to bring herself to do it. I finally met Esperanza in April. She was suicidally depressed and hearing voices. She was hospitalized, against her will, and spent 10 days in an inpatient psychiatric facility. She began seeing me twice a week for therapy, and an MGH psychiatrist for medication.

When Espíritu was a young adult, a political gang ravaged her family’s home and raped her. This was how she had contracted HIV. Her attacker told her he had HIV, but she was so overwhelmed by the event, she blocked it out of her memory. Her HIV diagnosis caused a re-emergence of post traumatic stress symptoms. For the first two years I worked with Espíritu, she was convinced she would die within a few weeks. She felt hopeless and alone. She felt she couldn’t tell anyone about her diagnosis because of the stigma HIV infection carries in her community.

It became clear to me early in our work together that spirituality was an important factor in Espíritu’s life. She struggled to find meaning in her illness, and wondered how God could have allowed this to happen. She thought she had done something bad and this was God’s punishment. This belief caused her to feel that God had abandoned her. Given the complexities of her case and the depth of her despair, I decided to consult with Reverend Mary Martha Thiel, director of the MGH Chaplaincy. I thought she might be able to access some of Espíritu’s spiritual issues differently, and that our work would complement one another’s. Though initially resistant, Espíritu, in time, agreed, and the three of us set up a time to meet.

Mary Martha
I met a young, pretty woman sitting stiffly in Sandy’s office. She couldn’t hold eye contact, and her face revealed no feelings. She spoke with very few words and in such a low voice I had to strain to hear. I explained that I was a chaplain, a Protestant minister, and that I would be happy to offer spiritual support in collaboration with Sandy’s therapeutic work.

Haltingly, the themes I expected came forth: she had been raised in the Protestant faith, she attended a church founded by missionaries. Her family had embraced Christianity, and the church represented an organizing principle of her family’s life. She believed God was omnipotent, and that whatever happened was God’s will. To be saved, she had to believe in Jesus and keep in touch with God through prayer and worship. But these beliefs didn’t work for her anymore. During the rape, she had prayed for God to save her, but He didn’t. She could no longer pray or attend church services. She felt utterly without hope, and experienced God only as absent.

As she spoke, I was reminded of Psalm 130, which I offered to read with her: “Out of the depths I cry to thee, O Lord…”

I said I took heart that prayers like this are included in the Bible, and that for thousands of years, part of the human experience of faith has been to cry out to God in lament, to protest against things that aren’t our fault.

“I have no hope now,” she said.

“Perhaps I can hold onto hope for you,” I said, “until you’re able to feel yours again.”

I felt we had begun an important relationship, and hoped I had enough strength of spirit to accompany her into the terror of her unknown.

Sandy
Mary Martha and I continued to meet with Espíritu, and despite the inevitable ups and downs, she began to stabilize medically, psychiatrically and spiritually. Because of her work with Mary Martha, it became clear to us that an indicator of the severity of her depression was how close she felt to God. Waiting for more traditional indicators to surface would have meant intervening later in the process, when her symptoms would have been worse and her suffering greater. I used this information to integrate a spiritual assessment into my meetings with Espíritu. All of these things enabled her to get adequate treatment as an outpatient, with less disruption in her life.

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Exemplar
continued from page 8

Mary Martha
I came to know more about Esperanza’s religious world and her community ties. She did not feel safe enough to tell her pastor of her spiritual struggle or of her HIV status. So I became her pastor. She felt the loss of her connection to church, God, and friends intensely. I offered to pray with her at the close of each session, and she never refused. Sometimes the prayers were laments: “Are you there, God?” Others were prayers of thanksgiving: “Thank-you that the medication is working.” By praying together, I wanted her to experience, in a repetitive and ritual way, her connection to me, her faith, God, her own inner resources, and her family and friends.

I asked about her understanding of depression. She told me that in her culture, it was believed to be inflicted by demons, which could be exorcised by religious elders of the community. She knew the American understanding of depression as an illness that could be treated by medication and therapy. She felt burdened with the pressure of holding these two different explanations, but she was unable to dismiss either one.

This was my challenge: Do I insist on my Western interpretation of depression as an illness and deny the existence of her demons (thereby implicitly denigrating her spiritual connections to the land of her birth, family and faith)? Or do I try to work within the world view of her country? And if I do that, am I enabling sub-standard medical care and aiding her psychosis?

