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Guidelines for the Assessment and Management of Metabolic Complications

The International AIDS Society–USA has convened a panel of 12 experts to develop guidelines for the assessment and management of metabolic complications in HIV infection and antiretroviral therapy, including glucose abnormalities and insulin resis-

tance, lipid abnormalities, body fat distribution changes, lactic acidemia, and bone disease. Chaired by Morris Schambelan, MD, and Constance A. Benson, MD, the panel will submit its report for publication shortly.

Telling Stories

Mary Fisher

At the International AIDS Society–USA course in New York in March, Mary Fisher reminded us of the importance of “telling stories” by and to the community of people affected by HIV and AIDS. The transcript of her speech is reprinted below. A community, she pointed out, is a group of people bound by a common story. A community weakens without the “glue” of shared stories. With the observance this June of 20 years since the first reported AIDS cases, and as many health care practitioners and patients enter their third decade of life and work with HIV, we thought it appropriate to begin sharing common experiences of the epidemic in Topics in HIV Medicine, through a new feature called “Telling Stories.” Selected stories from those involved in HIV and AIDS care will be published here periodically.

Thank you very much. It’s a joy to be back with you, and to be so warmly welcomed.

I was honored to address the International AIDS Society–USA in May 2000 at your gathering in Washington, DC. At that time Bill Clinton was still in the White House, we hadn’t yet learned to spell “chads”—and we still thought of NIH [National Institutes of Health] as the challenge, and Wall Street as our friend. What a difference a year makes!

Being re-invited gives me an opportunity to correct one mistake I made last year. I did not tell any stories. I want to correct that oversight, beginning right now—and the first story is really a reward for those of you who chose to stay to the end of today’s session.

During Bill Clinton’s last run for the presidency—1996—I was invited to speak at an AIDS-related event in Little Rock, Arkansas. It was an awards night for regional folk who’d made significant contributions to the fight against HIV. The room was packed with social workers, people with AIDS, family members, religious leaders, a few politicians and journalists—in other words, the room was packed with Democrats. Out of deference to me, every speaker had been very discreet never to mention politics or Republicans, until the community awards were being handed out, and the last recipient wanted to talk.

She was a wonderful, elderly public health nurse: bright, quick, tiny, 77 years old, and feisty. And you could hear every politically correct person in that room stop breathing when she reached up, grabbed the microphone and said, “I’ve had it with them dumb Republicans.”

Mary Fisher is a mother, author, and AIDS activist. She created the former Family AIDS Network, which is now the Mary Fisher CARE Fund of the University of Alabama at Birmingham. This not-for-profit fund sponsors long-term outcomes research that will impact HIV/AIDS care and public policy. Ms Fisher is a special friend of the International AIDS Society–USA and has contributed to the organization on many levels, not the least of which being to inspire us to think about new ways to serve our audience in their work in HIV/AIDS research and clinical care.

“For 15 years,” she said, “I’ve talked to them dumb Republicans. Over and over, I’ve explained there ain’t but 3 ways you can get AIDS: swap needles or blood, have sex, or get born with it. And, for 15 years them dumb Republicans been askin’, ‘But can’t you get it from mosquitoes?’”

She paused for a moment, and then she said: “I’m tellin’ y’all tonight that, from now on, I’m gonna tell ‘em, ‘Yep, you can get it from mosquitoes—but only in 3 states: Florida, Louisiana, and Arkansas. Cause them’s the only places mosquitoes grow so big Republicans can have sex with ‘em.”

Of all the stories I’ve collected while traveling the road to AIDS, this is probably my favorite. I’ve told it as truthfully as it happened—because you can’t improve on the reality of it.

Stories are important, also to you and me. When I was first diagnosed with HIV in 1991 and when many of you first joined the fight, the AIDS community had its own story. It was a story of mysterious reports and sudden wasting, of an unnoticed community of people with hemophilia whose lives were suddenly being cut short, and a previously hidden gay community whose fabric and texture was suddenly, brutally, being exposed by AIDS. Headlines told stories of families making 3 discoveries simultaneously: their brothers were gay, their brothers were sick, and their brothers were dying.

Part of the story was told quietly by the Names Project AIDS Memorial Quilt founded by Cleve Jones and friends. It was told in the ritual unfolding of panels in temple basements and college gyms across the nation. Walking the edge of the quilt, the mother—who’d insisted to her bridge club that her son had died of cancer—found courage to tell the truth, to tell his story, to crochet a memory into a panel the size his coffin had been. How many stories have you and I heard? How many times did the whisper of unfolding panels make us shiver, and tear-up, and grab hold of the hand next to ours? In their refusal to let us go anonymously to the grave, Cleve and company assured a memory of the stories.

Part of the story was blared into cameras and screamed into the night by Larry Kramer and his ACT UP warriors. They loaded press releases and aimed them at *The New York Times*; they loaded condoms and threw them at the president’s motorcade. In their rage, they told another story about AIDS: about those who believed gay men deserved to waste away, about those in power who preferred prejudice to compassion and cowardice to honor. So important was their story, and so powerful their fury, that I dreaded them when I spoke to the 1992 Republican convention. I feared they would say I had sold out: that I didn’t understand because I was a woman, not a gay man; that I didn’t belong with them, because I’d come from a family with means whose father spoke to presidents.

Both the quilt and ACT UP are, today, mostly memories. The past presidential election was the first in the history of AIDS in which the quilt, in all its grief and glory, was not lain across

Washington’s Mall. ACT UP is still alive, but its founder is fighting to live, not living to fight.

The image of the quilt and the echo of ACT UP remind us that, once upon a time, the American AIDS community had a common story. All of us—gay or straight—had tasted the stigma championed by select members of Congress and leaders in a series of administrations. The story of being disenfranchised by a virus was our story; it belonged to all of us. It helped make us a community.

All of us—male or female—had known the rage that built within us, the grim, unbending suspicion that if AIDS was a death sentence, people in power did not mind. We rallied and we protested. Tom Hanks’ *Philadelphia* was our story, our fight for dignity. It gave us a sense of community.

All of us—physicians and patients, Democrats and (God knows) Republicans—soon learned that dealing with AIDS was different than dealing with heart disease and cancer. We knew it when our families wished we’d come down with a different disease or our in-laws wished we’d chosen a different clinical specialty. The story of AIDS was seen as a dirty story, something not to be mentioned around the children. At the same time, it was our story: it was what bonded us. The sheer magnitude of AIDS shrunk the importance of gender and race, of politics and degrees. Our common affinity with AIDS made us citizens of a single community.

The hardest thing to find in the AIDS epidemic today—whether you are a physician or a policy buff, an activist or a journalist—is

an American AIDS community. We can use the phrase, “American AIDS community,” but it has no substance. We are not one anymore, no matter how a virus may be touching each of us. We are divided into silos of interest and self-interest, a few advocates and many drug manufacturers, researchers, and physicians. We are divided by economics and geography and ethnicity. We are seen less as a national community than as a government category. We are not a political force. We are, in fact, just barely a political issue.

Communities have leaders. Their names fall naturally from our lips. I mean no disrespect to the extraordinary women and men whose pictures decorate *Time* magazine and whose stories are well known within the world of infectious diseases. But when I think of an AIDS community, it feels as though the leaders have, mostly, died. When I wander through my art studio, and see works I finished in 1993, ‘94, ‘95, I remember again that Elizabeth is gone, Arthur is gone, Paul is gone. They’re all gone. It’s hard to lead when you’re dead.

Communities have rituals by which we remember our common tradition. That was the role of the quilt, constantly growing, constantly reporting its own growth. It told the AIDS community’s story as a growing story of a swelling epidemic. The community’s rituals have mostly faded now. We folded them up with the quilt in the fall of ‘96. We put them, mostly, away.

Communities have symbols, which was the importance of the red ribbon before other diseases—easier to champion, more popular at home—changed the color and the cause.

This is not, despite how it may sound to you at the moment, a wishing for “good old days” when people with AIDS were dying left and right. I’m not wistful for the agony that came along with those years, or naive about the vast improvements that have been made in the treatment of AIDS. I am grateful for the advances. But I am haunted, and some days distraught, at our collective and profound loss of community.