I made the decision to work within both models. I prayed with her for God to remove the demons, and prayed in thanksgiving for the knowledge of her providers and the efficacy of their medicines. We both experienced relief at this dual approach.

What seemed at first like a setback, turned out to be just another bump in the road of culturally competent care. Esperanza liked to do handwork to pass the time. Her favorite piece was an embroidered picture of Jesus the Shepherd with his goats. She said she felt calmer looking at the picture, and was reminded that Jesus was taking care of her.

“Do you identify with the goat in the picture?” I asked.

“Oh yes!” she said.

I was startled. In Western Christian iconography with which I am familiar, the goat is a symbol of rebelliousness. The sheep, in contrast, is a symbol of faithfulness. It is much better to be a sheep than a goat! I feared that in identifying with the goat, Esperanza was viewing herself as sinful, at fault for the rape and for contracting HIV. I asked her to tell me about the goat.

“The goat is a special animal to my tribe. It is a symbol of my people.” I re-oriented myself to her perspective, with relief. For Esperanza, the goat was a symbol of loving intimacy and safety!

Sandy
Esperanza still faced many daunting challenges. Since leaving school, she had lost her legal status in the US. This put her at risk for deportation back to her country where no HIV treatment was available. We began to talk about applying for political asylum, since her rape had been politically motivated. But the process was daunting, since it would mean re-telling and reliving the traumatic events many times. There was also the risk that her application would be denied. With the support of her MGH providers, legal assistance, and her faith, she was able to file the application. Waiting was extremely difficult; she needed our support more than ever. As her anxiety grew, she experienced more symptoms of depression. She sought a connection with a new church community, and found support there and from her friends.

After the hearing, it was months before the decision came. It was during this waiting period that Esperanza gave Mary Martha and me a very special gift. She gave us each a soapstone bowl that had come from her country. Carved into each bowl was an elephant with trunk lifted high. She explained that in her country, this is a symbol of hope. She wanted us to know that, no matter what the outcome of her asylum petition, we had given her back hope. Both Mary Martha and I accepted our gifts with tears in our eyes.

Fortunately, Esperanza was granted asylum. At first, she was overjoyed. But as time went on, her feelings became more complex. She was relieved to be able to stay in a country with good medical care, but pained at being separated from her homeland, a country she loved and where most of her family still lived. She explored these emotions in our work together, and mourned her losses. Then she was able to move on.

Esperanza returned to school to finish her degree. She has now completed three semesters and is doing well. She has hope that someday she will be able to return home to live without endangering her health. Her father visited this past summer, which brought her great joy. Despite our hope that she would break through her self-imposed wall of silence, she did not tell her father of her HIV status. She is clear that for her, this was the best decision. She says she will eventually tell him, but probably at a time when he is in the presence of, and has the support of, the rest of the family. She is very active in her new church, and has a great group of friends. Her HIV status remains her secret.

Mary Martha
When I ask Esperanza what got her through the last four years, she doesn’t hesitate. “God and my faith,” she says. She feels the only place she can be fully at home now is with God. Other supports are important, but God is central.

I continue to meet every few weeks with Esperanza, as her life unfolds. As her pastor, and a person of faith, I am wholehearted in praying with her: Gracious and mysterious God, thank-you for the healing you have already brought Esperanza. Let her continue to know your love for her, and sustain her as she walks with you in faith into the unknown. Amen.

Esperanza
When I read this, I was impressed by the part about the goat. This is the way I look at it: Although the goat is stubborn, naughty and rebellious, sometimes eloping and running off risking attack, it is still precious to the shepherd. The shepherd is ever faithful, loving, and patient, always running after the goat, to keep it safely within his care.

Reading this narrative made me think about something I wrote on the inside cover of my Bible...continued on page 13
Clinical issues from a social work perspective

I have the honor of working in the Infectious Disease Practice at MGH as a clinical social worker. Each day brings new experiences, rewards and challenges, allowing me to work closely with an extraordinary staff that exemplifies compassion and commitment to care on a daily basis.