And it is not only an American community for which I long; it is a global AIDS community. I’ve stood in the African dust with sisters whose children are dying. I’ve looked across acres of orphans while holding the hands of my own sons. This is not an academic exercise for me, or an emotional appeal for Americanism.

Most Americans believe there is no need to have an AIDS community because they believe AIDS has a cure, just like diabetes. They believe AIDS is an African problem because people in Africa can’t afford to be cured; if only those Africans had more cash, they too would be fine. When I try to explain that AIDS is not cured, most Americans believe I’m merely whining. There’s a cure—they’re sure of it; they know it. African American youth believe it because of Magic Johnson. Other folk believe it because what else would a “manageable disease” be, if not “cured”?

So, yesterday, many of us were asked to mount pressure on the administration to restore funding for AIDS-related programs that appear to have disappeared in President Bush’s budget for next year. The Minority HIV/AIDS

Initiative, some CDC [Centers for Disease Control and Prevention] prevention programs, and some HRSA [Health Resources and Services Administration] care programs all look to be emptied or gone. Congresswoman Nancy Pelosi, a Democrat from California, and Congressman John Shimkus, a Republican from Illinois, have drafted a letter calling for restoration of these funds. We need to drum up support.

The challenge we face is largely one of communication. These good congress people are going to cite statistics of infections. They’ll tell the president that the CDC reports 900,000 Americans with HIV. And in the backrooms and corridors where power brokers do their work; in the press rooms and editorial boards where the American mind is shaped; in the lobbying firms who want these monies for their clients—they know, they absolutely know, that there is no clamoring, protesting, voting American AIDS community, because AIDS in America is cured.

Which brings me back to the matter of stories. A community is, in many respects, a group of people bound together by a common story. What made Israel “Israel” is a common story brought down from Fathers Abraham, Isaac, and Jacob. What makes the Ute people or the Navajo people a “people” is not simply common DNA, but common stories. What sets the DiAngelo family apart from the Hernandez family and the Jones family is their uniquely woven set of stories called “family tradition.” It’s stories that tell us who we are, where we belong, where we find our place among others. The absence of such stories means we are, in some profound ways, orphans—which is why

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so many of those with AIDS today have no context, no support systems, no advocates. They are without the community that defines us and cares for us and makes us, somewhere between cradle and grave, human.

Stories are our way of making sense out of what cannot be explained, our way of making enduring what could otherwise not be endured. Paul Rudnick, the wonderful writer, once explained why gay men have written comedies about AIDS. "Only money, rage, and science can conquer AIDS," he said. "But only laughter can make the nightmare bearable."

One of the reasons I love telling the story of that sainted public health nurse and her Republican-loving mosquitoes is because it says something of the AIDS community. If you knew nothing of AIDS political history, it wouldn't be funny. But it plays on our American story, and our sense of the impossible. It's like Jewish humor or Italian humor; it's "inside humor," an AIDS community joke. Besides, it makes us laugh—which makes the nightmare bearable.

So here's my call to you today. I want you to start gathering, and shaping, and telling, and publishing stories. That's right: stories. We need to humanize AIDS again, taking it out of the dusty realm of statistics and projections. We need to reattach AIDS to something human, something that slashes into a family and matters to a congregation. Both the media and the politicians know the numbers; what they don't know is that the numbers matter. They don't think of a half-million deaths as a half-million stories; they think of them as one story told a half-million times.

When a congresswoman needs to move a piece of legislation, she puts out a call to her district for stories. Those stories become human when they appear in legislative rooms as witnesses, and in press stories as examples. When a president wants to advance a new policy, he looks for a family to plant in the House Gallery for his speech. He looks for people who are the story. These people know that, when thinking of the Holocaust, the number "6 million" has no meaning until you attach it to Anne Frank's story.

The fact that we have let the American AIDS community grow mute and scattered; the fact that our numbers are being reported but our story isn't being told—it is, if you'll forgive me for putting it this way, what is killing us.