HIV is now viewed as a long-term chronic illness. Due to the great advances made through research and various treatment options, an HIV or AIDS diagnosis is no longer considered a death sentence. Many individuals who have HIV or AIDS can make long-term plans and live healthy, productive lives. They’re able to maintain full-time jobs, have families, travel, and exercise; essentially, participate fully in life.

While it’s clear we’ve made enormous advances in the care and treatment of HIV/AIDS, there are areas that still need improvement. Prevention and education continue to be crucial factors in reducing the spread of the disease. Stigmatization is still a problem. Much of this is due to a lack of education, ignorance, and fear about HIV transmission. Patients still report incidents of rejection and mistreatment at the hands of friends, family members, and others due to a fear of ‘catching’ HIV or associating with someone who has the virus. Judgments are something our patients struggle with on a daily basis; asking them how they contracted HIV/AIDS can compound that feeling of ‘being judged.’ Rarely do other diseases carry such shame and ridicule. When a patient’s history indicates a potential risk for future exposure, it can be helpful to know how the disease was transmitted, so a dialogue about possible future risk factors can be explored in a safe and empathetic environment. As providers, we need to be thoughtful and sensitive about how and when this information is obtained.

Given the examples cited above, it’s understandable that some individuals choose not to share their HIV/AIDS status with others. As a practice, we encourage patients to disclose their medical diagnoses with those who will be loving and supportive. Unfortunately, imparting one’s HIV/AIDS diagnosis to others can result in rejection, discrimination, physical harm, and emotional trauma. As a result, healthcare providers are often the only people patients feel safe talking with about their illness. It’s crucial for us to know who, if anyone, is aware of our patients’ HIV/AIDS diagnosis so we can ensure their desired level of confidentiality is respected. It is our hope that continued education and heightened awareness will reduce the stigma and discrimination that still accompanies this disease.

There’s no doubt that new HIV medications have helped enormously in the fight against HIV/AIDS. But those same medications can cause complications that could potentially make a patient’s life even more difficult. Side-effects can range from mild to severe. Open dialogue between patients and providers ensures that an acceptable balance is reached between what is tolerable and what is unmanageable for the patient. Empowering patients through open dialogue helps them negotiate the complex decisions necessary to ensure quality of care as well as quality of life.

We’re fortunate that we have the opportunity to interact with individuals from all over the world. We care for patients from a wide range of backgrounds, traditions, beliefs and customs. We need to feel comfortable talking with our patients about their cultural and religious beliefs to ensure the care they receive is respectful and meaningful to them. I find that most of my education in this area comes directly from my interactions with patients themselves. Asking how illness in general, and HIV/AIDS in particular, are viewed from their perspective helps me provide thoughtful, effective care.

Family is another important aspect of culturally competent care. Many of our patients have same-sex spouses or partners. Learning about our patients’ families allows us to include that critical support system in our care. Arranging for a health care proxy, power of attorney, and/or guardianship for children is especially important. I have the honor of knowing and assisting people who strive to live well despite the challenges that come with living with a serious chronic illness. I am influenced and greatly rewarded every day by the interactions I’m fortunate to have with our patients. Time and again, I am reminded of how life can be lived with tremendous grace and dignity.

Brigid Schiano, LICSW, clinical social worker
What is a lifetime

—a poem by Shanee A. Haynes

I know I only sit with you for a short while but,
During that short while we converse for what seems like days
Giving me a glimpse of who you are.

I want to thank you for sharing you with me
I want to thank you for teaching me that there is so much more to who
you are
And that you’re not just a simple blood draw.

I have grown to know, care and feel for you even though I take care of
a small part of you.
And I want you to know that I enjoy every moment you allow me to
steal of your time.

I want to thank you for teaching me.
Allowing me to see a little more of you each time we meet.
I thank you for giving me a piece of who you are.
Showing me that many worlds exist besides my own.
Showing me the beauty in everyone I encounter even if I knew him or
her for a short moment.
It’s still a moment that I would not have had if it wasn’t for you.

I only hope that I have done the same for you.

Thank you

Walking toward Jerusalem

—a poem by Robert Young-Cooley

4:00 in the morning and the apartment walls
begin to close in and the silence is deafening
because it rings so loud

Emotions are on a vertiginous train
spiraling down, down, down
What are they?

Disbelief, not me
Denial, no not me
The test must be false-positive
So if I won’t think of it
And if it is not thought of
blotted out, it does not exist,
No Thing
Stop the silence

Acceptance. A big word heavy weighted with
freight too much to deal with at 4:00 in the
morning

Acceptance. Leading ineluctably to shame
An even bigger word with even more freight
causing, willy-nilly, emotional paralysis
the hanging of one’s head
Stop the Silence

Anger. An anger so intense that you feel it
burning at the base of the brain and in the bowels
like hot Ice and you then have to figure out
just who or what you’re angry with

Well.

Anger can be a revolutionary emotion
if it is channeled into passion and then into
action and the most revolutionary act any of
us can take, and it is a personal one: to
choose life

The silence stops
the sun shines
it is a new day

Robert Young-Cooley is a free-lance writer
living in Mattapan
HIV treatment successes and challenges

—by Sheila Davis, ANP, adult nurse practitioner

Global estimates currently indicate 42 million people living with HIV/AIDS. Of this number, 38.6 million are adults, 19.2 million are women, and 3.2 million are children under 15 years of age. New infection rates are even more alarming with 5 million cases of newly infected patients reported in 2002, and 3.1 million deaths. These numbers are staggering. It’s difficult to comprehend the astronomical global impact of these figures.

The United States alone had 900,000 people living with HIV/AIDS in 2001, and 12,000 HIV-related deaths. The numbers in this pandemic continue to grow, and although there have been numerous scientific advances, an effective vaccine for prevention remains elusive.

Well into the second decade of HIV/AIDS, the science and treatment of HIV has changed dramatically. People living with HIV are living longer, and HIV is now considered a chronic illness for those who have access to treatment. With the advent of numerous drug therapies, an HIV/AIDS diagnosis is no longer considered a death sentence.

There are four different classes of medications for HIV treatment: nucleoside analogs, non-nucleoside analogs, protease inhibitors and the soon-to-be approved fusion inhibitors. The medications pharmacologically prevent HIV from replicating by interfering with different steps of the virus’ life cycle. The medications are given in combination, usually with at least three medications together, often referred to as a 'cocktail.'

The HIV virus has the unique ability to adapt to sub-optimal levels of the drugs in a person’s body. It mutates to mitigate the ability of the drug to stop the HIV virus from replicating, which leads to resistance. That resistance has made HIV difficult to treat with the medications currently available. Also, within classes of medications, cross-resistance can occur. If resistance to one medication in a class develops, other medications in that class may also be affected.

Unfortunately, drug treatment is not benign. There are short- and long-term side-effects that can make drug treatment difficult to tolerate. Adherence, taking HIV medications in the exact way they’re prescribed, is a challenge, and clinical studies have shown that at least 95% adherence is necessary to prevent the HIV virus from mutating and becoming resistant. Many people HIV medications. Because of these side-effects, and the potential for others, clinicians are now delaying therapy for people with HIV. The Department of Health and Human Services and the International AIDS Society guidelines for HIV treatment have both changed their criteria to delay the initiation of HIV treatment.

We now have the ability to measure the amount of virus circulating in the blood, and according to this measurement we’re able to assess the success of drug therapy as well as the need to begin drug therapy. This viral load measurement in conjunction with the measurement of the CD4 or T4 cells, which are the markers of current immune function, enable virologic monitoring of HIV within patients.

“HIV is now considered a chronic illness for those who have access to treatment. With the advent of numerous drug therapies, an HIV/AIDS diagnosis is no longer considered a death sentence.”

— Allan Brandt

The immune system is very complex and researchers at MGH and Partners AIDS Research Center are among the world’s leaders in studying the HIV virus and immune functioning. This is a very exciting time in the field of HIV. People are living longer, leading normal lives, and theoretically, enjoying normal life spans. In December of 2001, the American College of Obstetrics and Gynecologists (ACOG) released a statement regarding mother-to-child transmission rates of the HIV virus. With effective HIV treatment, transmission rates have been drastically reduced from 28% to 0-2%, using medications to avoid mother-to-child transmission. Many women with HIV are now having children, and although the rate of transmission is not zero, the significant reduction in transmission is a welcome advancement.