We have a new administration forming in Washington, DC. We have hints that Colin Powell may regard the international AIDS crisis as a profound and moral responsibility that rests not solely, but seriously, with him. The secretary of state knows the numbers. But what he may need, either to bolster his own support or, more likely, to enable him to generate support among others, is stories: stories that show Americans care about AIDS, stories that rise from families who have lost loved ones and can identify with the African mother staring at her soon-to-be orphans. To mount an American response, he needs to know that there is an American community of interest—not just pockets of professional self-interest—in AIDS. (What do you think

America's policy toward Israel would have been for the past 50 years if there were no American Jewish community?)

Governor Thompson is now Secretary Thompson. His record, and his attitude, could give us reason for some hope. But what he experiences as "AIDS" is not—not in his office, not on his timeline—so much a human crisis as a budget dilemma. If all he hears is numbers and statistics from us—if we leave him to work in a nation that believes AIDS is cured—he'll have neither voices nor witnesses nor probably motivation with which to fight budget challenges and bureaucratic chaos. If he is to advance our cause, then he needs witnesses. And we must tell him the truth.

I understand that most of you are scientists, not street-level advocates. I thank God for you. Don't for a moment believe I think science does not matter. I have 2 children at home who love me. Science matters to our family. It matters very much.

But so do stories. Because it is not science that teaches us who we are, or what we are to do with our lives, or why we matter, or how we will be loved. We don't, and neither do you. You discover who you are when, after an impossibly long day of work with paper and people, you finally give up and go to bed. And, somewhere in the night, you hear the voice of someone with whom you once knew romance. If she says, "I love you," you drift off to sleep. And if she says, "I can't go on like this . . .," you stay awake. In the end, you see, it isn't our statistics that define us; it's our story.

If you want to support one another as scientists, physicians, caregivers, you need time to tell each other stories, not just statistics. You need inside humor. You need to be not only members of an academy but members of a community. If I had a wish to waste, it would be this: I'd love to get you to tell stories to each other and to me: the ridiculous and the sublime, the funny and the sad. Stories lift us up, inspire us, shake us from the professionalism and soberness that tend to associate with events such as this. They give us hope.

I am a great fan of the International AIDS Society–USA. I count a number of you here today as my closest friends and advisors. For example, there is Dr Michael Saag: my professional colleague, my personal physician, and my cousin. If he doesn't like what I say in these settings, he still tells my mother.

I know the importance of research and discovery to Michael. I know why the numbers matter to him. But it isn't statistics that will enable Michael, or any of you, to re-engage and build an AIDS community, it's stories. Let me give you an example on my way out.

This story is taken from *I'll Not Go Quietly*, a book we published in 1995.

Billy Cox came out of his hospital bed in Birmingham, Alabama, to bring me a hug in Montgomery.

I'd first met him a year earlier at the University of Alabama at Birmingham where I was visiting Michael Saag . . . Michael wanted me to meet Billy, to see his spunk and spirit. "Billy's the boxer in the

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ring,” Michael once observed. “The doctors and nurses and medical staff, we’re just the trainers in his corner. His friends and family are his fans, cheering him on.”

Now, a year later, I’d come to Montgomery to speak... But what I said there was not as eloquent as the events that soon played out in the life of Boxer Billy and Cousin Michael.

Six weeks after he’d brought his hug to Montgomery—7 years, 4 months, and 3 days after testing positive for the AIDS virus—Billy Cox died. November 23, 1994.

On Billy’s last day, Michael Saag was leaving town for a few days and stopped in just to say good-bye. When he heard Billy’s labored breathing, he called the family together and told them the end was near. And then—as nurses and old friends and Billy’s family crowded into the room, forming a remarkable community bound only by love for the boxer—Michael rested his head on Billy’s chest and, unashamed, before the crowd, sobbed, “I’m sorry, I’m sorry.”

Science has limits. Even community has bounds. But no one will ever know what love might do.

A community is defined by its stories: stories of victory and loss, of heroes and scapegoats, of tragedy and triumph. For the American AIDS community to become a community again, we must find ways to tell the stories again, to let others know that after Billy Cox came others, each with a name, each with a purpose, each with a life.

In my own story, you are the heroes. You are the ones whose stories matter most, whose values need to shape policies, whose passions need to find headlines. In my story, you are the ones who will be first to hear the words of the ancient rabbi: “Grace to you, and peace.”

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