Unfortunately, medical advances seem to have contributed to a sense of complacency with a rise in the number of new HIV infections and AIDS cases reported.
Medical Update
continued from previous page

in the United States for the first time in a decade. Dr. Ronald Valdiserri, deputy director of The National Center for HIV, STD, and TB Prevention at the CDC, reported an 8% increase in new cases between 1999 and 2001. Of those new cases, 14% were attributable to sexual transmission among men, and 10% to heterosexual transmission. Women are reducing the gender gap. Young women of color are among the fastest growing population of new cases in the United States. HIV continues to exploit the disenfranchised. Socioeconomic disparity and poverty are contributing to the rising rates of HIV.

Recent advances in HIV treatment have greatly altered the life cycle of the disease in the developed world. Unfortunately, the majority of people living with HIV/AIDS in the world today do not have access to drug treatment. Less than 4% of people needing antiretroviral drug treatment in low- and middle-income countries were receiving drugs by the end of 2001. The mysteries of the HIV virus continue to be explored in state-of-the-art laboratories with enormous progress being made in immunology and virology. But still greater challenges need to be addressed, including access to care, social and economic disparities, and gender inequalities that result in a disproportionate epidemic in a world of ‘haves’ and ‘have-nots.’

We need to celebrate the tremendous advances that have been made in the field of HIV/AIDS and at the same time, advocate for access to treatment for all. In 1988, relatively early in this epidemic, noted public health expert, Allan Brandt, said “In the years ahead we will, no doubt, learn a great deal more about AIDS and how to control it. We will also learn a great deal about the nature of our society from the manner in which we address the disease. AIDS will be a standard by which we may measure not only our medical and scientific skill but also our capacity for justice and compassion.”

Exemplar
continued from page 9

one day as I reflected on a session I had with Mary Martha. I wrote:
“My God is so gentle…
A bruised reed He will not break,
And a smoldering wick He will not snuff out.
He will heal my bruises, and help my flames burn a little longer.” (Isaiah 42:3)

Mary Martha

Indeed, Esperanza’s image of God has changed. For her, God is no longer omnipotent, but an ever-present source of strength and hope. Caring for Esperanza required religious/spiritual care alongside medical, psychosocial and psychiatric care. Without any one of these aspects, her treatment would not have been as effective. Given the centrality of her faith, and the crisis of faith her illness caused, my collaboration with Sandy was essential to her care. We were able to support each other during the more challenging periods of our work. We share a sense of joy that Esperanza has been able to rebuild her connection with God, and bring her own spiritual resources into her healing.

Comments by Jeanette Ives Erickson, RN, MS, senior vice president for Patient Care and chief nurse

Illness is the great unknown. As this narrative so dramatically illustrates, illness can be a source of fear, pain, confusion, and loss of faith. In providing support and guidance to patients, clinicians often seek the help of colleagues from other disciplines. Sandra was wise to turn to Mary Martha. Together, they were able to educate and support Esperanza, and help her through a crippling spiritual and emotional crisis.

Closely coordinating the culturally sensitive care they provided, Sandra and Mary Martha empowered this courageous woman to find meaning in her life and in her faith again. Thank-you, Sandy and Mary Martha. And thank-you, Esperanza.
My God is so gentle: spiritual issues and HIV/AIDS

—by Mary Martha Thiel, director, MGH Chaplaincy

My God is so gentle," quotes Esperanza, a young South American woman infected with HIV through a politically motivated rape (see example on page 8). This image of God as gentle, put forth by the Biblical prophet, Isaiah, has not always matched her experience of The Holy One. Esperanza’s experience highlights some of the spiritual issues that many people with HIV/AIDS face (this model is adapted from NANDA).

Most individuals diagnosed with HIV experience spiritual distress as part of their reaction. Spiritual distress happens when one’s core beliefs are broken or threatened, and spiritual distress is exacerbated when one is separated from one’s community. Esperanza faced both.

Who is God that this happened to me? Is God powerful after all? If He is, why didn’t He save me from this? If He isn’t, who is He then?

These questions mark the core spiritual struggle between fear and trust. Esperanza’s conservative Protestant upbringing led her to believe that if she was faithful to God, God would make everything work out well for her. Her rape and diagnosis struck down this belief.

Understandably, forgiveness has been a spiritual struggle for Esperanza. She needed to visit the possibility that she was somehow at fault for her predicament. Spiritually, it might have been simpler for her if there had been something she could have done differently to prevent the attack. Then her understanding of God could remain as it had been, with God in control of events. But there wasn’t anything she had done. Slowly, over the months of our work together, she was able to claim her innocence.

The issue of being forgiven is often a hard one for people with HIV/AIDS. It’s easy for others to say they brought the disease on themselves through various high-risk behaviors. But the real theological question is: Is God someone who would use illness to punish people? What about the Esperanzas of the world, or babies born to HIV-infected parents, or grandmothers who contracted the virus through a blood transfusion? Are other diseases the result of God striking down sinners, or just this one?

We cringe at the thought that cancer or diabetes might be God’s mark of judgment. So why would HIV be any different? These excruciating ruminations are often part of the experience of HIV/AIDS in our culture. Good pastoral care can help make a difference in a person’s ability to let go of his/her need to be forgiven for contracting the illness.

The flip side of this spiritual dynamic is the move to offer forgiveness. For Esperanza, what about her attackers? They certainly expressed no remorse or intention to change their behavior. Christian tradition does not insist on forgiving the perpetrator under these conditions. Maybe God can forgive her rapist, but the moral responsibility is not on Esperanza. So why didn’t He save me from this? If He isn’t, who is He then?

Esperanza refuses to date, marrying, and getting excellent medical care here at MGH. She has a future again. In her country of origin, where medical care is not of the same quality as it is here in the US, a diagnosis of AIDS means death. The stigma of HIV infection is powerful. To this day, Esperanza has told none of her family or friends about her health status. She feels a huge barrier between herself and those she loves. As her friends are getting married, Esperanza refuses to date, not wanting to put another at risk through their intimacy.

The spiritual struggle to love and be loved is ongoing for her. Esperanza knows she is spiritually stronger than she was before the violence. She is clearer in her life goals, and stronger in her resolve to achieve them. This is part of her ongoing journey to find meaning — another core spiritual dynamic. Finding meaning in suffering comes slowly. It is work that can only be done by the individual him/herself. Healthcare providers must refrain from imposing their own meaning on others.

Gratitude, the final core spiritual dynamic, may seem an oxymoron in the context of AIDS. But some people do come to a place of gratitude—not for the illness itself—but for the healing and love they experience because of the illness. Esperanza expressed her gratitude to her social worker and me by giving us handcrafted bowls from her country, decorated with her cultural symbol of hope.

Spiritual care of persons with HIV/AIDS is not for the faint-hearted. The same spiritual themes exist for the caregiver as for the cared-for. The spiritual struggles can be agonizing, and the caregiver must accompany the person through some bleak times. Part of the meaning I find in this work, is in celebrating the transformation that can come out of destruction and despair. New life out of death. For me, as a Christian minister, this core theological tenet is made real every time I meet with Esperanza. May God be with us both.
### Educational Offerings

**March 6, 2003**

For detailed information about educational offerings, visit our web calendar at [http://pcs.mgh.harvard.edu](http://pcs.mgh.harvard.edu). To register, call (617)726-3111. For information about Risk Management Foundation programs, check the Internet at [http://www.hrm.harvard.edu](http://www.hrm.harvard.edu).

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<tr>
<th>When/Where</th>
<th>Description</th>
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<tr>
<td>March 14</td>
<td>End-of-Life Nursing Education Program (Day II)</td>
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<tr>
<td>8:00–4:30pm</td>
<td>O’Keeffe Auditorium</td>
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<tr>
<td>March 17</td>
<td>CPR—American Heart Association BLS Re-Certification</td>
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<tr>
<td>7:30–11:00am,</td>
<td>VBK 401</td>
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<td>12:00–3:30pm</td>
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<tr>
<td>March 19</td>
<td>USA Educational Series</td>
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<td>1:30–2:30pm</td>
<td>Bigelow 4 Amphitheater</td>
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<td>March 20</td>
<td>Caregiver Skills</td>
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<tr>
<td>8:00am–4:30pm</td>
<td>Training Department, Charles River Plaza</td>
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<tr>
<td>March 20</td>
<td>Nursing Grand Rounds</td>
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<td>1:30–2:30pm</td>
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<td>March 21</td>
<td>CCRN Review Day II</td>
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<tr>
<td>March 24</td>
<td>BLS Certification–Heartsaver</td>
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<td>8:00am–12:00pm</td>
<td>VBK 601</td>
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<tr>
<td>March 25</td>
<td>CPR—Age-Specific Mannequin Demonstration of BLS Skills</td>
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<td>8:00am–12:00pm (Adult)</td>
<td>VBK 401 (No BLS card given)</td>
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<tr>
<td>10:00am–2:00pm (Pediatric)</td>
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<td>March 26</td>
<td>New Graduate Nurse Development Seminar II</td>
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<td>8:00am–2:30pm</td>
<td>Training Department, Charles River Plaza</td>
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<td>March 28</td>
<td>Nursing: A Clinical Update MGH School of Nursing Alumni</td>
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<td>8:00am–4:30pm</td>
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<td>April 3</td>
<td>CPR—American Heart Association BLS Re-Certification</td>
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<td>12:00–3:30pm</td>
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<td>April 3</td>
<td>Nursing Grand Rounds</td>
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<td>1:30–2:30pm</td>
<td>O’Keeffe Auditorium</td>
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<td>April 3</td>
<td>The Joint Commission Satellite Network presents:</td>
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<td>1:00–2:30pm</td>
<td>“Enhance the Relevance of JCAHO Standards: What’s New for 2003?”</td>
<td>Haber Conference Room</td>
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<td>April 4</td>
<td>Introduction to Culturally Competent Care: Understanding Our Patients, Ourselves and Each Other</td>
<td>7.2</td>
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<td>8:00am–4:30pm</td>
<td>Training Department, Charles River Plaza</td>
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<td>Intermediate Arrhythmias</td>
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<td>Pacing: Advanced Concepts</td>
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<td>April 9</td>
<td>New Graduate Nurse Development Seminar I</td>
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<tr>
<td>8:00am–2:30pm</td>
<td>Training Department, Charles River Plaza</td>
<td>(for mentors only)</td>
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<tr>
<td>April 9</td>
<td>OA/PCA/USA Connections</td>
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<tr>
<td>1:30–2:30pm</td>
<td>Bigelow 4 Amphitheater</td>
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<tr>
<td>April 10</td>
<td>Social Services Grand Rounds</td>
<td>CEUs for social workers only</td>
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<tr>
<td>10:00–11:30am</td>
<td>“When Trauma Hits Home: Dealing with Vicarious Traumatization.” For more information, call 724-9115.</td>
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<tr>
<td>April 11 and April 17</td>
<td>Advanced Cardiac Life Support (ACLS)—Provider Course</td>
<td>16.8</td>
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<tr>
<td>8:00am–5:00pm</td>
<td>O’Keeffe Auditorium. Day 2: Wellman Conference Room</td>
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— Page 15 —
Nursing Career Expo

Human Resources invites you to learn more about nursing at MGH, including opportunities for staff nurses (experienced and new graduates), clinical nurse specialists, patient care associates, and surgical technologists.

Sunday April 6, 2003
12:00–4:00pm
North and East Garden Dining Rooms

The Center for Clinical & Professional Development will provide a one-hour continuing education session to participants of the Expo. The session is free, and 1.2 contact hours will be awarded.

“Accelerating Wound Healing”
1:00–2:00pm
Haber Conference Room

For more information, contact: Megan Brown (mcbrown@partners.org) at 726-5593 or fax: 726-6866.

Get REAL!

Have you ever thought about the impact MGH has on the environment? Have you ever wanted to do something about it? Now's your chance.

REAL (Raising Environmental Awareness League) is a newly formed environmental group seeking new members.

The next meeting will be held on Wednesday March 19, 2003, at 3:45–4:30pm in the Blake 8 Conference Room.

For more information, contact: peaceout@quik.com or rhorr@partners.org

The MGH Nursing Alumnae Association presents
Nursing Update 2003
The Operating Room of The Future; The Framingham Heart Study; MGH and Disaster; Childhood Cancer; Gerontology/Psychiatry
March 28, 2003 8:00am–4:30pm
O’Keeffe Auditorium
7.2 contact hours. Cost: $40
For more information, call 617-726-3144

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